

# I Still Buy Green Bananas

Living with Hope, Living with Advanced Breast Cancer



## Acknowledgments

**I Still Buy Green Bananas** is dedicated to Linda Ragins, for her strength and service to women living with cancer, and to all of the breast cancer survivors who contributed their voices and spirits to this project.

This booklet was written by Michelle Melin, MA, former Y-ME Director of Patient Services. Special thanks to Dr. Katherine Billingham for writing and developing the section on talking to children about cancer, and to Laura Mayer, whose experience as a breast cancer survivor, writer, hotline counselor and special person influenced every aspect of this publication.

Much appreciation for the efforts of Y-ME Medical Advisors and all those who reviewed this booklet for content, accuracy and style. The development of this booklet was supported by the Linda Ragins Memorial Fund, and our deepest appreciation and gratitude extends to Linda's family for their initial support of this project.

# Introduction

You are not alone.

If you are reading this booklet, you are facing a diagnosis of breast cancer that has spread to other parts of the body or is locally advanced. Like many other women dealing with this diagnosis, you may be afraid and concerned, facing new treatments and the prospect that a cure is unlikely. On the Y-ME hotline, we talk to hundreds of women who are facing this difficult diagnosis, and are coping with their fears and concerns. Each of our counselors have talked with hundreds of survivors of advanced cancer, women who are living with cancer despite its daily presence in their lives.

We developed this booklet because we wanted to give you hope.

We wanted to share with you what we have learned from so many women who are living with advanced breast cancer — how they face each day, make medical decisions, give and get support from their families and friends, and how the experience of living with cancer has changed their lives. In much of the way that they have shared with us, this booklet is written in a straight forward manner.

There are quotes from women who completed a survey about their experiences with advanced cancer in this booklet. These women shared their thoughts and feelings, about their families and their future. Each of them was diagnosed with breast cancer that had spread to another site — lungs, liver, bones, brain, or chest wall. They all said the same thing — what they want to do most is to tell you that you are not alone, and that this diagnosis is not an automatic death sentence. The women who completed our survey range in age from 33 to 76 years old, and they have been living with advanced disease from 2 months to 20 years.

As you know, life as a patient with cancer is difficult, and some of the material in this booklet may bring up your fears and other feelings. You may want to discuss your feelings with your family or friends, or those in your support group. Please know that you can also call the Y-ME hotline to talk with a counselor at any time of the day or night.

The National Coalition for Cancer Survivorship defines a cancer survivor as someone who has been diagnosed with cancer and is living today. You are a cancer survivor.

The title of this booklet comes from one of the women who completed our survey. When asked how far in advance she plans for the future, she talked about the daily presence of cancer in her life. “However,” she said, “I still buy green bananas.” We thought that this simple idea spoke volumes; that despite a cancer diagnosis there is hope, there is life, and there are many trips to the grocery store — to buy more bananas and to see them ripen.

“There is a lot of living left, even with this diagnosis.” *Nancy*

“This diagnosis is not a death sentence. One can live with cancer. There is time to get a second opinion and to explore and evaluate treatment options.” *Rhoda*

“Remember that you are an individual, not a statistic. No one knows what will happen to you.” *Laura*

“Women do survive advanced cancer and can live long, productive lives while living with cancer.” *Cheryl*

“It takes time to learn to live with cancer.” *Lucille*



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## HANDLING THE NEWS AND COMING TO TERMS WITH IT

Many women living with advanced cancer describe the moment they found out about their diagnosis as truly devastating. You may feel betrayed by your body or angry at your doctors. You may be second-guessing the treatment decisions made prior to the cancer's return.

If you had cancer before and experienced a period of remission, you have had time to learn much about breast cancer and its complexities. Facing a return of the cancer at a time when you know a lot about the disease can be even more frightening.

There are many ways that women have found to cope with this upsetting time. Having information helps women cope. Most people have found that it was important to concentrate on understanding their new cancer diagnosis, researching all available treatment options, and taking time to get other medical opinions.

Many women find that using a coping strategy that has worked well for them in the past helps them deal with this stressful time. A plan for dealing with the first few weeks after diagnosis *could* include:

- taking time to talk with your spouse or partner about treatment options, finances, and other important decisions;
- asking friends to help with child care, car pool, grocery shopping, meal preparation, or other routine tasks;
- involving friends and family members in the process of researching your diagnosis and learning about available treatment options;
- finding a support group to talk with others facing your diagnosis;
- calling Y-ME to talk with a woman who is surviving advanced breast cancer;
- finding time to be alone to be with your thoughts and to clarify your concerns;
- taking time to talk with the children in your life about what this news means;

*"After the node biopsy, my husband and I, along with one of our children, left town for a few days to regroup and strategize. Family members spread the news while we were gone. When we returned, we didn't have to deal with the initial shock that others had." Susan, age 47*

*"Two weeks before our Alaska vacation, lung metastasis was diagnosed. I decided to go ahead with my vacation and begin chemo after returning. The vacation greatly helped my husband and me to deal with the situation."*  
Susan, age 34

- developing safe and creative ways to deal with your feelings of rage, anger, sadness and depression;
- attending church, talking with a member of the clergy, praying and having others pray with you;
- participating in yoga, massage or other relaxation and stress-reducing exercises.

One of the most stressful aspects of living with cancer is dealing with the many fears and feelings that come along with this disease. One of the most successful ways of coping with fear is to gain knowledge and a sense of control. This booklet will help you to know more about yourself, what you want, and what to expect in the future.

Many survivors emphasize that never talking to people, becoming isolated, and distancing family and friends have been least helpful to them. Most important, coming to terms with your diagnosis is a process that takes time, and this process is different for everyone. There are common steps that many people experience during this process, and it is often helpful to know that what you are feeling is normal and expected. Also, it is common to go through these feelings more than once. Some women never experience some of these feelings; others experience them all very intensely. This process is an individual one, and your way of dealing with these feelings will be very unique.

*“ I called Y-ME and found someone who was 7 years in remission. That gave me the hope I needed to get through the next few weeks — while I was trying to get ahold of what had happened.” Pat, age 36*

hope

## Fear

Fear about the future and all that it might bring is paramount in most women's minds; working through this fear is much more difficult. This section will cover many of the fears and concerns that women have in living with advanced breast cancer.

### Fear of the Progression of Cancer

All women with breast cancer are afraid that their cancer will recur, but for women living with a recurrence or metastasis, keeping the cancer in check is the primary concern. In many cases, women who are being treated for metastatic breast cancer receive ongoing treatment of some sort; each doctor's visit can be a reminder of the fear that cancer may have spread. In addition, like all women with breast cancer, any twinge, ache, or pain can cause great anxiety about whether or not the cancer has spread.

## Dealing With the Fear of Progression

For the many women who experience this fear, information and a sense of control can be most effective in managing these feelings. Stress management techniques can also help ease this anxiety. Relaxation techniques such as visual imagery, biofeedback and meditation have helped many women cope with these overwhelming feelings.

## Fear of the Unknown

When dealing with ongoing cancer management — either repeated doctor visits, tests, or treatments — it can be very scary to think about what the future may hold. Women who have been living many years with metastases often find that they and their doctors are navigating uncharted territory. While this can be very positive — after all, you're beating the odds — it can also be scary because the future is less predictable. It is like driving along a winding road, and you cannot see around the next bend.

When the future seems uncertain, most women with breast cancer feel that living in the moment — right now — can be the best way to focus on living. Some women even coach themselves through their anxiety, talking out loud, reminding themselves to live for today, and that tomorrow will take care of itself.

Well, that's easy to say and hard to do for some people. It can also be beneficial to develop an outside interest or hobby; time for you to focus on a current project or goal. This physical reminder of the present can be very comforting for many women.

