

FRANKLY
SPEAKING
ABOUT CANCER

When a Woman You Care About has Breast Cancer



People who care about someone with cancer can be active *participants* in enhancing health and wellne themselves and their *loved ones* and nurture their *relationships* through and *beyond* the cancer exper

People who *care* about someone with cancer can be active *participants* in *enhancing* health and *wellne*.



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This booklet is dedicated to the men, women, and children who offer their kindness, optimism, love, creativity and care when breast cancer affects someone dear to them. Thank you.

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PROLOGUE

In preparing this booklet, The Wellness Community gathered observations and experiences from some of the most thoughtful authorities working to help those who care about someone with breast cancer.

Whether it's a spouse, partner, mother, sister or friend that you care about, this booklet is written to help you navigate the diagnosis, treatment, survivorship, and possibly the bereavement issues that you may face.

For more than 25 years, The Wellness Community has encouraged people with cancer to become "Patient Active" — that is, to become fully engaged in learning about and creating strategies to manage cancer while gaining a greater sense of control, community, and hope.

Now, through a generous grant from The Breast Cancer Fund of National Philanthropic Trust, The Wellness Community is providing similar support, education and hope to people who care about someone diagnosed with cancer. The new offering is called the **C.A.R.E. Campaign** (Cancer Advocate Resources and Education). We recognize that caregivers are intimately affected by cancer and, therefore, may need guidance and assistance to improve their own quality of life.



The Wellness Community **CARE Active** Concept says:

People who care about someone with cancer can become active participants in enhancing health and wellness for themselves and their loved ones, and nurturing their relationships through and beyond the cancer experience.

Being **CARE Active** is more than just coping with cancer and the stress it brings. It is about actively recognizing your ability to care effectively for your loved one and, at the same time, it is about your ability to address your own physical and emotional needs.

HOW TO USE THIS BOOKLET

Since this information may be new and can be overwhelming, use this book as a guide. You don't have to learn it all at once. Read at your own pace.

- In the beginning of each chapter you will find a **"Consider This"** list of things that can help you navigate your situation. More depth is provided within each chapter.
- The **C.O.P.E. Model** of problem-solving (p.5) is incorporated throughout the booklet, with examples to illustrate how to use COPE. The COPE Model is an approach to help people communicate better and overcome problems as a team. This method will enable you to face cancer and other issues squarely, realistically, and determinedly.
- A **"Coach's Corner"** is offered in each chapter to provide practical tips about how to manage common challenges during each phase of cancer, from diagnosis through the future.
- At the end of the booklet are **Practical Resources** organized to help you navigate many difficult issues.

Overall, we hope the information provided here will help you feel empowered to make a difference in the outcome of this health crisis. This will give you increased hope and allow you to cope more effectively over the long haul.



When you are in the hospital and nurses are coming in asking about medications, you just want to throw up your hands and say, 'Do whatever' because you just feel so terrible. Having someone there giving consistent support the whole time is just as important as the drugs you're taking.

— Russ, colon cancer survivor, and caregiver of wife Linda, two-time breast cancer survivor



I remember when my mom was first diagnosed with cancer. This was a totally foreign experience. I didn't know who to turn to or what to do about it. By coming to The Wellness Community, I found a connection with people — something I really needed. I knew that I could find other resources that would help us too.

— *Tilda, long-distance caregiver to her parents*

You Are Not Alone

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1 You Are Not Alone

When someone you care about is diagnosed with breast cancer, you, your family, and your friends may be thrown into a state of disbelief. You might immediately jump to the worst possible conclusion, assuming that the person you care about will die. You may doubt the doctor's judgment, or try to minimize the significance of the situation. It is common to wonder:

- *How is she coping?*
- *How will she handle cancer treatment? or*
- *What fears does she have?*

Consider this:

- It is normal to feel shocked, fearful, or angry after someone you care about is diagnosed with breast cancer.
- When cancer strikes, routines will be altered, a sense of security will be shaken, and the future may seem unclear.
- You may not relate to the term "caregiver," but this is a term used for anyone who provides physical, emotional, spiritual, financial, or logistical support to a person with a serious illness.
- During this period of uncertainty, it will be important for you to maintain your energy and strong attitude to the best of your ability.
- Being CARE Active will help you, the person you love, and others in your life.
- Remember that this is about the person with breast cancer's body and life — her opinions matter most.
- The "COPE Model" of problem-solving can be a useful tool when problems feel overwhelming.
- Open communication must become a priority.

When this happens, your focus of concern can quickly become “the patient” while concerns about yourself either don’t occur to you, or if they come to mind, you quickly push them aside. You may think: “I have no right to complain. She is the one with the illness.”

No matter which response you have, you will probably set aside your pressing daily activities to rally around your loved one or friend during this crisis.

There is no doubt that with the discovery of the disease, your life has changed too.

Your routines have been altered, your sense of security shaken, your view of the future suddenly made unclear. These are common stressors for someone thrown into the role of “caregiver.”

AM I A “CAREGIVER”?

The term **family caregiver** or **caregiver** has become common in our culture over the last decade. A caregiver is *anyone who provides physical, emotional, spiritual, financial, or logistical support to a loved one with a chronic, disabling or life-threatening illness.*

Many people in this situation do not immediately identify with the term “caregiver.” You may not believe that it fits you, especially if you feel that you’re “**just doing what I’m supposed to do.**” You may even believe that drawing attention to your own needs will somehow detract from the efforts to help your loved one.

Being a caregiver is, however, an important role to recognize. It allows you to be an active participant and essential team member in the fight against breast cancer.

THE WEIGHT OF WORRY

All that occurs with the cancer patient can affect your life in unexpected ways. Caregivers often feel overwhelmed by the increased responsibilities that a loved one’s diagnosis may bring.

The persistent stress that accompanies cancer can build up over time. Stress can make you feel anxious, disrupt your sleep and darken your mood. You may become physically overwhelmed by the wear-and-tear of rushing to doctors’ appointments, managing additional financial and insurance responsibilities, maintaining your own chores, work, or family responsibilities — all of which can sap your physical and emotional reserves.

An estimated 1.3 million cases of cancer are diagnosed each year. 81% of caregivers say that they want to provide care and couldn’t live with themselves if they did not assume caregiving responsibilities.

Source: *Journal of Family Nursing*, November, 1998 Vol.4, Issue 4

MAINTAINING YOUR ENERGY AND STRONG ATTITUDE

Doctors, counselors and friends may have already insisted that you take breaks from caregiving and engage in activities that will help replenish your energy. Perhaps you listened and began considering what you could do to cope with the stress of caregiving.

It is just as likely, however, that you shrugged off others' concerns. You may have said to yourself, "I have to do what needs to be done for the sake of my loved one. I have no intention of backing off. I'm not going to run from my responsibilities."

The goal of this book is not to suggest that you run from responsibilities and stop caregiving. It is to give you ideas that enable you to get organized and find time to take enough care of yourself so that you can give your very best energies to the job of caring for someone with breast cancer.

Though it may be easier said than done, if you can improve the way you care for yourself, you can become a more effective caregiver. Think about the safety messages from airline staff on a flight. The instructions are to place your own oxygen mask on FIRST before assisting others. The same is true in this situation. Helping yourself get through this medical ordeal will serve the greater interests of your entire family and will enable you to fulfill your own goal of doing all that you can to help your loved one live as well as possible.

This willingness of caregivers to help themselves as they help others is the foundation for what we call *CARE Active* caregiving.

IT IS CRUCIAL TO SAFEGUARD THE HEALTH OF THE CAREGIVER

In May 2007, The Wellness Community conducted an online survey of 200 cancer patients, survivors and caregivers. It found that caregivers were just as likely as patients and survivors to receive treatment for depression and anxiety. In fact, up to 80% of caregivers reported they endured regular stress and anxiety. Caregivers can become so focused on the care of their loved ones, that they neglect getting regular care for their own chronic illnesses such as diabetes or high blood pressure. As a result, they may fare poorly and suffer worse outcomes for those medical conditions.

WHAT DOES IT MEAN TO BE CARE ACTIVE?

People who care about someone with cancer can become active participants in enhancing health and wellness for themselves and their loved ones, and nurturing their relationships through and beyond the cancer experience.

Being **CARE Active** is not just about coping with cancer and the stress it brings. It's about actively recognizing your ability to effectively care for your loved one and to be aware of and address your own physical and emotional needs.

This attitude requires thinking through the problems that arise to make small, incremental choices that will enhance the quality of your life and your relationship with the cancer patient. This doesn't mean sweeping challenges under the rug or making changes to focus solely on the person with cancer. Rather, it means figuring out how to exercise a reasonable amount of control in a situation that often feels out of control.

TEN CARE ACTIVE CONSIDERATIONS

1. Learn about breast cancer, its treatment, and available support services.
2. Get connected with others: utilize a support system for you and for your loved one.
3. Seek rest: do your best to carve out time to relax.
4. Remain involved with your community, friends, and family.
5. Recognize your "new normal."
6. Get organized now, and make plans for the future.
7. Learn to say, "Yes!" when people offer to help in ways that are worthwhile.
8. Set limits, and learn to say, "No!" when you need a break.
9. Stay healthy with good nutrition and exercise.
10. Find new ways to control stress.

By putting the *CARE Active* approach into practice, we believe that you will feel empowered to make a difference in the outcome of this health crisis. This will give you increased hope and allow you to cope more effectively over the long haul.

THE C.O.P.E. MODEL*

To help you become *CARE Active*, we offer the C.O.P.E. Model of problem solving. The goal of this model is to help people learn how to communicate better and systematically solve problems together. This process will improve the quality of your lives as you deal with cancer.

Women want to be connected to their caregiver — and open communication is the key to that connection. The C.O.P.E. Model (also referred to as “COPE”) is not about judgment or being “right” or “wrong.” COPE is about learning to pinpoint and define a problem, and explore solutions to overcome that problem. Of course, not all problems can be “solved,” but most can be managed, especially if you have a system to do so. Working towards solutions in an open-minded partnership is an important step.

* The COPE Model was originally developed by Dr. Peter Houts: Houts, PS (Ed.) *Home Care Guide for Cancer*. American College of Surgeons. 1994. COPE examples are from coaches: Matthew J. Loscalzo, MSW; Marc Heyison, President, Men Against Breast Cancer, Sage Bolte, MSW, ABD, and from individuals who shared their personal experiences.

Problem-Solving Using the C.O.P.E. Model

“COPE” represents four key steps to solve a problem:

- C** for Creativity
- O** for Optimism
- P** for Planning
- E** for Expert information

You probably use some or all of the steps in the COPE Model to solve problems already, but if you get “stuck” it can be productive to think about this more conscious and concrete way to discuss and solve problems.

To be clear, we will define a **problem** as something you care about that impacts you personally and must be managed for your life to “work.” *Problems can include communicating with the healthcare team or other family members, depression, cancer recurrence, financial or insurance difficulties, sex and marriage obstacles, a doctor you don’t trust*, to name a few. An **issue**, on the other hand, is something you care about but it does not severely impact your life. *Issues can include, for instance, missing social events for health reasons or not being able to eat certain foods*. You can live with issues, but it’s more difficult to live with problems. The COPE Model is designed to help solve problems.

After a problem is defined, the most effective way to use this model is to start backwards by gathering *Expert Information* and working towards *Planning*, while incorporating *Optimism* and *Creativity* along the way.

Expert information

Gaining knowledge about a problem and what can be done about it is the best foundation for effective problem solving. To gain this knowledge it helps to ask:

- What information would help me address this problem?
- Who are the experts on this topic?
- What obstacles are getting in the way of solving this problem?
- Who else is likely to have or have had this problem? What worked for them?
- Who has the ability to provide help, and who does not?
- What would be the ideal solution?
- What can I reasonably hope to achieve?

Planning

Once you've gathered expert information, you should develop a plan. This is something you may do automatically in your mind. When "stuck," however, it helps to develop a plan in an orderly and systematic way.

- Write down the problem.
- Evaluate your expert information and separate the facts from opinions.
- Consider your options. Brainstorm as many options as you can. Think about what has worked in the past and what has not. Then try to think outside the box. (Creativity and Optimism will be helpful.)
- Compare advantages and disadvantages of different options and approaches.
- Choose a strategy that you feel has the best chance of working.
- Think about what obstacles might interfere with your chosen strategy. Be *CARE Active* in thinking about what you can do to deal with those obstacles.

- Carry out and adjust your plan.
- Sometimes developing a calendar and keeping notes will help you stay on track.
- Evaluate how your plan is working. If you are not having the success you hoped for, what's getting in the way? Were your expectations for success or the pace of change unrealistic? We can be very hard on ourselves and that can become its own problem!

Optimism

When trying to solve a problem or address an issue, being optimistic simply means expecting to succeed, which enables us to do our best. This enthusiasm is contagious! In this context, "succeeding" means finding a workable solution to a problem whether or not the outcome is ideal.

Creativity

Creativity is particularly important during two periods of problem solving. First, it is helpful to be creative when brainstorming solutions and “outside-the-box” ideas might be needed. Second, it is helpful when a solution doesn’t work out as you had hoped the first time, so you need creative ideas to tackle the problem in a new way.

Caregivers are constantly challenged to think creatively. Potential solutions become evident when we open the door to a variety of possibilities. Creativity is also closely aligned with optimism. It’s easier to remain positive when you know that there are always more possible solutions.

The following tips help navigate road blocks creatively:

- View the barrier from someone else’s point of view. Ask questions such as: “What would the smartest person I know do in this situation?” or “How would my best friend handle this?”
- Ask how important the barrier really is. Can you work around or ignore the obstacle and still carry out your plan?

Sometimes it’s easier to see how the COPE Model works by seeing examples (see pp. 25, 43, 50, 59). It also helps to test the model with simple, concrete issues before moving to more complex problems.

Coach's Corner

When you find out that your most valuable teammate has been diagnosed with breast cancer, your world is turned upside down and forever changed. All of your feelings — from hopeless or helpless to angry or depressed — are normal, natural, and okay. Unfortunately, this is not a game you want to play. You have no choice but to “suit-up” and play whatever role your star player (the patient) asks for and needs.

You may be afraid that the woman you love will die. You will probably want to switch places with her if you could. At this point, as hard as it is, you have to accept that you are not in control and you cannot fix this problem. The ball is not in your court, but there is a playbook you can create and follow to assist you through this “new normal.”

The COPE Model offers a proven way to create your playbook and a great way to help you navigate the crisis of breast cancer together as a team with a single goal: to do whatever needs to be done from the point of diagnosis through treatment and into the future.

