



BREAST CANCER  
**PATIENT**

*Support Guide*

BRAZIL

susan g.  
komen. 

This manual was developed to complement activities conducted from 2016 to 2018 for the project **Integrated Approach to Improving Oncology Care in Aracaju**, made possible through a grant to Susan G. Komen (Komen) from the Pfizer Foundation.

Komen, in partnership with the Ministry of Health of Sergipe, Municipal Secretary of Aracaju and local implementing partners (Hospital de Câncer de Barretos, Hospital Perola Byington and Instituto Oncoguia), led strategic efforts to build the capacity of health care providers, equipping them to improve the quality of breast health services, and mobilized social workers and the community of Aracaju to inform breast cancer patients about their lawful rights and benefits.

Special thanks to Mulheres de Peito, a group of women and cancer survivors dedicated to improving cancer care in Sergipe, for their contributions and active participation in meetings, trainings, and the breast health care assessment.

We, the Global Strategy & Programs team at Susan G. Komen dedicate this manual to all women who have triumphed, fallen and those who continue the fight against breast cancer.

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Susan G. Komen (Komen) is the ONLY organization that addresses breast cancer on multiple fronts such as research, community health, global outreach and public policy initiatives in order to make the biggest impact against this disease. We envision a world without breast cancer, and strive to save lives by meeting the most critical needs in our communities and investing in breakthrough research to prevent and cure breast cancer.

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## ABOUT SUSAN G. KOMEN

In 1980, Nancy G. Brinker promised her dying sister, Susan, that she would do everything in her power to end breast cancer forever.

In 1982, that promise became the Susan G. Komen® organization and the beginning of a global movement. What was started with \$200 and a shoebox full of potential donor names has now grown into the world's largest nonprofit source of funding for the fight against breast cancer.

Komen partners with local governmental and non-governmental organizations in communities worldwide to implement innovative programs aimed at increasing awareness, education, screening and access to quality care.

To date, we've invested more than \$2.9 billion in groundbreaking research, community health outreach, advocacy and programs in more than 60 countries. Our efforts have helped reduce deaths from breast cancer by 39 percent between 1989-2015 and we won't stop until our promise is fulfilled.

## INTRODUCTION

No two people are alike. Some sections of this Manual may apply to you, while others may not. Or some may be more useful later on, in a different stage of your journey.

Our goal is to help you stay in control as much as you can and equip you with information that can help you lead a fulfilling and satisfying life. You can still have hope and joy in your life, even as you cope with breast cancer.

As you read this Manual, you will learn more about the experiences of Angela, Maitê, Fernanda, and Raquel, four women at different stages of their breast cancer journey.



## *four women, one journey!*



1

*I'm Angela, nice to meet you!  
I've been diagnosed, now what?*

In this section you'll find important information about a breast cancer diagnosis and how to cope with knowing that you are now one of thousands diagnosed with this disease each year.

*Hi there! I'm Maité,  
I'm in treatment, now what?*



2

This section offers you information and resources to help you understand your treatment options and make a decision about what is best for you.



3

*Hello! I'm Fernanda, I'm done  
with treatment, now what?*

In this section you'll gain some insight on things you can do to re-establish a sense of comfort with who you are, your body and mind after you've overcome the challenges of your treatment.

*Hi! I'm Raquel, my cancer  
returned, now what?*



4

This section will help you understand what it means to have a recurrence and deal with the emotions it brings as you begin another phase of care.

*reflection moment*

# you are loved

Don't forget that there are people, friends, family, and loved ones who may want to participate in this journey with you.



Invite them to read this manual with you.

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In the “Caregivers” section, we’ll share some tips on how those who care about you can help as you deal with the emotional and physical effects of the disease, and make important decisions about your breast health.



Above all, try to remember that you are still in charge of your life and how you respond to challenges faced in your daily journey.

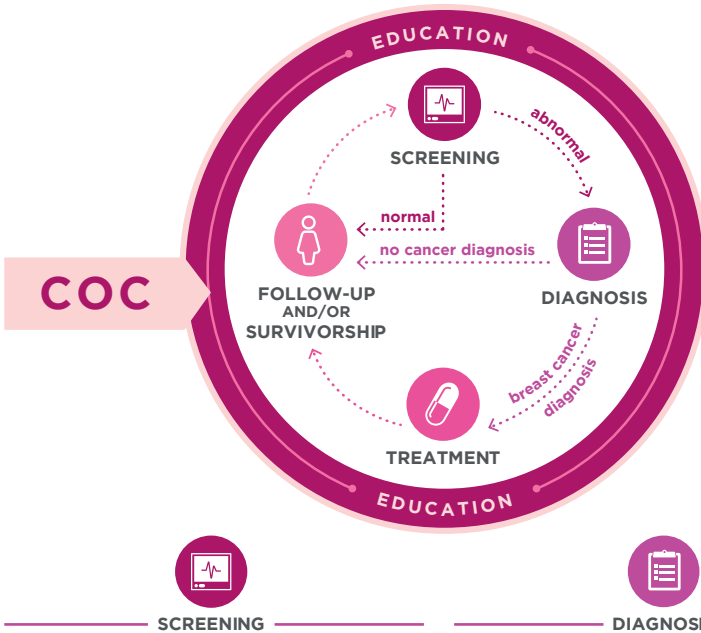
You may have trouble coping with your feelings from time to time and accepting that things may have gone a different way than you had hoped. This is normal.

Before you eagerly jump to the section that is most relevant to you, please take a moment to learn some key information about breast cancer, the breast cancer continuum of care and caregivers who can have an important role in helping you to overcome the physical, spiritual, psychological and emotional challenges in your journey.

# B

## BREAST CANCER CONTINUUM OF CARE

The breast cancer continuum of care (COC) is a model that shows how a woman or man typically moves through the health care system for breast care. It is possible that you may enter the COC at screening, diagnosis, treatment or follow-up and/or survivorship, which are all major milestones in cancer care.



is a term that is used to describe exams that are used to find breast cancer before it causes any warning signs or symptoms. Screening tests can find breast cancer early, when the chances of survival are highest.

Types of screening exams include a Clinical Breast Exam (CBE), mammogram or ultrasound. How often someone gets screened and by what method, should be discussed with a health care provider.

usually happens after screening. If something doesn't seem right during screening, your health care provider is likely to send you for a diagnostic procedure that will try to figure out if there is a problem and what it might be.

Breast cancer is often first suspected when a lump or a change is found in the breast or when an abnormal area is seen on a mammogram. Most of the time, these findings don't turn out to be breast cancer. However, the only way to know for sure is through follow-up exams.



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**TREATMENT**

can include surgery, chemotherapy, radiation therapy, hormone therapy and targeted therapy. After you've been diagnosed with breast cancer, the treatment plan your health care provider recommends will be based on your specific situation.



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**FOLLOW-UP AND/OR SURVIVORSHIP**

involves taking care of yourself, getting regular screenings and other medical care, managing the effects of disease, and if needed end-of-life care.

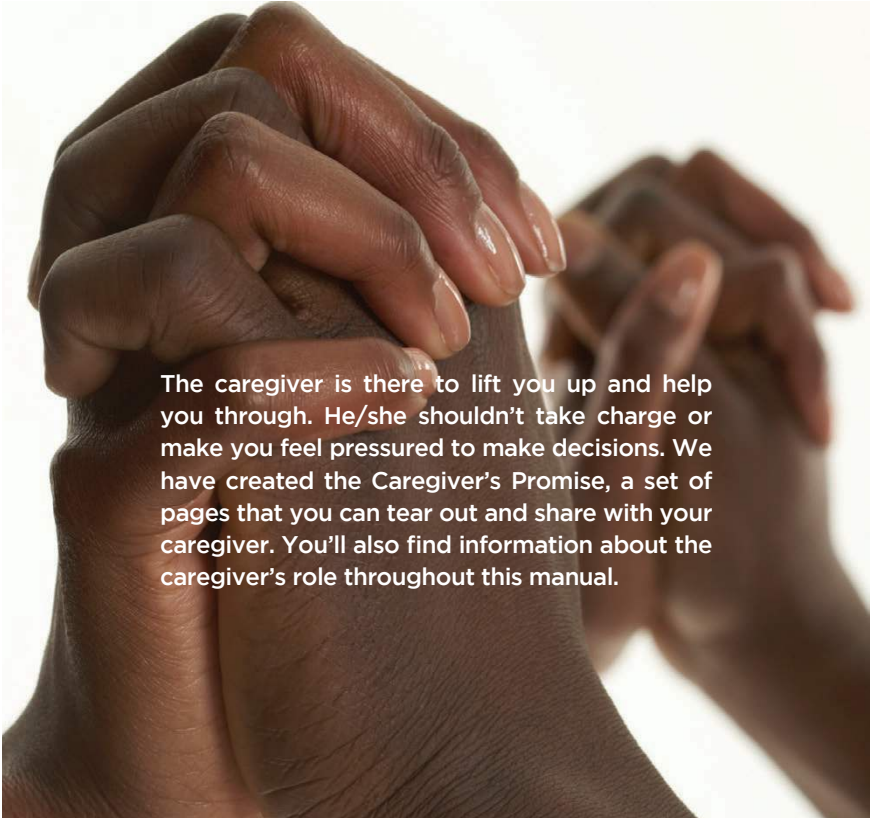
 *More detailed definitions are available in the Glossary on page 96.*

# C

## CAREGIVERS

Caregivers are people in your life that care about you and may want to help you along your journey. Some examples are spouses, partners, family members or close friends. Many people have never been a caregiver before, so it is important that they receive the proper support and guidance to help you transition through the continuum of care.

There are numerous resources available to caregivers, including support groups, programs, and services, that will help your caregiver(s) be as effective as possible in gathering information to help you with discussions with your doctor, driving you to and from doctor appointments, providing childcare, cooking, and cleaning, among many others.



The caregiver is there to lift you up and help you through. He/she shouldn't take charge or make you feel pressured to make decisions. We have created the Caregiver's Promise, a set of pages that you can tear out and share with your caregiver. You'll also find information about the caregiver's role throughout this manual.



