Caregiver Handbook

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

Brought to you by PearlPoint Cancer Support

Download at MyPearlPoint.org

© 2016 PearlPoint Cancer Support. All rights reserved.
Sign up for a FREE, personalized dashboard on *My PearlPoint* to find more resources like the ones in the Caregiver Handbook.

2. Fill out your profile by answering a few simple questions to receive personalized resources.
3. Use your dashboard to save resources and information you find helpful, track your well-being, and print additional worksheets.

What else will you find at *My PearlPoint*?

- Nutrition and side effects management
- Recipes
- Survivor stories
- Videos from cancer experts and survivors
- Clinical trial locator
- Cancer resource locator

Want more resources on the go?

Download the **Cancer Side Effects Helper** app for FREE at Google Play and iTunes. The app provides nutrition tips to help you manage side effects from cancer treatment.

Follow us on Facebook, Twitter, Pinterest, and YouTube.
# Table of Contents

## Introduction to Caregiving
- About the Caregiver Handbook ................................................................. 4
- How To Care for a Cancer Patient .............................................................. 5

## Caring for Your Loved One During Treatment .............................................. 8
- Preparing the House for Treatment ............................................................ 8
- Giving Care During and After Chemotherapy .............................................. 9
- Giving Care During and After Radiation .................................................. 12

## Helping Your Loved One After Surgery ..................................................... 23
- Wound Care .................................................................................................. 23
- Common Side Effects of Cancer Surgery .................................................... 25
- Caring for an Ostomy .................................................................................... 27
- Caring for Mastectomy Drain Bulbs ............................................................ 29

## Nutrition ....................................................................................................... 15
- Caregiver’s Role in Nutrition ....................................................................... 15
- Grocery Shopping Tips ................................................................................ 16
- Food Preparation .......................................................................................... 17
- Food Safety .................................................................................................... 19
- Snack Ideas for Treatment Days .................................................................. 21
- Nutrition Resources ..................................................................................... 21

## Practical and Relationship Issues .............................................................. 31
- Managing Insurance and Finances .............................................................. 31
- Appointments and the Healthcare Team ..................................................... 34
- FMLA for the Caregiver ............................................................................. 35
- Advanced Directives .................................................................................... 36
- Communicating with a Cancer Patient ....................................................... 38
- Intimacy During Cancer Care ...................................................................... 40
- Long Distance Caregiving .......................................................................... 42
Caring for the Caregiver ................................................................................................. 45
  Caring for Yourself ........................................................................................................ 45
  Emotional Support for Caregivers ................................................................................. 46

After Treatment Ends ..................................................................................................... 50
  Transitioning Out of the Caregiver Role .................................................................... 50
  Hospice and End of Life Care ....................................................................................... 52
  Mourning the Loss of Your Loved One ......................................................................... 55

Worksheets .................................................................................................................... 58
  The Patient’s Medical History ..................................................................................... 57
  Appointment Notes ....................................................................................................... 66
  Healthcare Team Contact List .................................................................................... 67
  Treatments and Side Effects Log ................................................................................. 70
  Laboratory Flow Sheet ................................................................................................. 73
  Budgeting Worksheets .................................................................................................. 76
  Calendars ....................................................................................................................... 77
  Grocery List .................................................................................................................. 82

Additional Resources .................................................................................................... 84
**Introduction to Caregiving**

*Welcome to the Caregiver Handbook presented by PearlPoint Cancer Support.*

**About The Caregiver Handbook**

If your loved one or friend has just been diagnosed with cancer, you probably have a lot of questions about being the best caregiver possible. The Caregiver Handbook from PearlPoint Cancer Support contains everything you need to know to more confidently manage your role as a caregiver for a cancer patient.

With the internet and search engines, it’s easy to find information about any cancer topic, but not all of it is reliable and trustworthy. But don’t worry! PearlPoint’s Caregiver Handbook is a reliable source of information. All of the content in the Caregiver Handbook has been reviewed and approved by medical professionals across the U.S. who serve on PearlPoint’s Scientific Advisory Team.

Using the Caregiver Handbook, you will read how to care for a patient going through different types of cancer treatment, including chemotherapy, radiation, and surgery. Discover tips for preparing the home, stocking the pantry, and serving healthy foods to make caregiving easier. Learn how to best communicate with the healthcare team.

The Caregiver Handbook also discusses the practical issues you may face as a caregiver such as managing insurance and finances or helping your loved one prepare his or her advanced directives.

While fulfilling the role of a caregiver, your relationship with your loved one may change. The Caregiver Handbook provides suggestions for talking to the patient—phrases to avoid and questions to ask. If the patient is your spouse, there may be changes in intimacy. This is normal. Learn what these changes may be and how to keep the intimacy even during treatment.

Another important part of caregiving is caring for yourself. In order to support your loved one, you need to be physically and emotionally well, too. Find out how to take time for yourself and locate the support you need.

Even when treatment ends, the cancer journey is not over. Transitioning out of the role of caregiver comes with its own challenges. Even if your loved one successfully finished
treatment, it may take time for things to return to normal. The final section of the Caregiver Handbook also covers end of life care and grieving the loss of a loved one.

We hope you find the Caregiver Handbook to be a valuable, frequently consulted tool as you manage your cancer journey. We encourage you to make it your own! Ask a nurse navigator or another member of your healthcare team to highlight the sections that most apply to your loved ones specific diagnosis and treatment plan. Use the worksheets in the back to keep track of all important information such as medical history and appointments. And finally, never hesitate to talk with the healthcare team—frequently, proactively, and openly.

**How To Care for a Cancer Patient**

**What is a caregiver?**
A caregiver is simply anyone who helps to care for a loved one with cancer. You may not think of yourself as a caregiver. You may just see it as taking care of someone you love, but what you are doing is extremely important. Helping a loved one with cancer isn’t always easy. Caregiving can be a full-time, non-stop job that wears on you physically and emotionally, but there are many things you can do to make it easier.

Caregivers are often family members or friends. They provide important ongoing emotional and physical care for a person with cancer. Caregiving takes on many different forms. It can mean helping with daily activities, like going to the doctor or making meals. It can also mean helping the patient deal with the wide range of feelings they’ll experience during this time. The jobs of a caregiver fall into three basic categories: medical, emotional, and practical. The kind of support needed will be different for each person.

This guide is filled with tips and advice to help you work through the challenges of helping the cancer patient in your life.

**What does caregiving look like?**
There are many ways caregivers help the person with cancer, and it’s a little different in each case. Here are just a few examples. You can help:

- Shop for food and prepare meals
- Take medicines
- Bathe, groom, and dress
- Use the bathroom
- Clean house and do laundry
- Pay bills
- Find emotional support
- Get to and from doctor’s appointments, tests, and treatments
- Manage medical problems at home
- Decide when to see a doctor for new problems
Managing Your Loved One’s Treatment
Here are a few ways to help manage your loved one’s treatment:

1. Gather information. Learn more about your loved one’s diagnosis and possible treatment options. Start by asking the doctor or nurse what resources he or she recommends. There are also many reliable websites and cancer organizations that can provide helpful medical information. See the Additional Resources section of the Caregiver Handbook for places to find reliable information.

2. Go to medical appointments and follow-ups together. Before leaving to see the doctor, write down any questions both of you would like to ask. Bring a notebook and keep track of the doctor’s answers so you can refer to them later. Get specific instructions on how you can help manage a side effect he or she may be dealing with and any dietary needs. If your loved one will be taking medications, write down the dosages and times he or she will need to take them.

   Your loved one will need to give written permission before doctors can share information with you about his or her medical treatment. This is also true for you to speak with other members of the healthcare team without the patient present. The Health Insurance Portability and Accountability Act (HIPAA) gives patients more access to their own medical records and more control over how their health information is used. Often, hospitals have papers your loved one can sign to allow you to speak to the doctor and hear details of the treatment plan on his or her behalf if needed. You may also want to talk to your loved one about filling out advanced directives including a medical power of attorney. Medical power of attorney lets your loved one name another person, such as a family member or close friend, who can make decisions about medical care if he or she cannot. For more information, see the Advanced Directives section of the Caregiver Handbook.

3. Offer physical care. People going through cancer and treatment may need help with things they would normally do themselves, like bathing or dressing. Ask your loved one to let you know if he or she is able to do all they need to do and if they could use your assistance. Things like cooking and cleaning may be a big help. Don’t be afraid to ask for help from other friends and family. They won’t mind cooking a casserole or folding laundry.

Planning for the Future
A common feeling both caregivers and people with cancer share is uncertainty. No one knows what the future holds. While planning isn’t easy, it can help. Try to schedule fun activities on days when your loved one feels up to it. You can also give yourselves something to look forward to by planning together how you’ll celebrate the end of treatment or each stage of treatment.

Accept the “New Normal”
Patients and caregivers both experience changes in normal roles after a cancer diagnosis. It may mean managing family finances when your spouse normally did that or taking on new day-to-day chores. It’s likely that your responsibilities as a caregiver will create new routines.
You’re taking on a new role in your loved one’s life as well as your own. This can be a challenge.

It may be helpful to identify the parts of your life that you can still control like your own health and relationships. By doing this, you’ll be able to create a strategy for mixing new routines in with old ones. It may also help to recognize that your home life, finances, and friendships may change for a season of time. Sometimes the laundry might not get done, or maybe takeout will replace home cooking. Manage each day’s priorities as it comes. It’s okay to put other tasks on hold. Taking care of yourself is also a crucial aspect of caregiving. Take a deep breath and realize that the support you provide means more than you can know.
If your loved one or friend has just been diagnosed with cancer, you may have a lot of questions. In the next few pages, learn more about how to care for a cancer patient during treatment.

**Preventing the House for Your Loved One**

**Making Home a Safe Place**

During and after cancer treatment, your loved one may find life at home more difficult than before. He or she may benefit by making some basic physical changes to the home. This can make life easier and safer.

Helpful changes that can be made include:
- Clothing rods in closets that are easier to reach
- Easy-to-get-to kitchen appliances and sinks
- Lowered bed height
- Floor surface that’s easy to walk or use a walker or wheelchair on
- Cart with wheels to reduce the need to carry things
- Door lever handles instead of turn knobs
- Ramps to get into the home easier

Helpful changes to your bathroom:
- Add a shower seat
- Hand-held showerhead
- Safety or grab bar
- Raised toilet seat or commode

You can make some physical changes without needing a contractor. Family or friends may be able to do the work. Bigger changes, like designing and building a ramp, may need to be done by a contractor. You may need a building permit to make more outside changes to your home.

**Cleaning Tips**

You'll be helping clean the house for your loved one. During cancer treatment, the patient’s immune system may be weaker and less able to fight off infections or the common cold. Keeping the home clean is an important part of caregiving.

There are some things you should know. Many household cleaners contain toxic ingredients. Chemicals in cleaning products can enter our bodies through the air we breathe, through our skin, and even through the water we drink. Chemicals aren’t good for us and high exposure can be a risk factor for cancer patients.

Despite all the advertising messages, you don’t have to spend a lot of money for safe cleaning supplies. Vinegar and baking soda are nontoxic items most of us have in our homes, and they
make effective and affordable cleaners. Mix baking soda and water into a paste to clean the oven and tackle toilet stains. Clean and shine mirrors, windows and floors with a vinegar and water mixture.

Follow these tips to safely clean your home and protect your family from harmful chemicals:

- Use products that are free from chlorine, ammonia, synthetic solvents, and artificial fragrances and dyes.
- Use products made with plant-based ingredients instead of petroleum-based ingredients. Good ingredients to look for include lemon juice, lemongrass, limonene (extract from orange peels) and tea tree oil.
- Use pump sprays instead of aerosols.
- Clean with the windows and doors open so you don’t trap air pollution inside your home.
- Never mix bleach with ammonia, vinegar, or other acids. These combinations can produce deadly gases.
- Avoid air fresheners. Use essential oils instead. Or, place a few cloves and orange rind in a small pot of boiling water and simmer to fill the house with a natural, delicious scent.
- Use a mechanical snake to unclog a drain.
- Use vacuums with HEPA filters that trap fine particles.

**Giving Care During and After Chemotherapy**

**About Chemotherapy**
Chemotherapy (chemo) uses medicines that prevent cancer cells from growing and spreading. Chemotherapy medicines destroy cancer cells or prevent them from dividing. Chemo affects the whole body and usually brings unwelcome side effects. Chemo doesn't refer to one treatment but many. There are a lot of different chemotherapy medicines. Some targeted therapies are also considered chemotherapy. Chemo can be taken by an IV in the arm or hand, through a port in the chest, or orally. Chemo treatment can be an overwhelming few months for your loved one. It can also be overwhelming for your family and for you. Chemotherapy is strong form of medication.

**How long is chemotherapy given?**
The length of chemotherapy treatment depends on the type of cancer, the extent of cancer, and the types of drugs given. Chemotherapy treatment is given in cycles. This means the cancer cells are attacked at their most vulnerable times, and the body's normal cells have time to recover from the damage.

Duration of the cycle: Chemotherapy treatment may be a single drug or a combination of drugs. They may all be given in one day, several consecutive days, or continuously as an outpatient or as an inpatient. Treatment could last a matter of minutes, hours, or even days, depending on the specific procedure.
Frequency of the cycle: Chemotherapy can repeat weekly, bi-weekly, or monthly. A cycle is usually defined in monthly intervals. For example, two bi-weekly chemotherapy sessions could be considered one cycle.

