

CAREGIVER HANDBOOK

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

Brought to you by PearlPoint Cancer Support.

Download at pearlpoint.org.

Personalized Nutrition Consultations

Answers to Your Food Questions During and After Cancer

PearlPoint Cancer Support offers one-on-one consultations with a registered dietitian with expertise in oncology nutrition. Consultations are available to patients and caregivers of all cancer types free of charge. Consultations are available by phone or email.



By speaking to a registered dietitian, you can learn

- ✓ Strategies to improve nutrition and side effects
- ✓ Tips for meal planning and grocery shopping
- ✓ How to care for a loved one during cancer treatment
- ✓ Answers to your nutrition questions
- ✓ Questions to ask your healthcare team
- ✓ Additional nutrition resources online and in your area

To schedule a consultation with a PearlPoint registered dietitian, call (877) 467-1936 X 101 or visit pearlpoint.org to use the online scheduling form.

Visit pearlpoint.org for more resources like the Caregiver Handbook.

Table of Contents

Introduction to Caregiving	4
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 Your Loved One	8
Chemotherapy.....	9
Giving Care During and After Radiation Therapy	11
Helping Your Loved One After Surgery	13
Wound Care	13
Common Side Effects of Cancer Surgery	14
Nutritional Guidelines After Surgery.....	15
Caring for an Ostomy	16
Caring for Drain Tubes	19
Nutrition	20
Caregiver’s Role in Nutrition	20
Grocery Shopping Tips	21
Food Preparation	22
Food Safety	24
Snack Ideas for Treatment Days.....	26
Nutrition Resources	27
Practical and Relationship Issues	28
Managing Health Insurance	28
Managing Finances.....	29
Health Insurance Options for the Uninsured or Underinsured	31
Social Security Disability Benefits and Cancer	33
Appointments and the Healthcare Team.....	34
FMLA for the Caregiver	35
Advanced Directives	37
Communicating with a Cancer Patient.....	38

Sex and 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.....	48
Transitioning Out of The Caregiver Role.....	48
Hospice Care and End of Life Care.....	50
Mourning the Loss of Your Loved One	51
Worksheets.....	53
Additional Resources.....	i
References.....	ii

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.

Like the content in the Handbook?

There is more online at pearlpoint.org. On pearlpoint.org, you can find more information about cancer and nutrition, tasty recipes, and timely blog posts.

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 the patient:

- Go grocery shopping and prepare meals
- Assist with personal hygiene and changing clothes
- Use the bathroom
- Clean
- Do laundry
- Keep track of finances
- Drive to doctor's appointments and treatments
- Provide emotional support
- Take medication and adhere to the treatment plan

- Change bandages after surgery
- Communicate with the healthcare team
- Communicate with other friends and family

Navigating Cancer Treatment

Depending on your loved one's overall health and response to treatment, you may be the one managing the patient's treatment. Here are some ways to help you navigate treatment for your loved one.

Educate yourself.

Learn as much as you can about your loved one's diagnosis and treatment plan. Only trust information from reliable resources. Good resources for learning about cancer and treatment include:

- National Cancer Institute (NCI)
 - www.cancer.gov
- American Cancer Society
 - www.cancer.org
- Cancer.Net from the American Society of Clinical Oncology
 - www.cancer.net
- The Leukemia and Lymphoma Society
 - www.lls.org

You can also ask members of your loved one's healthcare team for resources they recommend. Many large treatment centers offer information on their own websites, too.

Go to appointments with your loved one, and meet the healthcare team.

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. Always ask for specific instructions for taking medication and nutritional needs. Ask for instructions in writing as well.

Questions to ask the healthcare team:

- What is the diagnosis and stage?
- What treatment options are available and what do you recommend?
- Is the patient eligible for a clinical trial?
- What will the side effects of treatment be?
- How can the patient stay as healthy as possible during treatment?
- Whom should I contact with questions after hours?

Tip: If your loved one's healthcare team includes a nurse navigator, the nurse navigator will be your main point of contact for questions. An oncology nurse navigator specializes in coordinating care for cancer patients. Make sure to get the nurse navigator's contact information.

Take care of legal issues.

The hospital or treatment center will require the patient to give written permission for members of the healthcare team to discuss medical information with you. Make sure you take care of this early on so if any issues arise you will be able to contact the medical team on the patient's behalf. Make sure your correct contact information is listed for the patient's emergency contact.

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 Handbook.

Take Care of Yourself Too

After a cancer diagnosis, your day-to-day life and your role and relationships in your family may change. For example, your spouse may have always done the household chores, but for now, it may be your responsibility. If you're an adult caring for a parent, the caregiver role reversal may feel odd at first. Talk through these changes with your loved one.

Understand 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. Try to set aside time for yourself each day to practice self-care whether that be through meditation, exercise, reading, writing, a long bath, or just being alone for a bit.

Caring for Your Loved One During Treatment

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.

Preparing 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 for the patient.

Changes that can be made:

- Put items in easy to reach places such as clothing in baskets or drawers instead of on high shelves or in closets
- Low the patient's bed or get a step stool to make getting into bed easier
- Get rid of slippery rugs that can slide or bunch up causing a tripping hazard
- Add a shower seat and hand-held showerhead to make bathing easier
- Use nonslip bath mats in and outside the tub/shower and add a safety bar to reduce the risk of falls in the shower
- Find a raised toilet seat or commode

Depending on your loved one's diagnosis, treatment, and health, you may need to make larger changes to your home that require professional help. For example, if your loved one is wheelchair bound, you will need to add a ramp to the entrance of 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. Make your own safe, green cleaner with ½ cup vinegar, ¼ cup baking soda, and ½ gallon of water.

Here are a few more tips to avoid using harmful chemicals while cleaning.