As you will see, no one can tell you the right or wrong way to prepare your playbook or do this “caregiving” or CARE Active thing. You will have to find your own way with your most valuable teammate and partner. Your role is to help her through this, making sure that she knows you love her and will support her. Meanwhile, you need to be at your best to play this game, and that includes taking care of yourself physically and mentally along the way.



I wanted to feel like I had a job. We figured out, by trial and error, things I could do. Before a doctor's visit, I would write down the questions Marsha wanted to ask. I wouldn't ask for her, but I would take notes as we talked with the doctor. All of that turned out to be helpful. It would amaze me — we would walk out and Marsha would have no memory of what the doctor said just ten seconds ago.

— *Marc, husband of
breast cancer survivor, Marsha*

Understanding Breast Cancer

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2 Understanding Breast Cancer

This chapter provides a medical overview of breast cancer and the various treatment options for breast cancer. With the knowledge you gain, you will be able to talk to your loved one and her medical team, ask clear questions, and help make informed decisions about the best treatment plan.

This discussion will continue in Chapter 4, *CARE Active During Initial Treatment* and we offer resources for more in-depth information on these topics in Chapter 10.

Consider this:

- Gathering credible information will help you feel more in control and reduce fears. You can be CARE Active by learning as much as possible about her type of breast cancer.
- Ask if she would like help researching anything specific (don't assume) — you can collect information and discuss it with her when she's ready.
- Offer to join her for discussions with her medical team about treatment options. If she would prefer to have someone else join her, support that decision. It's important that someone is present to help listen, ask questions, take notes and sort out medical information.
- Offer to help with scheduling appointments or researching insurance options.
- Help prepare for possible side effects ahead of time (such as hair loss, nausea, fatigue), so if side effects do occur, they are better managed.
- Be aware that cancer will affect almost everyone in your family and social circle. Talk with your loved one about if and how she wants to talk about cancer with others.
- You can't know everything or fix all problems. Sometimes it helps to just "be there."

WHAT IS BREAST CANCER?

Breast cancer happens when cells in the breast grow out of control. It usually starts in the ducts or lobules inside the breast. The lobules are where milk is produced. The ducts take milk from the lobules to the nipple.

TYPES OF BREAST CANCER

There are different types of breast cancer. The doctor will tell your loved one what kind of breast cancer she has. Ideally the doctor will tell her if the cancer started in the ducts or in the lobules. He or she will tell her if the cancer has invaded other tissue in the breast. If the cancer is still contained within the small area where it started, it is called *in situ*. If it has grown beyond that area, it is *invasive*.

These are the most common types of breast cancer:

IDC – invasive ductal carcinoma

Breast cancer that started in the ducts and has invaded or spread into other tissue in the breast. It is the most common breast cancer diagnosis.

ILC – invasive lobular carcinoma

Breast cancer that started in the lobules and has invaded other breast tissue. It is not as common as IDC.

DCIS – ductal carcinoma *in situ*

Breast cancer that started in the ducts and hasn't spread beyond them. This is a very early stage of breast cancer but if it isn't treated, it can develop into invasive cancer.

LCIS – lobular carcinoma *in situ*

Breast cancer that started in the lobules and hasn't spread beyond them. Like DCIS, this is a very early stage of breast cancer.

STAGES AND STATUS OF BREAST CANCER

The “stage” of cancer is based on how big the cancer is, whether it has spread to the lymph nodes, and whether it has spread anywhere else beyond the breast. The lymph nodes are part of the lymph system that filters harmful substances from the body.

Knowing the stage of the cancer is important in forming a treatment plan. The stages of breast cancer can be grouped roughly into the following clusters:

Stage 0, I

Very early breast cancer that’s probably non-invasive. Treatment usually involves surgery and possibly radiation.

Stages II, and IIIa

Breast cancer that is invasive, meaning it has spread beyond the place where it first started. Treatment usually involves surgery and radiation to get rid of as much of the cancer as possible, followed by chemotherapy and possibly hormonal and/or targeted therapy to lower the chance of the cancer coming back.

Stage IIIb, Stage IIIc, and Stage IV

Late and advanced breast cancer. In these later stages of breast cancer, other parts of the body beyond the breast and nearby lymph nodes have been affected by the cancer. The goals of treatment for advanced breast cancer are to keep it under control for as long as possible while maintaining the best possible quality of life. Treatment is mostly systemic with treatments such as chemotherapy. Although these later stages of breast cancer are more challenging to control, many women live quality lives for years following this diagnosis.

Other terms

Primary breast cancer

The original cancer that was first identified in the breast.

Metastatic breast cancer

Cancer that has spread from the breast to other parts of the body. Breast cancer may spread to the bones, brain, or other organs. Breast cancer metastases (cancer cells that spread from their original location in the breast) are still treated with breast cancer treatments, even when they are in a different organ.

Recurrent breast cancer

Breast cancer that has come back after the initial cancer was treated and there were no more signs of it. It can return in the breast area, but more often returns in other places, like the bones. Recurrent breast cancer is treated with breast cancer treatments no matter where in the body it is found.

Second primary breast cancer

This is a new cancer diagnosed in the breast, not related to the initial breast cancer diagnosis. Treatment is based on its stage and type, like a primary cancer. Second primary cancers are not the same as recurrent cancer.

Hormone-receptor-positive breast cancer

Breast cancer that is stimulated to grow by the hormones estrogen and/or progesterone. There are treatments called hormonal therapies that can block these hormones or lower their production in the body. This can slow or stop the growth of cancer cells that are affected by the hormones.

HER2-positive breast cancer

Breast cancer that has certain characteristics that make it more likely to respond to a treatment called Herceptin (chemical name: trastuzumab).

Hormone-receptor or HER2-negative breast cancer

If the cancer is hormone-receptor-negative and/or HER2-negative, it will probably not respond to hormonal therapy or Herceptin. But there are still many other treatment options available.

INFORMATION FOR MAKING TREATMENT DECISIONS

As you learn about breast cancer diagnosis and treatment, you will hear lots of medical terms that can sound confusing. Start with this basic list to understand the broad categories of treatment. Later on, we'll discuss specific treatment options.

Local treatment targets the cancer in and around the area where it is located. Surgery and radiation are local treatments.

Systemic treatment is aimed at cancer cells that may be anywhere in the body. Chemotherapy and hormonal therapy or targeted therapy are systemic treatments.

Adjuvant [*pronounced: ADD-joo-vent*] **treatment** is treatment to lower the chance of the cancer coming back. Adjuvant treatment is usually systemic. The goal is to try to kill any undetected cancer cells that may still remain in the body.

Neoadjuvant [*pronounced: NEE-oh-ADD-joo-vent*] **treatment** is sometimes used to try to shrink the cancer before surgery. It is usually systemic.

Palliative care is when treatments are administered to improve a woman's quality of life. Often this term is used in situations where the cancer has progressed to an advanced stage, but palliative care can be provided at any point to reduce the severity of symptoms or pain. This is different than treatment which is used to reverse the progression of disease or provide a cure. Research supports using palliative care early for comfort and "normalcy."

Clinical Trials are research studies that may offer a new treatment or combination of treatments to determine if the new method to treat cancer is better than commonly used standard treatments. More information about clinical trials may be found at www.thewellnesscommunity.org — search "clinical trials," or through the National Cancer Institute's website www.cancer.gov.

Coach's Corner

You are sizing up the adversary: Cancer. Part of your role in being CARE Active can be to act like a general manager as you and the woman you love begin to put your medical team into place. Just as with any team, chemistry is very important. You should feel confident that you are all (physicians, nurses, other health care team members, you, your loved one) on the same page of the playbook at all times.

It takes teamwork to remain focused and positive in making sure the team you have assembled is proactive and willing to work hard for you.

Yes, nerves and fears will still be in play. Wondering if you are making the right choices is natural. Strategies like the COPE Model can help you select your teammates and game plan, and help you be a successful general manager.



My mom's cancer diagnosis affected our family in a bunch of ways. At first it felt sort of taboo to talk about it. Now it's not. You may be going through a tough time, and a lot of things may be changing about your mom really fast, but your parents, your siblings, they love you. It doesn't have to be silent.

— Emma, daughter of breast cancer survivor, Liza

CARE Active at Diagnosis

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3 CARE Active at Diagnosis

Most likely, you and your loved one have been on an emotional roller-coaster while waiting for the results of tests and biopsies. Now you finally have an answer — a woman you care about has breast cancer. You will find yourself worrying about the big things (survival and mortality) and the little things (vacation plans). You will likely find it hard to focus on work, household responsibilities, or other demands; yet, those pressures continue.

As you and the woman you care about come to terms with the cancer diagnosis and begin to navigate decisions about treatment, there are many things you can do to help gain a sense of calm and control.

Consider this:

- In almost all cases, you have time to slow down and think about your loved one's goals and priorities for treatment before she decides which treatment plan to follow.
- It is important to work with a medical team with whom your loved one (especially) feels comfortable.
- You can help identify oncologists and cancer centers for a second opinion.
- If she wants you to be present, you can play an important role in preparing for doctor's visits, listening to the doctor, asking questions, and taking notes to talk about after the appointment.
- Keep a notebook. Write down questions that come up. Share this list with your loved one in case she'd like to bring it to future appointments.
- Remember that your loved one is the "boss." This is her body, and treatment decisions are hers to make.

GATHERING INFORMATION

It is easy to feel pressured as you and your loved one begin to make decisions about which treatment(s) to pursue. In almost all cases, however, you do have time to slow down, think about your loved one's goals and priorities, and talk with others. You will both quickly gain a sense of control about the next steps as you ask questions and partner with the medical team to develop a treatment plan.

Many caregivers have shared that as their knowledge about cancer increases, they begin to feel more confident about managing all of the tasks before them.

Some things to keep in mind as you gather information at the time of diagnosis:

- Think about helping the woman who has cancer start a notebook or keep a folder where she can collect vital information about test results, treatment options, insurance issues, contact information, and valuable community resources.
- Know that you will not have all the answers to your (or your loved one's) questions right away.
- Remember that caring for someone you love with cancer is about the relationship you share together and about learning to manage the new stress that cancer has brought into your lives.

AIM TO KEEP LINES OF COMMUNICATION OPEN

From the moment a loved one is diagnosed with cancer, you will face many challenges. Do your best to share your feelings and concerns. You may each have deep fears that are hard to discuss. If you can cry, laugh, debate, and worry with each other, you will feel a greater sense of connection and understanding. If you are not able to share all of your feelings with your loved one now, find someone else with whom you can talk. It is also important to remember that sometimes the best thing you can do for each other is to just sit quietly together — be present, in the moment, sharing time.

DISCOVERING CARE ACTIVE STRATEGIES

It is often difficult to figure out how to respond to the ebb and flow of information, emotions, and important decisions that you and your loved one will make together and individually. The diagnosis of cancer can stress even the strongest relationships. Neither of you may know what you need and want at this point. You will likely feel numb, scared, and angry that cancer has come into your lives.

In the early phase after diagnosis, caregivers are often the ones actively seeking information in books and pamphlets, on the internet, and making phone calls to people who can help. Be careful about what you read and hear — treatment for breast cancer is constantly evolving, and you need to find credible sources of information (see Chapter 10).

Your loved one may feel so overwhelmed that she will welcome your assistance in doing this research. In this case, you can gather information for yourself and share it over time when you get cues that she is ready to hear and talk about it. On the other hand, she may want to be the one to do her own research. Either way, the information you gather will help you become a more informed and empowered caregiver.



People still have a very visceral reaction to the word ‘cancer.’ But it’s not a death sentence.

My mom’s prognosis is very strong. You have to keep up the hope and spirit that there will be a recovery.

— Annabella, daughter of breast cancer survivor, Ellen

COPING

Every person manages stress, worry, and other emotions differently, no matter what the situation. The ways people deal with emotions are often referred to as coping mechanisms. Men and women often differ in the ways they cope.

In general, it is good to become aware of how you cope with difficult situations to help you get through this immediate and intense time of stress. Ideally, you can adopt active coping mechanisms.

GENERAL DESCRIPTION OF COPING MECHANISMS

Active Coping Mechanisms

- Define the problem
- Decide what elements of the problem you can and cannot control
- Look for advice and information to deal with the problem (seek Expert Advice — in COPE Model, pp. 5 – 7)
- Make a plan to deal with the problem (think Optimistically and Creatively)
- Take action to solve the problem
- If the *problem* cannot be “solved,” try to adopt a new perspective to make it an *issue* you can live with
- Become aware of your feelings
- Find a support group

Using Avoidance to Cope

- Deny that the problem exists
- Avoid any thoughts about the problem
- Withdraw from social experiences
- Wishful thinking
- Keep extra busy and ignore the problem
- Use drugs or alcohol to forget the problem
- Blame and criticize yourself for the problem

FINDING THE RIGHT DOCTOR

Once the diagnosis is confirmed, the woman you care about should be referred to an **oncologist** (doctor specializing in cancer treatment) experienced in breast cancer. It is a good idea for you and your loved one to do some research as to where she wants to be treated and by whom. It may help to call people you know and seek advice about oncologists in your area.

Overall, it is critical that an oncologist evaluates your loved one. If it is possible, try to use a cancer center that has specific expertise and state-of-the-art breast cancer care. The following are resources to help you find a breast cancer specialist in your area:

- The National Cancer Institute (1-800-4CANCER) offers information about the nearest comprehensive cancer center(s).
- Cancer.net (www.cancer.net), provided by the American Society of Clinical Oncology, offers resources to find oncologists in your area.
- A primary doctor or a nurse you trust, with help from your insurance company, will often be glad to offer you a referral.

You and your loved one may have a lot of questions for a breast cancer specialist, and you should ask them all! It may help to write them down before going to the appointment, so you don't forget any questions while you are at the appointment.

SHE'S IN CHARGE

Many people with cancer prefer to do the majority of talking at appointments to maintain a sense of control. Be careful not to create a situation where your loved one feels that you are taking control away from her by asking all of the questions, or that she feels left out of the conversation or talked about as though she isn't in the room. It may be helpful to talk in advance about how your loved one wants to interact with the health care team.

KEY QUESTIONS WHEN MAKING TREATMENT DECISIONS

If your loved one would rather that you do the talking, you can help by asking these (and other) questions. If she prefers to do the talking, you can help by taking note of the answers.