**Possible Side Effects of Chemotherapy**

Short-term side effects of chemotherapy are often manageable and can include:

- Nausea and vomiting
- Loss of appetite
- Mouth sores
- Weight loss
- Fatigue
- Pain
- Hair loss

Chemo can also damage the blood-producing cells of the bone marrow. This means patients may have low blood cell counts which causes certain side effects, like:

- Increased risk of infection
- Bleeding or bruising after cuts or injuries
- Excessive tiredness or fatigue

Due to the increased risk of infection, the patient should not be exposed to friends and family members who are sick. A common cold for a healthy person can be much more serious for a cancer patient with a compromised immune system from chemotherapy.

Everyone’s body is different, so people experience different effects from chemo. The healthcare team will watch for side effects and help your loved one manage them. Most side effects go away after treatment ends. As an example, hair lost during treatment almost always grows back after treatment. Most patients are able to use wigs, scarves, or hats to cover, warm, or protect their heads.

**Notify the doctor if you notice any of the following:**

- Chills or fever (a temperature of 101°F or more)
  - Call the doctor immediately if your loved one develops a temperature.
- Shortness of breath, chest congestion, unusual cough, or sore throat
- Burning discomfort when urinating
- Pain, redness, or sores in the mouth
- Nausea, vomiting, or inability to eat or drink for more than 24 hours
- Diarrhea for more than 24 hours
- Constipation (no bowel movement in 2-3 days)
- Bleeding or bruising
- Pain current medications can’t control
- Any new or unusual symptom that causes concerns
What are they thinking?
Many cancer survivors report cognitive (mental) issues during and after cancer treatment. These issues include:
- Forgetfulness
- Memory loss
- Confusion
- Loss of concentration

Though these side effects are commonly referred to as “chemo brain,” factors other than chemotherapy can lead to cognitive side effects like:
- Brain cancer or brain metastasis
- The need for surgery or 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, as well as the age and overall health of the patient. If the cause is medication, cognitive issues should improve once the medication is stopped. If the brain or nervous system is damaged by surgery or radiation, side effects may not improve over time.

Delirium is a serious cognitive issue that includes 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. It’s most likely to occur in advanced cancer patients or those nearing end of life.

The direct cause of cognitive issues can be unclear, so they’re often difficult to treat. Healthcare professionals are continuing to research these issues as they relate to cancer and cancer treatment.

Home Chemotherapy Safety Tips
Depending on the types used, chemotherapy drugs may remain in the body for up to a week. The drugs are then released into urine, stools, and vomit. They can also be passed to other body fluids like saliva, sweat, semen, and breast milk. Other family members and friends, including children, babies and pregnant women, can safely visit your loved one while he or she is receiving chemotherapy. However, you should take the following safety measures listed below when caring for someone at home.
- Ask your medical oncologist about your individual situation.
- Put the lid down when flushing the toilet to avoid splashing. Do this for up to a week following treatment.
- Wash any items soiled with body fluids in a separate load. Choose the largest cycle that the fabric will allow. Line dry these items instead of putting them in the dryer.
- Keep disposable rubber gloves and cleaning cloths handy. Put any used gloves and cloths in a plastic bag before putting them in the bin.
• Wear rubber or disposable waterproof gloves when handling clothing or bed sheets soiled with body fluids like vomit, urine, or stools.
• If body fluids or chemotherapy medication spill onto household surfaces (like the carpet or a mattress), wear rubber gloves, soak up the spill with disposable paper towels, clean around the area with a disposable cloth and soapy water, and rinse the area with water.
• If medication spills on your skin, wash the area with soap and running water. If any redness or irritation caused by the spillage doesn’t clear up within the hour, call your healthcare team.
• Your loved one should avoid pregnancy while having chemotherapy. If she has a new baby, she’ll not be able to breastfeed during the course of chemotherapy.
• If the patient is your spouse, use a condom or a female condom if having sex within a week of chemotherapy treatment. Your doctor or nurse can give you more information about how long you need to use this protection.
• Chemotherapy tablets, capsules or injections should be stored as directed by your doctor or pharmacist. Do not keep them in a pill organizer with other medications. Keep them out of reach of children. Seal empty tablet containers in a plastic bag and return them to your pharmacy or hospital oncology department for disposal.

Giving Care During and After Radiation

About Radiation

Radiation therapy is also called radiotherapy or just radiation. It is a very effective way to destroy cancer cells. As defined by the National Cancer Institute, radiation is the use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill and shrink tumors. Radiation can be giving three ways:

• **External-beam radiation therapy**: The radiation comes from outside your body. It is targeted at a specific area of the body. This therapy usually consists of daily treatments over several weeks.
• **Internal radiation therapy (brachytherapy)**: A radiologist places radioactive material inside the body. These “seeds” give off radiation to destroy nearby cancer cells. The seeds may be placed inside the body with needles, catheters, or minor surgeries. Some of the seeds are permanent, and some are temporary. The permanent seeds stop giving off radiation over time. They do no damage by remaining in the body.
• **Systemic radiation therapy**: The patient swallows or receives injections of radioactive substance. This substance helps destroy cancer cells throughout the body.

Your loved one will need help during radiation treatment for cancer. This may include simple housework help like cooking and cleaning, nursing care, and/or managing their medicines.

The best way to provide care during this time is to help the patient get extra rest; eat a balanced, nutritious diet; treat the skin with lotions approved by the health care team; minimize exposure to the sun; and provide emotional support.

Food and Drink During Treatment
People undergoing radiation to the head, neck, or stomach area may experience too much nausea or fatigue to eat and drink like normal. It may help to offer smaller meals or snacks throughout the day. It’s also important to encourage them to stay hydrated. Bland foods and foods with little odor may help with nausea. Other side effects like mouth soreness and diarrhea may keep the patient from eating well, too. Ask the care team for help with these concerns, and ask your loved one how you can help.

**Side Effects of Radiation**

Radiation therapy causes few or no side effects for some people. For others, the side effects can be severe. Reactions usually begin during the second or third week of treatment and may last for several weeks after the final radiation treatment. The healthcare team can work with you to help ease or prevent many of these side effects. Your support is an important part of cancer treatment.

The most common side effects of radiation include fatigue and redness or dryness at the treatment site. Other side effects of radiation depend on the area being treated. For example, if the patient is being treated for mouth cancer, the patient may experience mouth sores or jaw stiffness. If the patient is being treated for colorectal cancer, the patient may experience diarrhea or digestive issues.

Side Effects (depending on the area being treated):

- Skin problems, like dryness, itching, blistering, or peeling
- Fatigue (constant tiredness or exhaustion)
- Dry mouth, difficulty swallowing, mouth sores, stiffness in the jaw
- Nausea and vomiting
- Diarrhea
- Shortness of breath
- Breast or nipple soreness
- Shoulder stiffness
- Cough
- Fever
- Pneumonitis (an inflammation of the lung)
- Rectal bleeding
- Bladder irritation
- Sexual problems
- Vaginal itching, burning, and dryness
- Inability to conceive a child or maintain a pregnancy

Nausea, vomiting, and diarrhea will likely disappear when treatment is completed. The doctor can prescribe medications for these side effects, and making changes to your loved one’s diet may also help.

Though most side effects go away after radiation is over, some long-term side effects may pop up months or even years after treatment ends. These late effects may even include developing a second cancer. The risk of developing a second cancer because of radiation therapy is low, and this risk is generally outweighed by the benefit of treating the primary, existing cancer.
Everyone’s experience with cancer treatment is different. It’s important to communicate with your healthcare team throughout the treatment schedule. Though there are many options for managing side effects, doctors and nurses need to know your loved one is experiencing them in order to help them feel better.

**How to Help Ease Side Effects**

- Help schedule friends and family members for things like preparing meals, cleaning the house, yard work, or running errands for the patient.
- Don’t push the patient to do more than they can.
- Help the patient set up a routine for activities during the day. When the patient is nauseated, offer to make meals or (ask others to make meals) that reduce food odors. Use kitchen vent fans to reduce smells.
- If the patient is vomiting for more than a few days, weigh them at the same time each day to help decide if dehydration is getting severe.
- Talk to the doctor about medicines that helps prevent vomiting and dizziness.
- Try to help the patient get plenty of fluids to avoid constipation and dehydration which can makes nausea worse.

**Will the radiation they receive during treatment be harmful to me?**

Patients receiving external radiation therapy are only exposed to radiation during treatment itself. There are two types of radiation treatment that could pose a risk of radiation exposure to you as a caregiver however: internal radiation and systemic radiation.

If the person you’re caring for is undergoing one of these treatments, there are some precautions you should follow to protect yourself. You may need to avoid physical contact with your loved one for a while, or limit the time you spend close to them.

The healthcare team can help you understand exactly what you should and shouldn’t do as a caregiver while treatment is under way.
Helping Your Loved One After Surgery

After surgery may be when your loved one needs the most care and assistance from you. In the following sections, learn about wound care and common side effects of surgery. If the patient needs an ostomy or mastectomy drain bulbs following surgery, learn how to properly care and clean these systems.

Wound Care: Helping Your Loved One Recover from Surgery

If the cancer survivor you’re caring for recently had surgery, you may have questions about caring for their surgical wounds. Here's what you need to know.

Different Wound Closures
After surgery, the surgeon may have closed the wound with stitches, staples, butterfly bandages (flexible skin-closure tapes), or adhesive glue depending on the type of surgery.

- **Stitches (sutures)** are the most common way to close wounds. They're made of nylon or silk material that looks like thread or fishing line. Some stitches dissolve after several days. Others must be removed by a nurse or the surgeon once the wound has healed.

- **Staples** are metal clips that hold the edges of the wound together. Wounds closed with staples may actually heal faster than those closed with stitches.

- **Butterfly bandages** are small strips of paper tape that hold the wound edges together. They can be used alone or with staples and stitches.

- **Adhesive glue** is often used on small wounds that aren’t very deep.

Most wounds heal within 2 weeks in healthy adults. Healing may take longer for those recovering from other cancer treatments and/or chemotherapy.

Wound Care and Healing Tips
The key to promote faster wound healing is for patients to eat a nutritious diet high in vitamin C, protein, and zinc. Citrus fruits and green vegetables like broccoli and Brussel sprouts are rich in vitamin C. Meats and milk products are high in protein and zinc. The doctor may suggest multivitamins or nutritional supplements.

Following the surgeon’s directions, keep the wound as clean and dry as possible for the first three days. The surgeon will tell you if the patient can shower after that. He or she will need to avoid baths, swimming pools, and hot tubs until the incision is completely healed to avoid infection.

The wound may be bandaged with gauze or another type of dressing. Just before going home, the surgeon or nurse will probably change the dressing, check the wound, and put on a new dressing, depending on the type of surgery and whether it is inpatient or outpatient.
If the patient goes home with a dressing on the wound, you'll need to change it every 1 to 2 days, as directed, and check the wound for any redness, drainage, swelling, or other problems. Make sure you wash your hands thoroughly with soap and water before and after touching or changing the dressing. Keep the dressing clean and dry.

If there are butterfly bandages, they may peel back a little bit a few days after surgery. Leave them alone until they fall off completely.

The patient may have pain or numbness around the wound at first. This is normal. The surgeon will prescribe medicine that should keep the patient comfortable. For the first few days after the operation, help make sure pain medicine is taken regularly or at the first sign of pain, as directed. Notify the surgeon immediately if the pain suddenly gets worse.

The wound may itch for a few days after surgery. This may or may not be a problem. It could mean there’s an infection or the stitches are too tight. Encourage the patient not to scratch the area, and call the surgeon if he or she is uncomfortable.

The patient may have a tube (or drain) in the surgical site to help remove extra fluid or blood. The fluid collects in a bag or small container. In a little more than a week, you should see less drainage, and it may lighten in color. Many surgeons will remove the drain when drainage is less than 30 mL (1 ounce). If there is a drain, empty the drainage bag three times a day. Keep track of how much fluid is collected. Follow the directions you both were taught in the hospital and try not to separate the drain from the bag.

Moving around is usually good even after surgery, but while the wound is healing, don’t let the patient overdo it or put any strain on the wound site. The patient should also avoid bending, lifting, or being too active. Your surgeon will tell you when the patient can get back to picking up small children, doing heavier household chores, and carrying groceries. In the meantime, if they feel up to it, they can continue light housework and activities depending on where the wound is located. Light exercise will also speed recovery. The surgeon will be able to tell you which ones are safe to do.

Scars from surgical wounds can sunburn easily. Help keep them covered or apply sunscreen once the wound is healed. Consider using green-colored concealer under makeup to help hide a red scar. Lotions and skin softeners also can soften scars.

When to Call the Doctor
Call the surgeon immediately if the patient experiences any of the following signs and symptoms:

- chills or fever over 101 degrees
- warmth, redness, swelling, or new pain at the wound
- pus, a bad smell, or more drainage than usual from the wound or drain
- sudden, extra bleeding from the wound or drains
- feeling of hardness or fullness around the wound
• any opening of stitches or staples

If the wound pops open, calmly cover it with gauze or a clean towel wet with salt water or clean water. Call the surgeon right away for more directions or go to the nearest emergency room.

**Common Side Effects of Cancer Surgery**

• **Pain**: Pain is common after any surgery. The amount of the pain depends on many factors, like the location of the surgery, how large the incision was, and how much tissue was removed. The pain decreases as the body heals. Pain medications can help with discomfort.

• **Fatigue**: Major surgery leaves patients tired, especially if the surgery involved the abdomen or chest. Anesthesia plays a part, as well. Healing also requires a lot of energy. Fatigue usually goes away within two to four weeks after surgery.

• **Appetite loss**: Poor appetite after surgery is common, especially with general anesthesia. This may cause temporary weight loss. Most patients regain their appetites and return to their normal weights as the effects of the surgery wear off.

• **Swelling**: Some swelling around the surgical site is natural after any surgical procedure. A surgical cut (or incision) in the skin is a form of injury and the body's natural response to injury is the inflammatory process, which results in swelling. As the wound heals, the swelling usually goes away.

