



MEN IN PINK AND BLUE  
**CAREGIVERS  
TOOL KIT**

A COMPLETE GUIDE TO  
HELP THOSE BATTLING  
CANCER

# When the Doctor Says "Cancer"

Approved by the Cancer.Net Editorial Board, 04/2017



It is a situation people often fear: sitting in the doctor's office and hearing the word "cancer." People diagnosed with cancer often say they were stunned when they heard the news and unable to process what was said afterward. After the initial shock, it is important to learn about what comes next. Consider the following steps to learn about your diagnosis, find treatment, and cope.

## Learn about your diagnosis

Cancer is a group of more than 100 diseases. It is important to understand the specific type of cancer or cancer-related syndrome diagnosed. This includes other tests needed as part of the diagnosis process and the treatment options. Take an active role in the cancer care by asking questions and using resources available. This information will help make informed treatment decisions.

During the initial doctor's visit, it may be difficult to process the amount of information received. The unfamiliar medical language may confuse you. Ask your doctor to explain any medical terms you don't understand. And don't be afraid to ask questions.

At all doctor appointments help listen and take notes or record the conversation so you can replay it later.

Some patients desire more information, while others prefer less. Tell your health care team your preferences for receiving information about your diagnosis, treatment, and chance of recovery. Ask if there is a learning resource center or other patient education resources available at the place treatment is being received.

It is important to use good judgment when searching for health information online. Ask yourself these questions as you visit cancer information websites.

## Find medical care

After receiving a cancer diagnosis, find an oncologist. Ask your primary care doctor, family members, and friends for referrals. Or search online to find an oncologist in your area.

Also consider getting a second opinion. This involves visiting another doctor to gather more information about the diagnosis, confirm the diagnosis, or hear about a different approach to treatment. Getting a second opinion can boost everyone's confidence in making decisions about the best course of action for the cancer care. Many doctors encourage patients to seek a second opinion.

Ask your doctor what clinical trials are available as a treatment option. A clinical trial is a research study to test

whether a new treatment is safe, effective, and possibly better than standard treatment.

## Get organized

You will need a system to track all of your research, appointments, test results, records, and finances. Organization helps you gain the most value from the time spent with your health care providers so you can make well-informed decisions.

## Find support for coping

Find other support from family, friends, and community resources to manage emotional, practical, and financial issues.

**Emotional support.** It is natural and expected that complex emotions will be experienced during the diagnosis and treatment. In addition to talking with the health care team, discuss any concerns with family members and friends. Consider joining a support group to share your experience and learn from others facing similar situations.

Counselors can also help you talk about difficult emotions. People who are living with cancer do have a higher than usual risk of becoming depressed. If you notice there is lost interest in usual activities or notice a struggle to concentrate, sleep, or eat, tell a member of your health care team and ask about counseling options. As a caregiver, you can also feel these same emotions. Be sure to share these feelings with a respected family, friend, health care member, clergy, social worker, and/or therapist.

Other outlets to express your emotions and relieve stress include:

- Writing in a journal
- Painting or drawing
- Praying or meditating
- Reading

**Financial support.** The cost of cancer care can be high and a burden for some people. Soon after the diagnosis, begin talking openly with your health care team about the costs of care.

Understanding what costs to expect before starting treatment can help you manage cancer's financial impact. Learn more about managing the cost of cancer care and find helpful financial resources.

Finally, although cancer is a serious disease, you have reasons to be hopeful. In the past several decades, major milestones have been reached in the care and treatment of people with cancer, including metastatic cancer.

# Making Decisions About Cancer Treatment

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including the risk of not being unable to have children.

## Consider the risks and benefits of each treatment option

Weigh the positives and negatives of each treatment option, including the:

- Chance of a cure
- Potential short- and long-term side effects
- Likelihood that the cancer will come back after treatment
- Chances of living longer with or without treatment
- Effect on your quality of life and independence
- Preferences of you and your family

Decisions about cancer treatment are personal, and you need to feel comfortable with your choices. But many people do not know where to start. Here are some simple but important steps you can take as you start the decision-making process.

