

Resources *for* Care *Givers*



INDEX

Caregiver Bill of Rights.....	3
Welcome from Inspira.....	4
Directory of Services.....	6
What You Need to Know as a Caregiver.....	7
Dealing With the Diagnosis	9
Getting Organized.....	12
Keeping Track of Medical Information.....	14
Medication Tracker.....	16
Patient’s Cancer History.....	17
Test Results Tracker.....	18
Treatment Tracker.....	19
The Cancer Team.....	20
Managing Symptoms at Home.....	24
Coping Checklist for Caregivers.....	36
Caregiver Self-Assessment.....	38
Spiritual and Emotional Care.....	41
Clinical Trials.....	43
Additional Resources.....	44
Notes Section.....	48

The information in this guide is for educational purposes only and is not intended to constitute medical advice. If you have health concerns or questions, please contact your healthcare provider.

CAREGIVER BILL OF RIGHTS

- I have the right...** to take care of myself. This is not an act of selfishness. Meeting my own needs will help me take better care of my loved one.
- I have the right...** to seek help from others. Even though my loved one may object to accepting outside help, I recognize the limits of my own endurance and strength.
- I have the right...** to maintain my own interests. I deserve to nurture the facets of my own life that do not include the person I care for. I know that I do everything that I reasonably can for this person, and it's okay to do some things just for myself.
- I have the right...** to have negative feelings. I'm human, and it's okay for me to occasionally express frustration, exhaustion, depression and other difficult feelings.
- I have the right...** to not be manipulated. I will reject any attempts by my loved one (either conscious or unconscious) to guilt or shame me into doing things.
- I have the right...** to feel compassion from others. I deserve to receive consideration, affection, forgiveness and acceptance from my loved one for as long as I offer these qualities in return.
- I have the right...** to be proud of my work. I can take pride in what I am accomplishing and applaud the courage it sometimes takes to meet the needs of my loved one.
- I have the right...** to protect my individuality. I need to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- I have the right...** to demand societal progress. I expect that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

Adapted from the book, CareGiving: Helping an Aging Loved One, by Jo Horne, published in 1985



Welcome to Inspira Health Network Cancer Services

When a loved one is diagnosed with cancer it can be both physically and emotionally overwhelming. The staff at Inspira Health Network is here to support the caregiver and patient through their cancer journey. This guide "Resources for Caregivers" is designed to answer many of your questions and provide you with resources along the way.

At Inspira we provide our patients with a complete range of cancer services including: infusion services, radiation oncology, and surgery. Supportive services include navigation, support groups, genetic counseling, cancer screening, nutritional counseling and a survivorship program.

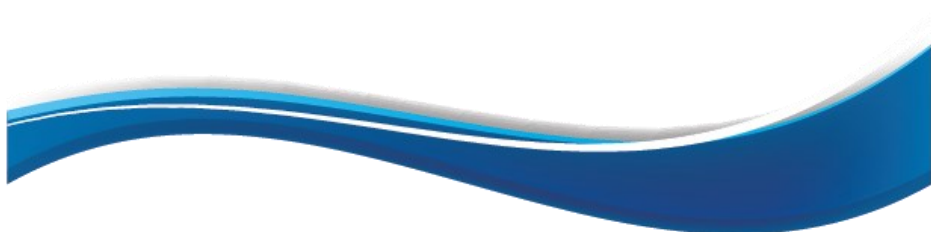
To ensure you receive exceptional care, and ease the stress you and your loved one may be experiencing during this challenging time, certified oncology nurse navigators are available to guide patients and caregivers through their treatment journey.

The Frank & Edith Scarpa Regional Cancer Pavilion at Inspira Medical Center Vineland offers community members comprehensive cancer care and specialists all under one roof. At Inspira Medical Center Woodbury we provide community members with access to surgical oncologists and partner with medical and radiation oncologists to facilitate the delivery of cancer care. The Frank & Edith Scarpa Regional Cancer Pavilion has been designated as a Comprehensive Community Cancer Program by the American College of Surgeons Commission on Cancer.

We hope this guide helps you and your loved one navigate the cancer journey.

If you would like to speak with me, please feel free to let a staff member know, or call me at 856-641-8670.

Sincerely,
 Judy Neuman
 Director of Cancer Services
 Inspira Health Network



Inspira Health Network

Directory of Services

name	phone
Frank & Edith Scarpa Regional Cancer Pavilion - Vineland	856.641.8670
Inspira Cancer Services - Woodbury	856.853.2075
Inspira Health Network	
<i>Medical Center—Vineland</i>	856.641.8000
<i>Medical Center—Elmer</i>	856.363.1000
<i>Medical Center—Woodbury</i>	856.845.0100
Navigators	
<i>Breast Oncology Navigator</i>	856.641.7974
<i>Genitourinary, Gastrointestinal and Oncofertility Oncology Navigator</i>	856.641.6005
<i>Oncology Navigator—Woodbury</i>	856.845.0100 x 42581
<i>Surgical Gynecologic Oncology Navigator</i>	856.641.8687
<i>Thoracic, Head and Neck Oncology Navigator</i>	856.641.6024
Oncology Social Worker	<i>Vineland</i> 856.641.8673 <i>Woodbury</i> 609.828.4591

What You Need to Know as a Cancer Caregiver

Who are caregivers, and what do they do?

Here we will talk about caregivers as the unpaid loved ones who give the person with cancer physical and emotional care. Caregivers may be partners, family members, or close friends. Most often, they are not trained for the caregiver job. Many times, they're the lifeline of the person with cancer.