• **Drainage**: There may be drainage from the site of surgery. Sometimes fluid builds up at the surgery site and drains through the wound. If the drainage smells bad or is accompanied by fever and redness, there may be an infection. Contact the surgeon or nurse navigator to have it checked out if there are signs of infection.

• **Bruising**: You may notice bruising around the surgical site. Some bruising is normal and part of the healing process. If the bruising is accompanied by significant swelling, contact the surgeon or nurse navigator to have it checked out.

• **Bleeding**: There is some blood loss in almost any surgery. The blood loss is usually minimal, and it doesn’t affect the normal function of the body. However, some surgical procedures cause the loss of a larger amount of blood, and the surgical team will have blood available if a transfusion is needed. The patient may also experience some bleeding from the wound after surgery. If this happens, cover it with a clean, dry dressing, and contact the surgeon or nurse navigator. If there’s a large amount of bleeding, apply pressure until it can be seen in your surgeon’s office or the local emergency room.

• **Infection**: An infection can happen at the site of the incision or elsewhere in the body. Surgeons know how to minimize the risk of infection during the operation. The healthcare team will share ways to prevent infection during recovery through proper
care. Signs of infection include redness, warmth, increased pain, and/or drainage from the wound. If these signs occur, have the wound checked out by the surgical care team. Antibiotics usually help treat most infections.

- **Lymphedema**: This is a common side effect after a lymph node dissection, which is the removal of lymph nodes. Lymphatic fluid collects in the surrounding tissues, making them swell and causing pain and tightness. It can also limit the movement and function of the area affected, like an arm or leg. Therapy or compression sleeves prescribed by a doctor can help manage this side effect. If lymph nodes have been removed under the arm avoid the following with the affected arm:
  
  o Heavy lifting
  o Tight clothing or jewelry
  o Sunburns
  o Injuries
  o IV’s or blood pressure checks

- **Organ dysfunction**: Sometimes cancer surgery in certain areas of the body, like the abdomen or chest, may cause temporary problems with the organs in those areas. For example, after abdominal surgery the patient may experience constipation or diarrhea as the bowel begin to move again. Organ dysfunction after surgery is usually temporary, and it usually goes away as the body heals.

Other Concerns After Cancer Surgery

**Dietary Concerns**

During recovery, the body needs extra calories and protein for healing. Eating regular food may be difficult though, depending on the type of surgery. The removal of any part of the mouth, throat, stomach, small intestine, colon, or rectum decreases appetite, limits the body's ability to take in nutrients, and increases problems after eating, like gas, cramping, or constipation. Some patients have difficulty chewing or swallowing food. Surgery for stomach cancer may impact the body's ability to absorb certain vitamins. Doctors usually prescribe vitamin supplements to help with this problem.

To eat well after surgery, follow these general guidelines:

- Talk to the healthcare team or consult a dietitian for help with nutrition after surgery.
- Take all vitamins and medications as prescribed by the doctor.
- Eat many small meals and snacks throughout the day.
- Always include a good source of protein such as meat, fish, beans, eggs, tofu, or nuts.
- Choose a variety of fruits and vegetables.
- Avoid fats and sweets.
- Drink plenty or water and fluids.
Body Image
Cancer surgery may change the way the body looks, feels, and functions. This can affect the patient’s body image, making some people feel insecure. The emotional side effects of cancer surgery may be hard to overcome for some. A counselor can help your loved one cope with these body changes. Some patients also find it helpful to join a support group of other patients who have gone through similar surgeries.

Caring for an Ostomy

How often should I change the pouch?
In most cases, the patient can change their own pouch, but he or she may need your help. How often you will need to change the pouching system depends on the type of stoma, the location, and the kind of drainage. There are three basic types of ostomies. Urostomies are for urine, colostomies are for drainage of the large bowel, and ileostomies are for drainage of the small bowel.

Using the right type of pouch system and putting it on the right way will affect how long your loved one can wear it. How long it can be worn can be affected by other factors as well like activity level, body shape, and perspiration. Many pouching systems are made to be worn for three to seven days. There are some pouching systems that are made to be changed every day. Contact the healthcare team if you or your loved one is changing the pouch system more often than expected or more frequently than the normal wear time.

When is a good time to change the pouch?
The best time to change the pouch system is different for everyone. The actual day and time is up to you and the patient. Try to pick a time when you won’t be disturbed and when the stoma is not putting out a lot of drainage. For most, the stoma is less active before eating or drinking in the morning. Some people prefer to change the pouch while taking a bath or shower. Others choose the end of the day or at least two hours after a meal.

How do you remove the old pouch system off?
Take your time when removing the pouch system. You don’t want to rip it off. This may hurt the skin. Try to remove it in the direction the hair grows. Loosen and lift the edge with one hand and push down on the skin near the skin barrier with the other hand. It’s usually easier to start at the top and work down to the bottom so you can see what you’re doing. That also allows the pouch to catch any drainage. Some people use warm water to remove the pouch system and others use adhesive remover. If you use adhesive remover, make sure you wash off all the adhesive remover from the skin with soap and water. Dry the skin completely before putting on the new pouching system. Skin discoloration is common and should fade away in a few minutes.

Cleaning Around the Stoma
All you really need to use is warm water and a washcloth or good quality paper towels to clean around the stoma. You don’t need to use soap to clean around the stoma, but if you do, use a mild soap that doesn’t have oils, perfumes, or deodorants. These can sometimes cause skin problems or keep the skin barrier from sticking. Rinse any soap off the skin around the stoma.
carefully. The residue may keep the skin barrier from sticking and can also cause skin irritation.

You may see a small amount of blood on your cloth. That’s normal. The stoma tissue contains small blood vessels. However, any bleeding that doesn’t stop should be reported to your health care provider.

The stoma has no nerve endings, so if you’re rubbing too hard, the patient won’t feel it. Be gentle when cleaning around the stoma. Don’t scrub. Don’t use alcohol, moistened wipes, or any other chemicals to clean the skin or stoma. They may be irritating to the patient’s skin. Unless recommended, don’t apply powders or creams to the skin around the stoma. They can keep the skin barrier from sticking.

What about the used supplies after changing the pouch system?

- Put the used pouch system into a plastic grocery bag and throw it away in your household garbage. Empty the pouch into the toilet first. Keep one or two plastic bags in a pocket or purse to help keep odor down when disposing of the pouch away from home.

- If you used a washcloth to wash the skin, wash it with your household laundry. Some people who wear a two-piece pouching system choose to remove the pouch to empty it and then attach a clean one. They may decide to rinse out the used pouch and reuse it later.

- Some people use reusable pouch systems that can be used over and over again. If you use this type of pouch, follow the manufacturer’s cleaning instructions. Wash the clamp and connector with mild soap and water. Wash your hands after taking care of the ostomy.

Can the pouch system wet?

Yes. Pouch systems are waterproof. Patients can shower, bathe, or even swim with the pouch system on. It’s a good habit to empty the pouch before any of these activities though. The pouching system may start to loosen up from the skin if in the water for a long time. On the day you plan to change the pouch system, the patient can either leave it on or can take the whole thing off to take a bath or shower. Some people prefer to shower or bathe without their pouch system. Take note that because the stoma has no muscle, urine or stool may drain from the stoma while showering or bathing.

Water won’t hurt the stoma. If the water pressure is strong don’t let it hit the stoma directly. Only use a gentle spray of water on the stoma. Some people secure the edges of the skin barrier with waterproof tape. Others use paper tape and then wipe the paper tape with a skin sealant to make it more waterproof. Gas filters don’t work after they get wet. It’s best to protect the filter with waterproof tape before water activities. After bathing or swimming, use a towel or a hairdryer on the coolest setting to dry the tape and cloth packing of the pouching system to prevent skin irritation from wetness.
How can you prevent infection?
The stoma is protected by mucus, so stool or urine won’t hurt it. Stomas rarely become infected. It’s important to protect the skin around the stoma. A correct fitting pouch system is the best way to prevent a skin infection. If you notice any signs of infection, speak to the healthcare team right away.

How can I prevent leaks?
Always empty the pouch before it reaches half-full. Release gas before the pouch gets too full. If your loved one has a lot of gas, consider using a pouch with a vent or filter. There are some medications that can be used to reduce gas. Check with your healthcare provider or pharmacist to learn more about these medications.

Caring for Mastectomy Drain Bulbs

The Drain
Patients who have breast cancer surgery may leave the hospital with one or more drains. The type of drain most commonly used is called a Jackson Pratt (or JP) drain. This drain consists of a small plastic reservoir bulb connected to a flexible drainage tube. It removes fluid from the surgical wound through a mild suction. This helps prevent swelling and reduces the risk for infection. The tube is held in place by stitches. This drain stays in place for an average of one to two weeks and can be removed by your surgeon.

Drain Care
A nurse will show you how to properly empty the drain and record how much fluid came out of the wound. Secure the bulb to clothing with a safety pin. This will help keep the tube from pulling out. The healthcare team will remove the drain when it’s no longer needed.

Stripping the Tube
“Stripping” or milking the tube will help to keep the tube clear of blood clots. Ask a nurse how often the tube should be stripped. Follow these steps:
- Hold the tubing with one hand where it leaves the skin to keep it from pulling on the skin.
- Pinch the upper end of the tubing with an alcohol wipe covering the thumb and first finger of your other hand.
- Firmly but slowly pull your thumb and first finger down the tubing. The alcohol wipe will let your fingers slide.
  - Stop pulling if it hurts or feels like the tube is coming out of the skin. Try again but more gently.

Emptying the Drain
Empty the drain twice a day or as often as instructed by the doctor. Empty it more frequently if the drain is full. Follow these steps:
- Wash your hands.
- Strip the tube. Lift the cap on the drain opening.
- Drain the fluid into a measuring cup. Wipe the drain opening clean.
- Squeeze the bulb until it is collapsed. Replace the cap while the bulb is collapsed. This will create a vacuum that helps drain fluid from the surgical site.
- Wash your hands again.
- Record the amount of fluid each time you empty the drain. Share this information with the doctor on your next visit.
- Dispose of the JP drainage (once it is measured) either down the sink or toilet.

**Changing the Dressing**
If keeping a bandage over the drain, change it every day. Follow these steps:
- Wash your hands.
- Remove the old bandage.
- Clean the area with an alcohol wipe where the stitch holds the tube in place.
- Put a new bandage on the incision and tube site. Make the bandage large enough to cover the whole incision area.
- Tape the bandage in place.

**Additional Practical Tips**
- If worn, bras should be supportive but not too tight. Some women prefer bras with front closure (like a sports bra with front closure).
- Wear clothes that are easy to get on and off while the drain is in place (like button down or zipper front shirts).

**When to Call Your Doctor**
Call your doctor right away if the patient has any of the following:

**General**
- Vomiting
- Fever of more than 100.4°F

**Incision**
- Incision seems to not be healing
- Redness, swelling, or warmth around the incision or tube
- Stitches get loose

**Drain Tube**
- Tube falls out
- Fluid leaks around the tube
- New or more pain around tube

**Drainage**
- Bad odor
- Drainage changes from light pink to dark red
- Sudden increase or decrease in the amount of drainage (over 30 mL, or about two tablespoons)
Nutrition

Nutrition and food are important in supporting health and recovery during cancer and cancer treatment. The food challenges begin when cancer, side effects, and appetite changes affect the patient. Favorite foods or go-to beverages may not be best the choices for the patient. Perceptions about what is healthy to eat and isn’t healthy to eat can also be an issue. The role of the caregiver is important in helping the patient make good food choices.

Caregiver’s Role in Nutrition

First, remember that your loved one may feel like he or she has lost a lot of control since being diagnosed with cancer. Just think about all the appointments, treatments, and medications. Yet, food choices and when to eat or not to eat are some of the few decisions still under the control of the patient. There are many factors that influence these food decisions. Understanding these factors may help you in your caregiver role.

Influences on Food Choices

As you look at this diagram, you can see that many factors influence a cancer patient’s food choices—health, treatment, facts, social factors. For example, a patient may know the fact that food promotes healing, but if the patient feels nauseated after chemo treatment, he or she may not want to eat. Even if a patient’s health isn’t strong enough for alcohol, he or she may feel social pressure to drink when out with friends. These are just a few examples of how these factors may interact.

Food provides valuable nutrients for cancer patients. Eating well during cancer treatment can help speed recovery, ease side effects, and keep the treatment plan running smoothly.
However, your loved one may not be able to plan grocery lists, grocery shop, eat, digest foods, or prepare meals like before cancer. This is where you as the caregiver can help. Depending on the health of the patient, you may need to assist with grocery shopping, meal prep and cooking, and encouraging the patient to make healthy food choices.

As a caregiver, there are many ways you can assist with food and meals. To get started, ask the healthcare team about specific foods or meal recommendations and restrictions, if any. A printed meal plan or food list is best. Ask to speak to a registered dietitian for help.

During cancer treatment, there may be times when your loved one needs to follow a special diet. Some examples of special diets include: clear liquid, full liquid, low-fiber, or low-iodine. The first three diets listed are common after surgeries that affect the digestive system. If the patient has thyroid cancer, he or she may need to be on a low-iodine diet while receiving radioactive iodine treatment. The healthcare team will let you know when a special diet is needed and provide you with specific guidelines to follow. Ask to speak to a registered dietitian for extra help. You can also visit mypearlpoint.org for more information on special diets.

Foods that you or a healthy person can eat may not be what a person with cancer can eat. Even what one cancer patient can eat may be different from what another cancer patient can eat. You and the patient may be bombarded with stories of miracle foods and diet tips by well-meaning family and friends. Remember—if something is too good to be true, it probably is. Always consult the healthcare team to know what’s best for your loved one.