### Understand the diagnosis

Individual treatment plans depend on the type of cancer and stage. So, you should learn as much as you can about your specific diagnosis. You may want to ask your health care team questions about the disease. Be careful when researching online. Your health care team can suggest trusted websites.

### Know your options-Talk to your doctor about treatment best for you including:

Surgery

- Radiation therapy
- Chemotherapy
- Hormone therapy
- Targeted therapy
- Immunotherapy
- Active surveillance, also called watchful waiting
- Palliative care
- Participating in a clinical trial

### Understand the goals of treatment

Doctor's may use some treatments to slow, stop, or eliminate the cancer. He or she may also use palliative care, also called supportive care, to manage symptoms and side effects. Make sure it aligns with your families personal goals for treatment.

### Ask about the side effects of each treatment option

Sometimes cancer can cause long-term side effects, or late effects, that might develop months or even years after treatment. In addition, discuss possible sexual or reproductive concerns with the health care team,

### Get a second opinion

Many people seek a second or even third opinion from another oncologist, and many doctors encourage it. Different oncologists may have different experiences with various treatments. So, seeking multiple opinions can help you make a decision or confirm your current treatment plan. First, check with your insurance company to find out if your policy covers a specific doctor or health care system.

### Find help managing the cost of cancer care

The cost of cancer care is often high, and you may have expenses that you were not expecting. Your health care team can help you identify costs related to your treatment options or suggest ways to manage medical and related costs. They can also refer you to support services that address the financial concerns of people living with cancer.

### Consult guidelines or other decision-making tools

The American Society of Clinical Oncology (ASCO) and other cancer organizations publish guidelines and treatment decision-making tools. These tools help doctors and patients understand various treatment options. Learn more about treatment recommendations for the specific type of cancer that you have. Talk with your health care team to learn more details about treatment recommendations..

### Discuss your decision with people you trust

Some people find it helpful to talk through their thoughts and concerns with people they trust. This may include:

- Family members
- Friends
- A member of the clergy
- A spiritual advisor
- An oncology social worker
- Another person with cancer

### Understand the role of statistics

Doctor's may mention statistics when describing treatment options. These may include relative survival rates, disease-free survival rates, and progression-free survival rates. These numbers may be a good way to learn how the treatment options differ. But they cannot predict how well the treatment will work for you. The health care team can explain how these statistics relate to the treatment.



# Steps to Building a Personal Medical Record

August 25, 2016 · Amy Thompson Revised December 20, 2018.

A personal medical record is a compilation of all medical information, including test results, treatment reports, and notes written by the health care team. While each office and facility keeps a record of care, it's important to have a complete file for your own use, so you can share it with a new doctor, review at home to better understand treatment, or manage health insurance claims, taxes, and other legal matters.

**Step 1. What to include:** A complete personal medical record should include the following:

- The diagnosis, including the specific cancer type and stage
- Date of diagnosis
- Copies of diagnostic test results and pathology reports
- Complete treatment information, such as chemotherapy drug names and doses, sites and doses of radiation therapy
- Start and end dates for all treatments
- Results of treatment and any complications or side effects
- Palliative information, to include pain management medications, nausea, or other side effects
- A schedule for follow-up care
- Contact information for the doctors and treatment centers involved in your diagnosis and treatment, as well as others who have cared for you in the past such as the family doctor
- Dates and details of other major illnesses, chronic health conditions, and hospitalizations
- Family medical history
- Details of past physical exams, including cancer screening tests and immunizations

**Step 2. How to compile your personal medical record**

The American Society of Clinical Oncology (ASCO) offers cancer treatment plans and summaries that can help keep track of information about your diagnosis and treatment.

Compiling this information on an ongoing basis will create a complete and easily accessible view of your health. Remember these strategies to help you collect the latest copies of your records:

- When there is a diagnostic test or procedure, ask for a copy of the results or report
- At all appointments, ask doctors or nurses for copies of any new or electronic medical record
- If there is time spent in the hospital, ask for a copy of all records when you're discharged
- Use an online patient portal to access medical records
- Keep copies of medical bills and insurance claims as they occur
- Talk to the healthcare team if you need help figuring out which records to include
- If collecting this information feels overwhelming, ask your friends or family for help.