Here are a few things caregivers might help the person with cancer do, or in some cases even do for them:

- Shop for and prepare food
- Eat
- Take medicines
- Bathe, groom, and dress
- Use the bathroom
- Clean house and do laundry
- Pay bills
- Find emotional support
- Get to and from doctor's appointments, tests, and treatments
- Manage medical problems at home
- Coordinate cancer care
- Decide when to seek health care or see a doctor for new problems

In general, caregiving tasks fall into three categories: medical, emotional, and practical.

All of this work costs caregivers time and money. There may also be a cost to the caregiver's health and well-being, but often the caregiver just keeps doing what needs to be done and may suffer in silence.

You may be glad to put the well-being of the person with cancer above your own well-being. And your love for this person may give you the energy and drive you need to help them through this difficult time. Still, no matter how you feel about it, caregiving is a hard job! And many caregivers are there for their loved one 24 hours a day for months or even years.

In this guide we will discuss some of the more common challenges caregivers may have to deal with while helping a loved one with cancer. It may help you to know this:

Caregivers who take care of their own needs and get the information, help, and support they need are better prepared to take care of their loved ones.

This guide will give you ideas on how to take care of yourself and find the support and help you need. We will also give you tips on how to be ready for some of the problems that might come up. Being a caregiver is a tough job, but it's an important and rewarding one, too. Today, more than 13 million Americans have or have had cancer. Each of them probably needed a caregiver at some point to help them through their cancer experience, especially the first year or two after diagnosis. This is when most of the treatment takes place and caregivers can be very important to its success.

How do we adjust to the diagnosis?

With time, the patient and loved ones will start to adjust to the cancer diagnosis. This is a time of change and action—everyone is getting used to the unexpected and scary situation that they now find themselves in. Even with all the activity, some people go through their days feeling numb and disengaged. Others may be sad, edgy, or angry. Emotions may change from minute to minute as everyone copes in their own way. Things may not feel settled for a long time, but there are appointments to keep, things to discuss, and plans to make.

It's important to get accurate, reliable information in writing to be ready when you or others must ask questions or coordinate care:

- What is the exact name and location of the cancer?
- What is the stage of the cancer?
- What treatments are recommended? How are they done, and how long do they take?
- Will the patient need to be in the hospital? When and for how long?

Information provided by the American Cancer Society — www.cancer.org

Inspira's Oncology Nurse Navigators connect cancer patients and their caregivers with a specially trained registered nurse who provides education in the form of practical and personalized information. They also support the patient's right to ask questions, to obtain and understand medical reports and to know what to expect from treatment. If you have questions about your loved one's cancer treatment, our Navigators are here to guide you. You can find contact information for the Navigators on Page 6.

How do we deal with the uncertainty?

When a person has cancer, they go through different stages. Your understanding and your care will change over time, too. There will be times when you don't know what will happen next, and with an illness as serious as cancer, that's a scary place to be. But there are no guarantees in cancer care. There's no way to know for sure whether treatment will work. No one can predict the side effects or problems your loved one will have during treatment. And even after successful treatment, there's still the chance that cancer will come back—there can even be a new, different cancer sometime in the future.

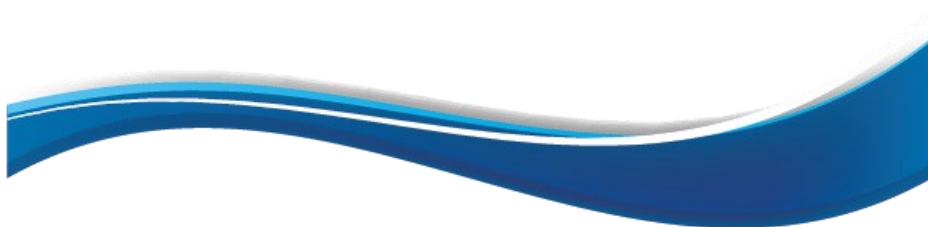
It can be hard to deal with this constant state of "not knowing" - for you and the person with cancer. Here are some ideas that have helped others deal with uncertainty and fear and feel more hopeful:

- Learn what you can to do to keep the person with cancer as healthy as possible, and learn about the services available to you. This can give you a greater sense of control. And don't forget to keep yourself as healthy as possible, too.
- Know that you do not have control over some aspects of the cancer. It helps to accept this rather than fight it.
- Try to let go of your fears, but don't deny them. It's normal for these thoughts to enter your mind, but you don't have to keep them there. Some people picture them floating away, or being vaporized. Others turn them over to a higher power to handle. However you do it, letting them go can free you from wasting time and energy on needless worry.
- Express feelings of fear or uncertainty with a trusted friend or counselor. Being open and dealing with emotions helps many people feel less worried. If you find that you're thinking about nothing besides the cancer, it may be helpful to find a way to express your feelings.

Information provided by the American Cancer Society — www.cancer.org

- Use your energy to focus on wellness and what you can do now to stay as healthy as you can. Remember to take care of yourself, as well as the person with cancer.
- Find ways to help yourself relax.
- Make time for regular exercise, and be as active as you can.
- Control what you can. Some people say that putting their lives back in order makes them feel less fearful. Keeping your life as normal as possible and making changes in your lifestyle are just a few of the things you can control. Even setting a daily schedule can give you more power. And while no one can control every thought, some say they've resolved not to dwell on the fearful ones.

You play an important role in the health of the person you are caring for, but you cannot control how they are doing physically and mentally. Be careful not to look at your loved one's progress and good days as proof of your caregiving skills. If you do this, you'll be more likely to blame yourself when they have bad days and set-backs. Uncertainties and highs and lows are part of dealing with cancer—no one, not even the best caregiver, can control them.



Organizing Medical Treatment and Paperwork

It helps to be organized.

You'll be getting a lot of information—new information that can be hard to understand—and it helps to keep it all in one place. Take notes. Some people rely on their electronic organizers, which is good as long as it's secure and there are backup copies. You can use this guide to take notes and keep track of appointments. Whatever you use, bring it to every office visit and every treatment.