Food choices are one of the few things over which a cancer patient has control. In some cases, food and food choices may be a touchy subject for your loved one. The patient may be resistant to eat at times. Try to encourage the patient without being too forceful. Cancer treatment is an emotionally challenging time. Before disagreements over food turn into full-blown fights or arguments, use counselors, pastors, chaplains, and other resources to help sort out any differences that may arise as you attempt to care for your loved one.

**Grocery Shopping Tips**

A trip to the grocery store for someone with cancer may be a tiring event. Some patients may need a little help such as a ride to the store or help carrying heavy items. For others with limited stamina and immunity, grocery shopping may not be possible. Here is where a caregiver, friends, relatives, and neighbors can really provide help! Use these grocery shopping tips to make the trip easier.

**Shop with a list:** Use the “Grocery List” list in the back of the handbook to get you started with a fully stocked pantry. Make copies of a standard a grocery list that can be added to each week which includes perishables like milk and bread. Add in-season fruits and veggies. Add any new items for changes in special dietary needs.

mypearlpoint.org 24
Be an early bird: Shop early in the day if you live in warmer climates so the food will stay cold while driving, and it will be cooler while unloading the groceries at home.

Bring a cooler: If you plan to buy chilled or frozen foods, take a cooler with you to keep the food at a safe temperature until you make it home.

Check the dates: Cancer patients often have decreased immunity. This means that they are at a greater risk for infection and disease. Be sure to only purchase foods that have not passed the expiration date. Also, don’t purchase foods with damaged packaging.

Read the label: Some dietary restrictions may limit specific ingredients like acid, alcohol, fiber, grapefruit, iodine, lactose, or sodium. The healthcare team or a registered dietitian can provide a written list of suggested and restricted foods.

Grab cold foods last: When shopping, select fresh items and room temperature items first. Then grab cold and frozen foods right before you check out at the grocery store. This helps keep the cold and frozen foods at a safe temperature on the drive home.

Use coupons: Look online and in the newspaper for coupons, especially for protein beverages and supplemental products recommended by the healthcare team. Some specialty products can be pricey. Check out the product websites for coupons or contact the manufacturer.

Save the receipt: Saving the receipt can help you and/or your loved one stick to a budget.

Treat your loved one: Your loved one may be on a limited budget for food. If you spot a special food, flower, or magazine that the patient might enjoy, pick it up for him or her.

Food Preparation

Fatigue, sensitivity to odors, and other side effects may make preparing food difficult for your loved one. Stress is another factor that may affect meal planning and cooking. Cognitive changes such as memory loss may even present a safety hazard for the patient. As a caregiver, food preparation may be the best way to help your loved one. You may want to reach out to family and friends for additional help. Here are some tips to help make food preparation easier:

- Maintain the self-esteem of the patient.
  - Offer to help with the prep work like chopping veggies or marinating meats, but let the patient do the actual cooking if able.
- Small may be better.
  - Your loved one may not have much of an appetite, so smaller portion sizes may be the way to go.
Serving small meals frequently through the day allow for better digestion, fewer stomach upsets, and more energy.

- Use smaller plates and cups to help control portion size.

- Ask for requests.
  - If you are preparing a meal as a caregiver, check with your loved one to see what food and drink sound good.
  - Try to avoid serving the same thing every day, unless the patient requests it.

- Avoid fat.
  - Prepare food by baking, slow-cooking, grilling, or broiling to limit fat. Fats can make some digestive issues worse.
  - But, there is an exception! If the patient needs to gain weight or stop losing weight, add in healthy fats and oils to add extra calories to the food.

- Check the spices.
  - Changes in taste and smell are common side effects of cancer treatment.
  - Check in with the patient. You may need to adjust or change spices for changing tastes.
  - If your loved one complains of a metallic taste, switch to plastic utensils and plates.

- Keep aromas to a minimum.
  - Sensitivity to smells or odors is another side effect of cancer treatment. If odor is an issue, cook while the survivor is out of the house or asleep.
  - Use fans to move food aromas and cooking smells out of the kitchen and house.
  - A small personal fan at the dinner table also may be helpful.
  - Prepare cold meals like sandwiches, fruit and cheese plates, crackers with peanut butter and celery, and smoothies.
  - Use cups with lids and straws.

- Write it down.
  - Friends and family may want to help prepare meals. Keep a list on the refrigerator of who is bringing what and when.
  - Label prepared foods with an eat-by date.
  - You can also use online resources to help with meal planning and coordination. See the “Nutrition Resources” section later in the Handbook.

- Sip liquids between meals.
  - Staying hydrated is important, so let your loved one sip liquids between meals, but stop drinking 30 minutes before a meal or snack to build an appetite.
  - Drinking too much at a meal, especially low-calorie beverages, can replace vital nutrient dense foods like meat, vegetables, and fruits.
  - Limit drinks with meals so more solid foods with calories can be consumed.

- Serve moist foods.
Foods with moisture like tomatoes, fruits, other vegetables, gelatin, soups, puddings, and ice cream all provide water. So, the patient won’t need a big glass of water with the meal.

Moist foods require less cutting and chewing which conserves energy to eat the rest of the prepared food.

Moist foods are also easier to swallow.

- Use pictures of food to stimulate appetites if your loved one doesn’t want to eat.
  - Seeing food advertisements and magazine pictures can help stimulate the appetite or trigger memories of good meals.
  - Share your magazines or grocery store ads with the patient, and use them for meal ideas.

- Be social.
  - Meals are only healthy and nutritious if the patient consumes them. Making meals social and fun can help with appetite.
  - Sit down and eat with your loved one and talk about something other than treatments and meal preparation.

**Food Safety**

The immune system is weakened during all types of cancer treatment. 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. Neutropenia refers to a very low neutrophil (white blood cell) count. 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. Encourage the patient to do the same.
- 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.
- Disinfect all food prep surfaces including sinks and countertops before and after cooking.
Cook food thoroughly.

- Avoid raw meat such as sushi, undercooked eggs, 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. Use this chart for reference:

<table>
<thead>
<tr>
<th>Meat</th>
<th>Internal Minimum Temperature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ground Beef</td>
<td>165º F</td>
</tr>
<tr>
<td>Turkey</td>
<td>165º F</td>
</tr>
<tr>
<td>Chicken</td>
<td>165º F</td>
</tr>
<tr>
<td>Steak or other cuts of beef</td>
<td>160º F</td>
</tr>
<tr>
<td>Whole chicken, turkey, duck, or goose</td>
<td>180º F</td>
</tr>
<tr>
<td>Pork</td>
<td>170º F</td>
</tr>
<tr>
<td>Egg dishes</td>
<td>160º F</td>
</tr>
<tr>
<td>Casseroles</td>
<td>165º F</td>
</tr>
<tr>
<td>Reheated leftovers</td>
<td>165º F</td>
</tr>
</tbody>
</table>

Store food safely.

- Always store food within 1 hour of purchasing or cooking if the temperature outside is above 90 degrees.
- Label food with the date to use by with a marker or pen if the packaging does not have an expiration date.
- Put foods with the soonest expiration date at the front of the fridge or shelves so you are more likely to use them.
- Discard leftovers or open packages within 3-5 days.

Be careful when eating at restaurants and shopping for food.

- Buy only from trusted vendors with high grades in health department inspections.
- Avoid buying food from street vendors.
- Do not eat free food samples when shopping.
- Do not choose restaurants with buffets when eating out. If you are at a party, ask if your loved one can go through the buffet line first.
- At restaurants, ask for meat to be prepared well-done.
• If taking home leftovers, ask to bag the food yourself and make sure to refrigerate the leftovers quickly.

If you or the patient catches a foodborne illness, have a plan. Let the healthcare team know as soon as possible. Symptoms of foodborne illness include—fever, diarrhea, nausea, vomiting, and/or stomach cramps. Mark any recently eaten food or beverage as DON’T EAT. Keep the containers in the fridge in case the healthcare team wants to test any of the foods.

**Snack Ideas for Treatment Days**

Treatment days can be long, tiring, and wearing on your loved one. However, good nutrition can give you both a boost in energy and strength during treatment.

Remember to take snacks with you on long treatment and appointment days. Pack a small cooler or insulated, thermal bag with snacks and beverages. Toss in an ice pack to keep cold foods and drinks cold.

**Here is a list of some snacks and treats that are easy to tote along:**

- Bottled water, juice boxes, or sport drinks
- Individual yogurt cups
- Sting cheese, cheese cubes
- Boiled eggs
- Peanut butter sandwich
- Granola bars, trail mix, mixed nuts, dry cereal
- Hummus and pita chips or crackers
- Nutritional beverages
- Tuna or salmon packets with crackers
- Whole fruits such as a banana, apple, plum, or grapes
- Raw vegetables such as carrots, pepper strips, or cucumbers
- Single servings of applesauce, fruit cups, gelatin, or pudding cups
- Single servings of cottage cheese and fruit
- Peanut butter or cheese crackers

**Tips for Success:**

- Suggest a nutritional beverage if he or she doesn't feel like eating.
- Wrap foods with wax paper and use straws and cups with lids if odors are an issue.
- Ask for popsicles, ice chips, or ice cream while at treatments for extra fluid intake.

**Nutrition Resources**

**Supplemental Nutrition Assistance Program (SNAP)**

SNAP offers nutrition assistance to eligible, low-income individuals. Call your local Department of Human Services to apply. Find more information at [http://www.fns.usda.gov/snap/](http://www.fns.usda.gov/snap/).
**Food Banks**
Food banks and pantries offer food to families in need in the local community. Visit foodpantries.org or feedingamerica.org to find a food bank in your area.

**Meals On Wheels**
Meals On Wheels provides home-delivered meals to people in need. Find out more at mealsonwheelsamerica.org or call (888) 998-6325.

**Meal Train, Take Them a Meal, and Caring Meals**
As a caregiver you will also face the practical issues of cancer care such as managing insurance and taking time off work. Your relationship with your loved one may change as well as you transition into your new roles as caregiver and patient. In the following sections learn how to manage the practical challenges of caregiving as well as the changes in your relationship.

Managing Insurance and Finances

Health Insurance and Financial Help for Cancer Patients
Having health insurance coverage for cancer treatment and all of the needed follow-up care is very important for most people. It takes time and a lot of work to manage medical bills, insurance, and finances. This can be especially hard when a loved one has cancer.

It’s important to have correct, current information and a good understanding of insurance coverage and finances. If your loved one’s monthly health insurance premiums are not deducted from a paycheck, it’s important to make sure you pay them on time to keep the coverage. Having no health insurance can be scary, but there are still options.

Options for Private Health Insurance
The Affordable Care Act (ACA) is intended to make private health insurance more affordable, especially for those with serious diseases like cancer. Most insurance plans are supposed to cover the healthcare that cancer patients and survivors might need.

Group Health Plans
Many people get insurance coverage through a group plan offered by their employer. Group health plans cover a number of people, usually employees of the same company, and their dependents. Some employers pay a portion of healthcare premiums for their employees. (Premiums are the monthly payments required to continue coverage.) Under the new healthcare law, employers with 50 or more full-time workers must offer health insurance or pay a penalty. Employers with less than 50 full-time workers are not required to offer health insurance.

If health insurance is too expensive through their employer’s coverage (more than 9.5% of their income), the law allows employees to buy a different plan through their state’s health insurance marketplace and receive financial assistance to help pay for it. Most people who now get their health coverage through work will more than likely continue to do so under the healthcare law.

Individual Health Plans
Insurance companies sell individual health plans directly to individuals, not through an employer. Some individual plans also cover family members. For many years, individual health plans could change based on the situation. This included the types of healthcare services they covered, the amount of care they would pay for, how much they charged, and the types of
people they covered. For example, insurance companies could decide not to offer you a health plan, or they could charge you higher monthly premiums than younger, healthier people. They could require people who were sick or injured to pay more for their care or even turn them down altogether. Regardless of the level of coverage, most plans didn't completely cover the care needed by someone with a serious illness like cancer.

The ACA has made some major changes to individual health plans. Many of them are designed to improve the coverage these plans offer and to make these plans more affordable for people with cancer or other serious illnesses.

For example, the law:

- Requires health plans to cover those with pre-existing conditions like cancer
- Makes cancer screening tests, like mammograms and colonoscopies, available at little or no cost to patients
- Prohibits insurance plans from canceling coverage if the person covered gets sick
- Requires that most plans cover 10 essential health benefit categories
- Prohibits insurance plans from charging sick people more for coverage than healthy people
- Prohibits annual and lifetime dollar limits on the amount the plan will pay for
- Requires insurers to provide a short and simple summary of their coverage
- Allows young adults to stay on their parents' health insurance until the age of 26
- Helps individuals with low incomes buy health insurance
- Requires that most Americans buy health insurance or pay a penalty with their income taxes

**Health Insurance Marketplace**
You can buy your insurance coverage on the internet, by phone, through the mail, or in person through health insurance companies in each state. All plans sold must meet the requirements of the ACA and cover certain benefits. Visit healthcare.gov for more information.

**Types of Private Health Plans, and What You Must Pay**
There are many types of health insurance plans. Most of them require that you pay a monthly fee (premium). Most also require that you pay either a flat fee for doctors' office visits and other services (co-pay), or a percentage of the total cost (co-insurance). Each year, you'll likely have to pay a certain dollar amount of your medical costs (deductible) before your insurance will start to pay. After you've met your deductible, your insurance will pay a percentage of your bills for medical care for the rest of the year.