- How much experience does the recommended doctor have in treating breast cancer?
- Is he/she board-certified in medical, surgical and/or radiation oncology?
- Does the medical team stay up-to-date on the latest treatments for breast cancer?
- Does this doctor and medical facility accept your loved one's insurance?
- Where will treatment be given? (In-patient? Out-patient? Location?)
- Will you and your loved one have access to an oncology nurse and/or oncology social worker to help with education and support?
- What other support services are available?
- How and when can you or your loved one contact the treatment team with ongoing questions? (Can you use email or phone, or does the doctor prefer only office visits?)
- Could you have the name of another oncologist, for a second opinion?

You can also be *CARE Active* by listening to your loved one's fears and concerns about treatment. You may find yourself acting as an advocate on her behalf to schedule appointments, get additional medical opinions and gather insurance information. If she doesn't want you to join her at appointments, insist that she bring a friend or other advocate. There's too much information being presented for any one person to absorb.

MAKING TREATMENT DECISIONS

Many people believe that making treatment decisions is one of the most difficult times during the cancer experience. The information can seem foreign, overwhelming and almost too much to bear at first.

An oncology nurse and/or oncology social worker can be an important resource for information and support. If you and your loved one are having difficulty understanding or making a decision about treatment, consider setting an appointment with the nurse or social worker to talk through your options. Try to think about your questions together ahead of time. Make time after the appointment to talk about what you both heard.

The first step in making a decision about treatment is reaching an agreement with the doctor about the goal(s) of treatment. Encourage your loved one to have this discussion with the oncologist so that you both have a clear sense about the purpose of the treatment options being offered.

The proposed treatment(s) may be recommended primarily to:

- cure (eradicate the disease)
- control/slow the tumor growth over an extended period of time
- provide comfort and relieve symptoms

A NOTE ABOUT FERTILITY

For women who wish to get pregnant in the future, fertility preservation is an important issue to consider **before** treatment. There are strategies to plan for fertility preservation if infertility is a possible long-term side effect, so it is important to discuss this question with the oncologist before treatment decisions are made.

It is important to understand treatment side effects for each option. It is critical to weigh the potential side effects against the benefits of treatments **before** a decision is made.

Overview information about treatment side effects is found in Chapter 4 of this booklet, and resources for more in-depth information can be found through organizations listed in Chapter 10.

In general, treatment options presented by the oncologist will be based upon the specific type and stage of cancer that your loved one is facing, her overall health, and available resources. It is useful to ask the doctor if a **clinical trial** would be an appropriate or preferable treatment option. Clinical trials are research studies of promising new treatments or combinations of treatments. Ask your physician or visit www.cancer.gov/clinicaltrials for more information.

The good news is that for every stage and type of breast cancer, there are many valuable treatment options.

KEY QUESTIONS ABOUT YOUR LOVED ONE'S TREATMENT OPTIONS

- What is the goal of treatment?
- Why is the doctor recommending one treatment over another?
- What are the benefits of each viable treatment?
- What are the risks?
- Are clinical trials an option?
- How can we manage or prepare for side effects associated with each treatment?
- How often will treatment be given, and where?
- How long does each treatment last?
- Does the facility where treatment will be given also offer resources for emotional support?
- If cost is a problem: Are there ways to help our family with the costs of treatment?

SECOND OPINIONS

It is a standard recommendation that cancer patients obtain a second or even third opinion about their diagnosis and treatment options. If you and your loved one agree, ask her oncologist to recommend another oncologist or cancer center to review her situation.

When seeking additional opinions, be sure to find an oncologist with expertise in breast cancer who is covered by your insurance plan. Once a second opinion is obtained, your loved one can receive treatment from the doctor with whom she feels most comfortable.

BREAST CANCER'S IMPACT ON FAMILY AND FRIENDS

Breast cancer can affect a woman's entire social network: children (young or adult), aging parents, siblings, extended family, friends, and colleagues at work. Everyone is affected to some degree, and it helps if this is acknowledged.

Impact on Younger Children and Teens

Children understand the world through their parents. How a child reacts depends very much on how the parents or other close adults are dealing with their own feelings. When a parent is sick or experiencing stress, children of all ages can sense this change, even if they cannot identify or understand the cause. It is important to have open discussions with children so that they do not develop their own ideas about the cause of stress.

You can always promise to be honest, open and loving to your children — and sometimes that's enough.

Explain the facts of cancer in an age-appropriate way that allows children to understand and participate in what is happening. For example, including children in discussions about how to help their mother feel better lets them feel they are contributing without giving them too much responsibility. Children cannot be shielded from all of the stressful parts of life, so it is important to teach them how to cope with this and other challenges.

Signs to watch for that suggest a child could use some help:

- Regression (acting/behaving younger than the child's age)
- Changes in a child's sleeping or eating patterns
- A drop in school grades
- Changes in behavior
- Getting into arguments with friends
- Emotional withdrawal

Teenagers may find it especially difficult to cope with cancer, combined with all of the common challenges in adolescent lives. They might be more able to share their fears and emotions with a trusted adult outside the immediate family, such as a grandparent, teacher, or athletic coach, who can lend support.

Cancer is not the same as other major life events; it is ongoing and often unpredictable. It is important to work together as a family to plan how each individual will have their needs met during and after cancer treatment. It helps to include children in decisions on how to "cut back" to make time for new family routines. Maintaining or developing a new family routine can help to minimize the impact and stress on everyone.

There are many excellent resources available for and about children who have an adult with cancer in their life. See Chapter 10.

Friends and Coworkers

Many people have a wide social network outside the family with whom they interact on a regular basis, including coworkers, teachers of school-aged children, friends and neighbors. Some of these relationships will be closer than others, and you may choose to share information about your loved one's situation with these individuals, or not.

It is common for some relationships to grow stronger while others become weaker during stressful times. Both you and your loved one will want to have access to people who can offer support when you are having a tough day. If you don't feel that you have enough people who can help you through emotional or practical issues, you should absolutely consider a caregiver support group. Professional counselors familiar with working with people affected by cancer can also be helpful.

SOCIAL RELATIONSHIPS AND THE WORKPLACE

If your loved one chooses not to tell coworkers or friends about her breast cancer diagnosis, it is important to honor her decision. If you feel her choice conflicts with your own, you should invite a conversation about this. As her caregiver and loved one, you may express your concern. Your loved one's preferences and decisions should always be respected, and it is important to work as a team to figure out how you both can best negotiate this journey.



I think this experience has brought us closer. Jenna was there for me throughout the whole journey. She made it possible. She made it easy for me. She was a real, real caregiver, from the heart. She would make the nicest tapes for me: reggae music, oldies but goodies, things that I could listen to during chemo. She would crack me up with this music.

— Gita, breast cancer survivor

COPE MODEL EXAMPLE: TALKING ABOUT CANCER

You feel unsure about what to tell people about this cancer diagnosis. Complicating the matter is that you are not sure what your loved one thinks about who to tell or what to say.

1 / Identify the PROBLEM.

Here it might be, “How do I talk about cancer with family, friends, and children?”

2 / Gather EXPERT INFORMATION.

As you think about where to seek guidance for talking with children, in particular, you might ask:

- Is there a child life specialist at the hospital who can help?
- Is the child’s school counselor available?
- Are there good books available to help talk with children about cancer?

You might want to:

- Begin by opening a conversation with your loved one by stating, “I would like to know how comfortable you are telling specific people about your diagnosis.” You could follow up by asking, “What, exactly, do you want people to know or not know?”
- You may need to ask, “How would you like to tell the children?”

- You could discuss how your child likes to receive information and take into consideration his or her developmental stage.
- You could talk about which people you want to tell face-to-face, on the phone, or via email.
- You can discuss if it is best to adjust the information shared based on relationships and how various individuals handle information.
- Decide if there are people you agree should *not* be told at this point.
- Determine what type of help, if any, you would like to receive from family or friends who ask to help (Dinners? Transportation? Childcare? A weekly phone call?).

3 / Make a PLAN.

You’ll want to brainstorm all of your possibilities being **optimistic** and **creative**. To help, you may want to ask questions like, “How would someone we really respect handle this situation?” In this example, a plan might include:

- The development of a page on a caregivers website, such as CarePages or Lotsa Helping Hands (see page 77), to manage the information that gets out to friends and family and inform others of your needs and requests.
- Involving a member of your family that you would like to designate as the “point person” to give out information to the others.
- A list of what help you would want and from whom.
- Consider timing: Do you want to wait until you learn more before telling specific individuals certain information?
- What other ideas do you have?

Remember to choose a plan that is realistic and pick no more than three solutions to try at first. Get started right away. You can always adjust your plan after you learn a bit more about what feels comfortable, and what works the best.

Coach's Corner

After receiving word of your loved one's diagnosis, you'll have to harness swirling emotions, try to identify your options, and manage how family and friends hear the news. In other words, this is a good time to set up your game plan.

A major part of the game plan may be for you and your partner to talk as a team with your children, other family members, and friends. You can bring out the best in this team if everyone has a responsibility and role to play. Your role is to form a cohesive team. There is no right way to do this; just think about what might be appropriate for everyone involved.

Just as if you were on the playing field, the only thing you can rely on is constant change. You can't plan for everything, but you can adapt to what is needed to make your partner feel loved and supported.

If you feel overwhelmed, don't worry. This is normal. This is hard, but you can be wise and courageous, and you can help to improve the quality of your teammate's life. All of the hard work you have both put into making your partnership successful in the past can help make this game plan a winner.

Men are not always comfortable reaching out, or talking about what's going on. We feel the need to fix things — so it's easy to start thinking about the 'what if's.' That will drive you crazy. It's important to get out of your head, find people to talk to, and get good at focusing on the present. Think: what can I do today? Worry about tomorrow, tomorrow.

— Scott, husband of
breast cancer survivor, Terri



CARE Active During Initial Treatment

4 CARE Active During Initial Treatment

As treatment gets started you may feel relieved that something is now being done to “fix” the breast cancer problem; however, you have a new series of things to think about such as side effects and practical issues. It helps to become aware of what to expect in advance, so you can develop a plan now that treatment is underway.

Consider this:

- Take time to check-in with each other and make a plan now that the decision-making phase is over and treatment is underway.
- Together, consider ways that friends and family can pitch in, so that when they offer, you can make the most of the help.
- If you cannot attend all of her treatment/doctor’s appointments, try to attend the first appointment for each type of treatment. This will help you know what to expect.
- Consider asking your employer for the Family Medical Leave Act (FMLA) paperwork. FMLA offers caregiver protected time away from work (though unpaid).
- Consider attending a support group for caregivers to gain practical information and support.
- If the woman diagnosed with breast cancer is your intimate partner, plan a “date night” and explore new ways to be emotionally and sexually intimate.
- Pay attention to your own health! There’s a natural tendency to push aside your own needs. However, it’s important for you and your loved one that you stay healthy.
- Remember that life “just is.” It’s not “supposed to be” anything.

Breast cancer treatment includes any action that your loved one takes to eradicate or limit the growth and effects of breast cancer. Treatment may involve surgery, radiation therapy, chemotherapy, targeted therapy, hormonal therapy or any combination of these. Some women also include complementary methods of treatment such as visualization, dietary changes or acupuncture.

To help you make a plan to get through the treatment period with your loved one and help her manage treatment side effects that might impact her life, we provide an overview of what to expect both physically and emotionally from various types of treatment.

Additional resources for more information may be found in Chapter 10.

SURGERY

The goal of surgery in most stages and types of breast cancer is to remove as much of the cancer as possible. Thanks to advances in personalizing surgical techniques, there are different types of surgery that can work for each individual. It's important to learn about the different types and discuss with your loved one and her health care team which option might be best for her.

The three main categories of breast cancer surgery are:

Lumpectomy

Surgery that removes the cancer and some tissue around it and leaves the rest of the breast intact. It is usually followed by radiation treatment. For some stages of breast cancer, this can be just as effective as removing a larger part of the breast.

Mastectomy

Surgery that removes the cancer and parts of the breast around it. How much tissue is removed depends on the size and location

of the cancer and other factors. It's usually followed by radiation.

Breast reconstruction

Surgery that uses implants or tissue from other places in the body to reconstruct the breast after the cancer is removed. There are many different types of reconstruction available. Some women choose to have reconstruction at the same time as their mastectomy. Some choose to wait until later. It's important to consider all options ahead of time.

Another type of surgery related to breast cancer is called **lymph node dissection**. This is a surgical procedure to remove lymph nodes from the area around the affected breast which can both help determine the stage of the cancer and remove cancer cells from the body. There are different types of lymph node dissection. Discuss with the surgeon which one might be right for your loved one.

Side effects of surgery

Immediately after surgery, there is pain that can be managed with medication. Range of motion or movement issues can be improved with exercise. Months or possibly years after surgery, **lymphedema** [*pronounced: LIMF-uh-DEE-muh*] may occur. This is a swelling in the arm on the side of the affected breast. It can be painful and could interfere with reconstructive surgery. It is important to pay attention to symptoms of lymphedema.

There are things your loved one can do to relieve the discomfort and swelling of lymphedema, and she can ask for a referral to a lymphedema specialist who can help. For more detailed support, contact the **National Lymphedema Network** (www.lymphnet.org).

SURGERY AND CARE ACTIVE CAREGIVING

The side effects of breast cancer surgery can sometimes be more psychological than physical. Losing a breast or part of a breast can have a big effect on a woman's body image and sense of self. This can also impact her close physical relationships. To be CARE Active you can:

- Encourage her to discuss her feelings, when she's ready.
- Explore together her new body and ways to be intimate (as a partner).
- Suggest sharing her experiences in support groups with other women who have gone through the same experiences.
- It always helps to be "present," listen, and be open to share **your** feelings after listening to hers.

It is common and understandable for sexual partners to feel a sense of loss when their loved one loses part or all of a breast due to breast cancer surgery. It is even more common for sexual partners to feel unsure about whether, how, and when to touch their loved one's breasts after surgery. Communication is especially important in this situation. Your partner's physician can tell you both when it is medically okay to touch and explore her breast or surgical site, and then you and your loved one should discuss what works for both of you. Couples often share how important it was to them to set time aside to explore new ways to touch and be intimate after surgery (see pp. 40, 43 for more information about sexual intimacy).

RADIATION THERAPY

This type of treatment uses radiation to kill cancer cells or keep them from growing. Radiation usually follows breast cancer surgery to target any cancer cells that might still be around the area of the surgery. Radiation is given for a number of consecutive weeks, 5-7 days a week, as determined by a radiation oncologist. The most common type of radiation is external, which means it is directed from outside the body to the area inside the breast where the cancer was removed. Internal radiation, which is less common, is given by inserting small “seeds” of radioactive material directly into the affected area.

Side effects of radiation

These include soreness, redness, and skin dryness, as well as fatigue. The side effects of radiation can sometimes be prevented or managed with good nutrition, hydration and skin care. Still, don't ignore them if they're affecting your loved one's quality of life!