Learn as much as you can about the illness and the treatment plan. This makes it easier to talk to the doctor and the patient. It also helps you better understand what to expect over time.

Here are some ways to help manage your loved one's treatment:

Gather information. Learn about your loved one's diagnosis and possible treatment options.

Go to appointments together. Before a medical appointment, write down any questions you would like to ask. Bring this guide to take notes so you can refer to them later.

Manage medications. Keep a detailed list of all medicine the patient is taking. Use the medication management tool on page 16.

Ask about special instructions. Check with the doctor or nurse to find out if there are any special instructions to be aware of. For example, any tips on managing a side effect, or special diet regulations during treatment.

Questions to Ask the Doctor

Here are some questions you or your loved one might want to ask the doctor:

What are the goals of treatment?

How long will treatment last?

Do you have any written information about this treatment?

What are the side effects of this treatment?

Are there any ways to help manage side effects?

How do we know if a side effect is severe enough to call you?

Are there any other treatment options?

Are there any clinical trials we should be aware of?

What is the best way to let you know when we have questions about treatment?

Use the "Notes" section on page 48 to write questions and answers, and any other useful information the doctors or nurses share with you.

Medical Information

It is important to keep a record of the patient's medical information.

- Keeping all of the patient's medical information in one place helps you avoid misplacing the information and going through old documents to find the original diagnosis.
- In the event that the patient sees a new doctor (cancer specialist or other), they will most likely want a record about the type of cancer and the treatment received.
- Over time, you and the patient will most likely block out many of the details of the cancer treatment - your brain's way of dealing with trauma and enabling you to move on with life. You'll want to have these medical history notes written down for future reference.

Patient ID Card

PATIENT Name _____

Home Address _____

Primary Care

Physician _____

PCP Phone # _____

Other Specialists _____

Current Medical Conditions _____

Current Diagnoses _____

Allergies to Medications _____

Insurance Information

Provider _____

ID # _____

Group # _____

Current Medications & Dosage _____

medication tracker

Use this section to keep track of the patient's medications, vitamins, and supplements.

Ask the patient's physician to print out a list of current medications and keep it in the sleeve provided. Be sure to get an updated list any time a medication is changed, added, or removed from the patient's regimen.

the patient's cancer history

Date of diagnosis/biopsy _____

Cancer Type _____

Further cancer details _____

For solid tumors:

Location of tumor(s) _____

Size of tumor(s) _____

Number of Nodes taken _____

Number of Nodes positive _____

Stage/Grade _____

Other details _____

Previous Cancers/Notes:

test results tracker

Use this section to keep track of radiology tests and scans.

date	name of test	results

treatment tracker

Use this section to track chemotherapy, radiation, immunotherapy, hormonal therapy, and other treatments.

date(s)	treatment (list drug names)	date(s)	treatment (list drug names)

the cancer team

Keep business cards here.

Even though you may program the cancer center, physician offices, and other phone numbers into your phone, it's helpful to have business cards and phone numbers in one safe location for your reference.

Write down important contacts.

These could include:

Doctors

Navigators

Support groups

Referrals

Other specialists

Fitness programs, pastors, and more...

The "Managing Symptoms at Home" section recommends when you should call the cancer team for serious symptoms. If the cancer team is unavailable and the patient is experiencing serious symptoms or a medical emergency, please call 911 or go to the closest Emergency Room.

Contact Name _____
Organization _____
Telephone _____ Fax _____
Address _____
Email _____
Referred by _____

Contact Name _____
Organization _____
Telephone _____ Fax _____
Address _____
Email _____
Referred by _____

Contact Name _____
Organization _____
Telephone _____ Fax _____
Address _____
Email _____
Referred by _____

Contact Name _____
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Address _____
Email _____
Referred by _____

Contact Name _____
Organization _____
Telephone _____ Fax _____
Address _____
Email _____
Referred by _____

Managing Symptoms at Home

This guide will give you information about caring for someone with cancer at home. It is an alphabetical list of some of the common problems people with cancer have. It gives you signs of problems to watch for and ideas for what you can do if any of these problems come up. The information given here is not meant to take the place of talking with a health professional. The people who know the patient's situation well can give you the information that you need the most.

Anemia

Anemia is when the body doesn't have enough red blood cells. Some types of chemotherapy cause anemia. Having anemia can make a person feel very tired or weak.

What the patient can do:

- Balance rest with activities ◦ take short naps during the day
- sleep at least 8 hours every night
- eat a balanced diet
- drink plenty of water

What the caregiver can do:

- Schedule friends and family members to prepare meals, clean the house, do yard work, or run errands for the patient
- watch for confusion, faintness, or dizziness

Call the cancer team if the patient:

- Has chest pains
- has shortness of breath when resting
- feels dizzy or faint
- gets confused or can't concentrate
- has blood in their stool
- has dark brown or bright red vomit
- has not been able to get out of bed for more than 24 hours

Appetite Changes

Two common changes the patient may notice during treatment are feeling less hungry and finding that some foods taste different. A poor appetite is most often a short-term problem. Let the cancer team know if the patient experiences weight loss.