**Keeping Up With It All**
It can be a challenge keeping track of all the bills, letters, insurance claim forms, and other papers that stack up at home after a cancer diagnosis. Keeping careful records will help you manage your money better and lower your stress level. One smart idea is to keep a simple notebook with tabs for each month. It's an easy way to track bills, insurance, payments, and more.
Keeping records is also important for those who want to take advantage of the deductions available in filing itemized tax returns. The Internal Revenue Service (IRS) has information and free publications about tax deductions for cancer treatment expenses. These rules can change from time to time, so the IRS is the best source for up-to-date information. Visit www.irs.gov.

Keep records of the following:
- Dates, names, and outcomes of calls, letters, or emails to insurers and providers
- Medical bills from all health care providers with the date you got the bill written on each one
- Claims filed with the date of service, the doctor, and the date filed
- Payments from insurance companies and explanations of benefits (EOBs)
- Medical costs that were either not reimbursed or are waiting for the insurance company
- Meal, hotel, and travel expenses to and from doctor's appointments, treatments, or the hospital
- Admissions, clinic visits, lab work, diagnostic tests, procedures, and treatments
- Drugs prescribed and prescriptions filled

Some tips for keeping records:
- Consider sharing the responsibility of record keeping. Get the help of a relative or friend, if needed.
- Set up a file system using a file cabinet, drawer, box, or binders.
- Review bills soon after getting them and note any questions regarding charges.
- Check all bills and explanations of benefits paid to make sure they're correct.
- Paying bills by check offers a clear record of payment. If you pay bills online, you can save electronic copies of payment documents on your computer, or print them out as a proof of payment.
- Keep a daily calendar of events and expenses with any necessary notes.
- Keep a list of your healthcare team members and other contacts with their phone and email addresses.
- Ask your accountant what is tax deductible and be sure to keep the originals of those records.
- If you ever have questions, ask your hospital's billing department or your insurance as soon as possible.

Managing Finances
As soon as possible you and your loved one need to work through your finances. Create a budget. Use the Budget Worksheets at the back of the Caregiver Handbook for help. You'll need to consider some of the following things:
- Insurance deductibles and co-pays
- Prescriptions or other medical products
- Daily expenses such as groceries
- Rent or mortgage payments, including electric, water, etc.
- Transportation
- Child care
- Decreases in income for you and/or the patient due to time off work
After you’ve made your budget, stick to it as carefully as possible. If you are struggling to make ends meet, ask the healthcare team or a social worker for help. Many hospitals and organizations offer financial assistance for cancer patients. Your loved one may be eligible.

CancerCare allows you to speak to a social worker about your options. Call (800) 813-HOPE or visit cancercare.org for more information.

**Appointments and the Healthcare Team**

**Communicating with the Healthcare Team**

Your team of doctors, nurses, and social workers can offer crucial support and encouragement as you help your loved one through cancer treatment.

When the word cancer first came up, you may have felt shocked, scared or numb. Everyone reacts to the news in his or her own unique way. All caregivers face similar challenges though. You need to learn about the diagnosis and treatment options, understand how the treatment plan will affect your lives and find out what resources are out there.

Your relationship with the health care team can make a big difference in how well you cope with these challenges. Research shows that people who have good communication with their health care team are more satisfied with their medical care. They are also more emotionally stable and can better manage symptoms like treatment side effects and pain.

**Medical Appointments**

The best time to speak with members of the healthcare team is at appointments. It’s normal to feel nervous and worry you’ll forget to ask an important question when going in for an appointment. Good preparation can improve how comfortable you are and can make you more satisfied with your doctor visits overall.

Here are a few tips to help you better communicate with your healthcare team during appointments.

- Write down your questions. Number your concerns in order of importance, asking the most important questions first. Let the doctor know you have a list so he or she can set some time aside during the appointment to cover your questions with you.

- Take notes. Write down the doctor’s answers to your questions. Also write down any other important information you need to remember. This can include the names of the members of your health care team, dates and times of future appointments, and when and how to take any medicines your loved one was prescribed.

- Keep everything in one place. This way, nothing gets lost, and you always know where to find the information.

- Ask for a contact. Important questions will probably come up between appointments. Find out who you can talk to if you have an important issue or emergency. If your doctor
is not available, is there someone else like a nurse navigator or social worker you can call?

**FMLA for the Caregiver**

Caregiving can affect your work. It can be challenging to balance work and caregiving. Medical appointments and other responsibilities can interrupt your work day. You may not be sleeping well, or you could be distracted by feelings of anger, depression, or anxiety.

**What is the FMLA?**
The Family and Medical Leave Act (FMLA) helps employees balance their work and family responsibilities. It allows them to take unpaid leave for certain family and medical reasons for a specified amount of time. The FMLA gives employees the right to take up to 12 weeks of unpaid, job-protected leave each year. It also requires that the employee’s group health benefits be maintained during the leave. FMLA applies to all public and private employers with 50 or more employees.

Employers must provide eligible employees with up to 12 weeks of unpaid leave each year for any of the following reasons:

- For the birth and care of a newborn child
- For placement of a child for adoption or foster care
- To care for an immediate family member with a serious health condition
- When the employee is unable to work because of a serious health condition

Some states have family and medical leave laws with broader rights. The US Department of Labor can help you obtain this information about your state.

**Who counts as immediate family?**
For FMLA purposes, an employee’s spouse, son or daughter under the age of 18, and parents are considered immediate family members. In this case, "parent" does not include a parent in-law. The terms “son” or “daughter” don’t include those age 18 or over unless they’re unable to take care of themselves due to mental or physical disability that limits one or more of the major life activities. (The terms are defined in regulations issued by the Equal Employment Opportunity Commission (EEOC) under the Americans With Disabilities Act (ADA).) The term “parent” may include people who are acting as parents to the child, though their legal relationship may not be formalized.

**How far ahead of time should FMLA leave be requested?**
If possible, an employee must give an employer at least 30 days of notice before the leave is to start. Knowing that far in advance is rarely possible when you’re taking care of a loved one with cancer. You will need to let your employer know as soon as possible, at least within 1 to 2 business days of when you first learn you’ll need leave.

**Can I use FMLA to take off several short periods?**
FMLA leave can be taken all at once or it can be taken in shorter blocks of time, like two days a week, or one week a month, as long as it’s taken for a single reason. FMLA can also be used
to reduce the amount of time you work each day. You could work a part-time schedule for a while if that fits your caregiving needs. You’ll need a doctor’s note to verify that the medical condition is serious and you’re unable to work for these times. Your employer will need to see that your family member’s serious illness requires you to take this time for his or her care.

Options in Addition to FMLA:

- When possible, try to schedule the patient’s medical appointments and other caregiving jobs during your breaks or at lunchtime.
- Ask your supervisor about your company’s policy regarding caregivers. Find out if they allow flex-time or alternative work schedules.
- Offer to work an unpopular shift in exchange for flex-time.
- Many large employers offer an Employee Assistance Program (EAP). If your company doesn't have an EAP, talk with the human resources (HR) department. Ask your boss what support services they offer.
- It’s usually more trouble for your employer to replace you than help you make it work. If you’re thinking of quitting, talk with your boss first. He or she may be more willing to help than you think.

If you need some time away from work, speak with your boss or someone in your human resources office. If your workplace has an Employee Assistance Program, check out what it offers. Some offer counseling services to help with money concerns, stress, and depression.

You may also find that the people you work with treat you differently because of the reduced time you spend at work. You can tell your coworkers as little or as much as you like about your situation. In most cases, your coworkers will probably be understanding. Most people know someone or have a loved one who has been through a similar situation.

Advance Directives

The Living Will
A living will is a document that controls future healthcare decisions when a person becomes unable to make decisions on their own. It’s for those who have a terminal illness or permanent unconsciousness (in a “persistent vegetative state”). Laws vary from state to state, but they usually allow doctors to stop trying to keep a patient alive when these things happen. If a person has hope of recovery, the living will generally does not apply.

The living will lays out the type of medical treatment your loved one would want or wouldn’t want in these situations. It can describe specific conditions for treatments like dialysis, feeding tubes, or artificial life support.

The living will is a formal legal document. It must be written and signed by the patient. Most laws say it must be witnessed and notarized. The witnesses will need to be someone other than his or her spouse, potential heirs, doctors providing care, or employees of the health care facility. A living will may be changed at any time.

Some things to consider when writing a living will include:
• The use of equipment like ventilators (breathing machines)
• Do Not Resuscitate (DNR) instructions (orders not to use CPR if breathing or heartbeat stops)
• Fluid (usually by IV) and/or nutrition (feeding tube in stomach) if unable to eat or drink
• Treatment for pain, nausea, or other symptoms (often called “comfort care” or “palliative care”)
• To donate organs or other body tissues after death

It’s also important to know that there’s a difference between choosing not to have aggressive medical treatment and refusing all medical care. A patient can still get antibiotics, nutrition, pain meds, and other treatments. The goal of treatment can become comfort rather than cure. Your loved one will need to make it clear exactly what he or she wants and doesn’t want.

Terminal Illness
A terminal illness is a condition that can’t be cured that is expected to result in death in the near future or a state of permanent unconsciousness. In some states, life-sustaining treatment could continue, even if the patient is mentally incompetent, until just hours or days before death is expected. It’s important to know the laws in your state so you and your family know what could happen if the time comes to use your loved one’s living will.

Health Care Power of Attorney
A health care power of attorney is a legal document where a person is named to be your loved one’s proxy (spokesperson) to help make all health care decisions if he or she becomes too sick to do so.

As proxy, you can speak with doctors and other caregivers on your loved one’s behalf and make decisions about treatments or procedures according to directions they gave earlier. If their desires in a certain situation are not known, you will decide based on what you think your loved one would want.

It’s a good idea to have your loved one name a back-up person in case you become unable to act on his or her behalf. The request must be in writing, signed by the person choosing you as proxy, and witnessed. In many cases, you will also sign the document.

Donating Organs and Tissue
Your loved one can include organ and tissue donation instructions in the advance directive. Many states provide organ donor cards or add notations to his or her driver’s license. Organ donation may be able to help other people struggling with advanced diseases.

Stay Encouraged
End of life care can be physically challenging and emotionally exhausting. We all need encouragement, but perhaps never more than when you’re caring for someone you care deeply about who is suffering or nearing death. Know that many have been where you are and support is available.
Communicating with a Cancer Patient

Knowing What to Say and How to Say it
It’s important to learn what your loved one’s limits and needs are. It’s just as important to let your loved one know your own limits and needs. It’s good to be open with each other and share right from the start. Remind each other that you’re working together on the same team. Share your fears and worries. Sometimes it may be hard. You’ll have disagreements and maybe even fight, but being honest with each other will help take away some of the stress and anxiety.

Knowing what to say and how to say it can be hard to do. Here are a few examples to help you communicate clearly:

- Instead of saying, “You never help me!” Say, “I need a break.”
- Instead of saying, “Why are you ignoring me?” Say, “Would you like to talk about anything?”
- Instead of saying, “You’re not even trying.” Say, “Do you think you can do it today?”

Cancer survivors have been through some serious trauma. They need reassurance that you’re in this for the long haul. Say things like:

- “This is a scary time for you and for me, but I’m here to help you get through this. You’re not alone.”
- “I’ll do whatever I can to help you. I might do the wrong thing sometimes, or not even know what to do, but I’ll do the best I can.”
- “We can do this together. Let’s try to be honest with each other and work together no matter what happens.”

You’re not alone if you’re not sure what to say to someone who has cancer. Sometimes the simplest of expressions of concern are the most meaningful. And sometimes just listening is the best thing you can do.

Make sure you speak from the heart. Here are a few ideas:

- “I don’t know what to say, but I want you to know I care.”
- “I’m sorry you’re going through this.”
- “How are you feeling?”
- “If you’d like to talk about it, I’m here for you.”
- “Please let me know how I can help.”
- “I’m praying for you.”

While it’s usually a good idea to be encouraging, it’s also important not to act too optimistic or tell people with cancer to always stay positive. This might seem to discount their legitimate fears, concerns, or sad feelings. It’s also tempting to say you know how they feel. But while you may be aware this is a trying time, no one can know exactly how any person with cancer feels.

When the person with cancer looks good, let him or her know. Avoid making comments when they aren’t looking so good, like “You’re looking pale,” or “You’re losing weight.” It’s very likely
that they know about it, and comments can be embarrassing or discouraging.

It's usually best not to share stories about family members or friends who have had cancer. Every person is different, and these stories may not help. Instead, let them know you're familiar with cancer because you've been through it with someone else. Then they can take the conversation from there.

**Funny Business**
Humor can be an important way of dealing with cancer. Let the person with cancer take the lead. It's healthy if they can find something funny about a side effect, like hair loss or increased appetite, and it won't hurt for you to join them in a good laugh. This can be a great way to relieve stress and take a break from the serious nature of the situation. But you never want to joke or kid around unless you know the person with cancer can handle it and appreciate the humor.

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

- Wait until your emotions are under control and decide what to say ahead of time.
- Tell the truth and answer questions honestly. Depending on your children’s ages, it may not be appropriate to give them all the details, but do be truthful.
- Let them know what to expect. For example, let them know that after surgery you will need a lot of rest and may need to stay in the hospital. If your chemotherapy may cause you to lose your hair, let them know. Keep your children in the loop as much as possible.
- Explain to your children, especially younger children, that they cannot “catch” cancer.
- Let your children know that it is okay to cry or be upset. This may be especially important for your teens to hear.
- Tell teachers, babysitters and others with responsibilities with and around your kids about your diagnosis in case they see behavior changes you may need to know about.
- Maintain normal schedules as much as possible.
- Let your kids help. Allow them to help with chores, and let them know that their help is important. Teens may want to take an active caregiver role. Let them do so, at appropriate levels.
- Look for support groups in your area. Many places offer support groups for children and teens whose parents have a cancer diagnosis.
- Know when to seek professional help. If your child begins to demonstrate unusual behavior such as angry outbursts, nightmares, or poor grades in school, ask your healthcare team for a recommendation for a counselor.
Intimacy During Cancer Care

Cancer can make relationships and intimacy a challenge. Treatments for cancer can cause changes in sexual desire and function. Many feel less attractive or desirable when their physical appearance changes or they are not feeling well. All of these issues can build barriers to intimacy.