## Fear of Physical Limitations

Much of the fear that women feel at the thought of developing or living with a physical limitation is the fear of dependence on other people. However, the thought of not being able to do all of the activities you are accustomed to doing can be upsetting as well. Although it may seem backward to think about it like this, it may help that most physical changes that accompany cancer are gradual. In this way, you are able to process these changes a little at a time, which can be easier. Some women also feel that they would rather be here with a physical limitation than not to be here at all.

## Fear of Being a Burden to Others

Most women with advanced breast cancer are afraid of becoming physically, financially or emotionally dependent on those they love. This may be because women are taught, in general, to take care of others' needs before their own. It can be very hard to accept love, concern and assistance of others, and the survivor may feel like she has become a "burden" to them.

In other cases, when the costs of treatment become high, or physical limitations become apparent, these can be very physical and real reminders of dependence on others.

Most often, reassurance can help you deal with this fear, as well as taking steps to assert your independence in whatever ways you can. In many cases, the family and friends who care for you are doing so out of deep love and respect for you, and for all that you have given to them. It may help to think about the assistance of others in a different way — that every routine task someone does for you, they are allowing you to save your energy for the things that really matter to you most.

Some people offer help and assistance because they feel that you are too fragile or are not able to do certain things for yourself. Speaking up honestly at these times can give you back some of the control that these "helpers" take away. By establishing your boundaries in this way, you can maintain a sense of independence.

Financial concerns, however, can be more serious to deal with. Reaching the maximum on your insurance policy, handling large payments for treatment or pursuing treatments that are not covered by insurance can be draining and frustrating. In these situations, it may be best to seek outside assistance, by meeting with a social worker or financial planner who can offer strategies to deal with these concerns. In addition, some women consider the option of viatical settlements in meeting financial needs. Viatical settlements are arranged with a company that purchases your life insurance for cash, so that funds are available for your immediate needs.

## Denial

Denial is the ability to avoid accepting upsetting information as true for you. Although denial may sound negative, it is actually a very important coping tool that many people use to deal with stress. Denial can be a way of introducing you to small amounts of new information, while allowing you to prevent feeling overwhelmed and maintain a sense of emotional control. However, if you are unable to make decisions, or are avoiding certain problems for too long, denial may be preventing you from taking care of yourself. At this point, it is helpful to talk with others (your support group, your spouse, a therapist) about your feelings to develop perspective and set aside some denial.

## Anger

It is easy to understand how anger and rage are a part of dealing with the diagnosis of advanced cancer. Anger is based in a desire for a change of circumstances and a valuing of oneself. It may be difficult to find constructive ways to deal with these feelings. Anger turned inward can become depression; anger turned outward can lead to inappropriate expressions toward friends and family at a time when you may need them most. To scream and cry, to yell and rage are normal and healthy; it may help to beat pillows, to write out your feelings, or to engage in physical exercise if you feel like it. One woman wrote about how she would go into the woods behind her house and throw rocks. Another would stomp on old ceramic tiles and break them into tiny pieces. Both of these women found safe and effective ways to deal with their anger.

It's nice to talk about safe and healthy anger, but anger often happens in the heat of the moment. It is inevitable to lash out in ways we don't mean, especially when facing a serious cancer diagnosis. Many couples set up a system where by they can express the anger that they are feeling about the situation to each other, but in such a way that the 'recipient' of these emotions does not take it as a personal attack. Friends can often be an outlet for these feelings when it seems that family members are too burdened.

Many times, anger and hurt have specific targets. Patients who experience a recurrence or metastasis after a period of remission may become angry at the doctors who treated them originally, feeling that the doctors were not aggressive enough the first time. Other women become angry at themselves, second-guessing the decisions they made and regretting lost opportunities to voice their preferences and concerns.

*"I was very angry and I still am. If the doctors had been more aggressive right at the start maybe all these recurrences wouldn't have happened so rapidly." Janet, age 51*

There are many ways to deal with these specific concerns. Often, people feel regret about the past. It may be important, depending on your situation, to find ways to reassure yourself that you made the best decisions possible during your previous treatment, and that these decisions were made with all the information that was available to you at that time. One of the most difficult aspects of making decisions is trying to understand the conflicting information about your diagnosis, and understanding the fact that there are many things we still don't know about breast cancer. You can also give yourself permission to talk with your doctors about your feelings, especially if you choose to stay with them the second time around.

## Bargaining

Bargaining often represents the desire to take control of a very uncertain situation. It is common for patients with cancer to say "I'll fight hard, as long as I can live to see my son graduate from high school" or "Let me live, God, and I'll go to church." Looking toward the future to see a child grow up, a grandchild born; to graduate from college, to make an important speech, or to take a special trip; these are important goals. To focus on these events during tough treatments can be a useful way to get through some low times. It is difficult, however, to make bargains for the short term and not want to wish for a cure.

Many women that we talk to say that this feeling is an up-and-down process; they know that there is no cure for cancer, and that to focus on the short term can be most helpful. But at the same time, they feel sad and upset that this is the case. Finding the right balance between hope for the future and coping with today is a difficult one, and can require small steps.

## Grief and Depression

A diagnosis of breast cancer can bring many losses — the loss of your breast, the loss of your hair, and the loss of control over your body during your treatment and afterwards. Facing a diagnosis of advanced cancer deepens the loss tremendously; the prospect of a shortened life, a dependence on doctors, medical care and often continued treatments can be, to say the least, discouraging. Working through these stages of loss can be a repetitive process, especially as you receive additional news about

*"We put up a small tent in the back yard and furnished it with a few chairs and a table. I go there when I don't want to mess with the phone or be bothered by people." Laura, age 39*

*"Being in a support group was extremely helpful – finding a support group was one of the first things I did." Kerry, age 44*

your condition. It may require the assistance of a professional who is trained to work with the important emotional issues that cancer survivors face. Whatever it takes, the way in which you deal with these feelings is completely up to you.

The most important aspect of dealing with loss and depression is to be aware of how you are progressing in dealing with your feelings. Dwelling on sadness and grief can compromise your health and well-being. One woman felt so sad that she began missing appointments for treatment. If you are feeling this way, it is crucial for you to share your feelings with a trusted health care practitioner, or to seek out a professional therapist for assistance. It is common for cancer survivors to seek assistance in working through their feelings. Many women have felt that a therapist can play an important role in helping them to deal with cancer treatments.

## Acceptance

It may seem ridiculous to talk about acceptance — it often feels like a burden, feeling like you have to accept a diagnosis of advanced cancer and all that it may mean. In many cases, survivors living with metastasis feel that in order to live, they needed to accept the limitations of their illness. Other women wrote that they feel angry and sad that they are faced with a life with cancer. For many of them, accepting their situation says that it's all right to be so ill, but it isn't all right.

Some women living with a serious cancer diagnosis may feel that acceptance can also mean forgiveness, especially in the case of a delayed diagnosis or opportunities for earlier treatment that were missed. It can be very liberating to realize that it can be possible to reach acceptance without forgiveness; although forgiveness can certainly be a part of accepting your cancer diagnosis.

*"I remain optimistic. In the two years since my cancer has metastasized, I have lived, worked and traveled. I refuse to be a victim." Rhoda, age 68*

## FACING WHAT COMES NEXT

If you have just been diagnosed with a recurrence or metastasis, or a locally advanced breast cancer, you are probably feeling very overwhelmed and frightened. All of the road maps that you have used in the past have become blurred; you have entered a world where there are many more treatment options and paths to follow. After completing many tests, your physicians will have a fairly sophisticated idea of how the cancer is behaving and what treatments might have an effect. At this point, it is up to you, and those you love, to evaluate the recommendations of your treatment team.

Some suggestions for gathering information and evaluating options:

1. Seek a second opinion at an established cancer center or academic medical center. If possible, try to locate oncology professionals who have worked a great deal in breast cancer treatment.