Contact Name _____

Organization _____

Telephone _____ Fax _____

Address _____

Email _____

Referred by _____

Contact Name _____

Organization _____

Telephone _____ Fax _____

Address _____

Email _____

Referred by _____

Contact Name _____

Organization _____

Telephone _____ Fax _____

Address _____

Email _____

Referred by _____

What the patient can do:

- Eat small, frequent meals
- choose foods that are high in calories and protein
- drink milkshakes or soups that are easy to swallow
- drink liquids between meals instead of with meals
- try light exercise an hour before meals
- eat as much as you want to—but don't force yourself to eat

What the caregiver can do:

- Try giving the patient 6-8 small meals and snacks each day
- keep cool drinks and juices within the patient's reach
- If the smell of food bothers the patient, serve bland foods cold or at room temperature
- create pleasant settings for meals and eat with the patient
- be encouraging, but try not to fight or nag about eating

Call the cancer team if the patient:

- Feels nauseated and can't eat for a day or more
- loses 5 pounds or more
- has pain when eating
- doesn't urinate for an entire day or doesn't move bowels for 2 days or more
- vomits for more than 24 hours
- is unable to drink or keep down liquids
- has pain that's not controlled

[Offer more of these foods and drinks that are high in calories or protein:](#)

Soups	Drinks	Main meals and snacks	Sweets	Extras
Cream soups Soups with lentils or beans	Some instant breakfast drinks Milkshakes Fruit Smoothies Whole milk	Chicken Lentils or beans Eggs Fish Nuts, seeds, and wheat germ	Custard Ice cream Muffins Pudding Yogurt	Butter, margarine or oil added to foods Cottage cheese, sour cream, and cream cheese Peanut butter Liquid meal replacements Powdered milk added to foods

Bleeding Problems

Cancer and cancer treatments can lower the number of platelets in your blood. Platelets are cells that help your blood clot, so you stop bleeding. The danger of serious bleeding is very high when the platelet count goes below 20,000.

What the patient can do:

- Use an electric shaver, not a razor
- avoid contact sports
- wear shoes all the time to protect your feet
- use a soft toothbrush
- if your doctor recommends, use a stool softener to avoid constipation
- blow your nose gently
- stay away from anti-inflammatory pain medicines
- if bleeding starts, stay calm—sit or lie down and get help

What the caregiver can do:

- For nosebleeds, have the patient sit up with head tilted forward, to keep blood from dripping down the throat. Put ice on the nose and pinch the nostrils shut for 5 minutes before releasing. Ice on the back of the neck may help also
- for bleeding from other areas, press on the bleeding area with a clean dry washcloth or paper towel until the bleeding stops

Call the cancer team if the patient:

- Is bleeding from anywhere (ex: mouth, nose, rectum)
- has bloody or dark brown vomit that looks like coffee grounds
- has bright red, dark red, or black stools
- has new bruises on the skin
- has heavy vaginal bleeding during monthly periods
- has weakness that gets worse
- has bad headaches, dizziness, or blurred vision

Constipation

Constipation is the infrequent or difficult passage of hard stool, which causes pain and discomfort. It's caused by too little fluid or not enough movement in the bowel. Lack of activity, weakness,

ignoring the urge to move the bowels, pain, or poor food and fluid intake can all add to this problem.

What the patient can do:

- Drink more fluids: fruit juices and warm fluids in the morning are often helpful
- eat more high-fiber foods every day
- avoid foods and drinks that cause gas
- avoid any foods that make you constipated, such as cheese or eggs
- get as much light exercise as you can
- do not use enemas or suppositories, ask your cancer team before using stool softeners or laxatives
- keep track of bowel movements so that problems can be noticed quickly

What the caregiver can do:

- Offer prune juice, hot lemon water, coffee, or tea to help make bowels move
- encourage extra fluids
- help keep a record of bowel movements
- offer high-fiber foods
- ask the cancer team before using laxatives

Call the cancer team if the patient:

- Has not had a bowel movement in 3 days
- has blood in or around the anal area or in the stool
- has belly cramps or vomiting that doesn't stop

[These foods may help if the patient is constipated:](#)

Breads & Grains	Fruits & Vegetables	Snacks
Bran muffins	Dried fruit	Granola
Bran or whole-grain cereals	Fresh fruit	Nuts
Brown or wild rice	Raw or cooked vegetables, such as broccoli, corn, green beans, spinach, and peas	Popcorn
Cooked, dried peas and beans		Seeds, such as sunflower
Whole-wheat bread, pasta, and tortillas		

Diarrhea

Diarrhea is the passage of loose or watery stools 3 or more times a day with or without discomfort. It happens when water in the intestine isn't being absorbed back into the body for some reason. Diarrhea caused by chemotherapy or radiation therapy may last for up to 3 weeks after treatment ends.

What the patient can do:

- Try a clear liquid diet (one that includes water, weak tea, apple juice, peach or apricot nectar, clear broth, popsicles, and gelatin with no solids added) as soon as diarrhea starts or when you feel that it's going to start
- eat small meals often, don't eat very hot or spicy foods
- avoid greasy foods, bran, raw fruits and vegetables, and caffeine
- avoid pastries, candies, rich desserts, jellies, preserves, and nuts
- don't drink alcohol or use tobacco
- avoid dairy products
- be sure your diet includes food that are high in potassium such as bananas, potatoes, apricots, and sports drinks like Gatorade
- keep track of the amount and frequency of bowel movements
- sitting in a tub of warm water or sitz bath may reduce anal discomfort
- clean the anal area with a mild soap after each bowel movement, rinse well with warm water and pat dry, or use baby wipes

What the caregiver can do:

- See that the patient drinks about 3 quarts of fluids each day
- keep a record of bowel movements
- ask before using over-the-counter diarrhea medicine
- check the anal area for red, scaly, broken skin
- protect the bed and chairs from being soiled by putting pads with plastic backing under the patient

Call the cancer team if the patient:

- Has 6 or more loose bowel movements in a day with no improvement in 2 days
- has blood in or around anal area or

in stool ◦ loses 5 or more pounds after the diarrhea starts ◦ has new belly pain or cramps for 2 days or more ◦ does not urinate for 12 hours or more ◦ does not drink liquids for 24 hours or more ◦ has a fever of 100.5 or higher when taken by mouth ◦ gets puffy or swollen belly ◦ has been constipated for several days and then begins to have small amounts of diarrhea or oozing of liquid stool, which could suggest an impaction (severe constipation)

Fatigue

Fatigue is when a person has less energy to do the things they normally do or want to do. Cancer treatment fatigue is different from that of everyday life. It's the most common side effect of treatment. Fatigue related to cancer treatment can appear suddenly and be overwhelming. It's not relieved by rest. It can last for months after treatment ends. Recent studies have shown that exercise programs during treatment can help reduce fatigue.