How Cancer Impacts Intimacy

Emotions play a big role in your desire for sex. Anxiety, fears, and physical changes during and after cancer treatment changes things. It's important to recognize these emotions and understand how it can diminish partner's desire for sex.

The causes of sexual dysfunction are often both physical and mental. Cancer and cancer treatments, especially those involving the genitals or reproductive organs, can directly affect sexual function and desire. The side effects of cancer treatments (like fatigue, nausea, vomiting, constipation, pain) can also decrease sexual feelings.

If your partner is dealing with anxiety and depression, that may hamper sexual desire and ability. Changes in physical appearance due to surgical scars, hair loss, weight gain/loss, and more can make your partner feel unsexy or insecure.

Cancer and Sexuality

The physical side of sex and the emotions of intimacy are strongly related. You may find that during this time of recovery and healing, your focus is more on intimacy and the emotional connection than it is on the physical focus of a sexual relationship.

Find new ways to be intimate with your partner:
- Be open and honest. Talk about how you're feeling.
- Ask your partner how they feel. Never assume you know what they're thinking.
- Explore new ways to have a physical connection. Try backrubs, foot massages, cuddling, reading together, or simply holding hands.
- Request a date night and suggest what you'd like to do.
- The level of connection you feel with your partner may depend on his or her own body image. Find out what you partner is thinking and talk about it.

Sexual Issues for Women with Cancer

For some women, cancer and its treatments may cause a range of symptoms that interfere with physical intimacy, like the following:
- Loss of libido (sex drive)
- Painful intercourse
- Vaginal dryness
- Loss of sexual function or sensation
- Emotional issues (e.g., anxiety, depression, guilt)
- Body image issues
- Fatigue
- Early onset of menopause
Some types of pelvic surgery (like the removal of the uterus, ovaries or bladder) can decrease vaginal lubrication and sensation, add to the loss of vaginal stretch ability, and cause pain. Breast cancer surgery may cause reduced physical sensation. The breasts may not be the source of pleasure they once were. Radiation therapy to the pelvic area can cause changes in the vaginal lining, which makes intercourse painful.

A doctor may recommend medical treatments like estrogen replacement therapy. (If the cancer is hormone related, estrogen replacement therapy may not be safe for your loved one.) Vaginal dilators, vaginal lubricants or estrogen creams can make intercourse more comfortable.

Counseling may help with body image issues as they can cause psychological and emotional distress.

**Sexuality Issues for Men with Cancer**

For some men, cancer and its treatments may cause a range of symptoms that interfere with physical intimacy, like the following:

- Erectile dysfunction
- Inability to reach orgasm
- Loss of sex drive
- Incontinence
- Emotional issues (e.g., anxiety, depression, guilt)
- Issues with body image
- Fatigue
- Concerns about sexual performance

Some treatments for men with cancer can interfere with the ability to have an erection or reach orgasm. For example, some surgeries, (like prostate, bladder and colorectal cancers) can damage nerves and blood vessels and result in erectile dysfunction and problems with orgasm.

Radiation therapy to the pelvis can damage the arteries that bring blood to the penis and cause problems with getting and keeping an erection. Chemotherapy may interfere with testosterone production, which can impact sexual function. Hormone therapy for prostate cancer may decrease hormone levels, reducing the ability to achieve an erection or orgasm.

A man should discuss his concerns with his doctor, who may recommend nerve-sparing methods to preserve erectile function. Medications, injections, vacuum devices, implants or testosterone replacement can also help.

Counseling may also be recommended. Physical changes can make a man question his masculinity, causing emotional distress.
Balancing Cancer and Intimacy

Intimacy has different meanings and importance for each of us. It can be expressed in various ways. Roles and relationships change when cancer enters your life. For many, an intimate connection with a partner is an important way to feel alive and whole during cancer treatment. While it may take persistence and teamwork to maintain intimacy in your relationship, it can be done.

Fertility

Cancer treatments can lead to infertility. Surgeries to reproductive organs 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. Chemotherapy can also affect fertility.

Cancer patients 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. Some men can bank sperm. Fertility-preservation can be a long process so you will need to factor this into your timeframe for treatment.

If the patient continues to have sex during treatment, it is important to use proper protection. For women, pregnancy during chemotherapy or radiation is not safe for the mother or the child. Since cancer treatment can compromise the immune system, be sure to always use condoms to protect against sexually transmitted diseases (STDs).

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

Long-Distance Caregiving

Giving care from a distance is more challenging and can cost more. The cost of travel, phone calls, time away from work, and out-of-pocket expenses are higher when you don’t live close to the person needing care. Sometimes a paid “on-site” caregiver will be needed.

There can also be more stress and greater feelings of guilt with long-distance caregiving. You may worry who will get your loved one to hospital if he or she needs immediate help or who will help with medication and food. If you have family living close to your loved one, you may feel guilty that the burden falls on them and that you aren’t doing your share. Here are a few tips to help you feel more engaged in the process and provide care even from many miles away.

Get your act together.

Get organized. Gather information about your loved one’s medical, financial, and legal needs. This will help you or family make informed decisions. Make sure that correct legal documents, like advance directives, are filled out and given to those who need them. This will help you make medical or financial decisions if the person with cancer is unable to. A binder or file folder can help keep track of everything.
Get to know the team.
Introduce yourself. Call the healthcare team members involved in the care of your loved one. Let them know that you play a key role in providing care and want to be involved as much as possible. Give them your phone number and email address in case they need to reach you. You may need to sign a release or have written permission from the patient to discuss medical conditions and treatments.

Get professional help.
Check into professional services. The health care team can help provide you with referrals for reliable home care services. These home care services can range from providing basic medical care to helping with household responsibilities, meals, and personal care. Your loved one’s insurance company may or may not cover home care services or certain companies providing those services.

Recruit and organize volunteers.
Get help from people who live with or near your loved one. Call family, neighbors, friends, church members, and any social organizations who may want to help with caregiving responsibilities. Create a list of things your loved one may need—meals, rides to treatment, etc. Your family and friends can volunteer and coordinate tasks using websites such as MyLifeLine (www.mylifeline.org). Using a website like this is also an easy way to keep a large group of people updated on your loved one’s well-being. Keep a list of friends and family who are helping you in case of emergencies.

On the Road Again
Get ready to travel, even for unplanned trips. You can prepare in a number of ways:

- Set aside extra vacation or sick days from work.
- Research travel options and find the best ways to get back and forth the most efficiently.
- Use discount travel sites such as Hotwire or Priceline to find inexpensive hotels quickly.
- If you’re not leaving any family at home when you travel, ask a friend or neighbor to help pick up mail, water plants, or keep an eye on things in case you need to leave suddenly.

Once you reach your loved one, you may be overwhelmed by everything that needs to be done. Having a plan will keep you focused and less stressed. Speak with the patient before you come about what’s needed and set clear goals for your visit. And don’t forget to visit while you’re there! He or she will probably cherish the time you spend just sitting and talking. Plan some activities together that you both enjoy.

If other family members are doing most of the work, step in for them and give them some much-needed time off. Maybe you can plan a visit so they can go on vacation or just get a break daily caregiving.

Get emotional.
Provide emotional support to your loved one and seek it from others. Reach out through
regular phone calls and e-mails to reassure the person with cancer that you’re still in this with them.

It’s normal for long-distance caregivers to feel guilty about living so far away from the person with cancer. You may also feel overwhelmed by the challenges of coordinating care. You need support too. Seek encouragement from family, friends, or even a counselor to help deal with stress and emotional struggles you may experience.
Caring for the Caregiver

As a caregiver you may neglect to take good care of your own needs because you are so focused on caring for your loved one. This is understandable, but to offer your loved one the best possible care, you need to be healthy and well yourself, physically and emotionally. In the next few pages, learn tips and tricks for taking better care of yourself.

Caring for Yourself

Caring for someone who is sick and worrying about what the future holds is exhausting and can quickly lead to burnout. Many times, caregivers will just keep doing what needs to be done and suffer in silence. Caregiving is a hard job. And you may be there for them 24 hours a day for months or even years. In one study, more than 50% of caregivers spent more than 8 hours a day caring for patients who were getting chemotherapy. There is often a financial burden to caregiving, too, such as time away from work.

Your love for them will give you energy for a while. Just remember to refuel.

Here are some tips to make sure you don’t forget to take care of yourself.

- Get some form of exercise like walking or an aerobics class.
- You need a support system. Call friends or family when you need to talk or need help.
- Pursue a hobby or start a fun project.
- Eat well-balanced meals. Caregiving can leave precious little time and many turn to fast food or junk food. Get the nutrition your body needs!
- Have a place where you can go to “escape” and just be by yourself.
- Set priorities each day and make sure the most important tasks get done.
- Try to cut out smoking and drinking alcohol.

Say “Yes” to Help

It’s perfectly fine to have helpers. In fact, you may find that learning to let go and to accept help will lower your anxiety and raise your spirits. People often want to chip in, but aren’t sure what type of help you need. It’s helpful to keep a list of all caregiving tasks and list them from the smallest to the largest. That way, when friends or family offer to help, you can give them specific choices.

Do What You Can, Don’t Do What You Can’t

Each and every caregiver will find themselves caught up in the whirlwind of appointments, daily errands, and medicine doses. Nobody can do everything. Acknowledge your limits. You will more than likely feel overwhelmed. Decide what you can and cannot handle. Your loved one needs you. You can’t do this alone. Together, you can get through.

Sleep Well

Adults should get seven to nine hours of sleep each day. Though this isn't always possible for caregivers, set a goal for how much sleep you want to get each day. That will help with fatigue in the long run.
Take a Break
If you’re a full-time caregiver, you can't always take a break. But learning techniques to get rid of stress throughout the day can be extremely helpful. Try to close your eyes for 5 or 10 minutes, listen to relaxing music, exercise, watch a movie, read a book, take a short walk, or call a friend for a quick laugh. It’s okay to laugh, even when your loved one is in treatment. In fact, it's healthy. Laughter releases tension. It makes you feel better. Keeping your sense of humor in trying times is a good coping skill.

However you choose to get away during the day, you need at least 30 minutes a day to yourself.

Support Groups
Support groups can meet in person, by phone, or online. They can help you gain new insights into what’s happening, offer ideas about how to cope, and make you see that you're not alone. In a support group, people may share their feelings, trade advice, and try to help others who are dealing with the same kinds of issues. Some people go just to listen. And others prefer not to join support groups at all because they aren't comfortable with this kind of sharing. If you can't find a group in your area, try a support group on the internet. Some caregivers say websites with support groups have helped them through.

Here are some organizations that offer support groups or peer counseling for caregivers:

- CancerCare
  - cancercare.org
  - (800) 813-HOPE
- Caregiver Action Network
  - caregiveraction.org
- Cancer Support Community
  - cancersupportcommunity.org
  - (888) 793-9355

Be Thankful
Many are thankful that they can be there for their loved one. You may be glad for a chance to do something that makes a difference and give to another person in a way you never knew you could. Some caregivers feel they've been given the opportunity to build or strengthen a relationship. This doesn't mean caregiving is easy or free from stress, but finding meaning in caregiving can make it easier to manage.

Emotional Support for Caregivers

Cancer and Your Emotional Health
Patients, families, and caregivers will face varying levels of sadness, stress, and fear when the diagnosis of cancer comes. These feelings are normal.

Those with cancer might feel the loss of control over their lives and struggle with changes in body image. It’s normal for them to fear death, suffering, pain, or all the unknowns that lie ahead.
You may have these feelings, too. You may be afraid of losing your loved one. You may also feel angry because someone you love has cancer, frustrated that you “can’t do enough,” or stressed because you have more responsibility at home. Anyone affected by cancer may need help dealing with the emotions that result.

There’s no doubt that cancer changes people’s lives. The emotional stress it causes can be overwhelming, but no one has to manage it alone.

**Depression and Cancer**
Grieving over the changes cancer brings to a person’s life is completely normal. Some dreams and plans for the future may be lost forever. But if a person has been sad for weeks or is having trouble carrying out day-to-day activities, that person may have clinical depression. Caregivers are at risk too. Many experience empathy for their loved one and a deep sense of loss over the new reality.

Clinical depression causes serious distress, gets in the way of normal activities, and might even make the person with cancer less able to follow their cancer treatment plan. The good news is that clinical depression can be treated.

If you or someone you know has symptoms of clinical depression, encourage them to get help. Clinical depression can be treated by medicines, counseling, or a combination of both. Treatments can ease suffering and improve quality of life.

**Symptoms of clinical depression:**
- Ongoing sadness, hopelessness, or an “empty” feeling for most of the day
- Loss of interest or pleasure in most activities most of the time
- Major weight loss or weight gain
- Being agitated almost every day
- Extreme tiredness (fatigue) or loss of energy
- Trouble sleeping, waking too early, or sleeping too much
- Trouble focusing, remembering, or making decisions
- Feeling worthless, guilty, or helpless
- Thoughts of death or suicide (not just fear of death)

If five or more of these symptoms happen nearly every day for two weeks or more or are severe enough to interfere with normal activities, you may have depression. If this is the case, speak to a mental health professional.

It’s important that you don’t keep these feelings inside. It’s also important that you don’t blame yourself for your loved one’s cancer diagnosis or for not “doing enough.”