**Step 3. Organizing and storing your personal medical record**

There are many ways to organize medical records. To figure out what works best for you, talk to other cancer survivors about what they have done and be sure to keep them in a secure location.

# When to Call the Doctor During Cancer Treatment

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Cancer and cancer treatments may cause side effects that need medical attention. It is important to ask the health care team which signs and symptoms to expect, and which ones need medical attention right away.

## Questions to ask your health care team

Each type of cancer and its treatment causes different side effects, so ask the health care team what side effects you should watch for. Consider asking the following questions:

What are the possible effects of the cancer?

- o Which of these should I call you for?
- o Which ones are considered an emergency that I should call 911 or go to the emergency room for?

What are the possible side effects of specific treatments?

- o Which of these should I call you for?
- o Which ones are considered an emergency that I should call 911 or go to the emergency room for?

Are there other situations when I should call the doctor during treatment? Keep their contact information handy.

When should I contact other members of the health care team? Keep their contact information handy.

What telephone number should I call after normal business hours?

When can I expect a return call from the doctor, the health care team, or the after-hours on-call provider?

When should I use email to communicate with the staff vs a phone call?



# Clear The Clutter

## Tips For Organizing Medical Information

March 20, 2014 Amber Bauer, ASCO staff

March 20, 2014

Amber Bauer, ASCO staff

As many people with cancer and caregivers know, there is an awful lot of information and paperwork that accumulates after a cancer diagnosis and throughout treatment and survivorship. So what information is essential to keep? And what is the best way to keep it all organized?

Should it stay or should it go?

Here's a quick (but by no means comprehensive) list of important medical information to keep on file:

- Complete contact information for all of the doctors, other specialists, and treatment centers that have been involved in your care
- Copies of diagnostic test results and pathology reports
- The diagnosis, including the specific cancer type and stage
- A list of the treatments received, including drug names and doses, sites and doses of radiation therapy, and details of any surgeries; as well, any complications or side effects experienced
- A schedule for follow-up care
- Details of any other major illnesses, chronic health conditions (such as diabetes or heart disease), or hospitalizations
- Any family cancer history
- Dates of past physical examinations, including screening tests and immunizations
- Copies of medical bills and insurance claims

As you sort through and clear out old paperwork, use a paper shredder for things that contain personal medical details and insurance information. This will help protect your identity.

Getting organized

# ASCO Treatment Plan

This Treatment Plan is a summary of your planned cancer treatment. You can keep it with your health care records and share it with your primary care provider or other doctors and nurses. When treatment is over you will also receive a survivorship care plan that will tell you what happens after treatment is over.

Patient Name:		Patient DOB:	
Patient phone:		Email:	
<b>Health Care Providers</b> (Including Names, Institution, Phone numbers)			
Primary Care Provider:			
Surgeon:			
Radiation Oncologist:			
Medical Oncologist:			
Other Providers (Navigator):			
<b>Diagnosis</b>			
Cancer Type/Location/Histologic type:		Diagnosis Date:	
Tumor size:	Lymph Nodes:	Metastasis:	
Stage: <input type="checkbox"/> I <input type="checkbox"/> II <input type="checkbox"/> III <input type="checkbox"/> IV <input type="checkbox"/> Not available/applicable			
Other information about the cancer:			
<b>Treatment Plan</b>			
<b>Treatment Goal:</b> <input type="checkbox"/> To cure the cancer and relieve symptoms and side effects of treatment <input type="checkbox"/> To slow the growth of the cancer and relieve symptoms and side effects of treatment			
<b>Treatment Plan</b>			
Surgery <input type="checkbox"/> Yes <input type="checkbox"/> No		Surgery Date(s) (year):	Procedure/location:
Radiation <input type="checkbox"/> Yes <input type="checkbox"/> No		Body area to be	How many treatments over how many weeks:
Systemic Therapy (chemotherapy, hormonal therapy, other) <input type="checkbox"/> Yes <input type="checkbox"/> No			
Name of regimen and agents used:		Number of cycles planned and frequency:	
Name of regimen and agents used:		Number of cycles planned and frequency:	
Additional information:			

# ASCO Treatment Plan

## Symptoms or Side Effects

Symptoms or side effects common **during** your treatments:

- Allergic reactions       Muscle/bone pain or soreness  
 Diarrhea/constipation       Nausea/vomiting

Please let us know if you have:

1. A fever over 100.5F
2. A brand new symptom;
3. A symptom that doesn't go away;
4. Anything you are worried about that might be related to the cancer or treatment.