What the patient can do:

- Balance rest with activities ◦ tell your cancer team if you're not able to get around as well as usual ◦ plan important activities for when you have the most energy ◦ ask your cancer team about appropriate exercise programs to reduce fatigue ◦ get enough rest and sleep—short naps and rest breaks may be needed ◦ ask others to help by cooking meals and doing housework, yard work, and errands ◦ eat a balanced diet that includes plenty of protein and water

What the caregiver can do:

- Help schedule friends and family members to prepare meals, clean the house, do yard work, and run errands for the patient ◦ try not to push the patient to do more than they are able ◦ help the patient set up a routine for activities during the day

Call the cancer team if the patient:

- Is too tired to get out of bed for more than 24 hours ◦ becomes confused or can't think clearly ◦ has trouble sleeping at night ◦ has fatigue that keeps getting worse ◦ feels out of breath or has a racing heartbeat after only a small activity

Infection

Many cancer treatments and cancers can cause changes in your blood counts. A low white blood cell count can put you at higher risk of infection. You may hear this called *neutropenia*.

What the patient can do:

- Always wash hands before cooking or eating, after using the bathroom, and after being in public places ◦ brush teeth after meals and before going to bed, use a soft toothbrush ◦ avoid anything that could cause cuts, scrapes, or other breaks in the skin ◦ don't squeeze pimples ◦ avoid crowds and don't visit people who have infections, coughs or fevers ◦ if you eat raw foods, wash them carefully and peel them to avoid germs ◦ have someone else clean up after your pet

What the caregiver can do:

- Watch for shaking chills, and check the patient's temperature after the shaking stops ◦ check the patient's temperature using a thermometer in the patient's mouth or under the armpit ◦ encourage visitors who have diarrhea, fever, cough, or the flu to visit the patient only by phone until they are well ◦ offer extra fluids ◦ help the patient take medicines on schedule

Call the cancer team if the patient:

- Has a temperature of 100.5 or higher when taken by mouth ◦ has shaking chills ◦ feels or seems "different" to others ◦ cannot take in fluids

Mouth and Throat Changes

Some kinds of chemotherapy and radiation treatment can cause mouth sores and throat changes.

What the patient can do:

- Clean your mouth with care—use a very soft toothbrush to brush your teeth and tongue after each meal and before going to bed
- use toothpaste or gel that has fluoride and baking soda in it
- rinse your mouth with this mix: 1 cup warm water, 1/4 teaspoon baking soda, and 1/8 teaspoon salt—take small sips, swish around the mouth, and spit
- use a lip balm
- sip water or suck ice chips
- try drinking through a straw
- choose foods that are soft, wet, and easy to swallow
- soften food with gravy, sauce or other liquids
- let food cool down if hot food hurts your mouth
- avoid acidic fruits and juices
- avoid fizzy drinks, alcohol and tobacco
- don't eat very salty, spicy, or sugary foods

What the caregiver can do:

- Use a flashlight to check the patient's mouth for red areas or white patches, which often become sores; if the patient wears dentures, remove them before checking
- offer liquids with a straw, which may help bypass the sores in the mouth
- offer soft foods
- offer pain medicines 30 minutes before mealtime, as directed by doctor

Call the cancer team if the patient:

- Has redness or shininess in their mouth that lasts for 48 hours
- has bleeding gums
- notices any type of "cut" or sore in the mouth
- has a temperature of 100.5 or greater when taken by mouth
- has white patches on the tongue or inside the mouth
- has taken in little food or fluids for 2 days
- can't take medicines because of mouth sores

Nausea and Vomiting

Nausea or vomiting can be caused by eating something that disagrees with you, by bacteria in food, by infections, or by radiation and chemo treatments for cancer. Frequent vomiting can be dangerous because it can lead to dehydration and other problems. Talk with the patient's cancer team about what is causing the nausea and vomiting and what can be done about it.

What the patient can do:

for nausea

- Eat small, frequent meals and have a snack at bedtime
- drink clear liquids served cold and sip slowly, also try popsicles or gelatin
- eat bland foods such as dry toast and crackers
- avoid fatty, fried, spicy, or very sweet foods
- try to rest quietly while sitting upright for at least an hour after each meal
- suck on hard candy with pleasant smells, such as lemon drops or mints, to help get rid of bad tastes
- talk to your cancer team about anti-nausea medicine
- relax and take slow, deep breaths

for vomiting

- If you are in bed, lie on your side so that you won't inhale the vomit
- ask that medicines be prescribed in the form of dissolving tablets or suppositories, if possible
- try liquids in the form of ice chips or frozen juice chips, taken slowly
- after vomiting stops, start taking 1 teaspoon of cool liquid every 10 minutes, gradually increasing to 1 tablespoon—if you are able to keep that down after an hour or so, try larger amounts

What the caregiver can do:

- When the patient feels nauseated, offer to make meals or ask others to make meals to reduce bothersome odors
- cover or remove foods with strong or unpleasant smells
- use plastic forks and spoons rather than metal ones, which

may cause a bitter taste ◦ if the patient is vomiting over a period of days, weigh them at the same time each day to help decide if dehydration is getting severe ◦ ask about medicines to prevent vomiting ◦ watch the patient for dizziness, weakness, or confusion ◦ try to help the patient avoid constipation and dehydration—either of these can make nausea worse