2. Call Y-ME to talk with a woman who has experienced a similar diagnosis. As a trained Y-ME hotline counselor, she will be able to provide you with the most up-to-date information about treatment options that you are considering. As a survivor who knows what you are going through, she can give you the emotional support that you need to get through these tough times.

3. Call the National Cancer Institute, and talk to your doctors about clinical trials that are available to you. For many women dealing with breast cancer, clinical trials offer the most sophisticated and cutting edge treatments that are available.

4. Ask your doctors about the treatments they have recommended, about the possible side effects, and what they expect the treatments to do for you. In addition to bringing prepared questions to your doctor's visits, discuss with your doctor how you will be able to address future questions and concerns that cannot wait until the next visit. When you are familiar with how your doctor would like to work with you and answer your questions, you will have an established avenue to evaluate the information that you have gathered.

*"I feel like I'm a professional patient. One time I felt an urge to write that for an occupation on a form in a doctor's office." Ruth, 54*

*"How you cope and when you cope is as individual as your fingerprints."  
Debbie, age 62*

## Treatment Options

It is very difficult to outline all of the possible treatments that you might be offered by your physicians. However, it is possible to talk generally about the different options your treatment team might recommend:

### Hormone Therapy:

It is very common for many women to be offered tamoxifen, megestrol or other estrogen-blockers upon diagnosis of a metastasis. Hormone therapies work by preventing estrogen from binding to the cancer cell and causing further growth. In some cases, it is possible to eliminate existing cancer cells through hormone therapy.

### Chemotherapy:

Many women are offered the option of chemotherapy to treat their cancer. For some women, this may be the first time that they have had chemo; for others, chemo is a familiar experience. Chemotherapy is often used in combinations; that is, a patient will be given several different types of drugs. These drugs are formulated to kill any rapidly dividing cells in the body, which include cancer cells. There are different strengths and uses of chemotherapy drugs, which can be referred to as “first-line,” “second-line” and “third-line” (and so on) therapies. This indicates the role of a chosen chemo treatment with respect to your previous treatments, and how often you have had chemotherapy. Another treatment option you may be offered is that of high-dose chemotherapy with a blood stem-cell or bone marrow transplant.

### Biologic Therapies:

Each year, there are new types of cancer treatments being tested. These new therapies attack cancer cells differently than current treatments, and are a result of significant advances in cancer research. With a more intricate knowledge of the human genetic code, as well as an improved understanding of how cancer cells behave and grow, new targets for treatments are being discovered.

Angiogenesis inhibitors interfere with a cancer cell's ability to attract a blood supply to the tumor. This process occurs when a cell produces a protein (a message) for the body to develop veins and capillaries to bring blood to the tumor. When a cancerous tumor is unable to receive nutrients from a blood supply, it can wither and die.

Cancer vaccines are being developed to treat a variety of tumors. While most of us understand vaccines as a preventative measure (to avoid developing the measles), in this situation, vaccines are used to target cancer cells and kill them. These vaccines are made from the tumor itself, and are intended to stimulate the immune system to eliminate the cancerous cells.

Monoclonal antibodies are a promising cancer therapy that is currently available to women with advanced breast cancer. One monoclonal antibody

(MA) treatment is called Herceptin and is now available for women with advanced breast cancer. This type of treatment is designed to seek out cancer cells that over-express a particular protein (send lots of messages). When a cancer cell produces lots of messages, they take the form of receptors on the cell's surface. It may help to think of receptors as the catcher's mitts. The mitt is designed to "catch" a protein that tells the cell to become cancerous. MA treatments can find the cancer cells with too many catcher's mitts, and attaches to them, preventing them from replicating further.

### Radiation Therapy:

Many women who have had a lumpectomy for breast cancer have also received radiation therapy. However, radiation can also be used in the treatment of locally advanced or metastatic breast cancer. If you have been diagnosed with breast cancer in the chest wall area, you might be offered radiation therapy to kill the cancer cells in the affected area. Many women with bone metastasis receive radiation therapy to alleviate bone pain. Other therapies used to alleviate bone pain include radioactive strontium and pamidronate.

### Complementary Therapies:

Many women feel that it is important to explore options that aim to improve their nutritional status and to deal with stressors in their lives. This may be as simple as taking vitamins, or receiving regular massage therapy. It is very important to inform your doctor if you are using any complementary therapies in addition to your cancer treatment. Even vitamins can affect the treatments you are already receiving, and your doctor can help to guide your choice of additional wellness options.

## Clinical Trials

Clinical trials are research studies that examine the effectiveness of new treatments for cancer. They are offered only after a rigorous review of the treatment being studied, the centers providing the treatment and the physicians participating in the study. Many years of research and numerous laboratory studies take place before women can participate in clinical trials. Trials most often compare new treatments with the best treatment options available, to see if the new treatments work better or differently for certain people. At first, many patients feel hesitant to participate in a clinical trial for several reasons. Some may feel that they might not get any treatment at all; this is not the case. Others feel that they will have no control over their treatment decisions or that their doctor cannot decide to do what is best for them. This is also not true. Most

importantly, many women feel that once they are in a clinical trial program that they cannot change their mind and leave the trial. The reality is that you can choose to be on a clinical trial, and you can choose to leave a trial.

It's understandable that the thought of being in a clinical trial can be scary. The best thing you can do is talk to someone who has been in one already. Y-ME has many hotline volunteers who have had this experience and who can reassure you from a first-hand perspective.

Participation in a clinical trial can offer many women the opportunity to receive treatments that are on the cutting edge of cancer therapy, under the careful supervision of a team of health care professionals. In addition, many women experience improvement of symptoms and in some cases can go into remission.

For more information about clinical trials available to you, contact the National Cancer Institute. When you call, be sure to have as much information as possible about your diagnosis and the staging of your cancer. The specialist who handles your call can refer you to specific trials that may be open to you.

## Working With Your Medical Team

Establishing and maintaining communication with your treatment team is an ongoing process. Even though you may decide to stay with your oncologist or surgeon, it will take time to understand the changes in your relationship with regard to your new circumstances. For many reasons, women sometimes decide to change their treatment team when diagnosed with a recurrence or metastasis. You may feel more comfortable with the physicians that you know, or you may feel you need to change. Either way, communication with your doctors can often change at this point.

Dealing with a metastasis can often present situations in which decision making is complicated, including many more treatment options and possibilities than before.

*"I have an understanding with my team of doctors — they make the recommendations—I make the decisions. In doing so, (I) don't feel quite so helpless and at everyone else's mercy." Carol, age 52*

*"I expect an honest answer to an honest question, even if it's 'I don't know.'" Debbie, age 62*

In addition, the heightened sense of the life-threatening nature of cancer can affect the way that you and your doctors think about these options.

It will be important for you as a patient to take the time to decide what you need to know about your diagnosis, and how you'd like to be told of any new developments. One woman wrote that it was very important for her not to be pressured to make any decisions in the doctor's office. She let her doctor know that she would have to think about the options that he had presented, and that she would call him in two days with a decision. This way, she felt more in control of her treatment, knowing that she had taken the time to think about what she had been told.

Maintaining a relationship with your primary care physician can also be important. Your internist can monitor your general health and well being, and can help you prepare questions for your oncology team. Most important, if you are in a health maintenance organization plan, your primary care physician will be the person to authorize your visits to your oncology team.

Some important areas of continuing communication between you and your doctors that you might want to consider are:

1. How much information do I want to be told about my diagnosis, or health status?
2. How do I want my doctors to communicate with me about these issues (for example, don't beat around the bush, or with tender loving care)?
3. Under what conditions do I need to talk with my doctors (quiet, uninterrupted, with a tape recorder or a family member present to capture information)?