## Other Concerns

People with cancer may have issues with the areas listed below. If you have any concerns, please speak with your doctors or nurses to find out how you can get help with them.

A number of lifestyle/behaviors can affect your ongoing health, including the risk for the cancer coming back or developing another cancer. Discuss these recommendations with your doctor or nurse:

Please note that it is important that you continue to see your primary care provider for your other health care needs throughout your treatment. When your treatment is done, we will give you a survivorship care plan that outlines what

Resources you may be interested in:  
[cancer.net](http://cancer.net)

Other comments:

Prepared by:

Delivered on:

# What to Expect When Having Chemotherapy

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It is normal to feel worried or overwhelmed when everyone finds that chemotherapy is needed.

**The chemotherapy team--** If chemotherapy is needed, a highly trained medical professionals will work together to give the best possible care. The health care team may include the following:

**Medical oncologist.** This is a doctor who specializes in treating cancer with medication. The oncologist works with other team members to develop your treatment plan.

**Oncology nurse.** An oncology nurse cares for patients with cancer, including giving chemotherapy.

**Other health care professionals.** Other team members include pharmacists, social workers, nutritionists, physical therapists, and dentists. Learn more about the oncology team.

## Before you start chemotherapy

**Meeting with your oncologist.** Before chemotherapy is started, there will be meeting with the medical oncologist. He or she will review the medical records/history and do a physical examination. Tests will be done to help plan treatment based on the type of cancer you have and other factors.

**Giving permission for chemotherapy.** The doctor will talk about the risks and benefits of chemotherapy. If decide to have it, your team will ask for a signed informed consent form.

**Eating food and taking medicines with chemotherapy.** The health care team will tell the patient what to eat, drink, or avoid on chemotherapy days so the treatment will work best. Tell the doctor about any prescription and non-prescription medicines being taken, including vitamins and other supplements.

**Questions to ask before chemotherapy starts-** These may include:

- Learning more about the schedule and side effects of specific treatments
- Getting after-hours contact numbers to contact doctors or nurses
- Where treatment is received, such as the specific building and floor

## Planning for your chemotherapy treatments

Preparing for side effects. Depending on the most common side effects of your chemotherapy, the team may recommend planning for nausea, vomiting, hair loss, reproductive issues, and other side effects.

An important part of cancer care is relieving side effects. This is called palliative or supportive care. It is important to talk with the health care team about the specific side effects you experience and the best ways to manage and treat them.

## What happens on your first day of IV chemotherapy

Make sure someone is with the patient if you are unable for some reason to be there the first day of treatment. Make sure there are items to make sure the treatment time more comfortable.

## Giving chemotherapy with a port

Before the first appointment, there may-be minor surgery to put in a port. This is a round metal or plastic disk that the IV goes in during treatment. With a port, the nurse does not need to find a vein to put the IV in for every treatment. Learn more about catheters and ports.

## How long does IV chemotherapy take?

The IV chemotherapy can take minutes, hours, or several days if there is continuous infusion chemotherapy. There is no need to stay at the hospital or clinic for continuous infusion. The nurse will give medication to prevent side effects such as nausea or possible allergic reactions. Then the chemotherapy medications are given to the patient.

After treatment is finished, the nurse or another team member will take out the IV. If there is a port, it will stay until all treatments are complete. The nurse will check blood pressure, pulse, breathing, and temperature again before you leave.

The oncologist or nurse will also talk with you again about side effects. They will give you medication, tips to manage side effects, and other tips.