### *the caregiver's promise*

- I am committed to supporting the needs of my loved one and in doing so, I will not forget about my other roles such as: individual, spouse, parent, friend and employee.
- I will be informed about my loved one's condition to help me prepare for the challenges ahead.
- I respect my loved one's ability to make decisions and will do everything possible not to overstep boundaries.
- I accept the limitations of the person I am caring for.
- To care for my loved one, I must first care for myself- physically, emotionally and spiritually.
- I won't feel guilty for taking vacations, spending time with friends, pursuing hobbies or meeting my financial needs through work.
- I will celebrate milestones and ask for help when I need it.
- I make mistakes and that's okay!

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Caregiver's signature

When someone you love has breast cancer, she or he may face physical and emotional struggles. You will want to do all you can to support them.



### Communication tips

- Spend time together – face by face or by phone.
- Tell your loved one how you feel or write a letter.
- Listen to your loved one and allow them to complete their thoughts before you respond.
- Don't be afraid to say the word “cancer.”
- Don't be afraid of silence or strong emotions such as anger, fear or tears.
- Give your loved one a hug or hold their hand. This can say much more than words.

### What else would you do ?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

### *I will help by...*

One way you and your family can help is by providing practical help. Here are some ways that you can help.



### If you live in the same house...

- Help with the daily chores – go food shopping, cook dinner, do the laundry, etc.
- Offer to take them to the doctor and take notes.
- Be there for them when they need a hug or need to cry.
- Gather information for them when they are too tired.
- Offer to make phone calls and screen calls or visitors.

### What else would you do ?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



**If you live nearby...**

- Invite them over for dinner more often or bring them dinner.
- Call to see if you can pick up anything at the store.
- Offer to go to doctor visits or support group meetings.
- Get them out of the house by taking them to a movie.
- Offer to come over to clean the house and do laundry.
- Offer to take kids to school or activities.

**What else ?**  
*would you do ?*

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



**If you live out of town...**

- Send a copy of your favorite book or video.
- Help celebrate holidays by sending flowers or decorations.
- Write letters, cards, poems or words of inspiration.

**What else ?**  
*would you do ?*

\_\_\_\_\_

\_\_\_\_\_

***I won't forget to...***

You may be so busy caring for your loved one's needs that you neglect your own emotions. There is no right or wrong way for you to feel, but it's important that you take care of your needs during this difficult time.

- Determine who you may want to share your thoughts and feelings with.
- Reach out to others to get support and help.
- Ask for help.



**Use this space to list the names and phone numbers of the people you can turn to:**

	NAME	TELEPHONE
Counselor		
Friend		
Social Worker		
Spiritual Leader		
Support Group		
Other		
Other		



You may not be able to do everything. Just by caring enough to read this information, you are making a difference.

**RESOURCES FOR CAREGIVERS:**

📍 *Cancer e Família:*  
<http://cancerfamilia.com.br/>

📍 *National Cancer Institute (INCA): Direitos Sociais da Pessoa com Cancer:*  
[http://www2.inca.gov.br/wps/wcm/connect/orientacoes/site/home/direitos\\_sociais\\_cancer](http://www2.inca.gov.br/wps/wcm/connect/orientacoes/site/home/direitos_sociais_cancer)

📍 *Instituto Oncoguia:*  
<http://www.oncoguia.org.br/de-familiar-para-familiar/>



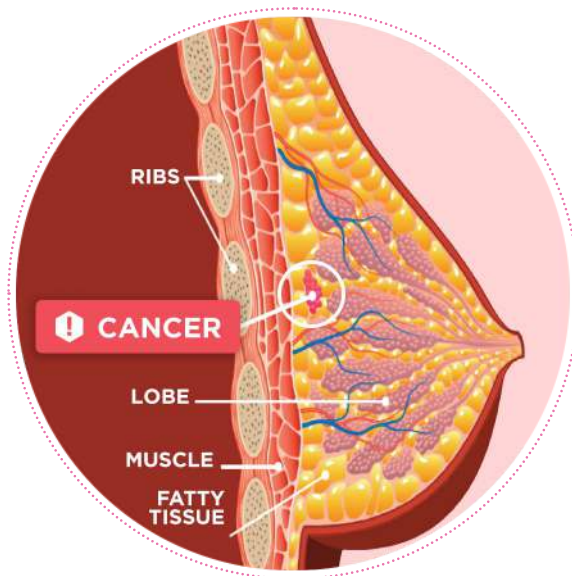
# U

## UNDERSTANDING YOUR BREASTS

Breasts are made up of fat and breast tissue, along with nerves, arteries, veins, and connective tissue that helps hold everything in place.

The main chest muscle found between the breast and ribs in the chest wall, is called the pectoralis muscle.

Your breast is a complex network of tissues, fat and cells. The way breasts look, and feel, can differ from woman to woman.



Every day, cells in our bodies divide, grow and die. Most of the time, cells divide and grow in an orderly manner. However, sometimes cells grow out of control. Breast cancer occurs when cells in the breast divide and grow abnormally and form malignant (cancerous) tumors.

“

Your breast is an ingredient of  
the greater recipe **that is you.**

”

Tauane Araújo Cruz, Advocate

# A

## ABOUT BREAST CANCER

### THE FACTS

-  All women are **at risk** of breast cancer.
-  Screening tests may find **breast cancer early**.
-  It's never too late to make **healthy lifestyle** choices.
-  Most women with breast cancer **do not have a family history** of the disease.
-  Cancer is **not contagious**. A person cannot “catch” cancer from someone who has it.
-  Not all breast cancers form **lumps**.
-  Complementary therapies such as prayer can improve quality of life, however, these therapies **do not cure or treat** breast cancer and **should not** replace medical treatment.
-  Breast cancer is **treatable**, but people can still die from it.
-  Breast cancer in **men** is rare, but it does happen.
-  **Young women** can also get breast cancer.
-  Research studies called **clinical trials** test the safety and benefits of new treatments, diagnosis methods and screening tests.

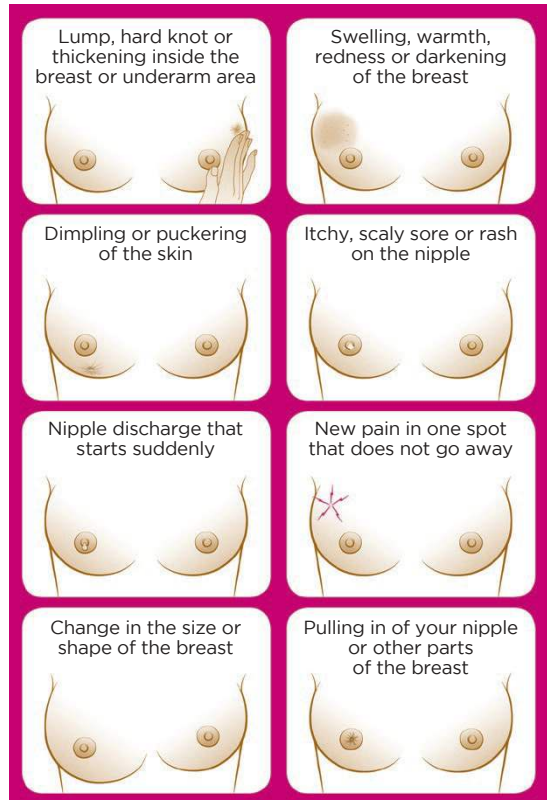


## Common warning signs of breast cancer

While the warning signs of breast cancer are not the same for all women, these are some common signs that you should be aware of.

You may or may not have noticed some of these signs or changes prior to your diagnosis. However, now that you've been diagnosed, it's important that you talk to your family about your diagnosis and any history your family may have with the disease.

Remember that breast cancer can affect anyone. While breast cancer occurs almost entirely in women, men can get breast cancer too.



No one knows the cause of breast cancer. No one knows how to prevent it. What we **do know** is the probability of **recovery** is higher if breast cancer **is detected early.**

📄 *For a printable version of Komen's breast self-awareness card visit:*  
[https://ww5.komen.org/uploadedFiles/\\_Komen/Content/About\\_Breast\\_Cancer/Tools\\_and\\_Resources/Translated\\_Materials/Breast%20Self-Awareness%20Messages%20in%20Portuguese%20FINAL%203-15.pdf](https://ww5.komen.org/uploadedFiles/_Komen/Content/About_Breast_Cancer/Tools_and_Resources/Translated_Materials/Breast%20Self-Awareness%20Messages%20in%20Portuguese%20FINAL%203-15.pdf)








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## MYTHS AND MISCONCEPTIONS

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Many factors have been studied to see whether or not they increase the risk of breast cancer. Some have been proven to be unrelated to breast cancer and do not increase (or in some cases, decrease) risk.

Based on scientific evidence, these are NOT linked to breast cancer or breast cancer risk:

-  Having an abortion
-  Wearing an underwire bra (or any type of bra)
-  Having saline or silicone breast implants
-  Drinking either coffee or tea
-  Using a cell phone
-  Using deodorant or antiperspirant use
-  Trauma or injury to the breast

Breast cancer is a disease where the cells of the breast **grow and divide** without the **normal controls**.

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## TYPES OF BREAST CANCER

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**Most common**

1. **Ductal carcinoma in situ (DCIS)** is a breast cancer inside of the milk ducts (the canals in the breast that carry milk to the nipple during breastfeeding). In DCIS, abnormal cells grow inside the milk ducts, but have not spread to nearby tissue. DCIS is a non-invasive breast cancer but, in some cases, can become invasive, and spread to other tissue.

- 2. Invasive breast cancer** occurs when cancer cells spread from the milk ducts (ductal) or lobules (lobular) to nearby tissue or other parts of the body.

Invasive breast cancer that spreads to other parts of the body is called metastatic breast cancer. Metastatic breast cancer is not a specific type of breast cancer, but rather the most advanced stage of breast cancer. Also called Stage 4 breast cancer or advanced breast cancer.



### **Less common**

- 3. Inflammatory breast cancer** is a rare and aggressive form of breast cancer with warning signs such as swelling (inflammation) and redness of the breast.
- 4. Paget disease of the nipple or breast** is a rare cancer in the skin of the nipple or surrounding the nipple. It's usually found with an underlying breast cancer.
- 5. Metaplastic breast cancer** is an extremely rare breast cancer with tumors that are larger and with cells that look different from other cancer cells.