*"I did change my radiation doctor because we didn't see eye to eye — he rushed me and was very condescending when I asked questions. It was like 'now, now dear — just trust me and leave everything to me.' Well it's my life and I have a right to be heard."* Janet, age 51

*"I have even said (to my doctor) 'I waited over an hour to see you and now I need your undivided attention — no phones, no beepers, no nurses interrupting' — it works!"* Ruth, age 54

4. How does my doctor like to make decisions, and how does he or she present information to me?
5. What is most important to me today when I consider my treatment options (I want to live longer, I want to minimize side effects, I want to avoid pain), and how can I communicate this to my doctors?
6. Is there anything I can do to make communication with my doctors easier?
7. Which of the side effects I might experience requires immediate medical attention?
8. How can I reach my medical team in an emergency?

It might help to utilize a nurse as a resource person for certain types of questions, or to choose one doctor to be the “head” of your treatment team. You may find that your doctor would prefer you to fax your questions before your next appointment. That way, your physician will have time to review your concerns, and can talk with you about the issues you have raised at your next appointment. It may also be beneficial to stop at points during a conversation with your physician, and clarify what was just discussed. This way, you can be sure that you are clearly understanding the information being presented to you by your doctor.

## Making Treatment Decisions

It is easy to think that because your cancer has returned that you have to make treatment decisions immediately, without delay. In most cases, this is not true. Despite the serious nature of a recurrence or metastasis, most women are able to spend several weeks obtaining additional opinions about their condition and exploring treatment options. Second opinions are very common. Most physicians see them as an opportunity to receive more information and do not view their patients as being disloyal. Many women find that being able to seek a second or third opinion gives them some perspective on their diagnosis and makes it easier to decide which treatment options are right for them.

To obtain a second opinion, it is important to go to a different facility than where you are currently being evaluated. This facility should be a major medical center that has a great deal of experience in dealing with cancer, and specifically with breast cancer. You can call Y-ME for information about treatment centers in your area, or ask your current physician for referrals.

Some women feel that obtaining other opinions can be anxiety-provoking rather than helpful for them. These women would prefer to work with their doctor and proceed with treatment sooner than later. This is fine too.

Regardless of your choice to seek other medical opinions, there are some important aspects of your treatment with which you need to feel comfortable. You should expect to be informed of all the procedures, tests, and treatments that are planned for you, and the risks and benefits of each. You should also expect to be informed of all possible alternatives open to you, and the consequences of each alternative.

Some questions you may have for your doctors:

1. Why do you recommend this treatment or procedure? What do you expect this treatment to do for me?
2. What are the possible risks of this treatment or procedure? How likely is it that I am at risk for certain side effects or negative reactions?
3. How long will this treatment take? How often do I receive it, and how is it given?
4. Are there more or less aggressive options open to me? What are those options?
5. What happens if I choose to receive no treatment?
6. What are the symptoms that usually develop with my type of cancer diagnosis, and how are those treated? Is this treatment any different than that aimed at remission?
7. How will each of these options affect my quality of life? Will I be able to do the things I enjoy? Can I work, take care of my kids, go on vacation?
8. What lifestyle changes would you recommend I consider during my treatment?
9. How and when will the effectiveness of this treatment be evaluated?

## Expectations of Treatment

In facing a serious cancer diagnosis, many patients hope that their cancer will be cured or go into remission. This is ok. In fact, hope for the future can often see you through tough times. However, it is also important to have realistic short-term and long-term expectations of treatment, especially as your situation changes. Knowing what to expect will come from conversations with your doctors, and will be confirmed with medical tests that monitor any developments of your cancer.

There are several expectations that every patient with cancer should have, including the following:

- the right to expect continued medical care, even if the cancer progresses.
- the right to expect proper pain control medications and therapies as needed.
- the right to choose when to continue and when to end treatment.
- the right to exercise control over how treatment decisions are made and therapies are administered, within reasonable constraints.

## Quality of Life

What does quality of life mean to you? How does your idea of quality of life affect the decisions you make with regard to your treatment? For many breast cancer survivors, these are very important questions to consider when facing a recurrence or metastasis. Some women feel that quality of life means living as long as possible, while other women feel that it means continuing daily activities that are important to them, as free of pain and disability as possible. Most people's definition of quality of life actually falls between these two points of view. Many women living with advanced breast cancer find that their definition of quality of life changes and evolves as time goes on.

Women often find that their families can feel very differently about her quality and length of life. Many family members experience anxiety at the thought of losing someone so important to them, and wish that their loved one would live as long as possible. The woman herself who is living with cancer simply wants the time she has left to be the best possible experience, even if it is not as long as she'd hoped. It is important for family members to understand these feelings.

*"Quality of life is a huge issue for me and more important than quantity. I want to feel as good as I can for as long as possible." Laura, age 38*

*"My work, and the feeling of being useful and needed has been a lifeline, a reason to keep going." Judy, age 49*

*"Getting into remission is my full-time job." Pat, age 36*

Regardless of your definition, knowing how you feel about these issues can help you make treatment decisions. Thinking about the quality of life that you would like to have can help you evaluate side effects before treatment begins, so that you can decide at the beginning which side effects you are willing to tolerate and which you would most like to avoid. And you've found another way to take charge of your life without cancer dictating exactly what you should do.

Most important, your feelings about these issues may change over time. It can be helpful to sort out these issues by talking with loved ones, even if you are not always in agreement with them.

## Facing Treatment Again

Most women who have dealt with breast cancer have experienced some kind of cancer treatments, which may include surgery, chemotherapy and/or radiation. Some women though, will have never had radiation or chemotherapy for cancer. Both situations can be frightening, for different reasons.

If you have never had chemotherapy or radiation, facing these treatments for the first time is difficult because you don't know what to expect or what will happen. There are several ways to find out more about these treatments, so you will feel more comfortable.

1. Call Y-ME to talk with a breast cancer survivor who has had radiation or chemotherapy. She can give you helpful hints and suggestions for coping with treatment, from a first-hand perspective.

2. Read more about these treatments. Y-ME has many booklets and suggestions for reading material.

3. When you go to your first consultation with your radiation oncologist and nurses, ask to see the treatment facility. Ask your medical oncologists and oncology nurses to show you the clinic where patients receive chemotherapy. Sometimes, being able to see first-hand what will happen can prevent you from imagining something much worse.

If you have already had chemotherapy or radiation, you may know what to expect, and sometimes, this can feel worse. Some women will have a different chemotherapy treatment or experience different side effects than they did the first time.

*"I have lost my hair for the third time and I am tired of it."  
Nancy, age 45*

Some women wrote that the only way they got through chemotherapy the first time was to count down until the treatments were over, and then they would never have to do it again. Other women expressed a very different feeling, that chemotherapy for the second or third time was not as scary as the first time. These women were relieved that they knew what to expect, and that at least the treatment would not be totally new to them. The treatment that they were more familiar with was better than a treatment they had never had. Some women even wrote that the side effects of chemo were not as bad the second time around. In this situation, you are often your own best expert as to how you are feeling and handling the treatments. When you share this information with your doctor, you will be able to work together to manage any side effects that you experience. There are a variety of treatments available for side effects of cancer treatment, which will enable you to receive treatments and feel as good as possible in the meantime.

If you have already experienced a recurrence or metastasis, or are on maintenance chemotherapy, you're going to be facing some different issues. Women who have had treatment a number of times can occasionally become depressed and angry about going to the hospital so often. It can be difficult to feel you are leading a normal life while making weekly visits to the hospital for treatments. Patients have dealt with this by talking with their doctors and negotiating a different treatment schedule that does not compromise their health status. For example, one woman decided that she could not tolerate long outpatient visits to the clinic any longer—spending half a day in the hospital getting tests was wearing her down. She decided that it would be better to have two or three short visits to have those same tests completed. That way, she'd be in and out of the hospital much faster and have more of her day left to do other things. It may require some creative thinking, and some trade-offs, but if it helps you take control of your day or your life, it's probably worth considering.