- Avoid products with chlorine, ammonia, synthetic solvents, and artificial fragrances and dyes.
- Choose products made with plant ingredients such as lemon juice.
- Avoid aerosol cans.
- Do not mix bleach with ammonia or vinegar. This can produce deadly gases.
- Instead of air fresheners use oils instead.
- Open windows and doors while cleaning or run a fan to let out strong fumes from cleaning products.

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, through an injection, or orally. Chemotherapy may be inpatient or outpatient or even taken at home.

How long is chemotherapy given?

The length of chemotherapy treatment depends on the type of chemotherapy being given. Your medical oncologist will tell you what type of chemotherapy is best for you.

Every chemo regimen or chemo round is made up of cycles. This means a period of treatment followed by a period of recovery. For example, you may get chemo one day and then have a few weeks to recover with no treatment. That would be one cycle. Several cycles make up a complete chemotherapy regimen.

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
- Diarrhea
- Higher risk of infection
- Early menopause in women

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.

Long-term side effects of chemotherapy can include:

- Infertility
- Neuropathy
- Confusion or forgetfulness (“chemo brain”)

If the patient experience side effects, call your doctor. It is better to address side effects right away, and there are numerous drugs available to help manage side effects. You can also learn to manage side effect by changing what and how the patient eats.

Everyone’s body is different, so people experience different effects from chemo. Most side effects go away or improve after treatment ends. However some side effects may be ongoing.

Preparing for Chemotherapy

As a caregiver, you can help your loved one prepare for chemotherapy in a number of ways.

- Make sure the patient has a dental check-up before beginning chemo.
- If the patient is a women, she should also get a Pap smear before chemo.
- If you will not be able to drive to every chemo appointment, organize rides for the patient with family and friends.
- Talk to a registered dietitian about the best foods to prepare for your loved one. Call PearlPoint at (877) 467-1936 to schedule at time to talk to a registered dietitian for free.
- Pack a bag for treatment day with snacks and items to pass the time such as books, music players, journal, or electronic tablet. Include socks and blanket to keep warm in cold infusion rooms.
- Buy unscented soap, shampoo, and detergent for the home since chemo therapy can make patients sensitive to strong smells.

Coming Home after Chemo

After infusion chemotherapy through a port or IV, it takes about 48 hours for the chemotherapy drugs to leave the body. Chemo leaves the body through bodily fluids and waste. For two days after chemo, use gloves when dealing with anything that may be soiled with chemo such as towels, clothing, or bed sheets. Wash your hands often, especially if you've been exposed to body fluids or waste. Ask your loved one to flush the toilet twice after using the bathroom. Check with the healthcare team for more specific recommendations.

Giving Care During and After Radiation Therapy

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.
- **Systemic radiation therapy:** The patient swallows or receives injections of radioactive substance. This substance helps destroy cancer cells throughout the body.

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.

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

- Dry mouth, difficulty swallowing, mouth sores
- Nausea and vomiting
- Diarrhea
- Shortness of breath
- Breast or nipple soreness
- Cough
- Fever
- Rectal bleeding
- Bladder irritation
- Joint pain and stiffness
- Sexual problems
- Vaginal itching, burning, and dryness
- Infertility (if treated in the pelvic region)
- Risk of secondary cancer diagnosis

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.

Will the radiation they receive during treatment be harmful to the caregiver?

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.

Leaving the Hospital

Before your loved one leaves the hospital, the surgeon should provide you with written instructions on how to care for the patient. These instructions should include:

- Medication times and dosage
- Wound care
- Dietary restrictions or suggestions
- Mobility and exercise restrictions or suggestions

Do not leave the hospital without these written instructions.

Wound Care

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. 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 keep the wound closed. They are used more often with large incisions, but staples may heal faster than stitches.
- Butterfly bandages are small strips of white tape that hold the wound edges together. (Similar to a band aide but stronger.) They can be used alone or with staples and stitches.
- Adhesive glue may also be used on smaller incisions.

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 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.

The surgeon or discharge nurse will show you how to change the dressing for the patient. You will likely be given extra gauze and dressing at the hospital to use at home. Ask how often you should change the dressing.

Keep the wound as clean and dry. The surgeon will tell you when you can clean the wound area and how to clean it safely. Once you are allowed to clean the wound, do not soak it in a bath, pool, or hot tub until it has completely healed.

Do not let the patient pick or scratch at the wound or stitches. (It may become itchy as it heals.) 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.

Moving around is usually good even after surgery. The patient may even receive a list of exercise to do from a physical therapist. However, 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.

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 or an increase in drainage
- Bad smell
- If the stitches or staples open
- Sudden increase in pain or if pain is not controlled with medication

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

Common Side Effects of Cancer Surgery

The side effects your loved one experiences after surgery depends on the type and extent of the surgery. The patient's overall health is also a factor. For example, a younger patient with no

other health issues may recover more quickly than an older patient. Ask the surgeon what to expect in advance.

Pain: Pain is a concern with any surgery. Pain shouldn't be ignored, and you loved one shouldn't attempt to tough it out. The most common pain management strategy post-surgery involves pain medications. There are a few different types of pain medications including opioids (narcotics) and non-steroidal anti-inflammatory drug (NSAIDS). It may take time to get the dosage correct for you. Always take these medications as prescribed by your doctor.

Decreased Mobility: After surgery, especially to a limb, your loved one may have difficult moving around. Ask the surgeon the best way to help the patient move safely to avoid injury.

Fatigue: Healing from surgery requires a lot of energy. Lingering anesthesia may also make your loved one feel tired. The best thing for the patient after surgery is lots of rest.

Scars: Try using over-the-counter lotions and gels to help minimize incision scars. Moisturizers made with cocoa butter also minimize scars.

Lymphedema: This is a common side effect after a lymph node dissection, which is the removal of lymph nodes. Cancer patients often have lymph nodes removed to check for the spread of cancer. 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: heavy lifting, tight clothing, blood pressure checks, IVs, and other injuries.

Nausea: After receiving general anesthesia, some people experience nausea. If you already know this is the case for your loved one, let the anesthesiologist know in advance. Anti-nausea medications can be provided.