Call the cancer team if the patient:

- Might have inhaled some of the vomited material
- vomits more than 3 times an hour for 3 or more hours
- vomits blood or material that looks like coffee grounds
- cannot take in more than 4 cups of liquid or ice chips in a day or can't eat for more than 2 days
- can't take medicines
- becomes weak, dizzy, or confused
- loses 2 or more pounds in 1-2 days (could be a sign of dehydration)
- develops dark yellow urine and doesn't have to urinate as often

[These foods and drinks may be easy on the patient's stomach:](#)

Soups	Drinks	Main meals and snacks	Fruits and Sweets
Clear broth, such as chicken, beef, and vegetable	Clear soda, such as ginger ale Tea Water Oral rehydration drinks like Pedialyte Cranberry or grape juice	Chicken-broiled or baked without skin Cream of wheat or rice cereal Crackers or pretzels Oatmeal Pasta or noodles White rice White toast	Bananas Canned fruit such as applesauce, peaches, and pears Gelatin (Jell-O) Popsicles and sherbet Yogurt (plain or vanilla)

Pain

Treating pain is an important part of good cancer treatment. If you find that the patient is in pain, don't put up with it. There are many medicines to help lower or get rid of pain. Talk with the cancer team to learn about what can help. Being in less pain will help the patient feel stronger and better.

What the patient can do:

- Talk with your cancer team about your pain—where it is, when it began, how long it lasts, what it feels like, what makes it better/worse, and how it affects your life
- if prescribed pain medicines don't work, let the cancer team know
- take pain medicine exactly as prescribed
- as pain is relieved with medicines, increase your activity level
- don't wait until pain is severe before taking medicine
- if you are experiencing a negative side effect from your pain medicine (nausea, dizziness, constipation), tell the cancer team
- do not crush or break your pain pills unless you get the OK from your cancer team—if medicines are in time-release form, taking broken pills can be dangerous

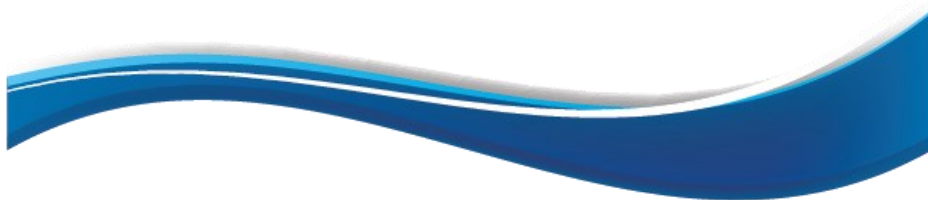
What the caregiver can do:

- Watch the patient for signs of pain
- try warm baths or warm washcloths on painful areas (avoid areas where radiation was given), you can also try ice or cool packs, or gentle massage
- watch for confusion and dizziness, especially after new pain medicine is started
- suggest enjoyable activities to distract the patient
- offer plenty of fluids and food with fiber
- if the patient seems forgetful, help them keep track of when pain medicines are due to avoid under- or over- dosing
- talk with the cancer team so you understand which medicines are for pain and how each is to be used
- keep all pain medicines away from others, especially children and pets
- if you help the patient with pain patches, be sure you know how to avoid touching the

part with medicine on it and how to dispose of used patches safely

Call the cancer team if the patient:

◦ Has new or worse pain ◦ can't take anything by mouth, including the pain medicine ◦ doesn't get pain relief, or if the relief doesn't last long enough ◦ has trouble waking up, or if you have trouble keeping them awake ◦ becomes constipated, nauseated, or confused ◦ has any questions about how to take medicines ◦ develops a new symptom (for instance, is unable to walk, eat, or pass urine)



All of the information provided in the "Managing Symptoms at Home" section is provided by the American Cancer Society's "Caring for the Patient with Cancer at Home: A Guide for Patients and Families" which can be found at <http://www.cancer.org/acs/groups/cid/documents/webcontent/002818-pdf.pdf>, and the National Cancer Institute's "Managing Chemotherapy Side Effects" sheets which are available at www.cancer.gov/chemo-side-effects.

These sources have additional side effect management information not listed in this resource guide. Please check them for further information.

Coping Checklist for Caregivers

Caring for someone with cancer, taking on new responsibilities, and worrying about the future can be exhausting at the very least—and it can quickly lead to burnout. When you're busy caring for your loved one, who's taking care of you? Check these lists to identify strengths and weaknesses you can build on or improve.

Healthy ways to cope. Take a moment to look at these statements. They describe some healthy situations and ways of coping. They'll give you an idea of how well you're holding up, and may help you identify areas where you need to make a few changes to take better care of yourself. The more of these statements you can agree with, the better. If you don't already have or do all of these, look for ways you can start working toward those that appeal to you. They can help you expand and strengthen your coping skills.

- I have supportive friends and family around me.
- I pursue a hobby or project for work, church, or my community.
- I take part in a social or activity group more than once a month.
- I am within 10 pounds of the ideal body weight for my height.
- I use relaxation methods like meditation, prayer, yoga, or progressive muscle relaxation at least 5 times per week.
- During an average week I get at least 150 minutes of moderate exercise (such as walking or yoga) or 75 minutes of vigorous exercise (such as jogging or basketball).
- I eat a well-balanced, healthy meal 2 or 3 times during an average day. (A balanced meal is low in fat and high in vegetables, fruits, and whole-grain foods).
- I do something fun "just for me" at least once during an average week.
- I have a place where I can go to relax or be by myself.
- I set priorities and manage my time every day (such as deciding what tasks are most important, how much I can and can't do, and getting help when needed).