The medical team can tell you activities to do or avoid on treatment days.

Before leaving the first treatment, confirm or ask for the phone number of the office and the oncologist's answering service. Call the doctor with any questions or concerns.



# What to Expect When Having Radiation Therapy

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It is normal for everyone to feel worried or overwhelmed when you learn radiation therapy is needed.

## The radiation therapy team

A highly trained medical team will work together to provide the best possible care. This team may include the following health care professionals:

**Radiation oncologist.** This type of doctor specializes in giving radiation therapy to treat cancer.

**Radiation oncology nurse.** This nurse specializes in caring for people receiving radiation therapy.

**Medical radiation physicist.** This professional has expertise in radiation equipment.

**Dosimetrist.** This professional helps the radiation oncologist calculate the right dose of radiation.

**Radiation therapist or radiation therapy technologist.** This professional operates the treatment machines and gives the scheduled treatment times.

**Other health care professionals.** Additional team members may help care for physical, emotional, and social needs during treatment.

**Before treatment--** Expect these steps before beginning treatment:

**Meeting with the radiation oncologist.** The doctor will review the medical records, perform a physical exam, and recommend tests. In this meeting, you will also learn about the potential risks and benefits of all options as it relates to radiation therapy. This is the opportunity to ask questions.

**Giving permission for radiation therapy.** If radiation therapy is agreed to, your health care team will ask for a signed informed consent form.

**Simulating and planning treatment.** The first radiation therapy session is a simulation. This is a practice run without giving radiation therapy. The team uses imaging scans identifying the tumor location. Depending on the area being treated, there may be a small mark on the patient's skin. This will help the team aim the radiation beam at the tumor.

The radiation oncology team cares about the patient's comfort. Talk with the team to find a comfortable and reproducible position for treatment. Make sure the doctor knows if the patient experiences anxiety lying still in an immobilization device. The doctor can prescribe medication to help you relax.

After the simulation, the team will review the information and design a treatment plan. Computer software helps the team develop the plan.

## During treatment

External-beam radiation therapy delivers radiation from a machine outside the body.

Internal radiation therapy Internal radiation therapy is also called brachytherapy. This includes both temporary and permanent placement of radioactive sources in the tumor site.

Most people feel little to no discomfort during treatment. But some may experience weakness or nausea from the anesthesia.

There will be precautions necessary to protect others from radiation exposure. The need for such precautions ends when:

- The permanent implant loses its radioactivity
- The temporary implant is removed

## Weekly reports

During treatment, the radiation oncologist will check how well it is working. Typically, this will happen at least once a week. If needed, he or she may adjust the treatment plan.

## Personal care

Many people experience the following during treatment:

- Fatigue
- Sensitive skin at the site of radiation exposure
- Emotional distress

Consider these ways to care for the patient:

- Plan for extra rest.
- Eat a healthy diet.
- Seek emotional support.
- Treat skin with lotions approved by the health care team.
- Minimize exposure to the sun.

## After treatment

Once treatment ends, you will have follow-up appointments with the radiation oncologist.



# Tracking Medical Bills & Healthcare Insurance Claims

Most people with cancer get a large number of bills and health insurance claims. This can be stressful if you do not have a system for tracking payments and filing documents. Keep your system simple and easy for you to follow.

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**What to track-** detailed records about their cancer care and track all related paperwork.

- Details about each appointment, include tests or procedures along with the date
- The name and dose of each drug prescribed and name of prescribing doctor
- Copies of checks and credit card receipts for co-pays and other health care costs
- A current copy of your medical insurance coverage
- Bills and invoices from health care providers, such as doctor's offices, hospitals, or labs
- Insurance claims filed by you, your doctor, or your hospital
- Explanation of benefits statements from your insurance company for processed claims
- Insurance reimbursements, insurance claim rejections, and appeal letters written
- Payments and insurance claims for any molecular testing

Your medical expenses may reach or exceed the Internal Revenue Service minimums for the year. You may be able to deduct a certain amount from your taxes. Check with a certified accountant to address your unique situation for tax advice.