Nutritional Guidelines After Surgery

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 of water and fluids.

Your loved one may also be told to follow a specific diet after surgery such as a liquid diet or a soft foods diet. If a special diet is needed, ask your healthcare team for written instructions and a list of recommended foods and foods to avoid.

Call PearlPoint at (877) 467-1936 x 101 to schedule a time to speak to a registered dietitian about your loved one for free.

Caring for an Ostomy

What is an ostomy?

Ostomy is the general name for a surgical operation to create an opening (stoma) from an area inside the body to outside the body to get rid of waste such as urine or stool. The waste is collected in a special plastic bag called an ostomy pouch. These pouches can be emptied and replaced as needed.

There are three basic types of ostomies:

- Urostomies are for urine.
- Colostomies are for drainage of the large bowel.
- Ileostomies are for drainage of the small bowel.

Ostomies are sometimes created with surgeries to remove colorectal cancer, anal cancer, and bladder cancer. Ostomies can be temporary or permanent depending on the extent of the surgery.

The care of ostomies requires special supplies and appliances. You and your loved one will be trained and educated on how to care for it by an ostomy (WOC) nurse or your healthcare team.

How often should the pouch be changed?

How often you will need to change the pouching system depends on the type of stoma, the location, and the kind of drainage.

Using the right type of pouch system and putting it on the right way will affect how long you 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 are changing the pouch system more often than expected or more frequently than the normal wear time.

When should the pouch be changed?

The best time to change the pouch system is different for everyone. The actual day and time is up to you. 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?

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.

How do you keep the stoma clean?

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, you 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 skin. Unless

recommended, don't apply powders or creams to the skin around the stoma. They can keep the skin barrier from sticking.

How should I dispose of waste or old pouch systems?

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 my loved one shower, bathe, and/or swim with the pouch system?

Yes. Pouch systems are waterproof. People 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, you 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 I 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 Drain Tubes

If surgery is part of the patient's treatment plan. A small drain tube may be placed in the wound during surgery. Breast cancer patients commonly have one or more drains after surgery. The type of drain most commonly used is the Jackson Pratt Closed Suction Drain (JP Drain). This is a long, flexible tube with a bulb on the end to collect the fluid. The tube keeps fluid or blood from building up in the wound. This reduces the risk of infection and helps the wound heal.

Caring for the Drain

You or the patient will need to drain the bulb three times a day. Before you drain the bulb, you will need to "milk" the tube by running two fingers gently down the tube to push the fluid away from your body and into the bulb at the end. This keeps fluid from building up in the tube or clogging.

You will also need to keep a log of how much fluid is collected each time you drain the bulb. The tube will be removed by your healthcare team when the amount of fluid in the bulb is below 25ml for two days in a row. This can take from 1-5 weeks depending on the surgery and the patient.

Your surgical team will teach you how to drain the bulb. You will also be given written instructions to take home with you.

Other things to remember:

- Always wash your hands before and after handling the tube and bulb.
- Do not pull or jerk on the tube or bulb. You can use a safety pin to attach the bulb to clothing so it does not accidentally snag. There is a tab on the bulb for the safety pin.
- The patient can shower with the drain in place. Do not scrub the area. Pat dry.
- Do not separate the bulb from the tube. Unplug the stopper to empty the bulb.

Contact the healthcare team if you notice any of the following:

- The tube comes out.
- Sign of infection—redness, pus, warm to the touch, bad smell, or increased pain
- Fever over 101.4.
- Fluid increases by more than 100ml a day.
- The tube stops draining.
- Fluid changes color or consistency.
- Fluid leaks onto your bandage or dressing.

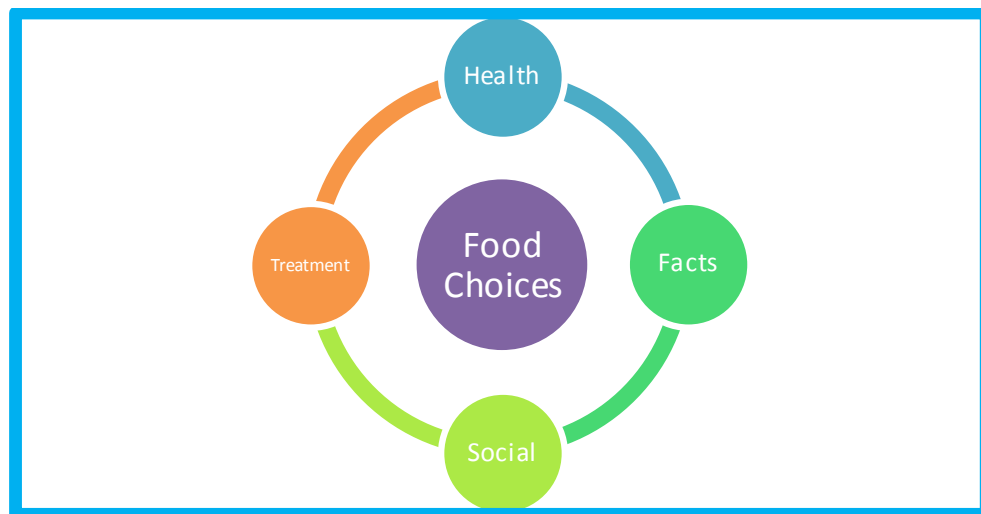
Nutrition

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 the best 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 pearlpoint.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.

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:

<i>Meat</i>	<i>Internal Minimum Temperature</i>
Ground Beef, Pork, Veal, or Lamb	160° F
Turkey	165° F
Chicken	165° F
Steak or other cuts of beef	145° F Allow to rest 3 minutes before carving or eating
Pork	145° F
Seafood	145° F
Egg dishes	160° F
Casseroles	165° F
Reheated leftovers	165° F

For more on cooking food to a safe internal temperature, visit eatright.org or FoodSafety.gov.