It can be hard to find the time to do all these things, but they can help a lot in keeping some balance in your life during this very stressful time. If your schedule is too crowded, see who you can ask for help. If there's no one to help you, talk to your loved one's cancer team to find out what resources may be available in your area.

Less healthy coping. If you use any of these strategies to help you get by, you may find that over the long term they actually lower your ability to deal with important issues in your life. They can also create health problems and worsen your relationships with loved ones. If you need help quitting tobacco, alcohol, or other drugs, please talk with your health care provider.

- I smoke cigarettes or use tobacco several times a week.
- At least once or twice during an average week I use medicines, alcohol, or other substances to help me sleep.
- At least once or twice during an average week I use alcohol, medicines, or other substances to reduce anxiety or help me calm down.
- I bring work home at least once or twice during an average week.

If you find it hard to cope or feel overwhelmed or sad all the time, you may want to talk with your health care provider about these feelings. If you feel unsure about whether you need help, see the Caregiver Self-Assessment.



Source: American Cancer Society—This checklist was adapted from one created by Dr. George Everly Jr. of the University of Maryland. The original appears in the U.S. Public Health Service pamphlet, "What Do You Know About Stress" and is in the public domain.

Caregiver Self-Assessment

How are YOU?

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own well-being. Please take a moment to answer the following questions. Once you have answered the questions, please complete the self-evaluation.

During the past week or so, I have...

- | | | |
|--|-----|----|
| 1. Had trouble keeping my mind on what I was doing | YES | NO |
| 2. Felt that I couldn't leave my relative alone | YES | NO |
| 3. Had difficulty making decisions | YES | NO |
| 4. Felt completely overwhelmed | YES | NO |
| 5. Felt useful and needed | YES | NO |
| 6. Felt lonely | YES | NO |
| 7. Been upset that my relative has changed so much from his/her former self | YES | NO |
| 8. Felt a loss of privacy and/or personal time | YES | NO |
| 9. Been edgy or irritable | YES | NO |
| 10. Had sleep disturbed because of caring for my relative | YES | NO |
| 11. Had a crying spell(s) | YES | NO |
| 12. Felt strained between work and family responsibilities | YES | NO |
| 13. Had back pain | YES | NO |
| 14. Felt ill (headaches, stomach problems or common cold) | YES | NO |
| 15. Been satisfied with the support my family has given me | YES | NO |
| 16. Found my relative's living situation to be inconvenient or a barrier to care | YES | NO |
| 17. On a scale of 1-10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____ | | |
| 18. On a scale of 1-10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____ | | |

Self-evaluation

To determine your score

1. Count up all your “Yes” responses EXCEPT do not count #5 or #15 yet
2. Now, look at questions #5 and #15. If you responded “Yes” to these questions, do NOT count these with your “Yes” count. If you responded “No” to either or both questions, add these to your “Yes” count. (For example, if you had 4 “Yes” answers on the rest of the questions, and you answered “No” to question #5 and “No” to question #15, your total score would be 6.)

To interpret your response

Chances are that you are experiencing a high degree of distress:

- If you answered “Yes” to either or both questions 4 and 11; or
- If your total “Yes” score = 10 or more; or
- If your score on question 17 is 6 or higher; or
- If your score on question 18 is 6 or higher

Source: American Medical Association.

If you are having a high degree of distress

- Call Inspira’s Oncology Social Worker (refer to directory of services)
- Consider seeing a doctor for a check-up for yourself
- Look for some relief from caregiving (talk to the patient’s doctor, social worker, or cancer team about resources available in your community)
- Consider joining a support group for caregivers. Online and phone support is available
- Call the American Cancer Society at 1-800-227-2345 for more information and referrals

If your distress is low

It isn’t unusual for caregivers to have some of these problems for a short time. But they may mean that you’re at risk for higher levels of distress. When caregivers don’t attend to their own needs and allow other pressures to take over, they may lose the ability to continue to care for their loved one. Part of caring for someone else is caring for yourself.

Now what?

Asking for help can be a good thing. See a doctor if you have serious distress, or if you can’t accomplish your day-to-day activities. We also encourage you to print out this checklist and talk it over with a doctor, nurse, social worker, or other professional on your loved one’s cancer team.

Spiritual and Emotional Care

Religion can be a source of strength for many people. Some find new faith during a cancer experience. Others find cancer strengthens their existing faith or their faith provides newfound strength. On the other hand, those who have never had strong religious beliefs may not feel an urge to turn to religion.

Spiritual questions are common as a person tries to make sense of both the illness and his or her life. This may be true not only for the person with cancer, but for loved ones, too.

Here are some suggestions for people who may find comfort in spiritual support:

- A spiritual counselor can often help you find comforting answers to hard questions.
- Religious practices, such as forgiveness or confession, may be reassuring and bring you a sense of peace.
- A search for the meaning of suffering can lead to spiritual answers that can be comforting.
- Strength through spiritual support and a community of people who are there to help can be priceless to the patient and family members.



Information provided by the American Cancer Society — www.cancer.org

Spiritual and Emotional Care

spiritual and emotional health matters.

Your spiritual and emotional health matters and we are here to listen and to help guide you, regardless of your spiritual or religious beliefs, by talking about your unique story, faith issues, ethical concerns, and ways to think about this life-changing experience. Whether you are seeking emotional support, spiritual counsel, prayer, or a sacrament, you and your family are welcome to contact us before, during, and after treatment.

Call the number below if you would like to talk, if you want someone to pray for you, or if you would like a chaplain to contact a spiritual or religious leader for you. The Spiritual Care Department is available to meet with you, listen to you, and to support you emotionally and spiritually.