*"The side effects of this chemo are different than those of the first, and in some ways not as bad. I would rather have the side effects and have my cancer go into remission than not have chemo." Susan, age 34*

## YOUR SUPPORT SYSTEM

While everyone's support system is different, nobody goes through cancer alone. For example, those you love who are a part of your life also feel the impact of your illness. Your doctors and nurses are part of your support system, and are affected by many aspects of your experience with cancer.

Every woman in our survey told us about people who were important to her — who helped her cope with cancer treatments and the daily effects of cancer. These special people were not always a spouse or a family member, sometimes they were friends or co-workers. And sometimes these people weren't people at all — they were pets. Women often consciously choose who they want to spend time with and depend on, especially during the rough times. You can choose your support system as well — to fill your life with people who will share it with you in ways that are uplifting and appropriate.

At times, those people we've counted on in the past as our support system will disappoint us later. It's hard to understand other people's reactions to a cancer diagnosis in someone they love. It is difficult when they withdraw at a time when you need them most. In the midst of disappointment, many women understand that fear can keep friends away, and that sometimes there is nothing that can be done to make them feel unafraid. However, women have also said that having cancer has brought them meaningful relationships with people who were only peripherally involved in their lives before they were diagnosed.

Some breast cancer survivors find that their relationships with friends and family change as a result of coming to grips with advanced cancer. Women living with advanced breast cancer often prioritize their activities, thinking in terms of the physical and emotional energy required for every aspect of living. In this way, women decide to spend their time with the people who are most special to them, doing the activities they truly enjoy.

*"I can't imagine how I could have survived without friends. My needs would have been too much for any one person — my husband — to shoulder alone. Most importantly, although they are not afraid to stand with me as I face cancer, they treat me as a friend FIRST and a cancer patient only when appropriate." Laura, age 38*

*"I still deal with feelings of resentment that others have much less complicated lives than my family." Nancy, age 45*

*"I know that there are some people that have to face their own fears of mortality when they see or talk to me, so they avoid such contact. I have come to accept their behavior as their problem, not mine." Nancy, age 44*

## Setting the Tone for Those Around You

Knowing how some friends and family members might react to your cancer diagnosis can help you to understand how they might relate to you. However, it is another question entirely to deal with the discomfort and awkward behavior of those who are well-meaning and loving but don't know how to act. Those who are filled with good intentions may still need some help in recognizing your comfort level, in talking about your cancer and treatments, and in understanding all that having cancer means to you.

Many survivors feel angry that they have to help family and friends deal with their reactions to cancer, at a time when they feel most in need of receiving help and support themselves. However, it may help to realize that some time and straight forward discussion on your part can help to put family and friends at ease; you will then be able to rely on them more. In addition, 'freeing' family and friends to talk openly can allow them to find support in each other, as well as with you. One woman wrote "when I can tell my family what I need from them and how they can 'be there' for me — as well as talking about the 'elephant in the room' (my cancer), I find that they are more supportive and helpful than if I kept quiet."

*"I have a few friends who, on hearing I just had an MRI or other test will say 'I'm sure everything will be all right.' That annoys me. It's trivializing my illness. You'll never find anyone who's been treated for cancer saying that." Ruth, age 54*

## Partner Support

In talking about partners, we want to encompass the many important close relationships that people have. Many women have soul-mates, and are not married to them. So, in talking about partners, we include husbands and lovers and life-partners in all types of relationships.

Many partners of women with breast cancer also regard themselves as a “breast cancer survivor” of sorts. No, they have not had cancer, but in their partner relationship with a cancer survivor, they participate in the same joys and disappointments that the patient experiences. Psychological research shows that partners experience the same degree of emotional distress as the woman with cancer.

To receive support from your partner, it may help to know the ways in which he or she experiences your illness. Partners often feel guilty and upset about their own emotions and concerns, thinking that they shouldn't feel the way they do, because their spouse or partner has cancer. It is also common for partners to feel helpless and to deny or not deal with the feelings that they have. Men often feel that it is important for them to ‘be strong’ for their spouse/partner, and may be frustrated that they cannot ‘fix’ the situation. It is extremely difficult for partners to realize that they have to address their own needs and concerns in order to be more supportive to their partner with breast cancer.

*“Please tell my husband that I don't expect him to fix my pain or cure my illness — just to be here with me and beside me is gift enough.” Judy, age 49*

*“I was married for the second time less than two months when I was diagnosed. He has been wonderful — we laugh and cry together. I think we deal with my cancer in a very straight-forward matter and in many ways we have become emotionally closer because of it.” Carol, age 52*

*“Some of the things I said out of my own pain and fear were hurtful to (my husband), and I think that he also feels at some level he ‘should’ be able to fix what's wrong with me. Like me, he is more irritable, sensitive and moody now than before. Cancer is a big-time stressor in both our lives.” Judy, age 44*

*“One of the major things that I have encountered is the lack of desire. I think my husband is more understanding than most, but it is a hard thing to deal with.”  
Linda age 48*

General issues that you and your partner might face together could include:

- temporary or permanent changes in your roles and duties at home and/or at work;
- changes in priorities and goals in both your lives; changes in communication;
- your needs for intimacy and sex may be different;
- fears and feelings may become more prominent in your relationship.

While most women with advanced cancer find that they become closer to their partners this is not always the case. And not all women have partners. These survivors count more on friends and extended family members for support, hope and friendship.

Many survivors with partners describe them as being supportive, loving and understanding. Getting there, however, required some work! These women talked about the ways in which they learned with their partners to get through the rough times and celebrate the good ones.

Some suggestions:

- Try to identify ways to establish routines and normalcy in the midst of treatment schedules and 'down' days. This might include a special time once a week to rent a movie, or take a daily nap, or make dinner together.
- Sometimes, spending time separately can improve the time you spend together; take a class, go to work, develop an interest. This may give both of you a break from the daily stress of dealing with cancer and some provide perspective and understanding.
- Give yourselves time to talk; about your fears and hopes, your sadness and joy. You are both dealing with the unknown, for the most part, and you need to articulate your concerns and thoughts to each other to help minimize anxiety.

## Intimacy and Sex

It is quite common to think that cancer patients do not have any interest in sex, or the desire for intimacy. On the contrary, intimacy and sex play an important role in the lives of many women with advanced breast cancer. For some women, the side effects of treatment and the nature of their cancer does interfere with the desire or the ability to have sex. In this situation, women and their partners have found other ways of being intimate. Most everyone agrees that intimacy, with or without sex, is very important to their relationship. Survivors feel that this aspect of their relationship adds meaning to the time they spend with their partner.

Many couples realize that in order to establish a healthy sexual relationship, each must deal with the fears and concerns they have about the presence of cancer in their lives. A survivor may experience changes in her self-esteem and body image and her partner may feel that she is fragile, or is afraid of hurting her during sex. A significant number of couples experience sexual difficulties during and after a spouse receives cancer treatment. It is very common for couples to seek assistance from a therapist in working through these issues.

Women who commonly experience bone pain, or other discomfort related to the cancer or its treatment, face very different issues with their partner. In this situation, a survivor may not necessarily feel like being sexual, especially if she is experiencing side effects from treatment. In other cases, women experience physical pain despite their sexual feelings. Finding other special ways to be together, like holding each other, kissing and hugging, and just talking can often fulfill needs for intimacy. In cases where desire is strong but physical limitations persist, for the woman with cancer to position herself on the side or on top of her partner is often helpful.

In most cases, women and their partners need to hear that they are still loved, wanted and desirable during intimacy. Expressions of love and reassurance can mean as much as physical touch during this time, allowing both partner and patient to feel an emotional bond.