RADIATION AND CARE ACTIVE CAREGIVING

One of the big challenges with radiation therapy is scheduling treatment. It often involves going to the doctor's office or clinic every day, or almost every day, for many weeks. You can help your loved one during this time by:

- Offering to drive or find others to drive her to and from appointments.
- Making sure she gets enough rest.
- Helping her find the best physician-approved creams and other treatments to soothe any painful areas.

Some women choose to continue working during radiation treatment, and for them the logistics might include making arrangements to be away from work for a period of time each day. Other women may be caring for small children at home.

If this is the case, you may find yourself searching for childcare, sometimes at odd hours and for relatively brief periods of time. Since each woman is different, it is helpful to find out what she would (and, just as importantly, would not) find supportive.

It is also crucial for you to think through what you feel able to provide in terms of help. It could be that your loved one would like for you to take her to her radiation treatment every day. Depending on your work schedule and the radiation schedule, it may not be possible or wise for you to take that much time away from work. Only you can determine this.

Finding balance is the key. There is a balance between meeting the wants and needs of your loved one during treatment, and managing your own practical matters. Discussing logistical possibilities in advance really helps.

CHEMOTHERAPY

Chemotherapy uses medicine to either kill the cancer cells or stop them from dividing. It's usually given through a needle in a vein (intravenously), but there are oral chemotherapy drugs as well. Chemotherapy affects any cells in the body that are dividing rapidly. These include cancer cells, but also cells in the blood, digestive system and cells related to hair and nail growth. That's why it can cause side effects in those areas and systems of the body.

Because of its wide-ranging effects, chemotherapy is usually given in cycles. This gives the body a chance to recover from one cycle before getting another.

Chemotherapy is probably the most feared cancer treatment because the side effects are so visible (most notably hair loss). Knowing what to expect ahead of time can lower anxieties significantly. It can also help you and your loved one plan ways to cope even before treatment starts.

Side effects of chemotherapy

Every type of chemotherapy has different side effects. Some common side effects and tips for dealing with them include:

Hair loss

If you and your loved one know ahead of time that she might lose her hair, there are ways to prepare. Cutting her hair short before treatment may help reduce the shock if/when her hair falls out. Finding wigs, scarves, or other head coverings that she likes (or at least can tolerate) may also make things easier. Hair loss can happen in all areas of the body including eyebrows, eyelashes, legs, underarm and genitalia. Most importantly: remind each other that the hair will grow back!

Nausea

There are now effective treatments that can help with nausea from chemotherapy, so many women find that this side effect is not

as bad as they expected. Complementary treatments like acupuncture and massage can help, but it is wise to ask your physician about this.

Low blood counts

Chemotherapy can lower the number of red blood cells (that carry oxygen throughout the body) and white blood cells (that help fight infection). There are treatments that can help increase the levels of red and white blood cells to healthy levels. However, recent research has found that not all of them are safe for treating people with breast cancer. Talk to the doctor about what options are available for your loved one.

There are other side effects specific to different types of chemotherapy. Find out ahead of time what to expect with each type, so you and your loved one can prepare to the best of your abilities.

CHEMOTHERAPY AND CARE ACTIVE CAREGIVING

During and after chemotherapy your loved one will most likely feel weak and tired and might need a lot of attention and care. This can be challenging for both of you. Some CARE Active ways to help during chemotherapy:

- Talk about what she needs and how much help you can offer (recognize your potential and your limits).
- Encourage your loved one to discuss any side effects and try available remedies until she finds one that works.
- Make sure she gets plenty of rest.
- Hydration and good nutrition are very important to managing side effects during chemotherapy. A registered dietitian might be a useful resource for her.
- If she feels okay, encourage her to take walks to regain energy.
- Offer to take her to and from appointments, or find someone else who can.
- Help with household chores, childcare, and other tasks. Again, find out from her what would be most helpful.
- Learn when to call the doctor with a problem, and when you shouldn't worry.

Logistics during chemotherapy include getting to and from the medical oncology clinic, spending a half-day or even a full day at the clinic, and, as with radiation therapy, incorporating this new activity into both of your lives.

Even if your loved one chooses to go to chemotherapy treatments on her own, her life at home may change as her energy declines, her sleep patterns change, and her appetite and exercise tolerance likely decline. Interestingly, it is not uncommon for caregivers to also report that they notice a change in their level of energy, mood, sleep patterns, appetite and exercise tolerance.

Recognizing that breast cancer affects the survivor's entire support system is important. Communicating with your loved one about how you can both best get the support you need and support each other during this stressful time is crucial.

HORMONAL THERAPY

This type of treatment works against breast cancer that has hormone receptors (see p. 12). Some hormonal treatments block the receptors so the hormones can't encourage the cancer cells to grow. Others stop or lower production of the hormones by the ovaries. The type of hormonal treatment selected depends on whether a woman is pre- or post-menopausal as well as other factors.

Side effects of hormonal therapy

When women are prescribed hormone-based medications as a way to control the disease or prevent recurrence, these medications may have side effects. Many women who take these hormone-based medications find their mood affected, may experience menopausal symptoms such as hot flashes (even if they are post-menopausal), and may find their bodies prone to gain weight. Vaginal dryness and other sexual side effects can also occur. This can be traumatic in a romantic relationship and may require a serious commitment to finding new forms of intimacy.

HORMONAL THERAPY AND CARE ACTIVE CAREGIVING

Hormonal therapy can make a woman irritable, hot, and not always pleasant to be with. As with chemotherapy, this can be challenging to an intimate or close relationship. You can help her deal with hormonal therapy side effects when you:

- Encourage open and honest discussion about anything that's bothering her, even if it might feel embarrassing.
- Suggest that she keep a notebook to record her side effects so that she can more effectively communicate with her doctor and find remedies to help.
- Be open and honest about your own needs, especially if you're in a romantic relationship.
- Be willing to work together to find new and creative expressions of intimacy.

Logistically, you can help simply by finding ways to remind her to take her oral hormone medications if she forgets, or by quietly staying with her when she feels out-of-sorts. You can always ask what you can do to help her feel better or find ways to lighten the situation and have a little fun (go to the movies, take a walk, go out with friends — anything to take her mind off of her discomfort).

TARGETED THERAPY

Targeted therapy works to destroy specific substances in or on cancer cells that cause the cells to grow. Herceptin is a targeted therapy that works against HER2-positive breast cancer. Avastin (bevacizumab) and Tykerb (lapatinib) are two more targeted therapies that have recently been added to the arsenal of breast cancer treatments. Side effects of targeted therapy tend to be mild, involving skin rashes and possibly flu-like symptoms.

TARGETED THERAPY AND CARE ACTIVE CAREGIVING

Targeted therapy is one of the most exciting areas of cancer treatment and research. Clinical trials are looking at many new types of targeted therapy. As a CARE Active caregiver, you can explore cutting-edge research and clinical trial options for your loved one.

For more information about Targeted Therapies, please refer to www.thewellnesscommunity.org for the *Frankly Speaking About New Discoveries in Cancer* publication or call 1-888-793-WELL for a free copy.



I've always loved Marc, but it just deepened it in the sense that this is a person who loves me, who obviously did so much to get me through this, and that sense of absolute trust, I think that came through.

— Marsha, breast cancer survivor

THE BALANCING ACT

Know that caring for yourself is not selfish... at any point during this process.

You may not feel entirely comfortable receiving support around such an intensely emotional life event. However, it helps to be mindful about your own needs and abilities while you juggle the schedule and stressors of your loved one's cancer treatment.

Make plans to exercise, join a caregiver support group, and/or meet with a friend, mentor, counselor, clergy or other support person to talk about your experiences. Caring for yourself during this time of stress enables you to be more available for your loved one, as well as the other people looking to you for support.

If you are working and you want to be with your loved one during her treatment appointments, you must decide what you will tell your employer. Depending on your length of employment and the size of your company, you may be eligible for federal Family Medical Leave Act benefits, which allows you to take unpaid time away from work when you have caregiving responsibilities (as little as one hour at a time or up to twelve weeks). To learn more: www.dol.gov/esa/whd/fmla/.

FORCED FUN

Many caregivers find that they have to make an effort to do things for themselves. The tasks of caregiving can crowd-out some of the fun and stress-relieving activities we enjoy. You may feel, "I can't seem to do the fun things I used to do because I find myself worrying about loose ends," or "I just don't have time." Consider that people in similar situations report that they were actually able to have a positive attitude AFTER they took time for themselves. One woman reported, "I call it 'Forced Fun'. I never feel like I have time, but I force myself to take the time anyway. Now my mother insists that I'm more fun to be around when I'm looking after myself."

Coach's Corner

When preparing to tackle the toughest opponent, a great coach will always scout that opponent and use strategies to get as much information as possible about them. In this case, you'll want to understand how treatment will affect the entire team — and especially the most important part of that team, the patient. Once all of this information is gathered, a decision will be made on how to best attack the opponent. You'll want to define positions and roles for everyone involved, from arranging doctor visits, to dealing with your family and well wishers, to researching and taking notes on treatment.

A major detail often overlooked is taking care of yourself during this time. You must make sure you are properly rested, so you can be the eyes and ears to help identify potential problems as they arise. You must take care of yourself so you can help make sure the most important person on your team has the best game possible (so she can focus on herself).



CARE Active When Treatment is Done

I've found it to be really stressful when she's doing very well. I think it's because our next step is to figure out what she's going to do with her life now that she's able to start working again. It's stressful because we just don't know what the next step is.

— Anabella, daughter of breast cancer survivor, Ellen

5 CARE Active When Treatment is Done

Many people affected by breast cancer, both survivors and those who love them, focus their energy on “getting through” treatment. Often on that last day of chemotherapy or radiation, or soon after, the question comes: “*Now what?*”

Consider this:

- Women do not necessarily feel better the moment treatment ends. Continue to ask how she’s doing.
- Acknowledge that you are still available to assist her even now that treatment is over. Some tasks or roles assumed by caregivers during treatment may need to continue while she reimmerses into routines and slowly regains energy.
- Be patient. The post-treatment recovery phase can last six months to one year or longer after treatment is finished.
- Be sure your loved one has a survivorship care plan. Practical help can include gathering copies of her treatment records for personal files.
- This could also be a good time to discuss some difficult but practical issues that affect every family. It is important to consider financial plans and wills. Hopefully you will not need these plans any time soon.
- Consider joining a support group, either together or separately, to work through the emotional impact of cancer.
- If sexual intimacy becomes a problem for you and your loved one, know that there are things you can do to help regain an intimate connection.
- Remember that life is different after cancer. Appreciate each moment together.

WHEN IS TREATMENT “DONE”?

Caregivers are often ready to get back into “normal” routines and address the many things that have been put off while treatment was underway. The woman who has just completed treatment, however, may find herself emotionally overwhelmed. She may feel as though she can only now begin to process what happened over the past months. Often this onslaught of feelings comes as a surprise to everyone. “I’m finally done with treatment. How can I be sad now?” is a common statement.

Alternatively, a caregiver may feel exhausted after treatment is done, while the woman who has completed treatment may want to fit all the “life” possible into each day. Open and clear communication between you and the women you care about can minimize misunderstandings and build a positive foundation for your relationship after cancer.

Many affected by breast cancer consider treatment done after the last scheduled chemotherapy or radiation appointment. However, women often must then continue treatment with oral hormonal therapy. Hormonal therapy involves oral pills or tablets that women post-treatment can take and manage from home. In some cases, hormonal therapy may last for up to ten years after treatment.

Some women are very satisfied to know that they take some form of ongoing breast cancer treatment. They may feel “protected” or safer since this may feel like an enduring way to keep the disease from coming back. Others may have conflicting thoughts about taking medication every day for five or more years to treat their cancer.

Some women feel distressed about taking hormonal therapy because it is a daily reminder of breast cancer. Also, some of these hormonal treatments may have side effects that are unpleasant or uncomfortable.

As a caregiver, you should ask your loved one or friend how she is feeling from time to time. There is a delicate balance between asking occasionally, and asking too much. Still, offering the opportunity to talk is usually helpful.

ACUTE SIDE EFFECTS

Some treatment side effects are acute and happen for a brief period during active treatment. Other side effects may be more chronic in nature and linger for a longer period of time. Still others may be delayed until long after treatment is over. In any circumstance, you should be attentive to the fact that treatment may not be over when it's over. Some effects of treatment continue to have a significant impact on a woman's life.

Also, although it is not always obvious, many women and their care partners feel a sense of protection while they actively receive treatment. When treatment is done, it can feel as though that protection is taken away. It can be unnerving for both patients and caregivers to realize that they will no longer see a health care professional every day, every week or even every month. A common fear is, "If the cancer comes back how will we know?" (You can read more about the "fear of recurrence" in Chapter 6 along with other longer-term side effects.)

Here we cover a few of the things your loved one may experience soon after treatment:

Emotional and psychological effects

Feelings of sadness, anger, grief, anxiety or depression are commonly experienced by women once treatment is over. Some are very sensitive about changes to their bodies or scars resulting from surgery, which in turn affects their self-image. Many women also gain weight during or after treatment which can become *another* troubling issue.

Emotional distress and fear can feel complicated and uncomfortable for both of you. Talk with close friends. You and your loved one may also consider seeking help from a support group. Sometimes the best people to help you understand and overcome emotional distress are those who are also "surviving" breast cancer. There are support groups for survivors separate from caregivers, groups for families, and groups for caregivers only.

Early menopause

Menopause may result from treatment for several reasons. Going through menopause early can cause upheaval in a woman's daily life. Caregivers should ask how a loved one might want to receive support when she feels uncomfortable (possibly due to hot flashes, mood changes, sleep, and appetite disturbances). It's an awkward time for her, so your sensitivity would be valued.

Fatigue

Fatigue is a side effect of cancer treatment that may linger. You can help simply by understanding that your loved one's (and your own!) stamina and endurance may take time to rebuild. You can help her find ways to rest and encourage her to get more sleep than in the past. Or if she's ready, encourage her to get out and walk with you or exercise to rebuild her stamina and strength. While many women want to get back on track and recapture the joy in life after treatment, it may take some time. Encourage patience and perseverance.

Sexual effects

Your loved one may experience a lower libido or have symptoms of menopause that could affect her intimate life. In fact, up to 90% of breast cancer survivors report having some sexual discomfort or body image issues. Sexual side effects can be addressed in a variety of ways. Most importantly, caregivers should be caring, thoughtful and encouraging.