 For more information visit:  
<http://www.oncoguia.org.br/conteudo/tipos-de-cancer-de-mama/1382/34/>

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## **TUMOR CHARACTERISTICS**

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A tumor is a mass of abnormal tissue. Those diagnosed with breast cancer have malignant tumors, which are cancerous and can invade and damage surrounding tissue. A biopsy is a test used to determine if cancer cells are present. The tissue removed from your breast during a biopsy is tested by a doctor called a pathologist. If the biopsy results in a benign finding, no further action may be required. If the biopsy result is malignant, further action is required. Health care providers can also learn more about your tumor by testing the tissue from the biopsy for hormones and monitoring its growth.

**Hormone receptor status (HR+ or HR-)**

Some breast cancer cells need hormones to grow. These cancer cells have special proteins inside, called hormone receptors. Another way to explain is that hormone receptivity (positive (+) or negative (-)) refers to how your cancer cells respond to estrogen or progesterone (hormones). If your tumor has hormone receptors (HR+), there are medications that can help treat it. Hormone receptor negative (HR-) tumors have different treatment options since hormone therapy won't work. Chemotherapy, radiation therapy, and surgery have been shown to have positive outcomes with HR- tumors. Knowing the hormone receptor status is important in deciding treatment options.

**HER2 status**

The pathologist may also test for the human epidermal growth factor receptor 2 (HER2) which is a protein that appears on the surface of some breast cancer cells. Understanding this also helps guide treatment options.

**Proliferation rate**

Knowing how fast your tumor grows (also described as proliferation rate) can help show how aggressive a tumor is and how likely it is to spread.

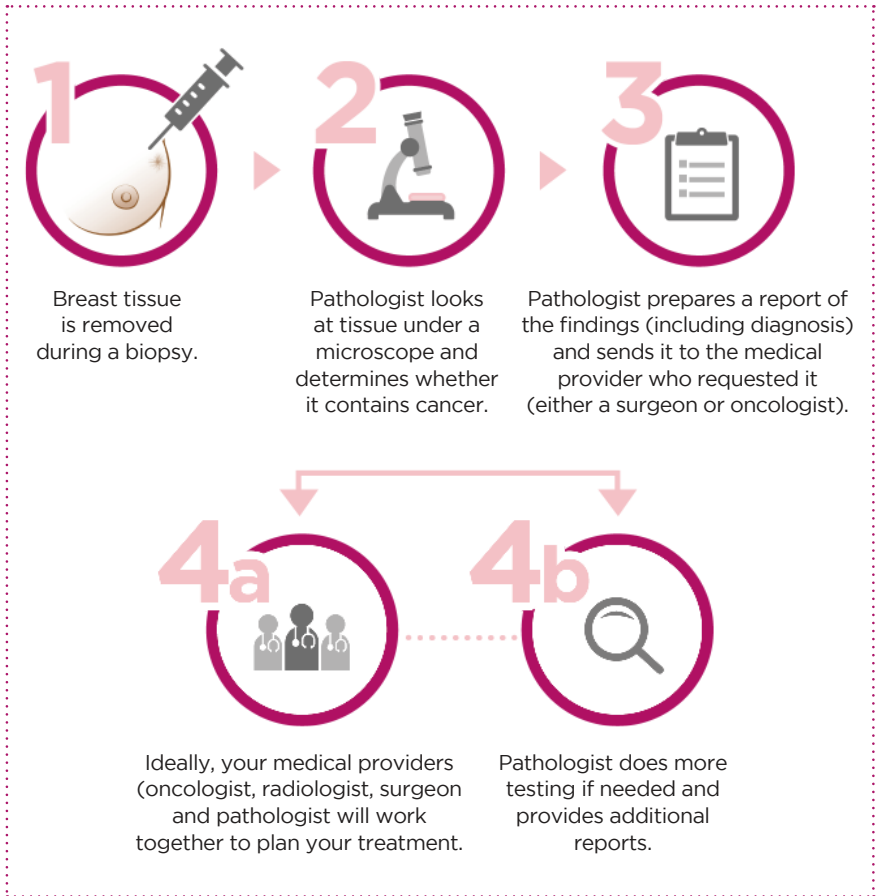
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**THE PATHOLOGY REPORT**


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Your pathology report contains important information that will help guide your team of health care providers to determine the treatment options that are right for you.

It contains the information that describes your diagnosis. Try not to focus on any one item in the report since it's the sum of all the information that's most important to your prognosis and treatment. Your will review the main findings of the report with you and answer any questions you may have. If you haven't already, familiarize yourself with the pathology report that was prepared for you. If you didn't receive it from your health care provider or pathologist, ask for one.



In the next section, you'll have an opportunity to document detailed information about your breast cancer, including data from your pathology report so that it is always available to you and easy to access.

 For more information about the pathology exam, visit:  
[http://www.breastcancer.org/Images/Pathology\\_Report\\_Bro\\_FINAL\\_2%20portuguese\\_tcm8-334610.pdf](http://www.breastcancer.org/Images/Pathology_Report_Bro_FINAL_2%20portuguese_tcm8-334610.pdf)

*reflection moment*

# you are among many

Breast cancer is the most common cancer among women around the world. In this section you'll learn that no matter who you are or where you live, breast cancer may touch your life.



“ I have a purpose. ”

Camille Costa, Survivor



# A

## ANGELA'S STORY



*I'm Angela  
and I  
was just  
diagnosed.*

### about me

My name is Angela and I am 37 years old. While relaxing one day on the couch, I felt a lump in my right breast. I hadn't felt it before, so I decided to ask my doctor about it. My doctor told me it was probably benign, but that I needed a biopsy to be sure.

I have SUS. It took a month and a half for me to make the appointment after having to go to the regulatory office and miss work to stand in line. I was finally able to get the appointment and now, three months later, I have the results of my biopsy.

### what I thought...

When the doctor told me that I have breast cancer, I didn't know what to think. I didn't even know what to ask the doctor since I didn't know much about this disease.

### how I felt...

*I'm too young to have this,  
why me? How could this be?*

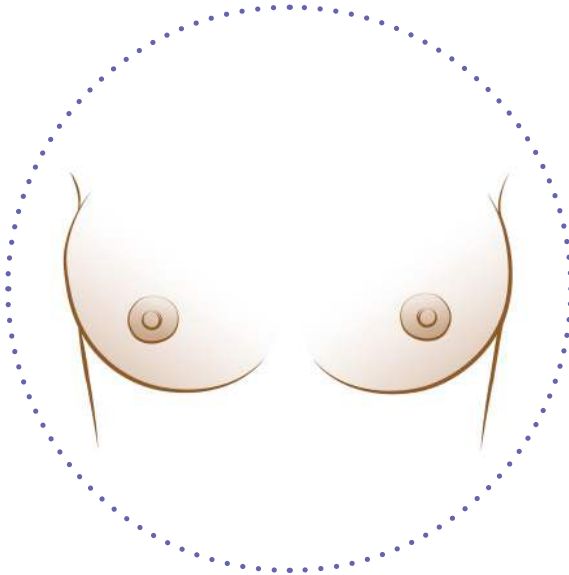
I have cried and thought about my family a lot. I have so many questions and really need someone to talk to that can help me through this and listen to me. It is frustrating to understand. I am terrified. Now what?

# U

## UNDERSTANDING YOUR DIAGNOSIS

What do you know about your diagnosis? Ask your doctor to help you document and understand the details of your diagnosis using this graphical guide.

 **Mark the location of your tumor(s) in the drawing.**



### Type of breast cancer:

- Ductal carcinoma in situ
- Lobular carcinoma in situ
- Invasive ductal carcinoma
- Invasive lobular carcinoma
- Other \_\_\_\_\_

**Stage of breast cancer (0, I, II, III, IV):** \_\_\_\_\_

**Genetic predisposition:**       Yes       No       Unknown

**Size of tumor:** \_\_\_\_\_ cm/mm


**Hormone receptor status:** \_\_\_\_\_ (HR+/-)

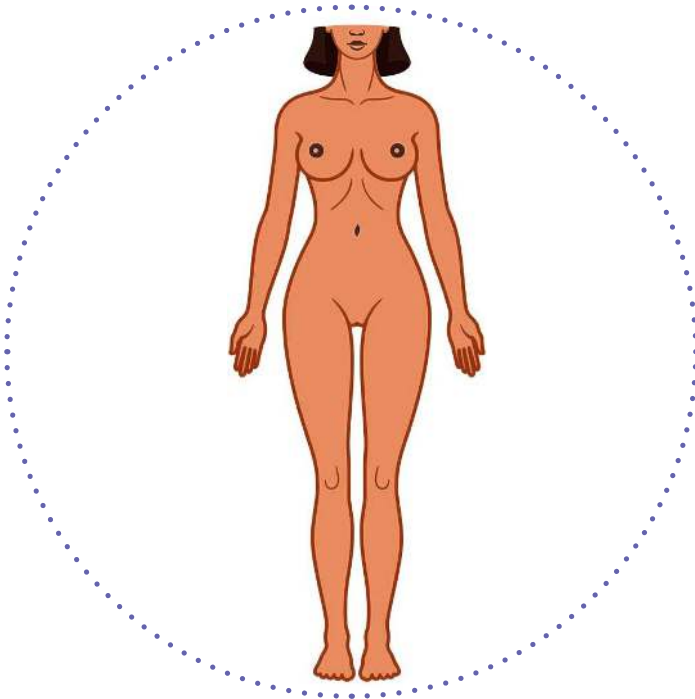
*If HR+ (Estrogen status):* \_\_\_\_\_ (ER+/-)

*If HR+ (Progesterone status):* \_\_\_\_\_ (PR+/-)

**HER2 status:** \_\_\_\_\_ (HER2+/-)

**Grade of Tumor (see below):** \_\_\_\_\_

 **In the case of metastasis or the cancer spreading to other parts of the body, indicate the location(s) where breast cancer cells are suspected.**





## Additional questions to ask your doctor about your diagnosis:

1. **How does the hormone receptor status** of my tumor affect my treatment options?

.....  
.....

2. **What type of doctors** should I see, and when?

.....  
.....

3. **How can I get a copy** of my pathology report?

.....  
.....

4. **Will my lymph nodes** (located under the arm) be removed? Why?

.....  
.....

5. **What tests will I have before surgery** to see if the cancer has spread to any other organs (liver, lungs, bones)? When will the tests be done?

.....  
.....