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 snacks to take with you:

- 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

More 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/>.

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

Free online services that help you organize and coordinate meals for a patient using a system of friends and loved ones. Visit www.mealtrain.com, www.takethemameal.com, and www.caringmeals.com.

Practical and Relationship Issues

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 Health Insurance

Even with insurance, the cost of cancer is high and often requires lots of visits with primary care doctors and specialists for labs, tests, and treatment. Insurance may not cover the cost of everything. There will also be out-of-pocket costs such as co-pays and deductibles that may build up. To stay on top of these, make sure you and your loved one know what to expect ahead of time.

Remember unless you are also on the insurance policy. You may not be able to contact the insurance company on your loved one's behalf.

Here are some tips for navigating your health insurance and the cost of cancer care:

Be familiar with your loved one's health insurance policy.

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

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

Know what your loved one is expected to pay.

Before your loved one starts treatment, take a look at the insurance plan and see what is covered and what additional costs will need to be paid.

- A portion of the costs will be out-of-pocket regardless of the insurance plan.
- See if there is an option to get this cost automatically taken out of a bank account or pay by check or with a credit card.

- Most health insurance companies have a deductible. A deductible is the certain amount that has to be paid before the insurance plan will start paying. Even with the deductible met, there may be co-payments.
- Always look in advance into what the co-payment will be for each appointment and treatment.

Make a budget.

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

- Use the budgeting worksheets provided at the end of this Handbook.

Submit everything to the insurance company.

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

Look for financial assistance.

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

The Patient Advocate Foundation may be able to assist with co-pays. For more information, call 1-800-532-5274.

Keep organized, detailed records.

Keep all your loved one's bills, receipts, and explanation of benefits (EOB) in the same place. Take notes whenever you or the patient speak with the hospital or insurance company regarding costs and payments. Remember some medical costs are tax deductible. Keeping good records is important to avoid overpaying and to stay on top of due dates.

Managing Finances

A cancer diagnosis can cause financial concerns. Even if your loved one has insurance, there are things you will both need to think about. Here are the questions you need to ask before your loved one starts treatment:

Can your loved one afford treatment? What other expenses can be expected?

Before treatment begins, ask the billing department for the expected cost.

- The healthcare team will give you a treatment plan. Take this plan to the billing department to get an estimate of the cost of your prescribed treatment plan. The more information you get the better you can prepare.

Ask the billing department if there are any ways your loved one might be able to save money.

- Many providers will give you a discount if you pay in full. Ask if your loved one can set up a payment plan where he or she pays a certain amount each month towards the bill.

Change your loved one's current budget to include costs related to the cancer diagnosis and care.

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

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

What other costs should be expected?

Additional expenses you both need to consider include:

- Transportation
- Child care
- Nutritional supplements
- Additional prescriptions
- Prostheses (artificial body parts) or wigs
- Household chore services (cleaning, grocery shopping, etc.)

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 cancercares.org for more information.

Health Insurance Options for the Uninsured or Underinsured

If your loved one is uninsured or underinsured and has been diagnosed with cancer, you should know the options for health insurance and reduced-cost medical care.

Medicaid:

Medicaid is an insurance program for those who are low income and meet the eligibility requirements. Medicare is funded by state and federal government.

- Eligibility depends on what state your loved one lives in because each state individually runs its own program.
- Visit the local government website or Department of Human Services for more information.
- Medicaid programs have strict rules about who can qualify. If someone in the household is able to work, the patient may not be able to receive Medicaid.
- Medicaid programs often include:
 - Children
 - Pregnant women
 - Social Security insurance recipients
 - People diagnosed with some cancer types
- Even if you are in one of the above categories, you will still need to qualify based on your income.
- Under the Affordable Care Act, many states expanded their Medicaid programs to include more low-income adults.
- For the most up-to-date information on these expansions, visit healthcare.gov and the Kaiser Family Foundation at kff.org.

COBRA:

The Consolidated Omnibus Budget Reconciliation Act (COBRA) was created to allow some people to temporarily keep insurance coverage if there are changes in their employment. The program allows people to keep their former job's insurance by paying the full price of the insurance to your employer (not the reduced rate paid as an employee).

- Examples of employment changes include the following:
 - Being fired or laid off from the job
 - Voluntarily leaving the job
 - Having hours reduced, making the person ineligible for insurance
 - Having health insurance through a spouse's job, and he or she died or are now divorced or separated
- COBRA is a very expensive option and may seem unaffordable, but COBRA can buy you some time. With a cancer diagnosis, medical bills from being uninsured could be more than COBRA.
- If your loved one is eligible but has not signed up for COBRA, you may be able to pay past premiums and obtain COBRA coverage.

Affordable Care Act:

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

- Open enrollment usually runs from the beginning of November to the end of January. After open enrollment has passed, the only way to apply for coverage through the ACA marketplace is to qualify for a special enrollment period.
- In the meantime, you can look to healthcare.gov to see if your loved one might qualify for a subsidy and what the deductible and premiums might be.
- Now that insurance companies can no longer disqualify individuals based on pre-existing conditions, the marketplace has multiple options that are good for those with a cancer diagnosis.
- If your loved one is under 26 years old, he or she can still be on parent's health insurance plan.
- Options through the marketplace depend on where you live. It is best to check the marketplace directly to see individual options. Visit healthcare.gov for more information.

Local Health Department and Local Free Clinics:

- Look to local free clinics for medical treatment.
- You can also do a search of free clinics in your area at The National Association of Free & Charitable Clinics at www.nafcclinics.org/clinics/search.

- In addition to free clinics, there are approximately 170 healthcare facilities that still provide free or reduced cost services under the Hill Burton free and reduced cost healthcare law.
 - Your loved one must apply at the admissions office of the participating hospital to determine if you meet eligibility requirements.
 - For more information, visit the US Department of Health and Human Services at www.hrsa.gov.