Some of these ideas may help reignite sexual interest after breast cancer treatment:

- Body changes caused by scars from surgery or lymphedema often affect one's self confidence. Consider what you could do to help her feel more attractive or more sexual.
- Exercise and healthy nutrition can help everyone feel less tired and reduce physical pain. An increase in energy from exercise may also trigger interest in sexual contact.
- If your loved one is experiencing depression or anxiety after cancer treatment (which in turn affects her ability to be intimate with you), know that her doctor might be able to recommend counseling or medication.
- Many people find they have distracting thoughts about cancer during sex that interfere with being able to relax and enjoy good physical feelings. Try to help each other focus on your personal sensations during sexual contact. Talk about other things that might help you both relax.
- If she is having pain during sexual touching or intercourse, it is crucial to get some help. A first step is usually to use a vaginal moisturizer regularly and use lots of water- or silicone-based vaginal lubricant when you have sex. If her pain persists, a gynecologist may be able to help. Never use petroleum-based jellies or body oils as lubricants.
- If the problem with desire is focused on a loss of attraction between you and your partner, couples or individual counseling can help.

CANCER CAN ACTUALLY IMPROVE THE INTIMATE RELATIONSHIPS IN YOUR LIFE

Many men or women in a committed relationship when diagnosed with cancer say they feel closer to their partner after the illness. They stop taking each other for granted. They are grateful to have each other's support. They are less likely to argue about the small hassles of daily life.

STAYING ORGANIZED

Since cancer isn't necessarily over after treatment, it helps to stay organized and prepare for follow-up visits or future needs. Your loved one should be given a survivorship care plan by her treatment team when treatment is over.

Practically speaking, while you and your loved one manage the emotions and side effects immediately following treatment, you can also help by organizing the “paperwork.” For example, you can gather information about the medical tests and treatments that she has just undergone by asking her doctors for all medical records. Often, you can simply ask for a CD to be mailed to you (with x-rays and other lab test results). Under the *Patient Bill of Rights*, your loved one has the right to have a copy of her personal records for use with future doctors, her insurance company, or for her files. Since it may take time to organize all of this, your help is very valuable.

Also, even though it can be emotionally difficult, you should consider working with your loved one to prepare legal paperwork such as *advance directives*, a *living will*, and a *Last Will and Testament*. It is easier to take care of these important documents and plans when everyone is feeling relatively well. It is also *much* easier on both of you, and the medical team, if you know your loved one's wishes in terms of end of life decisions in advance. You can aim to plan *CARE Actively*, then hopefully you will not need to think about these documents for a long time to come.

We offer more information about important legal planning documents on page 67 in Chapter 8.

SURVIVORSHIP CARE PLANNING

Survivorship Care Planning is a way to help people navigate the complexities and uncertainties of life after cancer. It can include information about key providers, previous treatment, and follow-up care. The Lance Armstrong Foundation (www.livestrong.org) offers practical worksheets online to help with Survivorship Care Plans.



It gives me comfort to prepare for when I'm no longer here, so that I've settled my affairs. I don't feel like it's a preparation for death, I feel like it's a preparation for life. My attitude is, 'While I can still move, I'm going to do everything I can...' and take advantage of the time that I do have.

— Chris, metastatic breast cancer survivor

MOVING BEYOND TREATMENT

The period after treatment ends can open many doors. Most women begin to explore what their “new normal” will be. This can bring a sense of closing one chapter and beginning a new chapter. Life-altering situations such as breast cancer can give women and those around them opportunities to pause, learn, grow and appreciate life differently.

Bottom line: Life is different after cancer. If cancer is a part of your loved one’s life, it brings the potential for positive growth for everyone involved.



Being a cheerleader sounds great in theory, but in practice, the patient has the right to all of these emotions.

If I were to say to Marsha, ‘Snap out of it, cheer up, it could be worse,’ then I’m sort of saying you don’t have a right to any of those feelings. It’s better for her to express the feelings and for me to just listen to them instead of trying to cheer her up.

— Marc, husband of breast cancer survivor, Marsha

COPE MODEL EXAMPLE: SEXUAL INTIMACY

Your partner completed all treatment six months ago, but you have not had sex since treatment began. You miss it.

1 / Identify the PROBLEM.

Here it might be, “**How can we reconnect sexually?**” This may be an accurate problem statement whether or not your sex life with your partner was fulfilling prior to treatment.

2 / Gather EXPERT INFORMATION.

You might:

- Take this time as an opportunity to discuss sexual functioning anew.
- Make an appointment with the doctor to find solutions if treatment has had physical side effects such as premature menopause, fatigue, lowered libido or increased vaginal dryness.
- Inquire online or at a support group if other couples have encountered this situation and learn how they handled it.
- Research other sexual practices that might “re-spark” your sexual relationship and/or be more comfortable.
- Consider intimacy — do you need to reconnect emotionally as well as sexually?
- What else would you do to gather expert information?

3 / Make a PLAN.

Brainstorm all your possibilities being **optimistic** and **creative**. To think outside the box, you may want to ask questions like, “If we had no limitations at all, how would we solve this problem?” In this situation, you might:

- Look at your sexual relationship a bit differently (creativity).
- Decide that you will try new things (optimism), but may need guidance from a professional.
- Schedule a “date” at least one time each week to spend one-on-one time together.
- Think about things you like to do together for a date — a movie, dancing, a hike, sitting on the porch.
- Go to a gynecologist (either as a couple or individually) to get suggestions on vaginal lubricants and other side effect management tools.
- Consider finding a certified sex therapist.

- What would others suggest? Your best friend? Her best friend? The oncology social worker at the cancer center? Your clergy or other spiritual guide?
- What brainstorming ideas would you include?

Pick two or three items that you think offer a good chance of success (don’t overcommit). Expect that your plan will work, but also know that you can make adjustments.

You might:

- Have a date night to reignite romance.
- See a doctor together to determine if there might be physical side effects affecting libido (sexual drive) or comfort.

If part of your plan is a “date night,” but you find that fatigue gets in the way, you can readjust. Perhaps you start the date night earlier in the evening, or you have your date on a Saturday morning. The goal is to find the plan that works for you. Plans usually require some adjustments, and by thinking creatively and optimistically you’ll be amazed by what you can do.

Coach's Corner

Good. Your MVP (most valuable player) is done with treatment. What now? How do you as a caregiver become settled with the "new normal"? One thing to come to terms with is that there is no concrete period of off-season anymore. You must be ready to get back in the game at a moment's notice. You will feel a loss of some of the freedoms that you used to enjoy in your "old normal."

Aim to remain in shape all year round, 365 days a year. You both need to be physically and emotionally strong, so you are prepared for any situation that may arise. As you know, a team that is well prepared with practice will perform at a higher level in any situation.

A role you should now be prepared to play is as the teammate who makes sure that your MVP adheres to, and complies with, all of her follow-up care and instructions. To be allstar teammates, you both must have a clear understanding of what you want the future to hold so that your partnership may flourish for a long time to come.



CARE Active During Long-Term Survivorship

Getting back to normal for me is having moments when there's not much going on and I don't immediately think about breast cancer. I mean, for the longest time after Liza's diagnosis there was no quiet time in my head because of all the 'what ifs.' [Now,] for me personally, things are quieter. Occasionally things lead us to worry and we get anxious again, but then it quiets down.

— John, husband of
breast cancer survivor, Liza

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6 CARE Active During Long-Term Survivorship

After some time passes, you may expect that you and the woman you care about could “put cancer behind you” and move on. In one sense this is true, but there are also long-lasting and/or delayed emotional, social, physical, and sometimes spiritual side effects for both the survivor and those who love her.

During long-term survivorship, the support your loved one wants or is willing to accept and the kind of support you feel able to give may change. As a result, you must renegotiate the delicate balance. Not surprisingly, communication will be the key to finding this new balance.

Consider this:

- Life is different after cancer. You and your loved one will each find a “new normal.”
- If you haven’t already started, consider keeping a journal. This can provide you with an emotional outlet and a reminder that the roller-coaster of emotions sometimes goes down but also goes back up.
- Take time to learn about potential delayed treatment side effects and the best ways to manage them. Knowledge is power.
- Likewise, research the signs of recurrence.
- Consider making a list of relaxing activities you’d like to do for yourself, and take time to incorporate them into your schedule.
- Make sure you’re taking care of your own health. Make appointments for yourself and follow-up with your own health care provider.
- When challenges arise, consider practicing the COPE method of problem-solving, either by yourself or with your loved one. It will become easier and you will be more effective with practice.

DEVELOPING A “NEW NORMAL”

Life is not the same after breast cancer for the person diagnosed with cancer or for those who love her.

When someone you care about has or has had breast cancer, it requires you to be flexible and to develop a “new normal.” For survivorship, this means incorporating the realities of cancer into your future dreams. It does NOT mean giving up your dreams (retiring to an island, traveling, fishing for hours...), just adjusting your dreams to fit current circumstances. As circumstances change (and they will, of course, because that’s the way life works), your new normal may also change.

As time goes on, life may feel like it used to, especially as the cancer survivor regains energy and returns to previous routines. However, unwelcome reminders may come up: perhaps through a regular follow-up appointment; a new lump; or a fever. These events can trigger a cascade of fear and worry in both the survivor and in those close to her. You may find yourself up in the middle of the night, once again unable to concentrate at work, and/or edgy until you get the “all clear” signal that everything is all right (e.g., the mammogram showed nothing unexpected, the fever went away).

A roller-coaster of feelings will become part of your new normal. Over time, individuals learn to recognize the pattern of ups and downs, and hopefully both you and your loved one will be able to prepare for, and manage, the pattern.

WHEN MOMENTS ARE UPSETTING

As time goes by, most women will think about cancer less often. However, some events may cause women to become worried or anxious, such as a new symptom that develops, a family member’s illness, a follow-up appointment, or the anniversary of the date when she was diagnosed. Caregivers can provide comfort if or when these feelings emerge by knowing that this is normal during the recovery phase.

WILL CANCER RETURN?

The fear that cancer will return can interfere with every aspect of a person's life — eating, sleeping, working, and playing. It can be triggered by reminders such as follow-up visits, birthdays, someone else's diagnosis, an ache, or a bump.

Tips for coping with the fear of recurrence:

- Learn the signs of recurrence.
- Keep up with medical tests or appointments.
- Talk about it. Enable your loved one to express her feelings and express your own.
- Be *CARE Active*. Encourage your loved one to take control of what she can, and know what you cannot control.
- Make plans for the future. Short- and long-term plans always help.

Some people prefer not to talk about the fear of recurrence because of superstition, or a concern about causing their loved one to worry. Fear tends to grow in the silence, however, and naming the fear will often empower you. The process of facing fear with the woman you love can strengthen your relationship. It is extremely unlikely that the survivor you love has not thought about the possibility that her cancer could recur.

Your loved one's doctor and other members of the health care team are good sources of information. When you have questions or concerns about the possibility of cancer recurrence or other health concerns, write them down and discuss them at follow-up appointments.



I'm not doing nearly as many scans as I used to, because I don't like getting amped up every three months.

After each test there is this relief when the scan is clear and I think, 'Well, I can go a little longer now...' It is different for different people — some people need to know [if cancer has returned] every three months — I have found that doing scans all the time almost made it worse.

— Liza, breast cancer survivor

LONG-TERM SIDE EFFECTS

Delayed treatment side effects may impact the survivor's "new normal." For instance, she may experience premature menopause or infertility, heart problems, lung issues, osteoporosis, second cancers, and cognitive (the process of thought) and memory issues. You may be able to help by assisting your loved one in finding a primary care physician experienced in working with cancer survivors. Long-term side effects can be treated, but only if they are identified. Early intervention is certainly ideal.

To be *CARE Active*, you may find it natural to continue helping with doctor appointments and follow-up plans. However, you should ask if your loved one wants this same level of care. Sometimes people who care about each other have different ideas about what is best. If the issue centers on her body or her health, then she has ultimate say about what she needs from you, but you have a duty to express your wants and concerns as well.

CHEMOBRAIN — COGNITIVE DYSFUNCTION

It is estimated that one in five people who undergo chemotherapy will experience what survivors refer to as *chemobrain*. Long-term (and short-term) symptoms like forgetfulness, lack of concentration, difficulty finding the right words, and difficulty multitasking have all been described by cancer survivors. Though no one knows why this occurs, some theories include: toxic effects of chemotherapy, severe stress, hormone shifts, or the cancer itself affecting the body.

HOW'S YOUR HEALTH?

Make sure you take time to care for your own health. This is a good time to make appointments and follow-up with your own health care providers if you need to.

It is common to worry about who would take care of *you*, if you were to become ill. Relatives of long-term survivors are sometimes concerned about the possibility that they are at increased risk for breast cancer, since some breast cancers are genetically linked. This can also be a concern for survivors. Speaking with an oncologist or a genetic counselor about whether genetic testing would be helpful or advised is a great way to be both Patient Active and *CARE Active*.

Overall, it is important to take care of yourself and find ways to relax and take breaks. Consider making a list of relaxing activities you'd like to do for yourself, and take time to incorporate them into your schedule.

Long-term survivorship is a journey for both the person who was once diagnosed with cancer and for you. It gets easier with practice, but most report that life after cancer is never completely the same as it was pre-cancer. On a positive note, survivors and loved ones report a variety of positive changes in their outlook and relationship which they attribute to the cancer experience.



Support is critical with whomever you are comfortable with. It doesn't have to look and feel the same way as others get support, but get some support.

— Scott, husband of breast cancer survivor, Terri

COPE MODEL EXAMPLE: FEARING RECURRENCE

It is very common for both women and the people who care about them to worry that cancer will return. Here is a way to use the COPE Model to address this problem.

1 / Define the **PROBLEM**.

In this example, the problem to be solved is: **“How should we manage our fear that breast cancer might recur?”**

2 / Gather **EXPERT INFORMATION**.

In this case, you might:

- Make an appointment to talk together with your loved one’s oncologist about signs of recurrence.
- Research online for additional information about recurrence (see Chapter 10).
- Look for online chat-rooms or inquire in a support group to learn how other survivors and their loved ones negotiate this part of the journey.
- Talk with each other about what the possibility of recurrence means to you, even if the discussion is hard. It is important for you to think **creatively** about how you can work together to meet both of your needs.

- Sometimes it can help to talk with an oncology social worker or lawyer to discuss end-of-life care planning (before a problem arises).
- What other expert information would you want?

3 / Make a **PLAN**.