6. **What are the chances** that my cancer will come back – or that I will develop another type of cancer?

.....  
.....

7. **Where can I find** a support group?

.....  
.....

# D

## DEALING WITH YOUR DIAGNOSIS

A breast cancer diagnosis can bring a wide range of emotions including shock, fear, sadness and anger. You don't have to face breast cancer alone. The support of family, friends and others can be helpful as you go through diagnosis, treatment and beyond.



### *Feeling like you are losing control?*

*When told you have breast cancer, you may feel like you have lost control of your life. You might be overwhelmed by the decisions you have to make. These feelings are normal. Do not let them keep you from taking action.*



First, learn about breast cancer at your own pace. Get information about treatment options, side effects and clinical trials. Remember, doctors can discuss options, but the final decisions should be made between you and your doctor.

Knowing what to expect is another way to feel in control. It may also help to keep as normal a routine as possible. Be patient. Coping with breast cancer requires time, acceptance, a fighting spirit and support. Many people also find strength in their spirituality and faith.

*reflection moment*

# your feelings matter

It's not easy to deal with the slew of emotions that come with a breast cancer diagnosis. You should strive to be emotionally aware and understand what you are feeling.



“ It's good to have your family and friends to help you and always put God first. ”

Lucinda Leaks, Survivor



### *a promise to myself*

- I promise to seek the help of others when I need it and not be afraid to ask for the specific things I need.
- I promise to share my feelings with those I love and those who care about me.
- I promise to attempt to feel comfortable with the changes that I will experience, both physically and emotionally each day.
- I promise to share my feelings openly with my partner or spouse, to talk about my thoughts, worries, and feelings.
- I promise to remember that I deserve to feel loved and cared for and give opportunities for my partner or spouse to remain close.
- I promise to share any concerns I may have regarding physical intimacy with my doctor and get help.
- I promise to not be afraid to face my vulnerabilities.
- I promise to always recognize that it's not my fault that I have cancer.
- I promise to be open and honest with my family and loved ones and allow them to share in my journey.

# T

## TALKING WITH LOVED ONES

It's normal to fear the unknown, to think about what to say to your family, especially your children, and to think about the chance of not seeing them grow up.

When something threatens your life, your first instinct is to protect your family. There are no rules when it comes to talking about your illness, you decide how much to say, and how to say it. It's best to be as open and honest as possible. As hard as it may be, it's important to welcome questions and give honest, real answers.

For more information about talking to your spouse and children, visit our website:

🔗 *Talking With Your Children:*  
[https://ww5.komen.org/uploadedFiles/Content\\_Binaries/translate/Talking%20With%20Your%20Partner-portuguese.pdf](https://ww5.komen.org/uploadedFiles/Content_Binaries/translate/Talking%20With%20Your%20Partner-portuguese.pdf)

🔗 *Talking With Your Children:*  
[https://ww5.komen.org/uploadedFiles/Content\\_Binaries/translate/Talking%20With%20Your%20Children-portuguese.pdf](https://ww5.komen.org/uploadedFiles/Content_Binaries/translate/Talking%20With%20Your%20Children-portuguese.pdf)



### Preparing to share information:

Here are a few tips to help you as you prepare to talk to family and friends about your illness:

- 1 Think about**  
who you want to talk to in person.
- 2 Share only**  
the amount of information you are comfortable sharing.
- 3 Find comfortable places**  
where you can talk openly.




- 4 Set expectations**  
for loved ones so they know if they can share the information you told them or not.
- 5 Ask someone**  
to accompany you.
- 6 Be direct**  
and tell people exactly how they can help.

It can be difficult and sometimes tiring to tell others about your condition. If they genuinely want to learn more, here's a list of resources for more information:

**RESOURCES FOR FAMILY AND FRIENDS:**

 *Fundação Laço Rosa:*  
<http://www.fundacaolacorosa.com/pagina.php?pagina=como-ajudar>

 *Instituto Oncoguia:*  
<http://www.oncoguia.org.br/conteudo/como-ser-um-bom-amigo-de-alguem-recem-diagnosticado/9402/183/>

# B

## BUILDING A SUPPORT SYSTEM

Whether you are newly diagnosed, are facing recurrence of breast cancer or have metastatic disease, it's important to identify the right support for yourself. There are four main types of support: informational, emotional, practical and social. You may need different kinds of support at different times. Your medical team, family and friends (co-survivors) can help in many ways. Be clear about what you need.



### 1 Informational Support

**Informational support** includes finding facts about your type of breast cancer, treatment options, patient rights or learning from others who have gone through breast cancer. For example, the 'Ligue Câncer' helpline from Instituto Oncoguia 0800-773-1666, offers support and guidance for people recently diagnosed with cancer.

A social worker or counselor can also help with a wide range of issues, including helping you detect possible social barriers that may interfere with your treatment, offer support with accessing your rights as a cancer patient, as well as other community resources.

It's also important for you to feel comfortable speaking openly with your doctor and asking questions.



### 2 Emotional Support

The second type is **emotional support**. You can receive emotional support from those who listen to you, give you a hug or are just there when you need it. Counseling with a qualified therapist either one-on-one or in a group, can help you improve your mental well-being and quality of life.



### 3 Practical Support

There's also **practical support**, when someone takes you to your appointment, and cooks or cleans for you.

## RESOURCES FOR EMOTIONAL AND PRACTICAL SUPPORT:

- ✎ *Mulheres de Peito:*  
Rua Geru, 464 – Centro, Aracaju, Brazil  
79-99988-7481  
<http://www.mulheresdepeito.org.br/>
- ✎ *Associação dos Voluntários a Serviço da Oncologia de Sergipe (Avosos):*  
79-3212-4702 / 79-3212-4717  
<http://www.avosos.org.br/>

*Learning and sharing with others affected by breast cancer can help you and your family.*



### 4 Social Support

Many people, when diagnosed with breast cancer, find it helpful to meet others in similar life situations, and to share their concerns and experiences. Research shows that taking part in support groups, where you both give and receive help, is an effective way to reduce the stress and anxiety that can come with a breast cancer diagnosis.

Although support groups can be a powerful source for healing, they aren't for everyone. While some people are naturally comfortable with expressing their feelings and fears openly in a group setting, others prefer to keep their feelings to themselves or share only with close family and friends.





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## TYPES OF SUPPORT GROUPS

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Support groups can be an outlet to share your feelings or a place of comfort where you can share experiences, thoughts and feelings with others and receive the same.






There are many variations of support groups, and you can decide what works best for you. Here are some examples:

-  Informal conversations in a group setting, at a hospital, school, home, religious or community center.
-  Open or closed (by invitation only) membership groups online.
-  Psychosocial support groups led by medical professionals that may include complementary therapies such as meditation.
-  Formal support groups made up of breast cancer patients or survivors, including groups for patients with advanced disease or rare breast cancers. Sometimes, if you are faced with these cancers, it helps to interact with others who have similar experiences and concerns.

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## BENEFITS OF SUPPORT GROUPS

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-  Offers you a place to **connect with others** during an experience that can sometimes feel isolating.
-  As you progress in your journey, you can use your knowledge to **help others**.
-  If you are emotionally able to hear both positive and negative experiences, while sharing your own, the support group can offer guidance and sometimes make you **feel better and more hopeful**.
-  When you initiate your treatment, it is also a space where you can discuss the challenges of treatment and help each other cope with the **emotional stresses** of overcoming disease.
-  Provides a space where you can **gain insights** from others on dealing with practical problems such as problems at work or school, guaranteed government benefits as a breast cancer patient, and other resources for support.



We find going to the **support group** at our hospital helps us face this challenge together.

**We are a team.**

Husband, Co-Survivor



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## PATIENT RIGHTS

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Did you know that as a breast cancer patient you have rights that are guaranteed by law? Unfortunately, most people are unaware of these rights or what to do to benefit from them.

### LAWFUL GUARANTEES AS A PATIENT

Regardless of any type of contribution, all citizens must have access to the Unified Health System (SUS), which is universal and free.

**1**

Every woman, from the age of 40, has the right to a mammogram.  
(Federal Law 11,664 / 2008).

**2**

The patient has the right to access his/her medical record and request a full copy of it.

**3**

The patient has the right to request a second medical opinion, to change doctors, hospitals or health institutions.

**4**

Children and the elderly have the right to accompany the patient during their entire period of hospitalization.

**5**

SUS has an obligation to take care of the patient in an integral way, providing all available exams and treatments.

**6**

Through SUS, everyone has the right to free medication prescribed by medical order, including high cost and oral chemotherapy.

As a cancer patient, there are some specific guarantees that may be available to you, including:

- ✓ Exemption from income tax on amounts received as income from medical leave benefits.
- ✓ Pharmaceutical assistance to access medications already included in the SUS Clinical Protocols and Therapeutic Guidelines free of charge.
- ✓ Early social security and retirement fund withdrawals (FGTS, PIS/Pasep).
- ✓ Medical leave benefit (INSS/Previdência Social).
- ✓ Early retirement due to disability.
- ✓ Exemption of income taxes on retirement or pension funds.
- ✓ Reconstructive breast surgery.
- ✓ Discount or exemption of taxes for the purchase of a new adapted vehicle (IPI, IPVA, ICMS).
- ✓ Free public transportation.

🔗 *For more details and information on other benefits, talk to your social worker or visit the page on **Social Guarantees for Cancer Patients** on the website of the National Cancer Institute (INCA):*  
[http://www2.inca.gov.br/wps/wcm/connect/orientacoes/site/home/direitos\\_sociais\\_cancer](http://www2.inca.gov.br/wps/wcm/connect/orientacoes/site/home/direitos_sociais_cancer)

No matter what type of support you receive, whether it is informal from family and friends, or more formal from a support group or one-on-one therapy, social support can improve your quality of life.

## **RESOURCES FOR SOCIAL SUPPORT:**

🔗 *Municipal Secretary of Health (Aracaju):*  
[http://www.aracaju.se.gov.br/assistencia\\_social/unidades\\_de\\_atendimento\\_da\\_assistencia\\_social](http://www.aracaju.se.gov.br/assistencia_social/unidades_de_atendimento_da_assistencia_social)

🔗 *Associação dos Amigos da Oncologia (AMO):*  
Rua Perminio de Souza, 270 - Cirurgia Aracaju- SE, 49055-530  
79-2107-0077  
<http://www.amigosdaoncologia.org.br>  
[amigosdaoncologia@gmail.com](mailto:amigosdaoncologia@gmail.com)

*reflection moment*

# you are strong



“

You may encounter many defeats, but you must not be defeated. In fact, it may be necessary to encounter the defeats, so you can know who you are, what you can rise from, how you can still come out of it.