Social Security Disability Benefits and Cancer

If your loved one is no longer able to work, he or she may qualify for Social Security Disability benefits.

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

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

The SSA offers two types of disability programs.

1. Social Security Disability Insurance (SSDI)
 - The patient must have worked jobs in which he or she paid Social Security taxes.
 - The patient must meet the SSA's definition of disability.
 - People approved for SSDI are eligible for Medicare after a two year waiting period.
 - SSDI is not health insurance.
2. Supplemental Security Income (SSI)

- SSI is a needs-based program. The patient must prove his or her income and assets are below the limit.
- The patient does not need work credits to qualify.
- The patient must meet the SSA's definition of disability.
- SSI is also available for individuals over 65 without a disability who meet the financial need requirement.
- People approved for SSI automatically qualify for Medicaid.
- In some cases, your loved one may qualify for both SSDI and SSI.
- SSI is not health insurance.

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

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

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 your loved one's medical appointments your regular breaks such as lunchtime or after/before work.

Talk to your supervisor or Human Resources representative to find out if your company allows for flex-time, or if you can modify your regular work schedule such as working on a Saturday or evening to free weekday time for appointments.

Some larger employers offer an Employee Assistance Program (EAP). If your company doesn't have an EAP, talk with the human resources (HR) department.

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.

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.

Advanced Directives

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

As a caregiver you may feel uncomfortable or uncertain about bringing up advanced directives. It can be a difficult and emotional topic for the patient. However, if the patient ever reaches a point where he or she cannot make medical decisions for his or herself, you will want advanced directives to make sure your help meet the patient's wishes.

Advanced directives may differ by state. The hospital or treatment center can give you the forms. Make sure you and the healthcare team receive a copy of the advanced directives. If the patient changes his or her mind about the kind of treatment preferred, advanced directives can be changed.

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

- **Life support or use of equipment such as dialysis machines, ventilators, and respirators**
- **DNR (Do Not Resuscitate)**
 - DNR orders tell the healthcare team not to do CPR if the patient's heart or breathing stops.
 - CPR (cardiopulmonary resuscitation)
 - First aid used when the heart or breathing stops. CPR can include chest compressions, electric shock, or medication.
- **DNI (Do Not Intubate) orders**
 - DNI orders tell the healthcare team not to put a tube through in the patient's nose or mouth to help with breathing.
- **Artificial nutrition and hydration**
 - If the patient is unable to eat or drink, the healthcare team will provide nutrition and fluids through an IV or feeding tube.
- **Treatment of new conditions**
- **Organ and tissue donation**
- **Medical Power of Attorney**

- Medical power of attorney lets the patient name another person, such as a family member or close friend, who can make decisions about his or her medical care if the patient is no longer able to do so. As the primary caregiver, you may be assigned medical power of attorney. However, this choice belongs to the patient.
- This may also be called a healthcare proxy, appointment of healthcare agent, or durable power of attorney.
- Most states will not allow anyone on the healthcare team to be your medical power of attorney.

Communicating with a Cancer Patient

Communication is key when it comes to caring for a cancer patient. 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.

What To Say and What Not To Say

You're not alone if you're not sure what to say to someone who has cancer, even someone you love. 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 here for you when and if you need me."
- "Let me know how I can help."

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.

Be careful when bringing up a cancer patient's physical appearance. Cancer brings with it a lot of physical changes—hair loss, weight loss, weight gain, skin changes, and swelling. Cancer patients often struggle with body image and may be embarrassed or sensitive about the changes to their bodies. You may want to tell a cancer patient that he or she looks great, but it may not come across as the compliment you intended. For example, weight loss for cancer patients is usually a side effect of cancer and treatment, so compliment on weight loss may come across as insensitive.

It may not be a good idea to share stories about family members or friends who have had cancer. Every person is different, and these stories may not help, especially if the friend or family member has passed away. 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.

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.

Set Caregiving Parameters

Try to set some parameters early. What will your role as caregiver include? For example, will you be the one scheduling most of the appointments, or does the patient prefer to take an active role? Find what works best for you both.

Keep the conversation going. As treatment progresses, you may need revisit the parameters you set. Before you assume, ask the patient if her or she would like for you to take over a responsibility. For example, before treatment side effects, perhaps the patient still wanted to do his or her own grocery shopping, but now nausea and fatigue make grocery shopping difficult.

Remember, cancer may mean the loss of your loved one's independence in many ways. The patient may resist your care at times to try to maintain a sense of independence and normalcy. Try not to take this personally.

Respect Your Loved One's Privacy

Ask your loved one who he or she plans to tell about the cancer diagnosis. Some patients prefer to keep their diagnosis private, especially in the beginning. If your loved one does not want people to know, respect his or her wishes.

Be careful about what you post on social media. Even if your loved one shares the diagnosis with friends or family, the patient may not want to share the diagnosis with acquaintances, co-workers, or classmates. Even private social media profiles, may not be as private as you think.

Caregiving can be a difficult job, so it's natural to want to talk about what you are going through too. If the patient wants to keep the diagnosis private, find someone you can talk to in confidence such a caregiver support group or a therapist.

Sex and 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. If you are a caregiver for your spouse or romantic partner, know that sex and intimacy may change after a cancer diagnosis.

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.

Sexual Side Effects for Women with Cancer

Women may experience the following sexual side effects due to cancer or cancer treatments:

- Lack of desire
- Painful intercourse
- Vaginal dryness
- Difficulty reaching climax or orgasm
- Body image issues
- Early onset of menopause
- Infertility

The patient should talk to the healthcare team about any sexual dysfunction. The patient may need to talk to gynecologist or a sex therapist. There are many ways to manage and improve sexual dysfunction. Estrogen therapies may help with lack of desire. (If the cancer is hormone driven, such as some breast cancers, estrogen therapy may not be safe for the patient.) Antidepressants may help with mood and emotional issues. Vaginal lubricants and moisturizers can help make sex less painful. Physical therapy may also help with pain.