To do this, you’ll want to think **creatively** and **optimistically** about how you and your loved one can cope with the fact that cancer can recur. Planning will look different for each couple or family. Ideas might be to:

- Keep regular follow-up exams with the oncologist(s) scheduled in advance.
- Have weekly “check-ins” for you and the survivor.
- Participate in a support group (individually or together) to allay this concern.
- Develop end-of-life care plans (such as advance directives, estate planning, wills, guardianship issues and life insurance) with the idea that having these plans in place can be empowering and allows everyone to move on with life in the present.

- Be more present minded and set dates on your calendar to do new and interesting things together *now* while everyone feels healthy and able.
- What else would you consider?

Pick two or three options that you think have the greatest chance of success. You might decide to develop end-of-life care plans and be more present minded.

If you find that you cannot, as a pair, find time or energy to complete the end-of-life care planning, reassess the plan. Get **creative** in how you overcome this barrier. What would your best friend say? What about her best friend? Others you respect?

Perhaps you can set aside time on a Saturday morning, followed by doing something you will both look forward to and enjoy.

Maintain **optimism** as you search for the solution. Optimism in this situation does not mean believing that the cancer cannot recur. It might mean understanding that it could recur but hoping that it will not. Still another version of optimism could be accepting that cancer

could recur but believing that if it did, you and your loved one would be able to handle it. Whatever defines your approach to optimism, it is important that you and your partner together find a way to be optimistic as a team.

The key to each step in the COPE method is communication. If you and your loved one can talk honestly, you will find an approach to overcome the fear of recurrence.



If you find out you have cancer again, remember that you've been through this and you know what to expect. You can kind of screw up your courage and say, 'Well, I dealt with this before and I'm going to do my best to get through it again.'

— Linda, two-time breast cancer survivor and caregiver for husband, Russ, colon cancer survivor

Coach's Corner

As you move into a period of long-term survivorship, your long-term goals as a team remain the same. The emotional uncertainty you had been feeling, more than likely, has improved but is not totally gone. This is okay and normal. Hopefully, you have gotten to know yourself through this process, so you can help yourself relax and stay fit to be a prime teammate.

Even though you may feel as if you retired from being a caregiver, this is a role for which you have to stay in shape. Stay current on treatment options, signs of

recurrence, your partner's medical records, and her wishes, should the cancer recur. Proper preparation will always be an integral part of the playbook.

As always, the best way to stay prepared and in peak condition is to keep lines of communication open with your most valuable player—your partner. Make sure you know her desires and needs so you can readily rise to the occasion if required.



When Linda got her test results after having had the first go-round with cancer, it was like: here we go again. We were scared, but we knew the drill and the routine, and feel blessed that there is support. We had confidence in the team that we'd been with before. We just kind of started into a routine.

— Russ, colon cancer survivor
and husband of two-time
breast cancer survivor, Linda

CARE Active if Cancer Recurs

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7 CARE Active if Cancer Recurs

Neither you nor your loved one is responsible for cancer that returns. Cancer is a biological process, and the success or failure of the first treatment (whether it was surgery, radiation, chemotherapy, hormonal therapy or some combination) is biologically determined.

Consider this:

- Jointly determine who should know about this new development. Your family and friends cannot help if they don't know what is happening.
- Think about your resources. Can people who helped in the past help you or her now? What have you learned that can be useful in this situation?
- Keep talking to each other. Honest communication is more important than ever.
- Expect that you won't always agree and try to accept your differences without struggle.
- If she was not fully satisfied with her doctors and her medical care during the first cancer, this is a good time to consider a change.
- Help her get a second medical opinion. Even if you have to travel to a distant cancer center, a single trip may be well worth it, and your partner can still receive treatment closer to home.
- Schedule something fun at least once a week — either together or apart.
- Consider making a "Bucket List." Everyone has things they want to do in life, and although it may seem overly sentimental, this actually is an opportunity to enrich your lives with marvelous experiences and people.

YOU CAN ADAPT AND THRIVE AGAIN

Some cancers are resistant to chemotherapy drugs or radiation, and sometimes treatments don't succeed in eliminating all of the cancer cells in the body. The focus now must be on doing everything possible to deal with the cancer that has returned.

It is also important to remember that this is not an immediate death sentence. Indeed, many women live years with metastatic breast cancer, and ongoing discoveries of new and better treatments are making this increasingly true.

If you were with your loved one the first time she had cancer, you have lived through this before, and it is likely that both you and your loved one will feel better in a couple of months as things settle down. Ironically, you gained the experience you need to adapt to the situation. Develop a good working relationship with each other and the doctors, and establish a new treatment routine that will work for everyone.

If you were not with your loved one during her first experience with breast cancer, she may be able to tell you some of the things that did and did not work for her in the past.

As with all serious problems, this will not remain an acute crisis after some time has passed. You will, together, learn to live with this new reality, and your support can make a very big difference. Together, you will be able to get through this.

YOUR ROLE

Your main job will be to support and encourage your partner, helping her continue as much as possible with the life that she loves, while recognizing that you are dealing with a very serious situation. Many caregivers decide that it is very helpful to find someone else with whom to talk about their own fears or worries. Consider meeting with an oncology social worker, or joining a family or caregiver support group.

GATHERING EXPERT INFORMATION

Before the two of you can think clearly about a plan for dealing with this news, you need to understand the basic medical situation. These next paragraphs will explain what it means to have breast cancer return, what the differences are between a local and distant metastasis as well as between a recurrence and a second primary breast cancer. Of course, this is general information and you'll want more specific information from your loved one's oncologist.

Although no two patients have exactly the same experience, it will be helpful to have a general understanding about recurrent breast cancer.

With breast cancer, there sometimes is confusion about whether a second cancer diagnosis is a **second primary breast cancer** or a **recurrence** of the first:

- If this new cancer is in the other breast, it is likely, but not certainly, a new, unrelated primary breast cancer. If the cancer is in the same breast, it may either be a second primary breast cancer or a local recurrence of the first tumor. A pathologist can look at the cancer cells under a microscope and decide whether this is the same or a different breast cancer.
- If this is a **second primary breast cancer**, it has nothing to do with the first, and will be treated independently. The prognosis for a second primary breast cancer is decided only by its characteristics and is neither better nor worse because there was an earlier cancer. If this is a second primary breast cancer, it is not a recurrence.

Both local recurrences and second primaries in the same breast are almost always treated with a mastectomy since radiation cannot be given a second time to the same area. A locally recurrent breast cancer is considered potentially curable. If a woman had a mastectomy the first time, and cancer has now returned to the chest wall, it is a different situation and is considered metastatic disease.

If the cancer has come back in some other part of the body, it is called **metastatic breast cancer** or a **distant recurrence**, and it is a spread of the first cancer. Unlike a local recurrence, which is potentially curable, a distant recurrence is rarely curable, although it is very treatable. Breast cancer that has returned in, for example, the lungs or the bones is still breast cancer; it is not lung cancer or bone cancer. It is described as “breast cancer that is metastatic to the lungs or the bones.” This is an important distinction because metastatic breast cancer (Stage IV cancer) will always be treated with drugs that fight breast cancer specifically.

Inevitably, recurrence is a distressing event. Many people, both those with cancer and those who are caregivers, say that these are the times when they need each other the most, yet these are also the times when relating and communicating are most challenging.

ONGOING TREATMENT

The basic plan of care for Stage IV breast cancer is ongoing treatments for the rest of your loved one's life. The reality is that no single treatment will be effective forever. Cancer cells, unfortunately, are smart, and figure out how to be resistant to any drug or medication. Periodically, there will be evidence that the cancer has grown, spread, or "progressed" and this will mean that the current treatment is no longer useful.

DIFFERENT APPROACHES TO RECURRENT DISEASE

While first time breast cancers are treated in a fairly standard fashion, there are differences in the ways that oncologists approach recurrent disease. This is when both the art and science of medicine are important. Because of this, it is often good practice to get a second medical opinion. Good doctors expect patients to seek second or third opinions, so you and your loved one should never worry about hurting her original doctor's feelings!

When a cancer can no longer be cured, the emphasis for treatment will be on both quality and quantity of life. Oncologists tend to describe metastatic breast cancer as a chronic illness (an illness that must be managed throughout the life of a patient). Unlike an initial diagnosis, when the medical goal was cure, the new goal will be to make life as long and normal as possible.

Since you will be in this for the long haul, you, your loved one, and the doctors should care a lot about how she feels every day and how she can manage her life. This is why treatment decisions should be based on the impact of side effects and cancer itself on her daily life.

RE-PRIORITIZING YOUR LIFE TOGETHER

One important thing to do is to help your loved one think seriously about her priorities. What is most important? How does she want to spend her time? Who are the people that matter most in your lives? Your best shared decisions will take into account both of your hopes and wishes, family needs, finances, available support and resources.

You may have different feelings about these issues. Perhaps she wants to stop working and spend time traveling while you are worried about maintaining your income and keeping your job. Or, she may not want to tell anyone about her new diagnosis while you want to tell close friends so that they can help and support you. It is vital that you talk about these things and, if necessary, find ways to compromise.

Since your partner is the patient, remember that she gets the trump vote in any treatment decisions and an equal vote in any life decisions. However, your opinions are important, too, and you need to honestly express your thoughts and feelings.

It is generally good advice to avoid major changes in the immediate future. Give yourselves a little time to adjust to this new situation, and then you will be in a better position to know what you need and want to do.

DIFFERENCES OF OPINION

I want to work so bad. Occasionally, I get a job where I have a day of work. And that makes me feel grounded back to my real life.

— Sharon, metastatic breast cancer survivor

This isn't a time to worry about work. It's a time to not work, if you can manage that, and to do anything you want.

— Chris, metastatic breast cancer survivor

YOUR NEEDS

As you try to support and help her, you must also think about your own needs. What helps you get through bad days? Are you able to throw yourself into your work? Do you enjoy sports or a hard workout at the gym? Are movies or good books an escape? How can your friends and family best support you?

To repeat: it is not selfish to think about yourself. In fact, it is vital that you do so. Caring for yourself is one of the most important parts of being a CARE Active caregiver. It is likely that you and your loved one have a long, sometimes bumpy, road ahead. Living with recurrent or advanced breast cancer is a marathon, not a sprint, and it will take all of your emotional energy to keep you both focused and moving forward.

Unlike the first time, you will now be dealing with cancer and cancer treatments on an ongoing basis. There will be good times and, unfortunately, there will be hard times. No one can tell you how long your loved one will live with metastatic breast cancer. Statistics refer to a large number of people, and you are worrying about just one woman. There are always people who do much better than expected, and hopefully, your loved one is in that category.

Remember that there are a lot of people who are eager to help you both. Learn to say “yes, thank you” to some of their offers, and resist the temptation to do everything yourself. You and your partner will benefit from the collective affection and energy of your family and friends.



There were things I wanted to do that I just felt like I needed to do, like running, or yoga class, or reading a book. And I would just ask her, ‘Well do you mind if I go out,’ and if she needed me there she’d tell me, and if she didn’t she gave me permission to do what I needed to do. That gave me the kind of strength and comfort that would get me through.

— Marc, husband of breast cancer survivor, Marsha

COPE MODEL EXAMPLE: DEPRESSION

You notice that your loved one is often tearful and is isolating herself more. She does not seem able to smile or laugh, even when doing things she used to enjoy. You wonder if she is depressed.

1 / Identify the **PROBLEM**.

Here it might be “How can she feel happier?”

2 / Gather **EXPERT INFORMATION**.

You might:

- Ask her how she’s feeling.
 - Discuss the symptoms that are of concern to her, and to you. How long have they been present?
 - How are these symptoms affecting your lives?
 - Are there situations that increase (or decrease) the symptoms?
 - Ask yourselves what you think depression is and what it looks like.
 - Discuss where you might find information, or who might be able to give you information on the symptoms and signs of depression.
- Ask your health care team for an assessment.
 - Rule out that this isn’t fatigue. Does she have no energy for the things she used to love doing, or is she not finding joy in them anymore?
 - Consider hormonal changes. Could that be impacting her mood?
 - Is there a medication that might be helpful?
 - Is there a psychosocial support team, social worker, or community therapist that her health care team would recommend?
 - What would your best friend recommend? Your religious/spiritual leader? Your child?
 - What other information do you need?

3 / Make a **PLAN**.

After you’ve gathered expert information, **creatively** and **optimistically** brainstorm ideas for a plan to help solve this problem. Some ideas include:

- Join a support group or see a therapist, either together or separately.
- Use prayer or meditation to find peace, either together or separately.
- Try an antidepressant, if recommended by her doctor.
- Start exercising either separately, with friends, or together. (Make a schedule: How many times a week? For how long?)
- Talk to someone who “gets it.”
- Make “dates” with a friend at least once a week.
- What other ideas does she have?
- What other ideas do you have?

Once you have your list of possible plans, pick two or three you think have a high chance of success. Start slow. If someone is experiencing depression, one task a day can seem like a lot, so be realistic as you begin to regain hope and leave depression behind. In this situation, perhaps the two of you might choose talking with someone who “gets it” and setting up a regular exercise schedule.

After one week, reassess to see how the plan is working. If either option is not working, get creative. For instance, if you agreed to exercise but haven’t done it, discuss why that is. Consider a reward for each time you get out to exercise. Or consider an alternative solution. Regroup and try again. There are always new solutions to try.

Barriers: When someone is depressed, a common barrier is that the depressed individual might not recognize that something is wrong or admit that there is a problem. In this case, you may have to get creative and redefine the problem. Rather than, “Can’t you see that you are depressed?” you might more successfully ask, “How can we laugh together again?” Sometimes redefining the problem can open new avenues for information gathering and planning.

Depression is serious and may require the help of health care professionals. Talk to your health care team about what might help.



Life is no less beautiful, and everything you have to offer is no less diminished because you have cancer. I would recommend that you find opportunities to grow closer, and absolutely do NOT be afraid. Fear kills your spirit, it doesn't help your children; it doesn't help your family lift itself up. Be brave, get support, don't be afraid to lean on everyone else and know that you'll come through it.

— Terri, breast cancer survivor

Coach's Corner

At the risk of overstating the obvious, any recurrence of disease is a game changer — whether it is 6 months post-treatment or 20 years. Feelings of fear, helplessness, and hopelessness come flooding back as if it were yesterday. It is critical that you understand all of these feelings and acknowledge that they are as normal and natural as they were the first time around.

If you have been involved from the beginning, it is very possible that you'll feel anger because you thought you were "done with this." This too is okay, but remember that in order to be there you must take care of yourself. Do what is appropriate, keeping in mind that what worked before can work again.

There are no easy words, and you will be challenged. Once you have gathered your thoughts and your emotions, then you and your loved one can put a game plan into action that works for your family and situation.