”

Maya Angelou

# M

## MAITÊ'S STORY



*I'm Maitê  
and I am in  
treatment.*

### about me

Two months ago, I was diagnosed with Stage 4 ER/PR positive breast cancer, also known as metastatic breast cancer. I remember it like it was just yesterday. When the doctor told me, I felt like I was in an earthquake. All of these thoughts ran through my mind...

*Is it my fault that I didn't feel something or notice something different? I probably shouldn't have missed my check up 6 months ago. But if I don't have a family history, I shouldn't have cancer.*

That day, the doctor sent me home a packet of information about breast cancer and talked me through my treatment options. Luckily, the healthcare team was attentive and answered all my questions, helping me understand how each treatment would affect me. They were also very clear that nothing is guaranteed, especially with an advanced stage disease like mine. They asked me to prepare my family for the best and for the worst. This was very difficult to hear and to do.



## what I thought...

Because my cancer was hormone receptor positive, I was able to receive hormone therapy. The doctor prescribed tamoxifen. My insurance plan covered 90% and I had to pay the remaining 10% copay. All I could think about as I started treatment, was how I would have to empty my savings to complete the 5 years of therapy the doctor prescribed. As I stressed out about the expenses, my social worker, Denise, talked to me about some benefits from the government that would help me offset some costs.

## how I felt...

While that made me feel a bit better, shortly when treatment began, I felt sick all the time. I had to take medical leave from work and ask one of my cousins from a different state to come stay with me for a while to help with my daily chores and to care for my children until I felt stronger.

It turned out that tamoxifen didn't work for me, and I had to have another type of treatment. After several tears and meltdowns, and feeling like I couldn't function, I am close to completing my second round of therapy.

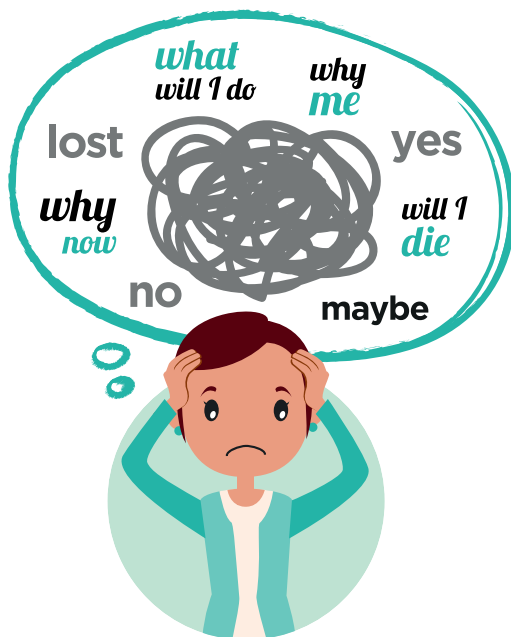
I'm not and won't be cured, and I dread the day that I will have to go through all of this again, but for now, I'm **thankful to be alive.** Hopefully the tips in this section will help you find **direction, strength and hope.**

# D

## DEALING WITH BREAST CANCER AS A PATIENT

When you are told that you have breast cancer, you may feel panic, uncertainty, helplessness or lack of control. These are all normal feelings.

The shock is intense for most people, but the right guidance and support, may give you the strength you need to begin to adjust to the reality of your diagnosis. Once the shock settles and you begin to consider what you can and cannot control, then you may be better able to begin processing your emotions in a positive way.

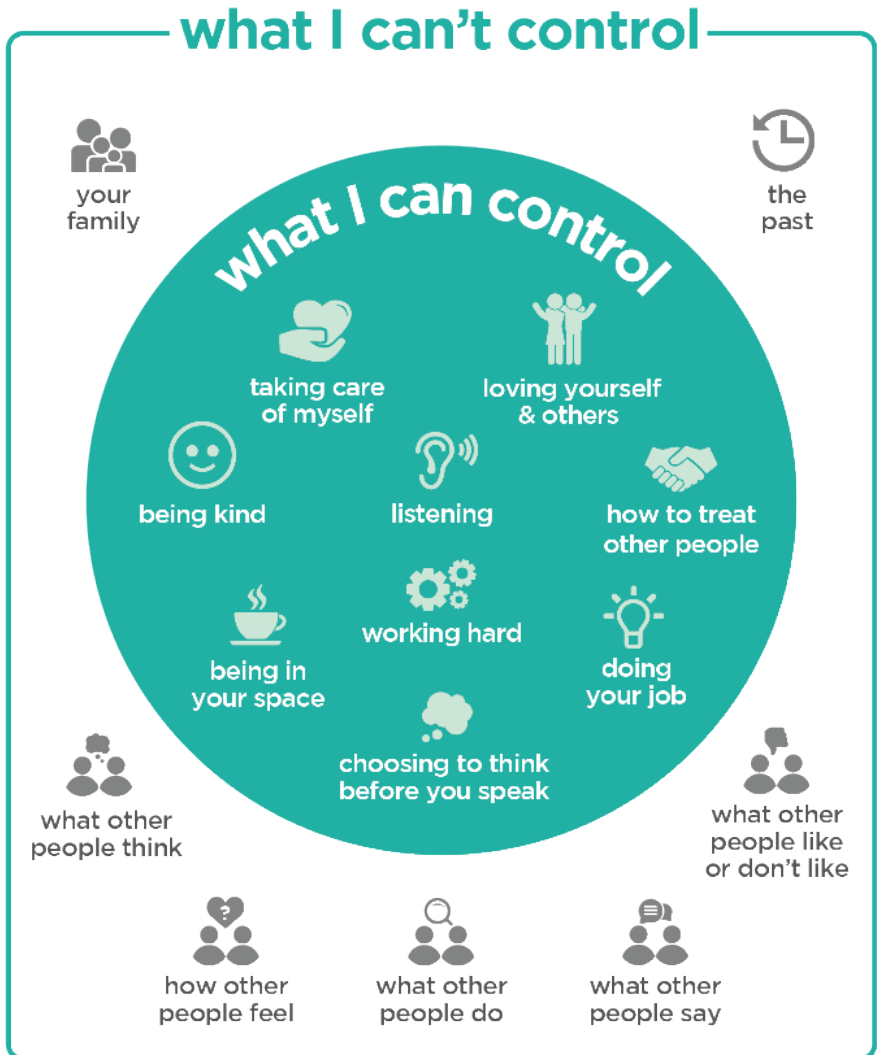


Depending on your diagnosis, and prescribed treatment plan, you may have to modify your lifestyle and activities as the symptoms and treatment side effects can affect both your physical body and your emotions.

You will likely have a lot of questions for the doctor, and your health care team, including a social worker. As your family and friends try to figure out how to be helpful to you during this time, they too will have a lot of questions, which can be overwhelming. Remember that you don't have to share everything with everyone, and you are not required to have all of the answers. This is a time for you to feel confident about the treatment process and to find sources of strength.

This is a life-changing event for most people, so make it a priority to live day by day and to take care of yourself.

On this page, you'll see an example of a "Circle of Control". This is a technique used in counseling to help individuals cope with their situation and establish some boundaries to prioritize and focus their efforts on what they are able to control. Take a look at the example and then on the blank circle, try to develop your own.





Now it's your turn. What will you include in your Circle of Control? Remember to place inside the circle the things you feel you can control, and outside the circle the things you cannot.

**what I can't control**








**what I can control**

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## COPING CHECKLIST FOR BREAST CANCER PATIENTS

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Everyone has a different way of coping with the emotions that come with a breast cancer diagnosis. The list below describes some feelings that others diagnosed with breast cancer have openly expressed as being healthy and helpful.

-  I talk with others and **share my concerns** when I face a problem.
-  I try to **lighten up** and see the humor in a tough situation.
-  On some days, I just try **not to think** about my illness.
-  I **keep busy** to distract myself from being sick.
-  If reliable information shows I need a **change in treatment**, I do it without delay.
-  Cancer has made me re-examine my life, but there are still **people and activities** I enjoy.
-  I look for **more information** when problems come up or I get bad news.

# T

## TIPS FOR LIVING WITH BREAST CANCER



### Finding strength

Finding strength to deal with the circumstances of your disease is important.

#### Identify

**the people and activities that make you feel better and healthier.**

- Enjoy the company of those who care about you
- Lead a healthy and active lifestyle, within your limitations
- Use exercise, relaxation techniques, journaling, music, or meditation to reduce stress
- Lean on your faith and spirituality

#### Find ways

**to feel more in control (learn more about your disease).**

- Learn as much as you can through your doctor, reputable websites like [komen.org](http://komen.org), books, articles, and support groups
- Learn how to take your treatment
- Help your partner/family learn about your illness
- Keep track of your symptoms and treatments

#### Take control

**of what you can (be an active participant in your treatment plan and ask questions of your doctor(s)).**

- Don't miss your appointments unless necessary
- Take your treatment as prescribed
- Attend support groups

#### Build a support network

**(communicate with others whom you trust, friends, and/or a support group).**

- Share your experiences and learn from others
- People with the same problem often understand best what you are going through

## Ask for help (don't be afraid to seek help).

- Clarify all of your doubts
- Write down a list of questions and take it to your appointments with a health professional
- Seek psychosocial support



## Day-to-day

There are simple things that you can do to help yourself through the difficulties of your treatment.

### Practical Tips

- Identify where the restrooms are wherever you go
- Have a roll of toilet paper with you in the car or take napkins in your purse for use as needed
- Have a list of symptoms and medications that you are taking easily accessible

### Garments

- Take at least one extra garment with you
- Lightweight shirts and tops with front closures are easy to slip on and can be helpful after surgery
- A shawl or lightweight jacket can help keep you warm and comfortable
- A high-quality, postsurgical bra can also be helpful

### Health & Diet

- Exercise may improve your mood. Try exercises like walking, swimming, aerobics and/or yoga
- Talk to your health care providers about bone health and how to keep your bones strong
- Some days everything might taste good and other days only a few things may taste good. A healthy eating plan may help you maintain your strength and heal



## Eating well during treatment

When you go through treatment for breast cancer, eating well can help your body:

- ✓ Stay strong
- ✓ Rebuild tissue damaged by treatment
- ✓ Deal with side effects of treatment
- ✓ Fight off infection



Be sure to eat a variety of foods: breads and grains, fruits, vegetables and dairy. You may need to eat more high-protein foods such as chicken, fish or beans during treatment. High-protein foods and plenty of calories will give your body energy needed to continue treatment.