*"We have sex but it is less important than being intimate. We spend more time just holding each other and sharing our time together to make it more special. Sex doesn't hold near the importance that it used to and I think my husband is being honest when he says that it is not as important to him." Laura, age 39*

*"You bet there's sex after an advanced cancer diagnosis. I am currently on (a treatment) and it or something has increased my libido substantially. It is an understatement that this disappoints neither of us." Debbie, age 62*

## The Role of Friends

Good, close, intimate friends are often the mainstay for many women fighting advanced breast cancer. One of the fears that many women have is being too dependent on one person; the presence of friends and family can alleviate this fear. These important relationships can have several qualities in common:

- Friends add “normalcy” to life, and the opportunity to be connected to the world and other things besides cancer.
- Friends help by seeing and relating to a woman with advanced cancer as a friend first and a patient with cancer second (or third or fourth).
- Friends are often those who can talk about anything, and act as a safe outlet for feelings and emotions.

It is also common for friends to want to help you deal with your cancer treatment and all that it means for you. Many women are often tired of hearing “What can I do?” “Is there anything you need?” and “Just call if you need anything” because it seems like everyone is doing something for them. At other times, friends actually do something to help, but it isn’t very helpful at all. There are ways that you can feel more in control of your situation, and one of them is to take charge of the way in which your friends take on a role in your life.

One woman wrote that she kept a list, with all of the errands and tasks that she needed friends to do. Her list included rides to and from the doctor’s office, and she actually kept a schedule of who signed up to give her a ride. Another woman said that when she was feeling terrible and in the hospital, she asked a friend to call other people to keep them updated as to how she was doing. Friends can often take some of the stress and anxiety out of managing life with cancer.

*“I soon learned that most (of my friends) would take their cue from me. I lost a couple along the way because they couldn’t handle my diagnosis — one I left behind because she was too pessimistic. Again, I have chosen to be candid and open about my illness, the limitations, and my feelings (good, bad and otherwise). Mostly I don’t want to feel ‘different.’” Carol, age 40*

*“Their support is precious beyond words. I have friends with whom I can share joy, anger, terror, depression. They will cook for me, drive me to the hospital, comfort me, distract me, pray for me and with me.” Judy, age 49*

support is precious

## Talking With Children and Family Members

How you communicate with family members as you are fighting cancer will depend on your relationship with them before you were diagnosed. Some women have very close knit families that help them every step of the way through their treatment. Others have strained relationships and feel the need to share information about their illness only with certain people. How you handle family members is up to you; only you know your comfort level in handling these delicate relationships.

Children can bring up very different concerns, and this can be hard for many women. If you were diagnosed with cancer before you were able to start a family, the children of others may remind you of the reality that you are not able to have children of your own. This tremendous sense of loss is one of the most difficult feelings to handle. Working through the sadness and pain of this loss may involve connecting with other children in your life who need the special attention that only you can provide.

At this point, what you tell children and how you talk about cancer becomes central to your relationship with them. Most of us know children who are inquisitive and unafraid to ask the awkward questions that most adults would not. This behavior tells us that children notice and try to understand many of the complex issues around them. If you have lost your hair, or are feeling bad, children will notice and ask you why. If you look different than other adults who they know, or have a physical limitation as a result of your cancer diagnosis, they will ask you about that too.

It may help to know how most children process and understand the idea of cancer, especially when a parent has cancer, and how they cope with this knowledge.

The ability of a child to understand your illness and treatment is often based on age. Young children, such as those from ages 4-7, only understand concrete notions —that is, what they see, touch, hear or have experienced. So their questions might be “What is that for?” (pointing to an IV) — or “Does your ‘ow’ hurt like mine does?” These children express feelings concretely also, often by taking actions. For example, a kindergartner brought her mother a band-aid after she was crying from a chemotherapy treatment. On the other hand, just because children of this age don’t say they are upset, doesn’t mean that they are emotionally unaware. Often distress is expressed physically, such as loss of appetite, bed-wetting, difficulty sleeping or nightmares, and hitting other children. If these problematic behaviors are consistent for over two weeks, a consultation with a child psychologist may be valuable.

School-age children, ages 6-12, can understand and identify with experiences that they have not directly participated in. They can also understand the meaning of events. For example, if mom goes to the hospital often, this pattern of events may mean that she is seriously ill. Children are

also more socially aware at this age, and may hesitate to voice a concern for fear of upsetting the parent. It is good to ask kids of this age group if they have any questions or concerns, on a weekly basis. This shows them that talking about worries is appropriate. Although children of this age group who are distressed may show it in the same way as younger children, the most frequent change to watch for is poorer school performance.

Adolescent daughters and sons have the most complicated reactions to their mother's illness. Adolescence is a time when they want to become independent, yet out of concern for the parent they want to be closer to the family. Even though they are very involved with friends, they feel a pull or obligation to be at home. They are also, for the first time, able to identify with the same sex parent as an individual, and may be frightened of loss. On the other hand, adolescents are also capable of great intimacy, intensity and understanding. They understand the meaning of loss and can talk about it.

Children of all ages have some traits in common. First, they understand events in their lives in relationship to themselves first. This may be confused with being self-centered or 'spoiled' when it is a logical way of understanding. Second, children need to repeat the same questions until they have mastered a concept. The younger the child, the more repetitive. This can be maddening for the adult. For example, a 5-year-old may ask every morning for five days straight, "Where is mommy?" only to be told over and over again that mommy is in the hospital. Third, children ask questions and talk in small doses, often abruptly changing the subject when they have had enough. This is not insensitivity, but rather a method for coping with anxiety or cognitive "overload." Finally, children have different issues than adults, often dictated by limits in understanding. For example, adults may be upset over a threatened loss, which is beyond the imagination of many adolescents. On the other hand, children tolerate helplessness better than most adults, because it is a more common experience in their daily lives. Additionally, children often teach adults about joy in the moment and acceptance.

Some hints:

- There is a universal rule when talking with children about serious subjects — answer only the question they ask, and don't assume that they are asking more than what they have actually said. If you can do this, you can help the children in your life understand the information you are telling them a little at a time, which is easiest for any child.
- Answer a child's question as honestly as possible.
- Reassure the child that it is not their fault that you have cancer.
- Explain the treatments, procedures and hospital visits you will have in the child's perspective. "When I have chemotherapy, my hair will fall out, and you will see me without any hair. Sometimes I will wear a hat or a wig, so that I can be warm and comfortable."

Adult children can present different challenges and concerns, which are no less important or emotional in nature. Many adult children of cancer survivors are very supportive and loving when a parent has breast cancer. For female children, however, dealing with their mother's breast cancer diagnosis can be especially difficult when they realize that their parent's diagnosis brings them increased risk. Often, female children will wonder if they are going to get breast cancer, and if they do, will it be like your experience with the disease.

Many women feel angry at the possibility that they might die before their children have fully grown, lived their lives, accomplished great things and started a family. Children often feel angry at the possibility that they might lose their mother sooner than they expected.

Dealing with these difficult feelings can be affected by where your children live, and whether or not they are close to you or far away. Many parents are emotionally closer to children who live near to them; this can affect how much you share with your children and how often.

## Finding a Support Group

Many women consider attending a support group at one time or another during their diagnosis and treatment. However, many women with a recurrence or metastasis are often afraid to go to support groups, for various reasons. One is that they do not have the patience or the sympathy to listen to a woman who is upset about her diagnosis with early-stage breast cancer. This is very normal and quite common. Another is that they feel they might scare someone else in the group who has a much better prognosis. It is also very common to be afraid to meet someone who is in a more difficult situation, and to be afraid to deal with the death of a support group member.