The one "constant" is that you will be there for her. Make sure she knows that you are with her every step of the way.



Nothing is normal, especially when you have metastatic disease. The first time you're diagnosed there's a chance you might go into remission and you might never get it again. And you have a lot of hope ahead. When you're metastatic, you have hope, but it's a different kind of hope.

— Chris and Sharon, metastatic breast cancer survivors caring for each other

CARE Active with Advanced Breast Cancer

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8 CARE Active with Advanced Breast Cancer

Advanced, or metastatic, breast cancer is cancer that has spread from the place where it first developed, in the ducts or lobules of the breast, to a different part of the body. A diagnosis of advanced breast cancer is not an immediate death sentence. Many women with metastatic disease have a high quality of life for years after being diagnosed.

Consider this:

- A woman can live a good life, even after a diagnosis of advanced breast cancer.
- Be sure your loved one is reporting pain and other symptoms to her doctor.
- Have hard conversations: ask her what is most important to her, and how you can help.
- If you haven't already — finalize plans for advance directives. It helps to do this together. You can ask a friend, social worker, lawyer or other "third party" to help. Be sure the doctor has copies.
- Make sure there is a plan of care, not only for her, but for you.
- Seek support! Family and friends, support groups, social workers and counselors who work with cancer can all help.
- Find enjoyment in the little things.

SYMPTOM MANAGEMENT

When you are supporting a woman in an advanced cancer situation, you may feel some combination of anger, fear, sadness, helplessness, hopelessness, and a range of other uncomfortable feelings. This is normal.

There are ways to cope with the uncertainty of not knowing when the disease will progress. Moreover, as a *CARE Active* caregiver, there remain many things that you can do to help the woman you love. The following chapter will offer practical suggestions; it will also offer ways to consider the preferences that your loved one might have and how to begin the “harder” conversations about these issues.

There are many important questions to consider:

- How can we ensure that my loved one is free of pain?
- How can we maximize the quality of her life?
- What are her preferences?
- How can I best help her? and,
- Are there special things that she wants to experience?

If the person you love has advanced breast cancer, she may have no symptoms or she may be tired, nauseous, in pain, and possibly breathless at times. Encourage her to report all of these symptoms to her doctor, so he or she can help her find relief. Your loved one should have access to a palliative care team for pain and symptom management. As mentioned earlier, it may

be helpful for you or a friend to join her at doctor’s appointments (assuming she agrees) so that you can hear what is said and help follow through with recommendations.

It is not uncommon for people with cancer to under-report and under-treat pain for any number of reasons. In order to help the doctor understand the pain she is experiencing, ask her to describe it as precisely as possible including where it is, how it feels, when it began, and how much it hurts on a scale from 1 (not very painful) to 10 (excruciating pain).

It is important for her to take pain medication as prescribed to manage long-lasting pain before it becomes unbearable. There are many types of pain medicines available to relieve symptoms.

EMOTIONAL DISTRESS

It is important not to ignore feelings of depression or anxiety (for either of you), but instead to seek help. Many support groups exist for both people with cancer and their loved ones. These are places for support, good ideas, and companionship with others experiencing the same situation. Individual counseling can be very helpful, as can medication (when appropriate) to relieve anxiety and depression and contribute to a better emotional quality of life. If you or your loved one feels depressed, it might help to try the COPE method to find ways to alleviate this distress.

Continue to ask her what is most helpful to her, and seek help for yourself when you need it. Try not to be too self-critical. Don't expect perfection from yourself or her. Supporting a loved one through a serious illness is both difficult and challenging.

By just “being there” and opening lines of communication, you are helping.

Also, it is important to try NOT to blame your loved one's medical team or let your loved one blame herself for the return of her cancer. Doctors would like nothing better than to prevent this from happening. Unfortunately, some breast cancers will spread no matter what anyone does and no matter how diligent one is about treatment and follow-up care.



I'd say, as a person who was raised to be independent, that I wasn't accustomed to leaning on anyone.

With cancer, you have to let go. You have to rely on the strength and love of other people.

— Terri, breast cancer survivor

HARD CONVERSATIONS

A diagnosis of advanced breast cancer will make you wonder how long your loved one may have to live, and you may experience fear, sadness and grief when envisioning the future. You may also find it difficult to talk about such painful topics.

Finding ways to talk about what is happening can be very helpful to both of you. Most people feel relieved once they begin to have conversations about death and the future. Not only can it help you to know what your loved one's wishes are, but it also helps both of you feel less alone.

If you are having trouble getting started, seek the help of a social worker or counselor skilled in working with people with cancer, or talk to a spiritual leader you trust. Often, you are both scared. Just admitting your fear may be enough to get the conversation started.

Among the most important discussions are those involving hopes about living life. For example, you may want to discuss thoughts about being with family, quality of life, being at home, and making peace with your circumstances, to mention a few. Perhaps these can be uplifting conversations that give you both a sense of peace.

PLANNING AHEAD

Your loved one's values and beliefs should guide medical choices, not the other way around.

While none of us likes to think about life's end, most of us *do* have ideas about what we would and would not like to have happen when death comes.

Ideally, you were able to consider issues of advanced care planning with your loved one when she was well, and now you can help her clearly communicate with health care providers about what is most important to her. Answers to questions like: "At what point would your loved one wish to stop active treatment?" and "What is most important to her at this time?" can help to guide everyone intimately involved.

In general, **advance care planning** is when a patient determines and documents her goals and wishes for specific treatments based on possible medical conditions and personal preferences. Clinical care is shaped by the person's choices in advance, so doctors can make appropriate decisions if the patient becomes unable to make decisions independently. By anticipating emergencies, you can avoid crisis decision making. Discussions with loved ones and health care providers are a part of this process.

There are several important documents to consider for advance planning. If you have questions, please speak with your doctor, nurse, or social worker.

Advance Directive

Simply defined as any statement, oral or written, made by a competent individual about her preferences for future treatment. This set of directives is very useful in the event that person becomes unable to make decisions at the time of need. Ideally, this should be a written document. Most doctors have a standardized state form available. Once completed, it is important that your doctor(s) have a copy, and that you and your loved one keep your copy in a place where you can easily get it.

Health Care Proxy

This is a method of giving a person legal power to make medical decisions for another person when they no longer can make decisions for themselves. The written form used to appoint the proxy is often called the “durable power of attorney for health care.” In many states this form is combined with the advance directive.

Living Will

A legal document that states how we wish to be treated if we become incapacitated by illness, injury, or old age. It states whether or not we would like to be placed on life-support if our bodies cannot survive without such intervention.

Last Will And Testament

A legal document that defines what will be done with property, money, and other possessions (including care for children) after one dies. Guardianship for young children or dependents may be a key element of a Last Will and Testament. If a Will is not written, the laws of the state will determine how wealth is passed along to family members. This can be a lengthy, and sometimes expensive, process.

QUALITY OF LIFE RESOURCES

People facing metastatic disease have a variety of needs, including comfort, family support, and guidance. Most benefit from care or consultation with a group such as a hospice or palliative care team.

- **Palliative care** means to “palliate” or to treat pain and other symptoms. The goals of palliative (or comfort) care are to achieve comfort, manage symptoms, and to improve quality of life. Some hospitals and hospice programs have palliative care programs. This can be especially helpful for people who are pursuing active cancer treatment such as chemotherapy or radiation. In any case, the doctor and health care team should always be offering comfort and symptom management.
- **Hospice care** is a coordinated program of care that uses a team of health care professionals to provide symptom management and support to patients and their loved ones in the last months of life. The hospice plan of care is aimed at relieving pain and other symptoms, and involves care coordinated by doctors, nurses, social workers, chaplains and volunteers. Hospice services are available in most communities and are offered where the person resides.
- **Respite care** is short-term care that helps family caregivers take a break from the daily routine and stress of caregiving. It can be provided in your home or elsewhere. Respite care is an essential part of the overall support that families may need to keep a woman with late stage cancer living at home. Sometimes it involves getting a health aide to take care of your loved one while you take time for yourself.

ENJOYING LIFE

Among the most important things to consider: Life is about how she lives. There are many things that she can enjoy, and plans she may like to make, with advanced disease or otherwise. You can be a part of helping to achieve these things. It is still possible to enjoy one another's company, to focus on the things that really matter, and to have times that are happy. Continuing to keep communication open and to support one another will make the quality of your lives that much better.



I think the simple pleasures of life are just so wonderful... On a summer night, we'll go out for a walk, and it's just really nice. It doesn't have to be a great trip or a dinner out, sometimes just spending time together in a very quiet way is really important.

— Marc, husband of breast cancer survivor, Marsha

Coach's Corner

This is a place you thought you would never be. If your partner is diagnosed with advanced breast cancer, you will feel unprepared, helpless, and fearful — again this is to be expected and normal. Your role as a valuable teammate is to be the “assist person” to make sure your partner has everything she needs to be comfortable and to find joy.

Part of being a great teammate is to be optimistic that you can enjoy a great deal of quality time with your most valuable player. Keeping her spirits up, and talking through things when you both are down, are invaluable

roles that you play. Communication is always the key to being a great teammate. Aim to reach out and sense how everyone is feeling. Do what is necessary to keep the team together in times that test your true measure.

If the cancer (your opponent) progresses to a terminal state, you may have to serve as general manager to conduct the unenviable task of ensuring that final preparations and wishes are put into place. This way, you have done all that you can to create a team of players who together can honor your MVP's (the patient's) wishes.



CARE Active During Bereavement

Bereavement and memory are tied to one another and seem to change with the passage of time. In the past weeks, there have been occasions when someone else's words have reminded me of her. Other times I want to turn to her and make a comment or hear her pithy response.

— Chris, metastatic
breast cancer survivor

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9 CARE Active During Bereavement

Losing a loved one is one of the most difficult and profound experiences in life.

Consider this:

- Find "safe" places to grieve. Find family, friends, support groups, or counselors who can support you through the grieving process.
- Remember that grief involves emotional, physical, cognitive, behavioral, and spiritual reactions. Try to take especially good care of yourself.
- You may wonder whether you will ever feel the same again. Be assured you will feel a sense of calm eventually.
- You may find yourself picking up the phone to call your loved one or thinking, "I can't wait to share this with her." This is normal.
- Create ways to remember your loved one in a peaceful way.
- Give yourself time.

GRIEF AS A PROCESS

In the weeks and months after a death, people feel an enormous mixture of emotions. It is important to know that practically any emotion you experience is normal — from expected feelings like sadness, to more surprising feelings like anger, guilt, numbness, relief, and even happiness. You may also experience physical symptoms such as sleeplessness, muscle tension, and decreased energy. If you're like many people, you may fear that this roller-coaster of feelings will never end.

You may find yourself wondering whether you will ever feel the same again. Be assured that you will feel a sense of calm eventually. You must give yourself time to grieve.

In this chapter, we will discuss these feelings — collectively called grief — to help you understand the process of grief, so you can take care of yourself and begin to plan for life ahead.

You may have heard that grief occurs in stages. Old research suggested that patients and loved ones moved through five stages as they came to terms with terminal illness: denial, anger, bargaining, depression, and acceptance.

In real life, grief is not so simple. People rarely progress through these stages in an orderly way. Instead, we move through them randomly. Some people move quickly through grief; others move slowly. Some repeat stages or go back and forth between them. No matter how you grieve, it is important to become aware of the normal aspects of grief.

Knowledge of this process gives us a very generalized map of the terrain we have to cover. Each of us will take a different route. Each will choose his or her own landmarks and will travel through emotional pain at his or her own speed using the unique tools provided by culture, experience, and faith.

Normal aspects of the grief experience

The process of grief includes responses at emotional, physical, cognitive, behavioral and spiritual levels. The following describes some of these.

Feelings

Most people who grieve experience at least one (usually more) of the emotions previously mentioned: sadness, anger, disbelief, numbness, relief, guilt, and gradual acceptance. These emotions may come and go, or appear unexpectedly in response to a memory, a song, or something else that reminds you of the person who has died. It may be confusing to experience such a wide range of emotions and/or to feel them with such intensity as you adjust to the loss you have experienced. This is a normal part of the grief experience, and over time you will experience these feelings with less intensity. You will gradually have a better sense of predictability in how and what you are feeling.

Physical sensations

Often after a loved one dies, people describe feeling a “hollowness” in the chest, increased sensitivity to noise or touch, weakness, loss of energy, and a sense of distance. These sensations add to the sense of being overwhelmed during grief. It is important to remember that these, too, are normal experiences, particularly in the early days and weeks after the death of someone you love.

Thoughts/cognitions

People who are grieving may experience many unfamiliar thoughts. A sense of disbelief or confusion, preoccupation with thoughts of the person who has died, disorientation, or even a sense of “presence” of their loved one may be experienced. It is important to be aware of your personal safety during grief, as being “preoccupied” can lead to distractions during driving, crossing the street, walking down stairs, or other aspects of normal life. These feelings will pass. Remember, to move successfully through grief it helps to take an active role in the healing process.

Behaviors

It is common to experience changes in sleep or appetite patterns. Some people say they sleep all the time, others cannot sleep at all. Some people can’t eat, others can’t stop. There may also be a sense of social withdrawal, as the energy it takes to interact seems taxing. It is normal to feel disoriented, exhausted, and as if no one else understands what you are going through. Some people have vivid dreams, cry constantly or can’t cry at all. Others comment that they think they see their loved one in a crowd, or find themselves reaching for the phone to give them a call.

Understandably, any combination of the above behaviors can cause the person who is grieving to feel a loss of control and to wonder if life will ever again have stability or meaning. While these experiences may not be normal for your “normal” life, they are normal for the grief experience, and they will pass.

Grief can shake your faith

Faith doesn’t just refer to religion. We have faith in lots of things: in ourselves, in others, in the future. When someone dies, our faith in these things can be shaken. It may seem like the world will never be the same because your loved one is no longer in it. You may even wonder if you will be the same.

You may find yourself asking, “How could this happen to such a good person?” or “How can the world be so unfair?” Death challenges our beliefs. We may believe that if we work hard and are good people, we will be rewarded for it. Death challenges not only that belief, but may also challenge our spiritual beliefs and perspectives. Although it is natural to question the fairness of losing someone you love, it is important to remember that your loved one died of a medical cause, and that at some point, death is an unfortunate reality for everyone.

In addition to questioning your faith in fairness, you may start to question your faith in yourself. You may wonder “Who am I without my loved one?” This is especially likely if you and your loved one were close for many years. You may have trouble remembering who you were before that person became part of your life. We tend to define ourselves by the roles we play: spouse, child, parent, sibling, or friend. When someone dies, we may lose one or more of these important roles. In this situation, it is natural to feel upset, confused, sad, or even angry.