**Anxiety, Fear, and Cancer**
Most caregivers go through varying levels of anxiety and fear when a loved one is diagnosed with cancer. Many questions pop up like “Will they be ok?” “Will the cancer come back?” “How can I do all of this?” Know that this is normal.
Symptoms of anxiety and fear:
- Uncontrolled worry
- Trouble solving problems and focusing thoughts
- Muscle tension
- Trembling or shaking
- Restlessness, may feel keyed up or on edge
- Dry mouth
- Irritability or short-tempered

A mental health evaluation could be helpful if you are experiencing a combination of these symptoms.

What to do:
- Share feelings and fears that you may be having with a friend or family member.
- Remember that it’s ok to feel sad and frustrated.
- Get help through counseling and/or support groups.
- Use meditation, prayer, or other types of spiritual support if it helps.
- Try deep breathing and relaxation exercises.
- Talk with a doctor about using anti-anxiety or anti-depressant medicines.

Asking family members and loved ones for support may help reduce the distress you’re feeling. Also, do not hesitate to speak with the healthcare team. You may need a referral to a mental health professional.

In the confusion and stress that come after a diagnosis of cancer, the emotional problems of both those with cancer and their caregivers can often become fairly serious before they’re recognized.

**When to Call the Doctor**
Going through a wide range of emotions is a normal part of coping with cancer. But some signs shouldn’t be ignored. Please call the doctor right away if the patient, you, or someone close to you has any of these problems:
- Thoughts of suicide or self-harm
- Unable to sleep or eat
- Lack of interest in normal activities for many days
- Unable to find pleasure in things enjoyed in the past
- Emotions that interfere with daily activities
- Confusion
- Trouble breathing
- Sweating more than usual
- Very restless
- New or unusual symptoms that cause concern

**What is psychological stress?**
Psychological stress describes what people feel when they’re under intense mental, physical,
or emotional pressure. Though it’s normal to experience some psychological stress from time to time, people who experience high levels of psychological stress or who experience it over and over for a long period of time may develop mental and/or physical health problems.

Stress can be caused both by daily responsibilities and routine events, as well as by more unusual events, like the trauma of having a loved one diagnosed with cancer.

How does the body respond during stress? The body responds to physical, mental, or emotional pressure by releasing stress hormones that increase blood pressure, speed heart rate, and raise blood sugar levels. These changes help a person act with greater strength and speed to escape a perceived threat.

Research has shown that people who experience intense and long-term stress can develop digestive problems, fertility problems, urinary problems, and a weakened immune system. People who experience stress over long periods of time are also more prone to viral infections, like the flu or common cold, and to headaches, sleep trouble, depression, and anxiety.

Lowering your level of stress and anxiety is important. Exercise, regular breaks from caregiving, a healthy diet, and sharing your feelings with family and friends can help you manage your stress levels.
Once treatment is over, if your loved one successfully completed treatment, you may find it difficult to stop being a caregiver and transition back into your normal roles. If your loved one has advanced cancer and chooses not to continue treatment, you will need to consider hospice or end of life care. If your loved one passed away, you will need time to mourn. In the following sections learn more about what happens once treatment ends.

### Transitioning out of the Caregiver Role After Cancer

During cancer treatment, you played an important role in supporting your loved one. You may have helped provide physical, emotional, and practical care on a daily basis for months.

But as the treatment and cancer changes, so does your role. At some point, the need for the type of care you gave will come to an end. This may be because the person you care for completes his or her planned course of treatment or goes into remission, with no signs or symptoms of cancer. This is when a caregiver may struggle to adjust to “normal life.”

### So what now?

As a caregiver, you’ve poured out an enormous amount of time and emotional support to your family member or friend. When your loved one no longer needs you to provide care, it can affect your sense of purpose or self-worth. These tips may help you start your “new life” after caregiving:

- Get back to hobbies you enjoy. As a caregiver, you were more than likely too busy to spend time on the things you enjoy. Or, you may have felt guilty taking time away from your caregiving responsibilities.

- Get back to your relationships. Reach out to family members, friends, or co-workers that you may have fallen out of touch with during your season of caregiving.

- Get back to work. Think about returning if you’ve taken a leave of absence or left your job altogether. This adjustment period will be easier if you stay busy.

- Take care of yourself. The stress of caring for a loved one with cancer often leads some people to start or increase unhealthy habits. These habits could be eating junk food, smoking, or drinking too much alcohol. Let the bad habits go and make time to exercise, eat healthy foods, and get enough sleep.

- Reach out to help others or support a cause. Giving care can be challenging, but you may have found it rewarding. You could offer your time to organizations that help people with cancer. Learn how to become a cancer advocate and make a difference.

- Keep a journal. Writing about the stress in your life experiences provides a personal way to express your feelings. Years from now you can look back at the journey with a grateful heart and a new perspective on your future goals.
Dealing with the Fear that Cancer May Come Back
Just like the cancer survivor, you may be concerned that the cancer will come back. You cannot control or predict the health of the person you care about, and that can be challenging. These strategies may help ease your concerns:

- Learn as much about cancer as you can. The chances of the disease coming back depend on the type and stage of the cancer. It also depends on how well the treatment plan worked. Your loved one’s doctor can provide information and statistics about the chance of a recurrence.

- Help in the follow-up. Cancer survivors are given a plan for follow-up care after treatment. This plan usually includes visits to the doctor and tests. Ask your loved one to keep you updated, and how you can help them follow the plan. Just offering your support may help you feel less anxiety about cancer coming back.

Support Resources
A number of studies have shown that caregivers are at an increased risk for depression. If you feel sadness or despair, or have other signs of depression, reach out to your doctor for help. These resources can help too:

- Counseling: Mental health professionals can help provide guidance and reduce stress. Your doctor or another health care professional can help you determine the type of counseling that might be best for you. It’s important to meet with a counselor or therapist who has expertise working with cancer caregivers.

- Support groups: A support group is a safe place to share experiences and learn from the caregiving experiences of others. Your doctor, hospital discharge unit, or social worker can help you find one.

Life After Cancer Treatment
A caregiver’s responsibilities during the patient’s transition out of active treatment may include things like keeping an eye on late side effects and the possibility of the cancer coming back. Caregivers may also coordinate care by setting and keeping medical appointments and continuing to maintain all the records. When active treatment ends, a primary care doctor may take over the patient’s care. There can be a lack of communication in the transition between providers. You may find yourself responsible for the coordination of care during this period.

You were probably so busy during treatment just getting through each day that it was hard to imagine what life would be like when it was over. Now that it is, you may feel glad, excited, and anxious all at the same time. While you’re happy to be done with treatment, the uncertainty about the future continues. This may be a tougher adjustment than you would’ve guessed. Remember to take each day as it comes and give yourself time to come to grips with all you’ve been through.
Hospice Care and End of Life Care

There may come a time when the cancer progresses and the loved one you’re caring for needs help at home. This can be a difficult time emotionally as well as physically, and there are options available to help meet both of your needs.

Home Care Services
Home care services for your loved one will give you some much-needed support. State or local health departments usually have a list of licensed home care agencies, and your healthcare team can suggest those they trust. Some of the services that home care agencies provide include:

- Visits from nurses, therapists, and social workers
- Help with errands, preparing meals, and bathing
- Medicine delivery
- Help with the use of medical equipment
- Hospice care for the patient

Hospice Care Services
Hospice care is offered to patients who are nearing the end of life and are no longer being treated to cure or control their cancer. The goal of hospice is simply to help patients live each day to the fullest by making them comfortable and relieving symptoms. The family caregiver often feels as much emotional distress as the patient during this time and needs help and advice to feel comfortable with how to care for their loved one in the final stages of cancer. The hospice care team helps with the emotional, social, and spiritual needs of patients, caregivers, and their families.

Hospice care services are usually structured according to the needs and desires of the patient and his or her family. These needs may change through the three different stages of care:

1. The final stages of cancer
2. The dying process
3. The grieving period

Depending on the condition of the patient and the stage of care, a hospice interdisciplinary team (IDT) may provide any combination of these services:

- **Nursing Care:** Registered nurses monitor the patient’s symptoms and medication, and inform you and your family on what’s happening. The nurse is also the link between you, your family, and the doctor.
- **Social Services:** A social worker offers advice to you and family members and makes sure you have access to the resources you need.
- **Physician Services:** Your doctor works with the hospice team and approves the plan of care.
- **Spiritual Support and Counseling:** Clergy and other spiritual counselors can visit you and provide spiritual support at home. Spiritual care is a personal process and may
include helping you explore what death means to you, taking care of any "unfinished business," saying goodbye to loved ones, and carrying out any specific religious ceremonies.

- **Home Health Aides and Homemaker Services**: Home health aides provide personal care like bathing and shaving. Homemakers can assist with light housekeeping and meal preparation.
- **Trained Volunteer Support**: Caring volunteers are the backbone of hospice care. They're available with a compassionate ear and can help with everyday chores like shopping, babysitting, and carpooling.
- **Physical, Occupational, and Speech Therapies**: These hospice specialists can help your loved one develop new ways to do those things that they may have become too difficult like walking, dressing, or feeding themselves.
- **Respite Care**: Respite care gives your family a break from the intensity of caregiving. A brief inpatient stay in a hospice facility provides a much needed "breather" for caregivers.
- **Inpatient Care**: There may be times when your loved one will need to be admitted to a hospital, extended-care facility, or a hospice inpatient facility. Medical intervention like pain medications will be recommended to ease the dying process. This requires 24/7 nursing care, so a facility may be a better option.
- **Bereavement Support**: Bereavement is the time of mourning we all experience following the loss of someone we love. The hospice care team will work with you and your family members to help you through the grieving process. Support may include home visits, phone calls, letters, and support groups.

**When is it time for hospice care?**

If your loved one is currently undergoing treatments intended to cure or control the cancer, it’s not time for hospice care. For some patients though there may come a point when treatment stops working. In those cases, continuing treatment can even be harmful or decrease quality of life. When hope for a full recovery disappears, there’s still hope for as much quality time as possible and a dignified, pain-free death.

The following are signs that you may want to consider hospice care:

- You've made many trips to the hospital and the patient’s health continues to grow significantly worse, affecting quality of life.
- The patient wants to remain at home, rather than spend so much time in the hospital.
- The patient has decided to stop receiving treatments for their disease.

**Who qualifies for hospice care?**

If your doctor has certified your prognosis as less than six months, your loved one is eligible for hospice care. This applies to anyone of any age. Hospice care can be received in a nursing home if the nursing home agrees to allow the hospice staff to provide the primary care. Hospice pays for all of the medications and equipment needed in the nursing home.

**End of Life Care**

Caring for a patient at home as they near the end of life brings a new set of challenges. The patient will depend on the caregiver even more for physical and emotional support. The
symptoms also may be more difficult to manage. The caregiver may feel extra stress and even more separated from their favorite activities and interests. Studies have shown that caregivers have a lower quality of life when providing the patient end-of-life care than they do during treatment.

Many hospital or hospice programs offer end-of-life services that will improve the patient's quality of life. This can also take a load of responsibility off of the caregiver. End-of-life support services help families with their physical, emotional, social, spiritual, and economic needs. They will include you in the medical decisions and in the management of your loved one's symptoms. They'll also watch you for signs of distress and lead you to any help you need.

There are a few things to consider when caring for someone who is near the end of life. This includes the following:

- Create a calm and peaceful atmosphere. Play soft music or light scented candles. (Be sure to avoid open flames if your loved one is using oxygen). Gentle physical touch and encouragement can be powerful.

- Expect changes in appetite. As cancer progresses, your loved one's need for food and drink will likely decrease. He or she may not even be able to eat or drink. Your health care team can help you find the right way to respond to any appetite changes.

- Silence can be golden. Remember that your loved one's voice may weaken. He or she may talk less and avoid long conversations. He or she may also begin to disconnect from family, friends, and their normal activities. Even if your loved one doesn't seem alert, remember that he or she can possibly still hear what's going on nearby.

- Be a good listener. Your loved one may occasionally feel like talking. It's important to let him or her share their feelings, which may include their sadness, pain, anxiety about unfinished business, or fear of death. It may not be easy, but just listening will ease your loved one's anxiety and fear.

- Help meet their spiritual needs. Reaching the end of your life often brings questions about death, guilt, forgiveness, the afterlife, and your relationship with God. At times, your loved one may feel angry or abandoned. At other times, he or she may embrace faith more firmly than ever before. Support from a pastor or clergy person may help him or her deal with these issues.

- Don't forget to laugh. If your loved one has always enjoyed humor, reject the idea that you need to be nothing but serious around him or her now.

- Remember yourself. The best way to give your loved one the support and care that he or she needs is to make sure your needs are met first. Get plenty of rest. Ask friends or family members to help you from time to time.
Mourning the Loss of Your Loved One

When we lose someone we love, we go through a normal process called grieving. This is natural and expected. Over time, it can help us accept and understand our loss. The outward expression of that loss and grief is known as mourning.

Grieving involves many different emotions, actions, and expressions, all of which can help you come to terms with the loss you’ve experienced.

Anticipatory Grief
When we think of grief, we usually think of the pain we go through after someone dies. However, the truth is this process starts on the day a loved one is diagnosed with a life threatening illness. Mourning before someone we love has passed away is called anticipatory grief.

You may also grieve over missing life the way it was and the state of your loved one’s health. If he or she is your spouse or partner, there will be many losses which can include intimacy and sex, control, privacy, independence, dignity, money, dreams, and friendship. These losses are often followed by feelings of anger, sadness, depression, and abandonment. It’s common for both you and the care recipient to feel isolated, alone, and numb.