For emotional and body image issues, talking to a psychologist or therapist may be helpful.

Sexuality Issues for Men with Cancer

Men may experience the following sexual side effects due to cancer or cancer treatments:

- Erectile dysfunction
- Inability to reach orgasm
- Loss of sex drive
- Body image issues
- Infertility

The patient should talk to the healthcare team about any sexual dysfunction. The patient may need to talk to urologist or a sex therapist. There are many ways to manage and improve sexual dysfunction. Prescription medications can help with erectile dysfunction by increasing blood flow to the penis. Penile injections, pumps, or implants may also help if medication does not. Testosterone therapy may help with lack of desire, but if the patient has a hormone-driven cancer, such as prostate cancer, testosterone therapy may not be safe.

For emotional and body image issues, talking with a psychologist or therapist may be helpful.

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.

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 your partner is thinking and talk about it.

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 home health 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.

Be organized.

Gather everything you need in one place—medical records, contact information, insurance information, advanced directives or other legal paperwork. You will need to reference this paperwork often so it helps to have easily accessible. Use a single binder or a flash drive to store information. You can use the worksheets at the end of the Handbook to get started.

Know the healthcare team.

If at all possible, try to go with your loved one to at least one appointment with each member of the healthcare team. If not possible, call or email the members of your loved one's healthcare team to introduce yourself. Gather all their names, contact information, and role and keep the information in safe place.

Reminder, your loved one will mostly likely have to give permission to the hospital or treatment center to allow you to discuss diagnosis and treatment information with the healthcare team.

Update emergency contact information with the hospital or treatment center.

Make sure you are listed as the emergency contact for your loved one with the appropriate contact information. For example, make sure the hospital has your cell phone number if you do not often answer a home number. It may also be appropriate to have a local emergency contact listed for your loved one. This way, in case of an emergency, someone can be present immediately if it takes you time to travel.

Explore home health services.

Home health services for your loved one may be necessary as treatment progresses and if your loved one is less able to care for himself or herself. 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

Ask for help.

Reach out to other friends and family where your loved one lives. People want to help, but may not know how to help. 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.

You can also reach out to local nonprofit and service organizations. For example:

- The American Cancer Society offers a program called Road To Recovery. Through this program, volunteers help drive cancer patients to and from appointments. Call (800) 227-2345 to find a Road to Recovery Program in your loved one's area.
- Meals On Wheels delivers healthy meals to seniors across the country. Visit www.mealsonwheelsamerica.org to find a local program.

Travel the right way.

Before you visit your loved one, make a plan to accomplish 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. Don't forget to make time for fun

activities as well so you can spend quality time together instead of rushing from place to place. If your loved one is in the midst of treatment, you may also need to factor in rest times and extra snack breaks to keep their energy levels up.

Travel expenses can add up. If you have to fly to visit your loved one, look for flights at less popular times such as weekdays or early in the morning or late at night. These can be less expensive. Use multiple websites to shop prices for hotels and flights. Take advantage of customer loyalty plans. See if any airlines or hotels you may frequent offer discounts to members or allow you to build up points or miles for free or discounted travel.

Expect unplanned travel. Have an emergency travel plan. Try to save and set aside some extra funds for emergency plane tickets or hotel rooms. Keep a bag packed with essentials. Give a key to your home to a trusted friend or neighbor so if you have to leave at a moment's notice someone can check on the home or care for any pets.

If other family members are doing most of the day to day caregiving, step in for them and give them some much-needed time off when you visit.

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.
- Try to stay connected with friends even if you do have to cut back on your personal life.
- 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.
- Get a good amount of sleep each night, and find time to rest throughout the day as well.

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.

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.

In order to care for your loved one, you have to take care of yourself too. As the saying goes, "you can't pour from an empty cup."

Emotional Support for Caregivers

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

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. It can be helpful to connect with other caregivers and cancer survivors. There are emotional support programs available that can help you and your loved one.

Support Groups

Support groups 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.

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 connections for caregivers:

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

You should also reach out to members of the healthcare team for local suggestions. Many hospitals and treatment centers host support groups for survivors and caregivers.

Depression and Cancer

Feeling sad, depressed, or anxious after a cancer diagnosis is normal. However, if these feelings start to interfere with your daily activities, you may need individual counseling from a medical professional.

Symptoms of clinical depression:

- Ongoing sadness or feelings of hopelessness
- Loss of interest or pleasure in most activities
- Major weight loss or weight gain
- Agitation or restlessness
- Fatigue or no energy
- Trouble sleeping
- Trouble focusing, remembering, or making decisions
- Feeling worthless, guilty, or helpless
- Thoughts of death or suicide

Don't be afraid to seek help. Reach out to the healthcare team for suggestions, visit your own primary care doctor, or call your insurance company for recommendations.

After Treatment Ends

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

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.

Finding Your New Normal

Many refer to the time after cancer treatment as the “new normal.” For both patients and caregivers, it’s difficult for life to go back to exactly the way it was before cancer. Be careful with your expectations. It may not be possible to go back for practical reasons. For example, maybe you had to quit your job. Or, maybe you don’t want to go back to the way things were. You may have gained a new perspective.

These tips may help you find your “new normal” after caregiving:

Go back to work. If you had to take a leave or left your job entirely, try going back to work. Reach out to your past employer or seek a new job. Working and having a regular schedule will help you adjust.

Reach out to friends and family. Your social life may have been pushed to the side while caring for you loved one. Rekindle these relationships.

Try volunteering. If you are retired or if you find yourself with free time on your hands, volunteer with a local organization. It doesn’t have to be a cancer organization. (In fact, it may be easier emotionally if it isn’t.) What cause do you care about—animals, education, hunger, the environment?

Take care of yourself. You can now focus on yourself. Improve the food choices you make. Stop smoking. Be more active. Do something you love—travel, write, paint, garden, or any other hobby you enjoy.