Should you go to a support group? That depends. Many women with advanced breast cancer feel that the only people who truly understand their concerns are other women who are also living with the disease. If you are someone who has had success in the past in attending support groups for any reason, or if you are comfortable with sharing your feelings in a group setting, you'll probably get something out of going to a group meeting. On the other hand, if you are shy, feel that you need privacy to share your feelings or are uncomfortable in groups, a support group may not be for you.

There are many different kinds of support groups: the Internet, telephone support groups and hotlines, and face-to-face group meetings. Many on-line services have discussion groups where people with similar cancer diagnoses can talk in real time. There are organizations that offer telephone conference calls with a group of people on specific issues, and you can always call Y-ME to talk with a woman living with metastatic breast cancer.

It can be much more difficult to find a group in your area that you are comfortable attending, but it is possible. Most women prefer to meet with

other women who have advanced breast cancer, and oncology social workers are often able to refer you to groups in your city or town. Many women find that their nurses are an important resource for finding out about support groups in their area. If it is difficult for you to drive, you might ask a friend to take you to the meeting and bring you home. Most women do find it difficult when someone in their support group becomes gravely ill or dies. Many of the groups that are available for women with advanced breast cancer are facilitated by trained professionals, who help women deal with their feelings when this happens.

## CONCERNS ABOUT LIVING WITH CANCER

This section of the booklet talks about when to continue or end treatment, how to manage cancer pain, and preparing for death. You may not be ready to read this section yet; if you are not, give yourself permission to skip this part for now. You can come back to it when you are ready. The booklet continues on page 33.

## When to Continue and When to End Treatment

There may come a time when some women feel that they do not want to continue medical treatment to manage their cancer. In some cases, treatments may stop working, or they have had to consider other treatment options. In other cases, the idea of continuing with treatment that is not curative may seem unproductive. For most women with advanced breast cancer, stopping treatment for them feels like giving up, and they do not want to do that at any cost. They feel that it is more important to live longer, even if they feel poorly at times.

The choice is yours, and it depends on your idea of quality of life. It can be reassuring to know, however, that if you choose to discontinue treatment, you have the right to change your mind. In addition, if you do not continue medical treatment you have the right to receive medications that control your symptoms and pain.

This decision is often made in the context of changing goals. For you, time may not be as important as quality of life, or you may want to stop treatment for a while to take that important trip and feel good. This decision is not easy, but as long as you are living, you can always change your mind.

## Dealing With Cancer Pain

While not every woman living with breast cancer experiences pain, it can be an overwhelming fear. Most women with advanced breast cancer do not have pain. However, most women say that they are more afraid of being in pain from their cancer than dying from it. Contrary to what we see on television and in movies, living with cancer does not have to be a painful experience. There are many effective therapies available to control pain, without making you feel woozy or tired.

Some women may worry that they could become addicted to pain medication, or that treating the cancer is more important than treating the pain that they feel. In reality, only 2% of patients with cancer ever become addicted to their pain medications, and that's because they already had a problem with addiction in the first place. And it is just as important to treat your pain as it is to treat the cancer. Treating your cancer pain does not interfere with the treatment you receive for your cancer.

## Talking to Your Doctor About Pain

It's important to talk with your doctor about your concerns regarding pain, and if possible, to do this at the outset of your treatment. Often, women have experienced a great sense of relief in talking with their physicians, who have reassured them that they will receive proper treatment for their pain and will not be made to suffer needlessly. When you are feeling good, you and your doctor can decide together how you would like to handle any future cancer pain that may occur. And you can set your mind at ease, because you and your doctor have a plan for treating your pain.

## Describing Pain

When you are in pain, it is very important that you are able to describe how you are feeling to your doctors as completely as possible. While you may hardly feel like it at the time, the more specific you can be about how you are feeling, the better your doctor can meet your needs. Is the pain that you are feeling sharp, like a stabbing sensation, or a dull ache? Is it located in a specific part of your body, or is it a general "wandering" pain? Does it radiate outward from where it starts, or is it specifically focused in one area? Even if it sounds silly, use any description you can think of to tell your doctors what your pain is like. Draw pictures for them if necessary.

In addition, it may help to describe your pain by rating it on a scale of 1 to 10. Many patients keep a journal that describes how they are feeling at different times of the day, with 10 being the worst, and 1 being the best (or in the reverse, if that is how you think about your pain). This information is helpful for your doctor to understand how you are feeling. It can also help you track your progress, and be prepared for the more difficult times of the day.

*"Bone pain is a complex and frustrating pain. It takes on many different forms and is seldom constant. We are raised thinking if something is "really" wrong it will hurt the same way all the time." Linda, age 48*

## The Truth About Cancer Pain

- Treating your cancer pain can help you maintain your energy and improve your mood.
- Treating cancer pain does not mean you're not tough enough.
- Having cancer pain does not always mean that you are about to die.
- You can still receive treatments to reduce pain even if you are not receiving cancer treatment. Reducing cancer pain can help give you the energy you need to fight the cancer, and can improve the quality of your life.
- Fatigue can increase pain. Take care of yourself.

## Preparing for Death

Considering our own death is sad and scary. As a woman with advanced breast cancer, it can be even more difficult because your life could end sooner than it should have in some cases. Everyone handles death differently and you may feel that you are not ready to consider your own death. This is quite normal; most of us feel exactly the same way. However, some women with metastatic breast cancer feel that in fighting cancer they are fighting death and have confronted it in a very personal way. To them, dealing with their own mortality is unavoidable, but a necessary part of continuing to live.

There are two distinct aspects of dealing with death. One aspect is working through the emotions and feelings that you have about your death. The other is to handle some of the practical aspects of your life so that if you are unable to express your wishes about how you would like to die your choices are known. In addition, dealing with the practical aspects of your death also involves expressing your preferences as to what should happen after you die.

*“I worry about how I am going to die. My personal affairs are all in order and include a living will —this frees me to live knowing that everything I can think of has been put in good order.” Carol, age 52*

## Practical Aspects of Preparing for Death

It helps to handle these issues before you become seriously ill. Some of the considerations that many women with advanced breast cancer have dealt with include:

- preparing a living will, which describes when life-saving treatment should and should not be given, and the point at which the maintenance of life should end;
- preparing a durable power of attorney for health care, which allows the patient to name a person who is able to make decisions about their treatment when they are not able to decide for themselves;
- especially for single mothers, making custody arrangements for young children;
- writing a will, which outlines who should receive your possessions and property (if you do not write a will, the state decides the disposition of your possessions);
- planning funeral and burial arrangements that let family members know how you would like to be remembered.

There are many important care options that you may consider as you become seriously ill and need continuing treatments. Many women feel that they would rather be at home if they are gravely ill and prefer to die at home than in the hospital. There are many home care services available that arrange for 24-hour nursing and for medical equipment to be brought into the home.

In addition, many patients and families have found hospice or palliative care to be a positive and supportive experience. Patients who enter a hospice program can receive treatment at home, or at a special care facility. Hospice provides multidisciplinary care to patients with a terminal illness and their families. In the hospice setting, patients receive pain medications, and other treatments that help to alleviate the symptoms of their illness. Daily visits and care are provided, as well as counseling and support groups. Social workers and health care professionals work with the patient and the family to prepare for death, and to deal with their feelings in the process. Most insurance companies provide some coverage for these services.

## Feelings and Fears About Death

Most women with advanced breast cancer told us that they are not afraid of death itself, but how they will die. These women often said that their greatest fear was being in pain, or dying alone. These are very common fears, and it helps a lot to share these fears with your medical team and your family. Solutions can be identified to resolve your fears by discussing them and planning for certain events.

Most people expect that when they die it will happen in an instant, leaving no person the opportunity to know what is happening. This is most often not true. When someone dies, there are physical stages of slowing down that a person goes through, over a series of days or weeks that are easily recognizable to a health care professional or trained caregiver. In most cases, these individuals can alert family and friends in enough time so that they can be there with you.