As you watch someone you love suffer in pain and discomfort, you may find yourself thinking you wish they were out of their misery. Those thoughts are usually followed by feelings of guilt and remorse that we "wished" this person could die. Talking about these feelings is important. Both you and your loved one need someone to listen and validate how you feel. Family members and close friends can offer support in this way. Support groups and mental health professionals can help too.

Grief Stage One: Shock and Denial
For the first hours, days and even weeks after someone you're close to dies, you may feel like you just can't take in what's happened. It can feel like there's a thick wall between you and your emotions. You can't grieve though you know you're sad. The numbness keeps you from breaking down, but it may feel a bit scary, too.

Losing someone you've lived with may also bring deep feelings of emptiness and loneliness as your daily life has suddenly changed. This is especially true if you've spent the past months or years as a caregiver.

What you may feel or experience:

- Numbness and confusion (you just don’t feel anything)
- Separated from others (like you’re in a dark tunnel and everyone else is happy)
- No sense of purpose (what kept you going every day is gone)
- Memory gaps (being unable to remember what you did yesterday)
- Being disorganized (like misplacing your keys or cell phone)

What you can do:
• Give yourself permission to feel whatever you feel. This has been an emotional earthquake, and the aftershocks will continue for a long time. It's okay if you can't cry at all, and it's okay if you cry all the time or at the wrong times.
• Break through denial. Numbness keeps you from falling apart. But if those distant feelings get to you, reach out to family members and close friends. Share your experiences and reminisce about your loved one.

Grief Stage Two: Pain and Guilt
When the protective shell of denial slowly peels back, intense feelings start to surface. This is usually the darkest time. You may blame yourself and replay conversations and decisions in your mind wondering if you should have done things differently.

If your loved one had been suffering or in pain, you may feel a confusing mix of relief and guilt. Just remember that relief is a perfectly normal reaction.

What you may feel or experience:
• Big mood swings (feeling fine one minute and overwhelmed with sadness the next)
• Physical and emotional exhaustion, and lethargy (Getting out of bed in the morning can even be a challenge.)
• Guilt (If you lost someone who died relatively young, you may feel guilty that you are healthy.)
• Unexpected tears
• Negative thoughts about yourself
• Obsessive thought patterns

What you can do:
• Find ways to stop the negative thought patterns. If there are images that are painful to remember, talk through those memories with family members and friends who went through them with you.
• Force yourself to reach out. Let a few close friends or family members know you may need them on the front end by saying, "I'm having a hard time right now. Can I call you when I'm feeling down?" Doing this ahead of time gives you more comfort reaching out when you need them.

Grief Stage Three: Anger, Frustration, and Bitterness
Beyond denial and pain comes anger. Almost anything can set you off in this stage. A TV show, a conversation with a friend, a billboard—almost anything can set off an explosion of anger. This anger can be a shield protecting you from feeling intense pain. What you are going through is real, and bitterness and frustration can pop up at any time.

What you may feel or experience:
• You may think things along the lines of "Why me?" or "This isn't fair!"
• A desire to avoid social situations, like those where others are celebrating
• Irritation when others complain about “tiny” things compared with what you went through
• Being sarcastic and not trusting others
• Anger and bitterness over sincere expressions of sympathy such as someone saying "I understand" or "Is there something I can do?"

What you can do:
• Steer clear of those who bring you down. If you notice that certain people or situations make you angry, it's perfectly okay to stay away from them.
• Tell people what's happened. It can be hard to bring up your loss, but people will be more supportive than you think.
• Have compassion for yourself. Feelings of anger and bitterness can separate you from others. You've just lost someone extremely important to you. Remind yourself you won't always feel this way.

Grief Stage Four: Acceptance
At first, it will more than likely feel like taking one step forward, and two steps back. Little by little, your mind and heart will accept what's happened, and you'll find new strength. Life has a way of throwing moments our way that wake us up to the possibilities that still ahead of us.

What you may feel or experience:
• A sense of "waking up" and coming alive again to the world around you
• Moments of surprising joy followed by guilt
• A new source of strength and determination
• Finding humor again
• The rediscovery of the things you once enjoyed
• Feeling like yourself again

What you can do:
• Look for experiences that feel meaningful. If seeing your children or grandchildren is the only thing that gets you out of bed in the morning, try to find as much time as possible to spend with them.
• Fight off "survivor's guilt." You shouldn’t feel bad about being happy. Life goes on, and we're supposed to go on with it.
• Give back to others. When grieving a loss, many people find peace in helping others. Working for others takes you out of your situation and put things in perspective.

Remember all those who helped you through your loved one's illness? You can offer the same level of compassion and understanding to others who need you.

Grief in Children
Children grieve differently than adults do. A child may cry or seem sad one minute, then ask to go out to play the next. Children often work out their difficult feelings through play. What looks like regular play may be an important part of your child’s grieving process. Play can bring comfort to him or her and give the two of you a chance to connect without speaking.
The following worksheets can help you organize your life and keep track of all important information during the cancer journey. If you visit My PearlPoint at mypearlpoint.org and sign up for a personalized dashboard, you can print as many worksheets as you need.

- The Patient’s Medical History
- Healthcare Team Contact List
- Treatments and Side Effects Logs
- Laboratory Flow Sheet
- Budgeting Worksheets
- Calendars
- Appointment Notes
Patient’s 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:
Patient’s 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>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## 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>
</tbody>
</table>

Do you know any other pertinent family medical history?
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________
___________________________________________________________________________

________________________________________________
Patient’s 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>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

List all allergies.

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

<table>
<thead>
<tr>
<th>Vaccine</th>
<th>Date Given</th>
<th>Next Date Due</th>
<th>Comments/Reactions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tetanus</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diphtheria</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pneumococcal</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Influenza</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MMR</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis A</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Influenza (Flu)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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>
<td></td>
</tr>
<tr>
<td>Test:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Date:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Next Appointment: ______________________________________________________
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:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td>Primary Care Doctor</td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td>Oncologist</td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td>Nurse</td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>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:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td>Surgeon</td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td>Hospital</td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td>Name</td>
<td>Contact Info</td>
</tr>
<tr>
<td>------</td>
<td>--------------</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Phone:</td>
</tr>
<tr>
<td></td>
<td>Fax:</td>
</tr>
<tr>
<td></td>
<td>Email:</td>
</tr>
<tr>
<td></td>
<td>Address:</td>
</tr>
</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>Breakfast</th>
<th>Lunch</th>
<th>Dinner</th>
<th>Snacks</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Activity or Exercise:**

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

<table>
<thead>
<tr>
<th>Medications:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name</td>
</tr>
<tr>
<td>------</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</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.
Laboratory Flow Sheet

Your healthcare team monitors the effects and toxicity of chemotherapy treatments by watching your Complete Blood Count and Differential (CBC) results. These ranges are listed on the report your doctor receives after routine blood work. Use this report or ask your healthcare team to help you fill out the sheet below so you can monitor your CBC.

If you notice a change in levels, ask your healthcare team for an explanation. Lab work will be ordered for your needs. Lab work may vary slightly between males and females and between different labs.

<table>
<thead>
<tr>
<th>Lab Values</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CBC</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WBC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ANC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HGB</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HCT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PLT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RBC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MPV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCH</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MCHC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RDW</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Differential</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Lab Reports and Terminology

Complete Blood Count and Differential

Your WBC, RBC, HGB, HCT, PLT, and MVP will be monitored throughout the course of your treatment. These lab results give important information about how your body is affected by the chemotherapy.

**WBC:** white blood cells or leukocytes. White blood cells help the body to fight infections. There are several different types of white cells that have different functions. The WBC is the total of all the white cells counted.

**RBC:** red blood cells. These are also called erythrocytes or corpuscles. Immature red blood cells are called reticulocytes. RBCs carry oxygen from the lungs to the tissues of the body.

**HGB:** hemoglobin. Hemoglobin is the pigment of the red blood cells that actually carries the oxygen.

**HCT:** hematocrit. This is the percentage of RBCs in the volume of the whole blood in your body. This is also called packed cell volume or PCV.

**PLT:** platelets or thrombocytes. These cells help the blood to form a clot when your body has had a trauma or is bleeding.

MCH, MCHC, MCV, RBC, HCT, HGB all give us information in the diagnosis of anemia. Anemia is defined as a lack of the proper amount of red blood cells.

**MVP:** mean platelet volume. This is the average volume of platelets. A high MPC means there is the presence of larger platelets. A low MPV indicates the platelets are smaller than normal.

**MCV:** mean corpuscular volume. This is the calculation of the average volume of the RBC and is determined by the hematocrit count divided by the RBC count.

**MCH:** mean corpuscular hemoglobin. This is the calculation of the average weight of Hgb of each RBC. This is determined by the hemoglobin divided by the RBC.

**MCHC:** mean corpuscular hemoglobin concentration. This number tells us the concentration of hemoglobin in an average RBC. It is calculated by dividing hemoglobin by hematocrit.

**RDW:** red cell distribution width. This is the numerical expression of the degree of variation in the volume of the population of red blood cells. Normally, as new normal sized cells are produced, the RDW increases.
**Differential:** a differential count calculates the total white blood cells and categorizes their different types. The differential is reported as a percentage and an absolute number by type of cell.

**Other Terminology**

**Granulocyte:** white blood cells with a grainy appearance under a microscope. Neutrophils, eosinophils, and basophils are all granulocytes. Neutrophils are further classified as either bands or segs. This defines the level of maturity of these cells. These cells fight infection.

**Polymorphonuclear leukocytes:** also called PMNs or Polys. These refer to granulocytes which are neutrophils, eosinophils, and basophils. The name means “possessing a nucleus (or center) consisting of many parts or lobes.” This is another descriptive name for white blood cells.

**Blast, myelocyte, metamyelocyte, progranulocyte:** these are immature WBCs that are not normally in the peripheral blood circulation.

**ANC:** absolute neutrophil count. Neutrophils are white blood cells that help the body fight infection. This number is used to monitor neutropenia and the effects of chemotherapy and colony stimulating factors.
### Budgeting Worksheets

#### Sources of Income:

<table>
<thead>
<tr>
<th></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</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Investments</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

#### Monthly Expenses:

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

|                   |               |         |            |         |       |
|                   |               |         |            |         |       |
|                   |               |         |            |         |       |
|                   |               |         |            |         |       |
|                   |               |         |            |         |       |
|                   |               |         |            |         |       |
# Calendars

Month: ________________

<table>
<thead>
<tr>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes:

___________________________________________________________________________

______________________________________________________________

___________________________________________________________________________

_______________________________________________________
Calendars (continued)

Week: ______________________________________

<table>
<thead>
<tr>
<th>Monday</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tuesday</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Wednesday</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Thursday</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Friday</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Saturday/Sunday</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes:
_______________________________________________________
_______________________________________________________
_______________________________________________________
_______________________________________________________
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:
___________________________________________________________________________
___________________________________________________________________________
Grocery List

Eating well during and after cancer treatment can help enhance your overall health and improve your response to treatment. Keep your kitchen stocked with these healthy foods to ensure your loved one is getting the proper amount of calories and nutrition.

The Pantry:
- Whole grain breads
- Whole grain rice and pasta
- Crackers
- Oatmeal and hot cereal
- Couscous, bulgur, and quinoa
- Non-sugary cereals
- Natural popcorn
- Canned and dried fruit
- Unsweetened applesauce
- Potatoes and sweet potatoes
- Onions and garlic
- Tomatoes and canned vegetables
- Non-fat dry milk
- Evaporated milk
- Whey protein powder
- Canned fish and chicken (packed in water)
- Natural peanut and almond butter
- Unsalted nuts and seeds
- Canned and dry beans
- Protein bars
- Olive and canola oil
- Low sodium soup and stock
- Dried herbs and spices
- Assorted vinegars
- Decaffeinated tea
- Pudding and gelatin
- Honey or Stevia
- ______________________
- ______________________
- ______________________
- ______________________

The Refrigerator:
- Fresh fruits and vegetables
- Packaged salad
- Low-fat milk
- Low-fat yogurt
Low-fat cheeses
Fortified soy, almond, and rice milk
Eggs
Skinless chicken breast
Lean pork
Lean beef
Turkey breast
Hummus
Mayonnaise
Low-fat salad dressings
Low-fat sour cream
Sports drinks
100% juice
Nutritional Drinks

The Freezer:
Whole wheat waffles
Whole grain breads
Fruits and vegetables
100% juice concentrate
Sherbet, yogurt, and low-fat ice cream
Chicken breast
Fish and shrimp
Fruit popsicles

Other:
Paper towels
Wet wipes
Antibacterial hand sanitizer
Additional Resources

Cancer is every bit as stressful for the caregiver as it is for the loved one they're caring for. It takes a toll in different ways, but both struggle from day one. There are a number of websites and organizations who can help you with more practical advice and encouragement. We’ve included some of the best here for your reference. These are organizations we trust.

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.
mypearlpoint.org
(877) 467-1936 X 101
guidance@pearlpoint.org

The 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 supporters worldwide, ACS helps people stay well, help people get well, find cures, and fight back against cancer.
1-800-227-2345
www.cancer.org

The National Cancer Institute
A collection of information run by the National Institutes of Health.
1-800-4-CANCER
www.cancer.gov

CancerCare
CancerCare provides telephone, online and face-to-face counseling, support groups, education, publications and financial and co-payment assistance.
1-800-813-HOPE
www.cancercare.org

Family Caregiver Alliance
Family Caregiver Alliance supports and sustains the important work of families nationwide caring for loved ones with chronic, disabling health conditions.
caregiver.org
(800) 445-8106

Caregiver Action Network
The Caregiver Action Network serves a broad spectrum of family caregivers.
www.caregiveraction.org