Fear of Recurrence

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

Educate yourself. Know the actual risk of recurrence and what can be done to lower the chances. Talk to the healthcare team and ask the following.

- What are the chances of recurrence?
- What can the patient do to lower the risk of recurrence?
- What signs should the patient look for to know if the cancer has returned?
- Do I, as family member, need to look into genetic testing or change my screening schedule? Am I at increased risk for cancer because of my loved one's diagnosis? (This question only applies to caregivers caring for a blood relative.)

Talk to someone. You may find it comforting to connect with fellow cancer caregivers. You can still do so even if you are no longer providing care. Find a support group in your area or reach out to someone you know. If your fears begin to interfere with your day-to-day activities, you may need individual counseling from a medical professional. Ask your primary care physician for a recommendation.

Caregiving after Cancer Treatment

After cancer treatment ends, you most likely will not be providing the same level of care, but there are still things you can do to support your loved one.

- Learn the late side effects possible from the patient's treatment. Keep an eye out for them.
- Go with the patient to follow-up appointments and scans.
- Help the patient collect medical records as the patient transitions back to a primary care doctor instead of an oncology healthcare team.
- Be there for your loved one to offer emotional support. The years and months after cancer treatment can be just as difficult if not more so than the actual treatment time.

Survivorship can be as difficult as treatment, especially emotionally. Treatment offers a goal and an end date. Without this you and your loved one may feel lost. As you transition out of the caregiver role and your loved one transitions to survivorship, take everything one day at a time.

Hospice Care and End of Life Care

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

Palliative care

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

Hospice

- Hospice is a type of palliative care.
- Hospice is end-of-life care. Terminal patients with a life expectancy of six months or less often use hospice.
- Hospice care is not usually given at the same time as other treatments such as chemotherapy and radiation. Hospice is given after treatment options have been exhausted.
- Hospice care can be provided at home or in a special facility. Most patients prefer hospice care at home if possible.
- Medicare pays for all hospice costs. In most states, Medicaid pays for hospice costs. Most other insurance plans have hospice benefits.

End of Life Care

End of life care is a challenging and emotional time for the caregiver and the patient. It's important during this time to respect the patient's wishes and to provide care that improves quality of life and makes your loved one more comfortable.

When should hospice care be considered?

- If that patient is making lots of trips to the hospital or emergency room, but he or she would prefer to be at home.
- If the patient has a life expectancy of six months or less
- If the patient decides to stop receiving treatments

- If the patient has daily, ongoing medical or care needs beyond your ability to provide

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. There is no time line of grief. Deal with each new emotion as it comes.

Anticipatory Grief

We usually don't think of grief as something that happens before someone dies, but grief can be very complicated. It doesn't just follow death. You may begin mourning from someone before they pass away. Sometimes this is referred to as anticipatory grief.

As you watch your loved one suffer, you may wish he or she would pass away so he or she would no longer be in pain. After this thought, you may feel guilty for having thought it at all. Don't beat yourself up for these feelings. They are all normal feelings.

Ambiguous or Unconventional Grief

You may also grieve for other things you have lost such as a way of life or the way a person used to be. While in cancer treatment, your loved one may change physically, mentally, and emotionally. You may find yourself missing the person you knew before cancer. You may also find yourself missing the way *you* were before becoming a caregiver. It's normal to have these feelings.

Stages of Grief

You may have heard of the five stages of grief:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

The five stages may come quickly or slowly, and they may not be linear. You may even skip one. However, knowing the five stages may help you put some context around your feelings and anticipate what may come next.

Give yourself permission to feel whatever you feel when you feel it and how you feel it. You may cry as soon as your loved one passes or you may feel a sense of calm. You may cry later. You may be in shock and not feel much of anything at all. You may want to yell or feel anger. Everyone responds to loss differently.

Find Emotional Support

While grieving, seek some form of emotional support for yourself. Talk to family or close friends. If you are religious or spiritual, reach out to a religious leader in your community. Join a caregiver support group. You may even wish to speak to a mental health professional.

Find other healthy ways to express your emotions such as journaling, art, or exercise. Take a mental health day and do something you love like going to movie or a spa.

Don't deny yourself the care you need.

Worksheets

The following worksheets can help you organize your life and keep track of all important information during the cancer journey. If you visit, pearlpoint.org, you can print as many worksheets as you need.

- The Patient's Medical History
- Food Intake and Side Effect Log
- Meal Planning Calendar
- Questions for Healthcare Team
- Medication Log
- Grocery List
- Appointment Details
- Calendars
- Lab Flow Sheets and Lab Reports and Terms
- Budgeting Worksheets



Medical History

When visiting a doctor, especially for the first time, it is helpful to prepare your medical history in advance. Your healthcare team needs as much information as possible so they can determine the care that is best for you. Your healthcare team may have specific forms for you, but these 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 DOCTOR

Primary Care Doctor: _____

Practice: _____

Phone Number: _____

Address: _____



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: _____

Policy Holder's Employer: _____

Employer Address: _____

Employer Phone Number: _____



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 surgeries, imaging, hospitalizations, or other major procedures you've had in the past.

Procedure	Description/Purpose	Date



FAMILY MEDICAL HISTORY

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

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

Do you know any other pertinent family medical history?



DATE :

Food Intake & Side Effect Log

Keeping track of your food intake, side effects, and overall well-being is very important during your cancer journey. Seeing how your food intake affects the way you feel can provide insight for you and your healthcare team.

Additional Notes:

Time of Day	Food & Beverages	Amount	How Do You Feel? <small>List any side effects you are experiencing.</small>
BREAKFAST			
SNACK			
LUNCH			
SNACK			
DINNER			
SNACK			

Circle your overall well-being for the day.

0 WORST 1 2 3 4 5 6 7 8 9 10 BEST



Meal Planning Calendar

Planning your meals in advance is a great way to help you include a variety of healthy foods in your menu each week. Your written meal plan can also remind you of leftovers to use for lunch or snacks later in the week. It takes the guesswork out of meal time. Use the Meal Planning Calendar while writing your grocery list so you'll have all the ingredients you'll need on hand.