### RESOURCES FOR HEALTH AND NUTRITION:

- 📌 *Susan G. Komen: Healthy Living:*  
[https://ww5.komen.org/uploadedFiles/Content\\_Binaries/translate/Healthy%20Living\\_Portuguese.pdf](https://ww5.komen.org/uploadedFiles/Content_Binaries/translate/Healthy%20Living_Portuguese.pdf)
- 📌 *National Cancer Institute (INCA):*  
<http://www2.inca.gov.br/wps/wcm/connect/cancer/site/prevencao-fatores-de-risco/alimentacao>



I am convinced that life is **10% what happens to me**  
**and 90% of how I react to it.**  
And so it is with you... We are in charge  
**of our Attitudes.**

Charles R. Swindoll







## Talking with your medical team

Asking questions, can help you become more knowledgeable about your disease, clear up any false information or myths and misconceptions, and help you better understand your treatment options as a patient. Don't just rely on your doctor for information. Nurses and social workers can also answer some of your questions.

### Talking with your medical team

#### Learn all you can

- Take time to learn all you can about your breast cancer and your treatment options. Don't let anyone pressure you into making a decision before you are ready.
- Talk with your doctor and make a plan. And if needed, don't be afraid to get a second opinion.

#### Learn about

your treatment choices and the benefits and risks of each.

#### Don't be afraid

to ask questions related to your sexual intimacy with your partner or personal hygiene.

- The more answers you receive, the better informed you'll be.
- Even if your question doesn't quite make sense, just ask it.

#### Someone like your caregiver

or an individual you trust might be of help in listening, taking notes and asking questions as well.

#### Write things down.

If you take notes, you can always refer back to them for clarification.

*reflection moment*

# you have a voice

Sometimes it can be overwhelming to cope with your emotions and to make sound decisions about your treatment plan. If you need more information, don't be afraid to ask your health care team. You should have an open dialogue with those caring for you.

Feel empowered to ask questions.



This is your body, your condition,  
and your treatment plan. Decide  
what is best for you.

---

# M

## MAKING TREATMENT DECISIONS



### Talk with your doctor

Talking openly with your doctor is one of the best ways to feel good about your breast cancer treatment decisions. Receiving your diagnosis can be difficult, and you may need time to process all of the information you received.

Remember that you are in control. Take the time you need to deal with your emotions and learn more. Clearly state your concerns and don't be afraid to ask questions.

Doctors are just like anyone else; they want to do their job well. Sometimes doctors may be in a hurry or they may not be able to give you a fully detailed response because they may not be aware or truly understand what you are going through. It is important for you to share your feelings and concerns with your doctors so they can help. When meeting with your doctors, it is a good idea to bring a friend, loved one, or your caregiver who can help ask questions and discuss the answers later. Having an extra pair of ears may help recall and understand the information that was given. It may be helpful to record the conversation with your cell phone or small recorder and take notes.





**Here are some tips to help you get the most of your doctor's visit:**

1

**Be prepared.**

Gather information about your health concerns. The more you know, the more comfortable you will be talking with your doctor.

2

**Organize your questions ahead of time.**

Write down your concerns and questions to help guide your conversation. You should be able to talk openly and honestly with your doctor to make sure all of your questions are answered.

3

**Tell your story.**

When your doctor comes in, ask if you can take a few minutes to briefly explain your situation and concerns. Be as specific as you can. Then give your doctor your list of questions and ask them.

4

**Give feedback.**

If your doctor's responses were helpful, say so. This kind of feedback will encourage your doctor to talk with you, listen to you and continue to help you.



**Consider your quality of life**

Whether you are newly diagnosed, a long-term survivor or still in active treatment, breast cancer can affect how you feel inside and out. They may help you cope with the emotional strain of the diagnosis and the challenges of treatment, as well as the stresses of everyday life.

Even though your diagnosis may be similar to another person's, the way breast cancer impacts your life is unique to you.

“Quality of life” describes your overall well-being, including:

- ..... Mental and physical health
- ..... Ability to perform daily roles
- ..... Sexual function
- ..... Pain, fatigue and other side effects of treatment or symptoms of the breast cancer.

Non-health related issues (such as financial concerns) are also part of quality of life. Managing side effects and other issues that have a negative impact on your quality of life is an important part of breast cancer.

 For additional information, talk to your social worker.



### Clear up any doubts

Before making a final decision about your treatment plan, ask yourself these questions:

- Will I have to travel to receive treatment?**  
Depending on where you live, it is possible that you may need to travel to another city to receive treatment. If so, you may need to consider where you will stay during treatment. The social worker at the hospital, family or friends may be able to help you.
- Can I participate in a clinical trial?**  
In a clinical trial, you have a chance to be one of the first persons trying a new treatment for cancer. You contribute to research that may one day help others. On the other hand, the trial study may not be as effective as the standard treatment options. Ask your doctor about pros and cons for you.
- What type of social support do I have?**  
Do you have someone to take you to and from your treatment? Can someone stay with you at home while you recover? Some types of treatment may require more support than others.



### Ask for help

Involve your  
support network  
**in your journey.**

**Asking for help** may be difficult, but most people are willing to help if they just know what to do – how they can help. With families, sometimes it's good to meet with a counselor and work together to plan how you will support each other and work through any problems that may arise as you fight this disease.

Feelings like worry, anger and fear often extend to close family and friends. Someone may need to take time off from work to assist you with your treatment, pay bills, cook and run errands. Understand and encourage your family members to seek some help with processing their emotions during this difficult time.

**Sharing with your children** can often be tough when you are trying to deal with your own feelings and emotions. You may think about shielding a child to keep them from worrying, but your child will know something isn't right when they begin to witness side effects like tiredness, weight changes, hair loss, or vomiting.

The amount of information you share depends on a number of factors, including age, personality, and how much they understand. Nonetheless, it is recommended that you talk openly about your treatment so that the child doesn't imagine the worst.

The child should still go to school and take part in sports and other fun activities. It may be helpful for them to seek support from their teachers, family members, and religious or spiritual leaders.

**Preparing your spouse/partner** to share in your journey can help you stay connected to one another as you go through this moment of fragility. You may feel less attractive, anxious, and even depressed. Symptoms like these can last up to 3 years after your diagnosis. Remember that your spouse/partner may also feel the same emotions and in some cases, even guilt for not being able to do more for you. The best way to stay connected is to communicate by talking, writing, or through a counselor so that you can work together through your emotional needs.

Share the declaration on the next page as a reminder for you and your spouse/partner about your shared journey.



### *our promise to one another*

- To find opportunities to talk about treatment options and respect each other's need for involvement in the decision-making process.
- To thank and appreciate you for the little things and the big things that make me feel loved and cared for.
- To speak openly about my needs and wants, as well as my likes and dislikes as we seek to strengthen one another.
- To think through things together as a team and find solutions that best meet the needs of our family and our lifestyle.
- To find time to care for ourselves spiritually and emotionally, either together or apart.
- To continue to enjoy those special activities that brought us close before breast cancer came into our lives.
- To enjoy the ups and work through the downs of going through treatment.
- To accept that we are not perfect and promise to do our best to stay positive and forgive one another.

\_\_\_\_\_

My signature

\_\_\_\_\_

Your signature

*reflection moment*

# you are not alone

There are many people who have been where you are today. They had the same fears and made the same tough choices. These people have gone through treatment, they can talk with you and answer questions.



You can find support from other people diagnosed through local nonprofit organizations, and also by asking your doctors, nurses or social workers where to find a support group.



# T

## TYPES OF TREATMENT

Treatment for breast cancer includes some combination of surgery, radiation therapy, chemotherapy, hormone therapy and/or targeted therapy. The goal of treating breast cancer is to remove the cancer and keep it from returning. Talk to your doctor about your options.

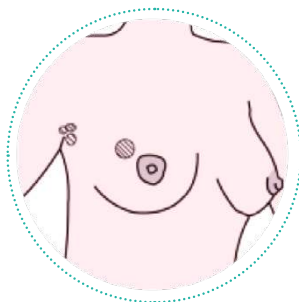
If you were diagnosed with early stage breast cancer, take the time to think through all your options so you can make the best possible choice along with your doctors.

---

### TYPES OF SURGERY

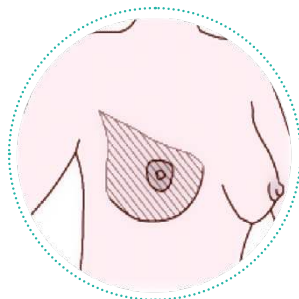
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**Surgery** may be a lumpectomy (also called breast conserving surgery) or a mastectomy. With either type of breast surgery, some lymph nodes in the underarm area (axillary nodes) may be removed and checked to see if they contain cancer.



#### a. Lumpectomy

removes the tumor and some normal tissue around the tumor. The general shape of the breast and the nipple area are preserved. With a lumpectomy, you are likely to have numbness along the surgical incision (scar).



#### b. Mastectomy

removes the entire breast. Overall survival with lumpectomy plus radiation therapy is the same as with mastectomy. Most mastectomy procedures remove all of the breast tissue including the nipple and areola. With a mastectomy, you will be numb across your chest (from your collarbone to the top of your rib cage). This numbness may not go away. Ask your doctor about a skin-sparing mastectomy and nipple-sparing mastectomy.

TYPES OF SURGERY

**SIDE EFFECTS**

from either surgery can include pain, numbness and lymphedema if lymph nodes from under the arm were removed. Learn more about lymphedema in the “Post-Treatment Section”.

**ALERT**

Exposing breast cancer to air, removing some tumor tissue with a needle biopsy or cutting through the cancer during surgery does not cause it to spread.



**Decide on the best treatment option for you.**

You may have a choice between a lumpectomy or a mastectomy. Research shows that, for women who have a choice, survival with lumpectomy plus radiation therapy is the same as with mastectomy.