## Tracking information with a calendar

Using a paper or electronic calendar to record every medical appointment, test, procedure, and prescription drug purchase on the days it happens.

Many people also have a paper or computer-based system for tracking cancer care information. You can create your own spreadsheet or use software templates to manage your medical data.

You can also use websites to save insurance information and manage medical bills. Carefully review each site before choosing one for safety and any potential costs.

**Create a filing system** for all documents you receive during cancer treatment.

**Hire someone to manage for you-** health insurance claims assistants for a fee provide professional help and advice for dealing with all of your insurance claims.

The Alliance of Claims Assistance Professionals provides references to Claims Assistance Professionals in several states.

## Help for Medicare beneficiaries

People with Medicare have online access for storing and accessing personal information.

# Estate Planning

A sound, comprehensive estate plan consists of several key documents including: a Last Will and Testament, personal or charitable trusts and foundations, insurance, a Living Will and Health Care Authorization, qualified retirement asset and incapacity planning, and a Power of Attorney. Our goal in this paper is to help you better understand the role of a Power of Attorney in your estate plan.

## What is a Power of Attorney?

A Power of Attorney is a relatively simple and inexpensive way for you ("the principal") to appoint one or more persons ("the agent(s)") to act on your behalf on financial and legal matters. Typically this includes paying bills, making investment decisions, conducting real estate transactions and other relevant matters.

## Who can be appointed an agent?

In general, any person may be appointed as agent. Depending on state law, it may also be possible to appoint an entity as agent, but typically individuals, and often family members, are chosen. You may be able to name multiple agents, who function as co-agents who can be specified to act jointly or separately.

## Tips

- Consider naming successor agents, who would act in the event the original agent is no longer able to act.
- Since a Power of Attorney confers significant authority, you should consider your selection of an agent carefully.

## What powers does an agent have?

The powers granted to the agent may be broad or limited, depending on your wishes. In addition to making decisions on financial and legal matters, an agent can be empowered to make gifts on your behalf. Depending on which state you reside in, it may be necessary to specify whether and what type of gifts are authorized.

## What types of Powers of Attorney are there?

There are two basic types of Powers of Attorney—Durable and Springing. However, there is also a Healthcare Power of Attorney, which is also referred to as a Medical Directive or Healthcare Proxy. Below is an overview of all three of these types.

### Durable

- Remains effective even if you subsequently become disabled or incompetent.
- Note: In order for any Power of Attorney to be valid, you must have the requisite capacity to execute the power at the time it is signed.

### Springing

- "Springs" into effect only upon the happening of a specific occurrence (such as incompetence).
- Since the springing power may require the agent to prove that a certain event has occurred, it may be more cumbersome to use.

### Healthcare

Although Durable and Springing Powers of Attorney are useful for financial and legal matters, they are generally not used to convey medical decision-making authority. In order to authorize someone to make medical decisions, a Healthcare Power of Attorney is used.

- Typically executed in conjunction with a Living Will.
- Appoints an agent to make your healthcare decisions if you become incapable of making or communicating them.
- Agent is often a spouse, adult child, or other person you trust to make such decisions for you.
- The agent carries out the wishes expressed in the Living Will and may also be authorized to make decisions on matters not specifically covered in the Living Will.



# More on Estate Planning

## Considerations

- Tax and other practical issues which may arise if agents are authorized to make gifts to themselves.
- Some state laws allow you to authorize agents to take other actions that affect your estate plan, but generally require they be expressly authorized in the Power of Attorney document.

## Additional considerations

- In order to prevent abuses associated with Powers of Attorney, many states have enacted legislation dealing with such issues as execution requirements, successor agents, authority for making gifts and sanctions for failure of third parties to accept Powers of Attorney.
- Depending on state law, it may also be advisable to include provisions relating to the revocation of the power and termination of the agent's authority.
- The laws regarding Powers of Attorney, Healthcare Proxies and Living Wills vary from state to state. You should consult with your estate planning attorney to determine if these documents are appropriate for you and to make certain you are in compliance with applicable law. Since circumstances change over time, it is also advisable to periodically review these documents to make sure they continue to express your wishes.