Grief takes time because it involves accepting the loss of certain roles and redefining yourself. During this time, it is important to remind yourself of what hasn't changed. Although much has shifted, there are some constants in your life. Your remaining family and friends are a good start. Take comfort in what is stable.

Grief usually leads to acceptance

Grief is a process that eventually leads to a sense of acceptance or at least reconciliation. Although you will always miss your loved one, the painful emotions that you feel shortly after the death will almost certainly become less intense and less frequent. It is important to keep this in mind during the times that are difficult.

Try to reassure yourself that this is normal and won't last forever. It is important not to rush grief. Well-meaning people will give you estimates on how long grief will last. Grief is very personal, and you are entitled to your own schedule. While people continue to experience moments of sadness even several years after losing a loved one, most people's strong feelings of grief lessen substantially within a few months. Don't criticize yourself, however, if your grieving is different.

Accept your feelings as much as is possible and remind yourself that feelings most likely soften with time.

Regret, guilt, and self-criticism

For some people, emotions like regret and guilt are major parts of the grief experience. These emotions are normal both before and after the death of a loved one. Although sometimes there really is something worth feeling guilty about, more often guilt results from being too hard on yourself.

It is important to recognize if you are distorting things, as it can stand in the way of healing. Some thoughts may be, “I didn't say or do enough,” “I made a wrong decision,” “I am a bad person.” While there may be some regret, most often people do the very best that they can under the circumstances. Try to be gentle with yourself and accept that you did what you thought was right and what was possible for you and your loved one at the time.

Let yourself grieve

Grieving appropriately means allowing ample time to remember and feel the loss, as well as opportunities to distract yourself and regroup. Following is a list of ways you can remember and grieve for your loved one. These activities may bring up a variety of emotions. If emotions are there, don't run from them, but you also don't have to experience them all at once.

- Write about your loved one in a journal
- Create a scrapbook of photos
- Tell stories about your loved one to friends and family
- Say a prayer for your loved one
- Light a candle in her memory
- Visit her favorite place
- Plant a tree in her memory
- Hold a gathering to celebrate your loved one's life

When and how to find help with grief

Finding people to support you is perhaps the most important thing you can do following the loss of someone you love. People with greater social support tend to do better while grieving. This isn't to say you need to always be with people. It means finding "safe" places where you can receive support for feeling the many emotions that you will experience during grief.

Friends and family members may be able to buoy you up emotionally, provide distraction, and even help you with practical matters. Most importantly they can listen. Although you won't always feel like talking, knowing that there is someone who will listen is important.

Support groups are a great way to meet others who share the experience of loss, especially when and if you don't want to rely exclusively on family or friends. Also, you should consider professional counseling when negative emotions or grief lasts for an extended period of time

or interferes significantly with your life. Most local hospitals or hospices can help you find support groups or can refer you to professional counselors experienced in working with grief.

LOOKING FORWARD

You have been through a very difficult time. Take time to recover and to grieve. You will never stop missing your loved one, and things will never be entirely the same again. As you grieve, however, don't ignore ways that you might be growing or becoming stronger. People who experience loss sometimes become closer to family or friends, become more spiritual, have a new appreciation for life, or gain new perspectives.

You will never stop remembering, nor should you. Nonetheless, in time you will look ahead toward the future, and in the long run you may be stronger and more fully alive.

Coach's Corner

Whatever planning and preparations you and your partner may have made in advance of her death, you can never prepare for the grief you will feel when the journey ends for the teammate you loved and cherished.

No one can predict when or how your emotions will play out. They will surprise you. How you manage them is up to you and at your own pace. Let them come to you and don't push them away.

Reach out to whomever or wherever you find spiritual strength or to professional help to get a handle on your feelings. As painful as it is, you will find other teammates to help you make new game plans. But remember, you will never replace the honored and cherished memory of the person who kept your team together and the one you cared about deeply.

Honor her by never forgetting her and how she made you feel. What better tribute to the most valuable person in your life?



It goes deeper than, 'You need to make sure you eat and get exercise.' You need spiritual nourishment. And even though it's a terrible thing, I think that cancer can reveal so much beauty. Going through this process introduced me to all of these people who are some of the most beautiful and strong souls that I have ever come across in my life.

— Jenna, yogi student of and caregiver to breast cancer survivor, Gita

Practical Resources

10 Practical Resources

ONLINE TOOLS AND EDUCATION

American Cancer Society (ACS)

(800) ACS-2345

www.cancer.org

ACS provides a variety of information including information about talking with children when a parent has cancer and financial resources.

ASCO's Cancer.net

www.cancer.net

Cancer.net, provided by the American Society of Clinical Oncology, provides oncologist-approved information about cancer. Information specific to caregiving can be found at www.cancer.net/patient/Coping/Caregiving.

AGIS (AssistGuide Information Services)

www.agis.com

This site offers advice on what to expect, how to get started, and where to turn for help when a loved one faces illness.

CarePages

(888) 852-5521

www.carepages.com

CarePages provides free patient blogs that connect friends and family during a health challenge.

CaringBridge

www.caringbridge.org

CaringBridge provides free, personalized websites that support and connect loved ones during critical illness, treatment and recovery.

Family Caregiver Alliance (FCA)

National Center on Caregiving

(800) 445-8106

www.caregiver.org

The Family Caregiver Alliance addresses the needs of families and friends providing long-term care at home through information, education, services, research, and advocacy.

Lotsa Helping Hands

www.rci.lotsahelpinghands.com

Lotsa Helping Hands was created to support family caregivers and volunteers by empowering others in the community who are eager to help. They offer an online calendar tool to help caregivers schedule times and ways family, friends, neighbors or volunteers can help support family needs.

FINANCIAL & LEGAL CONCERNS

Lymphedema Network

(800) 541-3259

www.lymphnet.org

Lymphedema Network provides credible information about prevention and treatment of lymphedema.

National Alliance for Caregiving (NAC)

www.caregiving.org

The National Alliance for Caregiving is a coalition of organizations that focuses on issues of family caregiving.

National Cancer Institute (NCI)

(800) 4CANCER (422-6237)

www.cancer.gov

NCI is the government agency specializing in cancer information and resources.

National Family Caregivers Association

(800) 896-3650

www.nfcares.org

The National Family Caregivers Association reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well being.

Strength for Caring

www.strengthforcaring.com

Strength for Caring is a comprehensive website providing family caregivers with a broad range of expert content and information including online "chat" services, daily inspiration, and support.

The Wellness Community

(888) 793-WELL

www.thewellnesscommunity.org

The Wellness Community provides support, education, and hope at no cost to anyone affected by cancer. Direct services are offered at over 100 locations worldwide and online.

Cancer Legal Resource Center (CLRC)

(866) THE-CLRC (843-2572)

www.cancerlegalresourcecenter.org

CLRC provides free and confidential information and resources on cancer-related legal issues to survivors, their families, friends, employers, health care professionals, and others coping with cancer.

CancerCare Assist

(800) 813-4673

www.cancercare.org

CancerCare provides free education and one-on-one counseling to people with all types of cancer. The CancerCare Assist program helps specifically with financial issues.

Family Medical Leave Act (FMLA)

www.dol.gov/esa/whd/fmla/

FMLA is a federal program that protects many caregivers and patients from job loss.

National Breast Cancer Coalition (NBCC)

(800) 622-2838

www.stopbreastcancer.org

This advocacy group offers a very helpful guide to finding affordable care called: *Guide to Quality Breast Cancer Care — Finding Affordable Care* which can be accessed online.

National Coalition for Cancer Survivorship (NCCS)

(888) 650-9127

www.canceradvocacy.org

The oldest survivor-led cancer advocacy organization in the country, NCCS advocates for quality cancer care for all Americans and empowering cancer survivors.

NeedyMeds

www.needy meds.com

This site provides information about patient assistance programs for prescription medications.

Partnership for Prescription Assistance (PPARx)

www.pparx.org

The Partnership for Prescription Assistance helps qualifying patients get the medicines they need through a public or private program that's right for them.

Patient Access Network Foundation (PAN)

www.panfoundation.org

The Patient Access Network Foundation has established several funds to assist patients with out-of-pocket treatment costs for a variety of illnesses.

Patient Advocate Foundation (PAF)

(800) 532-5274

www.patientadvocate.org

Patient Advocate Foundation (PAF) offers assistance to people coping with life-threatening illness with specific insurance, employment, and/or creditor issues in debt crisis matters. **PAF's Co-Pay Relief (PAF CPR)** program provides co-payment

assistance for pharmaceutical products to insured Americans who financially and medically qualify. CPR call counselors are available for questions at www.copays.org.

Social Security Disability Insurance Program (SSDI)

(800) 772-1213

www.ssa.gov/applyfordisability

The Social Security Administration's disability insurance program pays benefits to disabled individuals (as determined by Social Security Disability Determination) and certain family members depending on Social Security taxes paid.

Survivorship A-Z

www.survivorshipatoz.org

This website provides information about insurance, employment, financial planning and other topics. A web-generated individualized care plan can be developed specific to your situation.

SUPPORT GROUPS & HOTLINES

Breast Cancer Network of Strength

(800) 221-2141

www.networkofstrength.org

Breast Cancer Network of Strength hosts a 24/7 toll-free hotline staffed exclusively by trained peer counselors who are breast cancer survivors.

Living Beyond Breast Cancer (LBBC)

(888) 753-LBBC

www.lbbc.org

LBBC provides education and support, including a Survivors' Helpline staffed by trained volunteers affected by breast cancer.

Men Against Breast Cancer (MABC)

(866) 547-6222

www.menagainstbreastcancer.org

MABC targets support services for men; educating and empowering men to be effective caregivers when breast cancer strikes a female loved one.

The Wellness Community

(888) 793-WELL

www.thewellnesscommunity.org

The Wellness Community provides support, education, and hope at no cost to anyone affected by cancer. Direct services are offered at over 100 locations worldwide and online.

WellSpouse Association

(800) 838-0879

www.wellspouse.org

WellSpouse advocates for and addresses the needs of spouses caring for a chronically ill or disabled wife, husband, or partner, by offering peer to peer support and by educating health care professionals about the special challenges and unique roles “well” spouses face every day.

SEXUALITY & FERTILITY

AASECT

www.aasect.org

The American Association of Sexuality Educators, Counselors and Therapists is an interdisciplinary professional organization offering a “Locate a Professional” tool on their website, to help you find a sexuality educator, counselor or therapist in your area.

Fertile Hope

www.fertilehope.org

Fertile Hope is a national, nonprofit organization dedicated to providing reproductive information, support and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

CULTURALLY SPECIFIC RESOURCES

Nueva Vida

(202) 223-9100

www.nueva-vida.org

A support Network for Latinas with cancer.

Sisters Network, Inc.

(866) 781-1808

www.sistersnetworkinc.org

A national African-American breast cancer survivorship organization.

The Mautner Project

(866) MAUTNER (628-8637)

www.mautnerproject.org

A national lesbian health organization.

PUBLICATIONS FOR FAMILIES

Dealing with a Cancer Diagnosis in the Family

American Cancer Society

www.cancer.org

When a Parent Has Cancer: A Guide to Caring for Your Children

Wendy Harpham, MD

www.wendyharpham.com

When Someone in Your Family Has Cancer

National Cancer Institute

www.cancer.gov

When Your Parent Has Cancer: A Guide for Teens

National Cancer Institute

www.cancer.gov

OTHER USEFUL PUBLICATIONS

After Breast Cancer

*A Common-Sense Guide to
Life After Treatment*
Hester Hill Schnipper, LICSW

Breast Cancer Husband

*How to Help Your Wife (And Yourself)
Through Diagnosis, Treatment, & Beyond*
Marc Silver
www.breastcancerhusband.com

For the Women We Love

*A Breast Cancer Action Plan and
Caregiver's Guide for Men*
Matthew J. Loscalzo, MSW,
with Marc Heyison, President,
Men Against Breast Cancer
www.menagainstbreastcancer.org

Frankly Speaking About Cancer:

Advanced Breast Cancer

The Wellness Community
www.thewellnesscommunity.org

Frankly Speaking About Cancer: **Coping with the Cost of Care**

The Wellness Community
www.thewellnesscommunity.org

Helping Yourself Help Others:

A Book for Caregivers
Rosalynn Carter
www.rosalynncarter.org

The Emotional Survival Guide for

Caregivers: Looking After Yourself and

Your Family While Helping an Aging Parent
Barry J. Jacobs, PsyD
www.emotionalsurvivalguide.com

The Total Cancer Wellness Guide:

Reclaiming Your Life After Diagnosis
Kim Thiboldeaux, Mitch Golant, PhD
www.thewellnesscommunity.org



*[My wife's cancer]
really made me
understand who she
was in a deeper way.
She's different than*

*I am in a lot of ways, and that's OK —
she can have her way of coping, and I
can have my way of coping. That doesn't
make us incompatible — in a way it drew
us closer because we could fit those two
pieces together.*

— Marc, husband of breast cancer
survivor, Marsha

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The Wellness Community would like to recognize and thank all of those who contributed to the success of *Frankly Speaking About Cancer: When a Woman You Care About has Breast Cancer*.

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GRAPHIC DESIGN

Kessler Design Group, Ltd.

THE WELLNESS COMMUNITY'S FRANKLY SPEAKING ABOUT CANCER SERIES

The Wellness Community's *Frankly Speaking About Cancer: When a Woman You Care About has Breast Cancer* program is part of a national education program that provides support, education and hope to people affected by cancer. The programs consist of educational books, clinically facilitated workshops and online content on The Wellness Community Online at www.thewellnesscommunity.org.

Frankly Speaking About Cancer books feature information about treatment options, how to manage side effects, the social and emotional challenges of the diagnosis and survivorship issues.

All publications are FREE and are available ONLINE. Copies of this book are available by request.

For more information about this program, the *Frankly Speaking About Cancer* series or The Wellness Community, please visit our website or call us toll free at 888.793.WELL (9355).



The Wellness Community provides this information as a service. This publication is not intended to take the place of medical care or the advice of your doctor. We strongly suggest consulting your doctor or other health care professional to answer questions and learn more.

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THIS PROGRAM IS MADE POSSIBLE BY A GRANT FROM:

THE BREAST CANCER FUND OF
NATIONAL PHILANTHROPIC TRUST

People who care about someone with cancer can be active participants in enhancing health and wellne themselves and their loved ones and nurture their relationships through and beyond the cancer exper
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