Almost all women who have a lumpectomy will have radiation therapy to the breast and sometimes the underarm area, after surgery. Some women who have a mastectomy may also have radiation therapy to the breast and/or the underarm area.

The choice of surgery does not affect whether you will need chemotherapy, hormone therapy and/or targeted therapy. Drug therapies are given based on the characteristics of the tumor, not the type of surgery you have.



**Questions to ask your doctor  
BEFORE surgery:**

**1. Where** will the surgical scar(s) be?

.....  
.....

**2. Will I have a surgical drain** when I go home? If so, how will I care for it? When will it be removed?

.....  
.....

**3. Will I need** other treatments? If so, which one(s)? How long after surgery will I begin the other treatment(s)?

.....  
.....  
.....  
.....

**4. Tell me about** breast reconstruction. If I decide I want reconstruction, when can I have it (at the same time as the mastectomy or at a later date)? What are the risks? What about a prosthesis as an option? Who else should I see to discuss and plan for reconstruction or the use of a prosthesis?

.....  
.....  
.....  
.....

**5. What do I need** to consider before treatment begins if I would like to have a child after I have been treated for breast cancer?

.....  
.....



**Questions to ask your doctor**  
**AFTER surgery:**

**1. Will I need** more surgery? Or any other procedures?

.....  
.....

**2. When will I be able** to get back to my normal routine? When can I go back to work? (Be specific about your job duties and activities)

.....  
.....

**3. Are there any precautions** I should take? Any activities I should avoid?

.....  
.....  
.....  
.....

**4. When can I start** exercising again? Are there exercises I should avoid? Should I see a physical therapist?

.....  
.....

**5. What problems** should I report to you right away?

.....  
.....

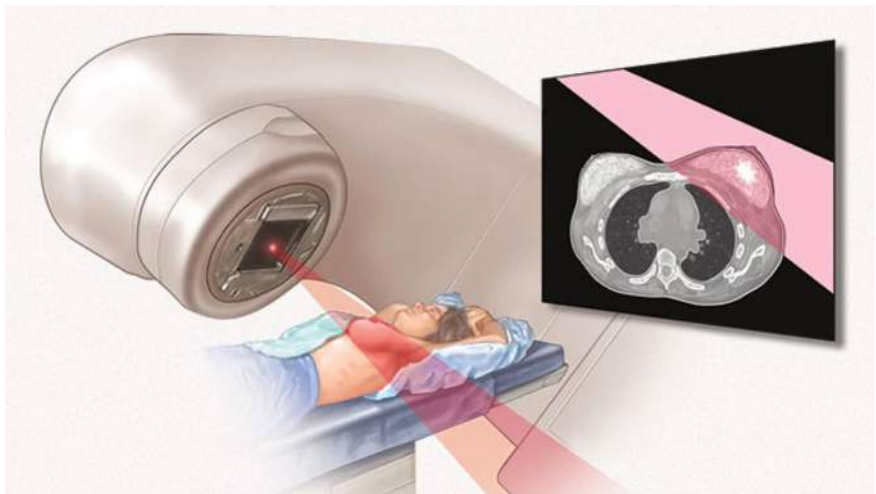
**6. Where can I find** a support group?

.....  
.....

## RADIATION THERAPY

**Radiation therapy** uses high energy X-rays to kill cancer cells that may be left after surgery. This lowers the chances of recurrence.

During each radiation therapy session, you will lie on a special table. You will get a small amount of radiation each day over a period of weeks so that the least amount of damage is caused to normal cells. This allows the normal cells to recover more quickly.



© Mayo Foundation for medical information and research.

Radiation can come from a machine outside the body (external-beam radiation therapy) or from radioactive material placed in the body near cancer cells (internal radiation therapy, known as brachytherapy). Brachytherapy is available at some medical centers and may be an appropriate option for some women. However, its long-term safety and effectiveness are still under study.

The type of radiation therapy prescribed by a radiation oncologist depends on:

- The type of cancer
- The size of the tumor and its location in the breast
- The patient's general health and medical history
- And several other factors.

During and just after treatment, the treated breast may be rough to the touch, red (like a sunburn) and swollen. Sometimes the skin may peel, as if it were sunburned. Your radiation oncologist may suggest special creams to ease this discomfort.

Try to treat your skin like you would if you had a sunburn – wear loose, soft clothing over the treated area (for example, wear a soft cotton bra without an underwire) and use lukewarm water for bathing. If you notice tenderness and sensitivity on the skin, let your doctor or nurse know so that they can help you feel better.

**RADIATION THERAPY**

**SIDE EFFECTS**

such as fatigue may begin within a few weeks of starting treatment and go away after it ends. During treatment, the treated breast may be rough to the touch, red (like a sunburn), swollen and sore.



**Questions to ask your doctor about radiation therapy:**

**1. How will radiation therapy affect** my risk of a local breast cancer recurrence, metastasis or a new breast cancer? Please explain the differences.

.....  
.....

**2. Can I come to treatment sessions** alone, or should a friend or relative come with me?

.....  
.....

**3. What clothes** should I wear to the treatment sessions?

.....  
.....

**4. Can I wear a bra** during the course of treatment?

.....

**5. What lotion, soaps or other skincare products** should I use or avoid?

.....

.....

**6. Who do I contact** if I have problems or questions about my treatment?  
What about on weekends or holidays?

.....

.....

.....

---

## CHEMOTHERAPY

---

**Chemotherapy** uses drugs to kill or disable cancer cells throughout the body. While usually given after surgery, chemotherapy given before breast surgery is called neoadjuvant or preoperative chemotherapy.

In most cases, chemotherapy is given after breast surgery (adjuvant chemotherapy), but before radiation therapy.

It is often given in cycles over 3-6 months, with days or weeks off between treatments. This gives your body a chance to recover. The schedule depends on the combination of drugs used.

**CHEMOTHERAPY**

**SHORT-TERM SIDE EFFECTS**

- Hair loss
- Nausea
- Vomiting
- Mouth sores
- Lowered blood cell counts
- Fingernail Toenail weakness
- Fatigue

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**LONG-TERM SIDE EFFECTS**

- Early menopause
- Weight gain
- Problems with memory and concentration



## Questions to ask your doctor about chemotherapy:

1. **Why do you recommend** chemotherapy for me?

.....

.....

2. **What are my chances** of a breast cancer recurrence, metastasis or a new breast cancer with these chemotherapy drugs? What are my chances of survival? Please explain the differences to me. How do these numbers compare with those for other therapy options, including a plan without chemotherapy?

.....

.....

.....

.....

3. **Was cancer found** in my lymph nodes? How many nodes had cancer? How does this affect my treatment plan?

.....

.....

.....

.....

4. **In what form and how often** will the chemotherapy be given? How many treatment sessions will I have? How long will each treatment session take?

.....

.....

.....

.....

.....



## HORMONE THERAPY

**Hormone therapy** treats breast cancer by preventing cancer cells from getting the hormones they need to grow. Hormone therapies are only used to treat hormone receptor-positive breast cancers. Hormone therapy drugs slow or stop the growth of hormone receptor-positive tumors by preventing the cancer cells from getting the hormones they need to grow.

Some hormone therapies such as tamoxifen and/or aromatase inhibitors lowers the risk of:

- Breast cancer recurrence
- Breast cancer in the opposite breast
- Death from breast cancer

### HORMONE THERAPY

#### SIDE EFFECTS

most often include menopausal symptoms such as hot flashes (and with aromatase inhibitors, joint and muscle aches).

#### NOTE

*Hormone therapy should not be confused with **hormone replacement therapy** which is used to increase hormone levels in the body to treat menopausal symptoms.*

📖 For more information, visit:  
[https://ww5.komen.org/uploadedFiles/Content\\_Binaries/translate/How%20Hormones%20Affect%20Breast%20Cancer\\_Portuguese.pdf](https://ww5.komen.org/uploadedFiles/Content_Binaries/translate/How%20Hormones%20Affect%20Breast%20Cancer_Portuguese.pdf)



### Questions to ask your doctor about hormone therapy:

1. **When will the hormone therapy** be started? How long will I take it?

.....  
.....

2. **How do I take it?** How often?

.....  
.....

3. **What are the possible side effects** of my hormone therapy? How long will they last? Which ones should I report to you?

.....

.....

.....

.....

4. **What are the risks** if I stop taking the hormone therapy?

.....

.....

.....

.....

5. **If there is a generic form** of this hormone treatment, is it as effective as the name-brand?

.....

.....

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## TARGETED THERAPY

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**Targeted therapy** drugs kill cancer cells with certain markers or proteins. An example is trastuzumab (Herceptin) used to treat HER2 positive breast cancers.

TARGETED THERAPY

**SIDE EFFECTS**

can include heart problems but most people who develop a heart problem improve after stopping the drug. Effects differ depending on the type of drug.

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## COMPLEMENTARY AND INTEGRATIVE THERAPIES

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Many people use **complementary therapies** (such as acupuncture and prayer) during or after their breast cancer care. Complementary therapies are not considered standard medical treatments (such as surgery, radiation therapy and chemotherapy) and should not be used to treat breast cancer.

However, they may be used to:

- ✓ Reduce side effects of treatment or the cancer itself (such as pain, nausea and fatigue)
- ✓ Reduce stress
- ✓ Improve quality of life

# T

## TREATMENT FOR METASTATIC BREAST CANCER

Metastatic breast cancer (also called stage 4 or advanced breast cancer) is not a specific type of breast cancer, but rather the most advanced stage of breast cancer. Metastatic breast cancer is breast cancer that has spread beyond the breast and axillary lymph nodes to other parts of the body (most often the bones, lungs, liver, or brain).

Metastasis is when breast cancer spreads beyond the breast to other organs in the body (most often the bones, lungs, liver or brain). If you've been diagnosed with early breast cancer (stage 1 or stage 2) you will probably not need additional tests for metastases. However, if you have been diagnosed with locally advanced breast cancer you may need more tests to check for metastasis.

It may be difficult to hear, but there is no cure for metastatic breast cancer. Unlike breast cancer that remains in the breast or nearby lymph nodes, you cannot get rid of all the cancer that has spread to other organs.