## What is a Living Will?

A Living Will (also referred to as an “advance directive”) is a written statement of the medical treatment that you wish to receive—or reject—under stated circumstances. It provides evidence of your wishes, and guides your family members and healthcare providers if you become incapable of communicating these wishes.

Typically, a Living Will states conditions under which certain extraordinary forms of medical care should not be administered. Depending on state law, it may also specify under what circumstances artificial nutrition and hydration should be withheld or withdrawn. A Living Will generally becomes effective when an individual is no longer able to express his or her own wishes.

A Power of Attorney is one of the most important legal documents a person can have. Without it, decisions regarding your finances and healthcare may not be able to be made without seeking court intervention.

## A Helpful Ways to Show You Are In This Together

Say This	Don't Say This
<p><b><i>I love you.</i></b></p> <p>These are the most important words you can say – over and over.</p>	<p><b><i>I agree with you.</i></b></p> <p>It's a conversation stopper. Tell her why.</p>
<p><b><i>I think I heard you say (blank), is that right?</i></b></p> <p>Repeat back what she's told you to show that you were listening.</p>	<p><b><i>I understand how you feel.</i></b></p> <p>This can sound to the woman like a refusal to discuss the issue.</p>
<p><b><i>I don't understand, can you explain that?</i></b></p> <p>It's okay to admit it.</p>	<p><b><i>If you would just...</i></b></p> <p>Don't try to be Mr. Fix-It. She'll resent it, and it won't help.</p>
<p><b><i>What can I do to help?</i></b></p> <p>You won't know unless you ask.</p>	<p><b><i>There's nothing to be afraid of.</i></b></p> <p>This seems like a dismissal of her fears. Besides, you both know it isn't true.</p>
<p><b><i>How do you feel about...</i></b></p> <p>This invites her to speak and shows that you care.</p>	<p><b><i>It's all for the best.</i></b></p> <p>No chronic or life threatening disease is ever for the best, and you don't have to pretend it is.</p>

## Guide to Seek Professional Help

Danger Signs	Call the Physician	Call a Mental Health Professional
Thoughts of suicide	X	X
Refusal of treatment without adequate discussion	X	X
Anxiety	X	X
Depression	X	X
Intense, sustained anger	X	X
Violent behavior	X	X
Social withdraw	X	X
Confusion	X	
Physical pain	X	
Not eating and drinking	X	
Sleep extremes (insomnia or sleeping all the time)	X	
Incontinence	X	
Unable/unwilling to talk	X	X
Prolonged, uncontrollable crying	X	X

# Talking to Children:

## Helpful techniques

- Share information that will impact the child using age-appropriate language
- Reassure the child that you will always be available to explain what is happening
- Tell the child that when people get sick, it's no one's fault
- Give the child plenty of time to understand complex information
- Encourage open expression of feelings. Say that it is normal and healthy to talk about sadness and to cry
- Always offer but never pressure the young person to talk
- Buy books that explain to children why people get sick and may die (make sure they are of age-appropriate level), then discuss them together
- Be quick to speak to a mental health counselor when you are in doubt

## Unhelpful Techniques

- Tell the boy that he is now the man of the house
- Tell the girl that she now the woman of the house
- Suggest that if the child behaves, the sick woman is likely to get well sooner
- Imply that the child caused the illness in any way
- Tell a child that a person who has died is sleeping

# Helpful Ways to React

## Do React By...

- Listening
- Believing what she tells you
- Sharing your own concerns and feelings
- Actively participating in problem solving
- Being supportive and reassuring
- Being respectful of her suffering
- Taking on some of the chores
- Accepting that role reversals are sometimes inevitable

## Don't React By...

- Avoiding the subject
- Getting angry in response to her mood swings
- Acting like you know what she is going through
- Being proud of your ignorance (“I don't want to know!”)
- Treating her like a child or a helpless patient
- Making fun of her
- Trying to find an easy fix
- Telling her the changes are all in her head

## Some Helpful Ways to Take Care of Yourself:

### Tell her about your concerns

- This illness will change the dynamics of your interaction, but it shouldn't alter it completely
- A relationship between a man and a woman is a partnership, and no matter what the circumstances partnerships are built on mutual support