Emotional and Spiritual Care

Vineland : 856-641-7886

Woodbury : 856-853-2114

Please call one of the numbers above or reach out to a staff member to contact the Spiritual Care Department

Clinical Trials

Clinical Trials are research studies that involve people. They are the final step in a long process that begins with research in a lab. Understanding what they are can help you decide if a clinical trial might be an option for your loved one.

Cancer clinical trials are designed to test new ways to:

- Treat cancer
- Find and diagnose cancer
- Prevent cancer
- Manage symptoms of cancer or side effects from treatment

Any time you or a loved one needs treatment for cancer, clinical trials are an option to think about. Trials are available for all stages of cancer. It is a myth that they are only for people who have advanced cancer that is not responding to treatment.

When you or a loved one takes part in a clinical trial, you add to our knowledge about cancer and help improve cancer care.

At any given time, Inspira is involved in more than 25 clinical trials covering a wide range of cancers and related conditions. Inspira's commitment to research has given hundreds of cancer patients in our area access to cutting-edge medicine.

To explore the clinical trials offered by Inspira please visit www.inspirahealthnetwork.org and search for "clinical trials" or call Inspira Cancer Services Vineland (856) 641-8670 or Woodbury (856) 853-2075.

*Information provided by the National Cancer Institute
www.cancer.gov and Inspira Health Network
www.inspirahealthnetwork.org*

Additional information can be found at www.clinicaltrials.gov

Online Resources

Caring for the Patient with Cancer at Home: A Guide for Patients and Families

www.cancer.org/treatment/treatmentsandsideeffects/physicalseffects/dealingwithsymptomsathome/caring-for-the-patient-with-cancer-at-home-toc

This resource provides a guide to the most common problems people with cancer experience, signs of problems you can look for, and some ideas for things you can do if problems come up.

HelpGuide.Org

<http://www.helpguide.org/>

Support for stress and burnout caregivers may experience while caring for a loved one. Links to local adult daycares in the area. Information on respite care. Information on homecare, palliative care, and linking caregivers with the resources. End of Life/Late Stage information—saying goodbye and coping with a loved one's terminal illness.

NetofCare.org

<http://www.netofcare.org/content/default.asp#caregiver>

This website provides information on important subjects like: What a family caregiver is, coping with your new role as a caregiver, how to ask for help, communicating with medical professionals, and managing medical costs.

NJCaregivers.org

<http://njcaregivers.org/>

This resource features legal information and links caregivers with legal resources they may need. Help with support coordination (a person-centered planning process), and information on trainings and events.

Additional Online Resources

NJ.Gov

<http://www.nj.gov/humanservices>

Linking caregiver with either direct care or emotional support. Direct Care-statewide respite care program, Jersey Assistance for Community Caregivers (JACC), Managed long-Term Services and Supports (MLTSS), a NJ FamilyCare Program. Emotional Support - National Family Caregiver Support Program (Title III-E), a federal matching program, Care2Caregivers, Peer Support (1-800-424-2494), Women's Caregiver Retreat.

Family Caregiver Alliance's Online Caregiver Support Group

http://lists.caregiver.org/mailman/listinfo/caregiver-online_lists.caregiver.org

An online support group geared directly toward caregivers.

Family Caregiver Alliance; National Center on Caregiving

<http://www.caregiver.org/caregiving-webinars>

This site offers online webinars, policy and advocacy, and current articles on caregiving issues and strategies.

NJHelps.org

<http://mynjhelps.org/programs/>

This website provides direct links to resources caregivers may need with food and nutrition, child and family resources, utility assistance, income support for adults, seniors, and people with disabilities.

NCI Dictionary of Cancer Terms

<http://www.cancer.gov/publications/dictionaries/cancer-terms>

This website offered by the National Cancer Institute offers a searchable dictionary of cancer terminology.

Additional Online Resources

Family Medical Leave Act (FMLA)

<http://www.dol.gov/whd/fmla/>

Provides information on the Family Medical Leave Act.

National Respite Network

<http://archrespice.org/respitelocator>

The National Respite Locator Service helps parents, family caregivers, and professionals find respite services in their state and local area to match their specific needs.

Online/Telephone Resources

American Cancer Society

<http://www.cancer.org/treatment/caregivers/index>

1-800-227-2345

A place where caregivers can learn about various types of cancer, find support, find treatment information, explore past or current research, and connect caregivers with local resources. The site also has a LiveChat.

CancerCare

<http://www.cancercares.org/>

1-800-813-HOPE

A resource where caregivers can get information for counseling with an Oncology Social Worker, support groups, education workshops, financial assistance, co-payment assistance, publications, and community programs.

Cancer Hope Network

<http://www.cancerhopenetwork.org>

1-877-HOPENET

This resource connects caregivers with trained volunteer cancer survivors who themselves have undergone and recovered from a similar cancer experience.

Cancer Support Helpline

<http://www.cancersupportcommunity.org/>
1-888-793-WELL

This resource provides emotional and educational services for all people affected by cancer. On the website, caregivers will be able to find a range of information, tools and support to help you cope with the impact of cancer.

Gilda’s Club South Jersey

<http://gildasclubsouthjersey.org/>
609-926-2699

Gilda’s Club South Jersey is the ONLY cancer support community in southern New Jersey offering a free, comprehensive program of psychosocial support including educational lectures, workshops, social activities, and support groups to men, women, teens, and children impacted by cancer. Caregivers can attend the group called “Family & Friends” to get support

Aging & Disability Resource Connection (ADRC) (Respite)

<http://www.adrcnj.org/>
1-877-222-3737

This resource provides a direct link for caregivers that need directed options, caregiver education, and caregiver help

National Alliance for Caregiving

<http://www.caregiving.org>
1-301-718-8444

Provides links to other helpful caregiving sites and resources.

This informative resource provides information for family caregiving through current research, innovations, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues.

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*Helping you and your loved
one navigate the journey.*