*"I really had to accept dying before I could go on living." Pat, age 36*

## THE EXPERIENCE OF LIVING WITH CANCER

### What It's Like to Live With Cancer

"Cancer is kind of like a leaky faucet. It's always there, annoying, but accepted and familiar background to everything else." [Laura](#)

"Cancer changes everything about your life. I no longer get upset if the grandchildren mess up the house." [Dora](#)

"I do experience cancer on a day-to-day level. I do not have any pain or discomfort but I think about it often. I have trouble with waiting in line, as time has become very precious and I get frustrated when I have to waste it." [Ruth](#)

"I used to be there only for others, now I am taking care of myself." [Helga](#)

"I'm more likely to say what I think; not worrying about others and (I'm) less tolerant of what I regard as unnecessary demands on my time." [June](#)

"I don't live life differently, just more accelerated." [Laura](#)

"I do live life differently with advanced cancer. I am no longer willing to wait for things I want. If I want something, why wait? I am not able to do as much as I used to, as I tire more easily. If I want to go out for the evening, then it usually means I have to take a nap during the day or not do as much." [Susan](#)

"People think that when you have (cancer) your life stops and you do all kinds of wonderful things. I think the most important thing that you do is go on with your life." [Linda](#)

## Practical Strategies for Living a Normal Life With Cancer

Sounds great, doesn't it? It may seem difficult to imagine living a 'normal' life with cancer, but it's possible and many women are very successful. It's easy to think that your life with cancer revolves around doctor visits, hospital stays, tests and treatments, and sometimes it might. However, many, many women are surviving advanced breast cancer, and they continue to work, volunteer, travel, and raise children and grandchildren — for many, many years.

Many women who completed our survey are working — as teachers, real estate agents, lawyers, designers and business owners. Others volunteer their time for a worthy cause and are involved in community service in schools, hospitals and cancer organizations. For some women, their diagnosis has freed them to do the things they have only dreamed of, like traveling and going to school.

Most women say that to the extent that they are able to live normal lives and maintain a routine helps them to feel productive and happy, and allows them to have some perspective on their disease. However, many women find that in order to do this, they need to be realistic about what they can and cannot do. Some women take naps during the middle of the day, so that they will have the energy to be with their families in the evening or go out to a movie. Other women make adjustments for themselves at work; one teacher arranged for special adaptive equipment, a tall stool and an overhead projector so that she could continue to lecture without being on her feet. Knowing how much you are able to accomplish involves listening to your body, and when you are in pain or are tired to adjust your plans. Eventually, you'll be able to accommodate your schedule so that you are able to do what you enjoy, when it matters most.

*"I hold my breath and plan about six months ahead; at times, it's been difficult to plan more than one week ahead." Laura, age 38*

*"I need to make plans and set goals, they can be amended if necessary." Donna, age 57*

*"As a former teacher, I now do extensive volunteer work. It is an important way for me to feel needed and productive. It is also very helpful to keep me focused on life, not cancer." Kerry, age 44*

## RESOURCES FOR SUPPORT AND INFORMATION

**Adopt America Network:** Coordinates the adoption of children who have special needs. 1-419-534-3350, Contact Name: Beverly Moore. [www.adoptamerica.org](http://www.adoptamerica.org)

**American Institute for Cancer Research Nutrition Hotline:** Focuses exclusively on the relationship between nutrition and cancer, and has a hotline staffed by registered dietitians who reply promptly. 1-800-843-8114. [www.aicr.org](http://www.aicr.org)

**Cancer Care:** Provides support and counseling through a toll-free hotline staffed by social workers. 1-800-813-HOPE. [www.cancercares.org](http://www.cancercares.org)

**Cancer Information Service:** A program of the National Cancer Institute which provides information to callers about current clinical trials. 1-800-4-CANCER. <http://cancertrials.nci.nih.gov>

**Partnership For Caring:** Provides information about living wills, powers of attorney for health care and other issues related to the end of life. 1-800-989-WILL. [www.partnershipforcaring.org](http://www.partnershipforcaring.org)

**Corporate Angel Network:** Attempts to locate free corporate air travel services for people with cancer needing to travel for treatment. 1-914-328-1313. [www.corp\\_angel\\_network.org](http://www.corp_angel_network.org)

**Mary-Helen Mautner Project for Lesbians with Cancer:** Provides comprehensive support services for lesbians with cancer and their partners and caregivers. 1-202-332-5536. [www.mautner\\_project.org](http://www.mautner_project.org)

**National Hospice and Palliative Care Organization:** Provides information about hospice and referrals to local programs. 1-800-658-8898. [www.nhpco.org](http://www.nhpco.org)

**National Lymphedema Network:** Provides up-to-date information about lymphedema and its treatment. 1-800-541-3259. [www.lymphnet.org](http://www.lymphnet.org)

**Angel Flight America:** Provides air transportation for patients and their families with financial need to hospitals, clinics and specialists. 1-877-621-7177. [www.angelflightamerica.org](http://www.angelflightamerica.org)

**Air Lifeline Inc.:** Provides air transportation for patients with limited resources on private aircraft throughout the country. 1-800-822-7972. [www.lifelinepilots.org](http://www.lifelinepilots.org)

**Well Spouse Foundation:** Offers support and information to the partners of people with serious and chronic illnesses. 1-800-838-0879. [www.wellspouse.org](http://www.wellspouse.org)

**Wellness Community:** Provides professional psychological and emotional support to cancer patients and their families, free of charge, as an integral part of conventional medical treatment. 1-310-314-2555. [la.wellnesscommunity.org](http://la.wellnesscommunity.org)

Y-me National Breast Cancer Organization provides information and support to women with breast cancer and their families and friends.

Y-me offers a 24-hour national hotline that is staffed entirely by breast cancer survivors and operates seven days a week. Y-me has many chapters across the country, serving women and their families locally with support group meetings and information referral.

For more information about these services, or to talk with a breast cancer survivor, please call

1-800-221-2141.

## SUGGESTED READINGS

Brack, Pat with Ben Brack. Moms Don't Get Sick. Melius Publishing: Aberdeen, South Dakota. 1990.

*A journal of a mother and her youngest son, and their experience in dealing with her breast cancer diagnosis and treatment.*

Butler, Sandra and Barbara Rosenblum. Cancer in Two Voices. Spinsters Book Co.: San Francisco, CA. 1991.

*A personal account of the life of a woman with advanced breast cancer and the experience of her lesbian partner.*

Gaynes, Fanny. How Am I Gonna Find a Man if I'm Dead? Morgin Press, Inc.: Wayne, PA. 1994.

*A touching and funny autobiography written by a woman who lived with advanced breast cancer for over ten years.*

Lerner, Michael. Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer. MIT Press: Cambridge, MA. 1994.

*A comprehensive guide to current cancer therapies and complementary approaches for dealing with cancer.*

Mayer, Musa. Advanced Breast Cancer: A Guide to Living with Metastatic Disease, 2nd Edition. [www.oreilly.com/catalog/advbc](http://www.oreilly.com/catalog/advbc)

Moyers, Bill. Healing and the Mind. Doubleday: New York, New York. 1993.  
*A publication based on the author's PBS series of the same name.*



## Mission

The mission of Y-ME National Breast Cancer Organization is to ensure, through information, empowerment and peer support, that no one faces breast cancer alone.



212 W. Van Buren Street, Suite 500  
Chicago, IL 60607

24-hour Y-ME National Breast Cancer Hotline  
1-800-221-2141\*  
1-800-986-9505 (Español)

\*Peer support available in nearly 150 languages.

*Chrysanthemums generally denote cheerfulness and rest.  
The ancient Chinese saw the flower as a symbol of the ease that  
followed the season's fall harvest.*