### Look after your physical health

- The big problem in your life can quickly overwhelm the little stuff
- Don't underestimate the heavy toll that physical deficiencies (of nutrition, exercise, sleep, etc.) take on your ability to bear up under pressure

### Don't try to escape your feelings

- Withdrawing is probably the worst thing you can do to yourself and to the woman you love
- Running away from whatever is bothering you can make you feel weak

### Don't (always) grin and bear it

- Acknowledge the emotional impact her illness is having on you
- Pretending to be cheerful and refusing to acknowledge stress can add to her concerns

## Some Ways to Help Make Her Life Easier:

- **REASSURE HER OF YOUR CONTINUED LOVE**
- Make her favorite meal
- Do the laundry
- Take care of the children or make sure someone is helping out
- Give updates to friends and family
- Talk to the doctor, nurse or social worker
- Go to her appointments with her; make sure someone with her if you are not able to be there
- Plan small vacations
- Remember she is in control of her environment and the remote control
- Research treatments, doctors & alternatives
- Look at any scars & feel them when you are both ready
- Provide all the special & unique things only you can provide as her partner
- Keep appointment & treatment calendars
- Be the best *ears* & note taker during medical consultations
- Be the advocate with the medical community
- Provide moral support and listen without judging
- Share feelings openly
- Give massages, hugs & tenderness
- Be a buffer between well-meaning friends or family
- Handle phone calls from well-wishers if requested
- Help her shop for a wig or prosthesis if needed
- Arrange for the household chores & upkeep to be maintained
- Help make hospital stays more comfortable
- Take care of financial & insurance matters
- Keep her gas tank filled
- Pick up medications
- Schedule counseling sessions
- Help her avoid unfulfilling social engagements



# How Men Can Engage Women:

- Make eye contact – face-to-face
- Support the process of expressing concerns and feelings as an important outcome
- Accept the need to repeat the stories
- Avoid offering solutions unless asked first
- Admit you may not know what to do
- Don't feel insulted by the natural desire of women to call out the troops
- Express your own concerns and fears

## Some Suggestions on How to Be Helpful If You Are Not The Primary Caregiver

- Visit her whenever possible. Your presence will mean a lot
- Maintain telephone, e-mail, letter, or some other contact if you cannot be physically present
- Call first – don't wait to be called
- Talk with the primary caregivers see how you can best support the patient
- Offer to accompany her to medical visits if needed
- If you have children of your own, ask if she would like to spend time with them If she says yes, be sure to follow through



# A Few Things to do Together, or Encourage Her to Try Independently as Appropriate:

- Take up a new hobby
- Shop
- Exercise
- Cook new recipes
- Dance
- Attend concerts or plays
- Write letters
- Write stories
- Keep a journal or blog
- Watch old movies
- Build a website
- Play with a family pet
- Volunteer
- Become politically active
- Go to church
- Join a club
- Read

# Websites You Might Find Helpful

American Cancer Society	Cancer.org
American Hospital Association	AHA.org
Cancer Care	CancerCare.org
Centers For Disease Control ( <i>Search disease specific information</i> )	CDC.gov
Chronic Disease Foundation	CDFund.org
Family Caregiver Alliance	Caregiver.org
Health Well Foundation	HealthWellFoundation.org
Hospice Foundation of America	HospiceFoundation.org
Kids Konnected	KidsKonnected.org
Men Supporting Women With Cancer	MenSupportingWomenWithCancer.org
National Coalition For Cancer Survivorship	CancerAdvocacy.org
National Family Caregivers Association	TheFamilyCaregiver.org
National Hospice & Palliative Care Organization	NHPCO.org
National Institutes of Health	NIH.gov
Partnership for Prescription Assistance	PPARX.org
Patient Access Network Foundation	PanFoundation.org
Patient Advocate Foundation	PatientAdvocate.org
Prevent Cancer Foundation	PreventCancer.org
Safety Net Foundation	SafetyNetFoundation.com
Well Spouse Association	WellSpouse.org