THE WEEK OF:

Day	Menu Items	Leftovers
MONDAY		
TUESDAY		
WEDNESDAY		
THURSDAY		
FRIDAY		
SATURDAY		
SUNDAY		
Notes & Grocery Reminders:		



Questions For Your Healthcare Team

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

What is my diagnosis?

What stage is my cancer? What is my prognosis?

What are my treatment options? What would you recommend?

Am I eligible for a clinical trial?

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



How can I manage these side effects?

How can I keep myself as healthy as possible during treatment?

Will I be able to have children? What are my options to preserve fertility?

Where can I find help with financial concerns?

Where can I find help with lodging or transportation?

What will my follow-up care plan include?



Grocery List

PANTRY

Grains

- Whole grain breads
- Crackers
- Whole grain rice & pasta
- Oatmeal & hot cereal
- Couscous, bulgur & quinoa
- Cereal
- Natural popcorn
- Flour & breadcrumbs
- Whole Grain Cereal

Fruit/Vegetables

- Canned & dried fruit
- Applesauce (unsweetened)
- Potatoes & sweet potatoes
- Onions & garlic
- Canned tomatoes & veggies
- Instant mashed potatoes

Dairy

- Nonfat dry milk or whey protein powder
- Evaporated Milk

Proteins

- Canned fish & chicken (packed in water)
- Natural peanut & almond butter
- Unsalted nuts & seeds
- Canned & dried beans/peas
- Protein bars

Fats & Oils

- Olive & canola oil
- Cooking spray

Other

- Low-sodium soup & stock
- Dried herbs & spices
- Assorted vinegars
- Decaffeinated teas
- Decaffeinated coffee
- Flavored drink mixes
- Pudding & gelatin
- Honey, sugar, or stevia

Extra Groceries

- | | | | |
|--------------------------|-------|--------------------------|-------|
| <input type="checkbox"/> | _____ | <input type="checkbox"/> | _____ |
| <input type="checkbox"/> | _____ | <input type="checkbox"/> | _____ |
| <input type="checkbox"/> | _____ | <input type="checkbox"/> | _____ |



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
- Other

Transportation: _____

Lodging: _____

Notes: _____



Monthly Calendar

Month: _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Notes:



Calendar

Week: _____

Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday/Sunday	

Notes:

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:	Expected:	Actual:
Salary		
SS/SSDI		
Employment Benefits: Short-Term Disability		
Investments		
Total:		

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

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

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?

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

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.needy meds.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?
 - o For Road to Recovery call the American Cancer society at **(800) 227-2345** or visit www.cancer.org.
 - o 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?

	Expected:	Actual:
Total Income:		
Total Expenses (Monthly/Medical):		
After Expenses: (Total Income – Total Expenses = After Expenses)		

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.

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

References

American Cancer Society. If You're About To Become A Cancer Caregiver. www.cancer.org/treatment/caregivers/if-youre-about-to-become-a-cancer-caregiver. Accessed May, 5 2017.

American Cancer Society. What A Cancer Caregiver Does. www.cancer.org/treatment/caregivers/what-a-caregiver-does. Accessed May 20, 2014.

Cancer.Net. Adjusting to Life After Caregiving. Last Updated April 2015. www.cancer.net/coping-with-cancer/caring-loved-one/adusting-life-after-caregiving. Accessed May 2, 2017.

Cancer.Net. Side Effects of Surgery. Last Updated July 2016. www.cancer.net/navigating-cancer-care/how-cancer-treated-surgery/side-effects-surgery. Accessed May 5, 2017.

CancerCare. Caregiving for Your Loved One With Cancer. www.cancercare.org/publications/1_caregiving_for_your_loved_one_with_cancer. Accessed May 21,2014.

Cancer Treatment Centers of America. *Think green: Tips for safely cleaning you home and saving money*. Date last modified October 24, 2013. www.cancercenter.com/discussions/blog/green-cleaning. Accessed May 22, 2014.

Caregivers. Cancer Support Community. www.cancersupportcommunity.org/caregivers. Accessed May 21, 2014.

Livestrong. Making Changes to Your Home. www.livestrong.org/we-can-help/managing-your-life-during-treatment/making-changes-to-your-home. Accessed May 22, 2014.

National Cancer Institute. Support for Caregivers of Cancer Patients. www.cancer.gov/about-cancer/coping/caregiver-support. Accessed May 5, 2017.

National Cancer Institute. *Caring for the Caregiver* [Pamphlet]. September 2014. www.cancer.gov/publications/patient-education/caring-for-the-caregiver.pdf. Accessed May 2, 2017

Sarvis, Connie RN, CON©, CWS, IWC, MN, FCCWS. "Patient Education: Postoperative wound care." *LPN2007*. September/October 2007, Volume: 3 Number 5. Lippincott Nursing Center. www.nursingcenter.com/journalarticle?Article_ID=737320. Accessed May 20, 2014.

Social Work Bloggers. "Cancer caregivers: 4 tips to reduce stress." The University of Texas MD Anderson Cancer Center. Last Updated November 11, 2013. www.mdanderson.org/publications/cancerwise/2013/11/cancer-caregivers-4-tips-to-reduce-stress.html. Accessed May, 20, 2014.

University of Michigan Comprehensive Cancer Center. What to Expect from Outpatient Cancer Therapy. www.mccancer.org/chemotherapy/what-to-expect. Accessed May 22, 2014.

Wound Ostomy and Continence Nurses (WOCN) Society Practice Ostomy Subcommittee (2012). *Basic Ostomy Skin Care: A guide for Patients and Health Care Providers* [Pamphlet]. www.ostomy.org/uploaded/files/ostomy_info/wocn_basic_ostomy_skin_care.pdf?direct=1. Accessed May 21, 2014.