Although metastatic breast cancer cannot be cured, it can be treated. Treatment of metastatic breast cancer focuses on length and quality of life. As research continues and treatment improves, so does survival.



*Treatment of metastatic breast cancer is highly dependent on your individual situation, your cancer characteristics and whether you've had prior treatments. Most importantly, you and your doctor should discuss your options and agree on the best care plan for you.*



## Tips for speaking with your doctor:

- 1 Listen carefully**  
to your doctor but also make sure the doctor listens to you.
- 2 Determine what is important for you**  
quality of life, pain control or an aggressive treatment that may have severe side-effects, and communicate clearly with your doctor.
- 3 Ask your doctor**  
to explain in detail your treatment plan.
- 4 If you don't feel comfortable**  
with your doctor, depending on your situation, it may be possible to ask to see another doctor and get a second opinion.

For some people with metastatic breast cancer, it's important to assess the positives and negatives of treatment. Asking yourself some of these questions as you learn more about your treatment options may help.



- What is your current state of health? Can you tolerate more aggressive treatment?
- How important is it for you to maintain your lifestyle, feel comfortable and be able to enjoy your time with family?
- Is the cost of treatment a concern for you?
- Would you be willing to try an experimental drug?







**Questions to ask your doctor about metastatic breast cancer:**

**1. Where else in my body** has the breast cancer been found?

.....  
.....

**2. What is my prognosis** (chances for survival)?

.....  
.....

**3. What are my treatment options?** Which options do you suggest for me and why?

.....  
.....

**4. What are the possible side effects** of this treatment(s)? How long will they last?

.....  
.....  
.....

**5. What lifestyle changes** will I have to make?

.....  
.....

**6. Where can I find** a metastatic breast cancer support group? What support is available for my family?

.....  
.....  
.....



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## TYPES OF TREATMENT FOR METASTATIC BREAST CANCER

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### 1 Treatment for hormone-receptor positive breast cancer

If the cancer is hormone receptor-positive, the first treatment is **hormone therapy**.



Hormone therapy drugs work by preventing the cancer cells from getting the estrogen they need to grow. This approach of blocking estrogen is also known as anti-estrogen therapy.



Hormone therapy depends on menopausal status and any past hormone treatment for early breast cancer.



Some hormone therapy drugs (like tamoxifen and aromatase inhibitors) are given in pill form. Others are given by injection.

As with hormone therapies, if the first chemotherapy drug (or combination of drugs) stops working and the cancer begins to grow again, a second or third drug can be used. It is not uncommon for multiple drugs to be prescribed during the course of treatment for metastatic breast cancer.

### 2 Targeted therapies to treat metastatic breast cancer:

**Targeted therapies** are drugs designed to attach a particular type of molecular agent or pathway involved in the development of cancer. Unlike chemotherapy drugs, targeted therapies kill cancer cells with little harm to healthy cells. A targeted therapy will only work on cancers that have the specific marker it was designed to attack.

#### A Treatment for HER2-positive breast cancer

If the cancer is HER2-positive, anti-HER2 targeted therapy drugs such as trastuzumab (Herceptin), is used treat HER2-positive early and locally advanced breast cancer.

- HER2-negative breast cancers have little or no HER2 protein.
- HER2-positive breast cancers have a lot of HER2 protein.
- Trastuzumab, given through an IV, can shrink tumors and slow the growth of HER2-positive metastatic breast cancers when used alone or combined with chemotherapy.

In addition to trastuzumab, there are several other therapies available that may be used to treat HER2-positive breast cancers.

TREATMENT FOR HER2-POSITIVE BREAST CANCER

**IMPORTANT  
ADVANCES**

If you rely on SUS, it's important to know that in 2017, SUS approved and began the use of trastuzumab for treatment instead of only for preventing metastasis. In December of 2017, ANVISA (Brazil National Health Surveillance Agency) responsible for the approval and supervision of health products, also approved the use of Zedora® a medication very similar to trastuzumab and with similar effects for the treatment of patients with HER2+ breast cancer in hopes that this will decrease overall treatment costs.



**Ask your doctor about new drugs and therapies that may help you.**



**Hormone therapy for metastatic breast cancer**

Some people are diagnosed with metastatic breast cancer after having received treatment for early-stage breast cancer. If this is the case for you, and your cancer uses estrogen and progesterone hormones to grow and spread, hormonal therapy may be an appropriate treatment. Also known as endocrine therapy, the goal of this treatment is to lower the level of estrogen and progesterone in the body or block these hormones from getting to cancer cells so that the cancer cannot use them to grow.

Some targeted therapies except chemotherapy may be recommended along with hormonal therapy for metastatic breast cancer. Examples include: lapatinib and letrozole, and palbociclib and fulvestrant. Hormone therapies are not as widely recommended for cancers that are worsening quickly and affecting the function of organs of the body.



**Ask your doctor what is right for you.**

## 3 Triple negative breast tumors

**Triple negative breast cancer** is an aggressive form of cancer. Triple negative breast tumors have little or no HER2 protein and also don't have estrogen or progesterone receptors. This type of cancer is more common in younger women and in African-American or Hispanic/Latina women. Because the cells don't have hormone receptors, hormone therapy is not helpful.

Even though triple negative tumors are aggressive, they can be treated successfully. Treatment for this type of cancer includes a combination of surgery, radiation therapy and chemotherapy. Triple negative breast cancers appear more likely to recur than other breast cancers. They tend to recur within a few years, and triple negative breast cancers have a poorer prognosis than other breast cancers.

 *Learn more about recurrence in the next section.*

**Breast cancer isn't  
one disease as we once thought,  
but a family of diseases –  
some aggressive, some advanced, some  
deadly – and all requiring  
our best efforts to  
treat and cure.**

## COST OF TREATMENT



Cancer treatment is costly. It takes a toll on your finances, your health, your emotions, your relationships, your time and your lifestyle.

If you don't have insurance or are unemployed, there are resources available to help you.

Don't miss your treatments or doctor visits. Someone at the doctor's office or at the clinic or hospital may be able to give you a list of organizations that offer financial assistance.

### RESOURCES FOR FINANCIAL ASSISTANCE AND PATIENT RIGHTS:

📌 *National Cancer Institute (INCA):*  
[http://bvsmms.saude.gov.br/bvs/publicacoes/direitos\\_sociais\\_pessoa\\_cancer\\_3ed.pdf](http://bvsmms.saude.gov.br/bvs/publicacoes/direitos_sociais_pessoa_cancer_3ed.pdf)

📌 *Femama:*  
<http://www.femama.org.br/novo/associadas.php>

**ABC** Here are some tips in case you are still able to earn an income through work during your treatment:

1 **If you feel** that your co-workers can be a source of support, you may wish to share your situation with them.

2 **Plan chemotherapy treatments** late in the day or right before the weekend to allow time to recover.

- 3 **Explore options**  
like working from home on some days. This might help you feel less tired and allow you to take care of yourself easily if you have problems.
- 4 **Getting help at home**  
can mean more energy for work. Allow chores to be divided among friends and family members who want to help.
- 5 **Keep your supervisor**  
up to date on how well your schedule or other changes are working for you and how he/she can help.
- 6 **Make a detailed list**  
of your job duties so you can direct others in handling things when you're out of the office.

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## COMPLETE YOUR TREATMENT PLAN

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Breast cancer treatment is most effective when all parts of the treatment plan are completed. Medications, such as oral chemotherapy and hormone therapy (tamoxifen and aromatase inhibitors), only work if you take them as prescribed. And, radiation therapy is most effective when you finish the entire course.

*People who complete their treatment plan have a higher chance of survival than those who don't. This is why it's important to follow the treatment plan for medications and other therapies prescribed by your doctor.*



If you have any side effects, tell your doctor right away. He/she may be able to treat your symptoms or change your treatment plan to ease symptoms.

*reflection moment*

# you are beautiful



“

Beauty like her is not born. It is suffered for, earned and shaped, until the day that it finally becomes. For there is nothing quite as beautiful as the honesty of breaking and the strength of fragility.

Becca Lee

”

# F

## FERNANDA'S STORY



*I'm Fernanda  
and I completed  
my treatment  
plan.*

### about me

Last year was extremely difficult. My world was turned upside down when I was diagnosed at stage 3 with HER2, ER, PR positive breast cancer. The cancer was found in my left breast and 4 lymph nodes. I had to rely on my daughter and a long-time friend who came from the South to stay with me while I was in treatment. Between the two of them, they made sure I had someone to talk to, appropriate foods to eat according to my treatment plan, a clean home, and strength to recover from the many side effects of chemotherapy.

### how I feel...

Despite having lost all of my hair, I feel grateful to be alive, and faithful that God has great plans in store for the remainder of my life here on earth. Last week I celebrated my 45th birthday, and my husband and I made the very difficult decision to fertilize one of the embryos we had stored prior to starting my treatment.

*We are optimistic, excited  
and looking forward to  
life beyond breast cancer!*



## LATE EFFECTS OF BREAST CANCER TREATMENT

Once breast cancer treatment ends, most side effects of treatment go away. However, you may have some long-term side effects and new health effects that may occur months or even years after treatment ends. These late effects of treatment vary for each person. Some common effects include pain, lymphedema, fatigue, emotional distress and intimacy issues that affect one's quality of life.

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### PAIN

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For most people, any pain from breast cancer treatment is temporary and goes away after treatment ends. For some, pain can be a long-term effect of breast cancer treatment. Some experience pain in the location of surgery, joint pain and achiness, and/or muscle pain.

Pain control is important. Let your health care provider know as soon as possible if you experience any pain or discomfort. Waiting until pain is severe before seeking relief can make it harder to control and may require more medication.

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### LYMPHEDEMA

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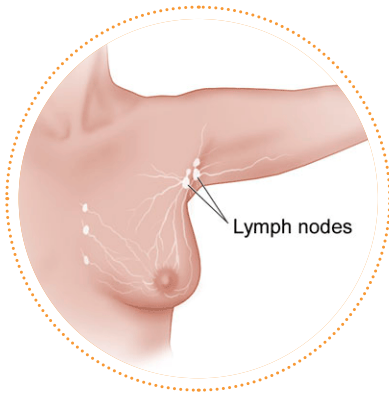
When lymph nodes are removed (called axillary surgery) or are treated with radiation therapy, some of the lymph vessels can become blocked. This may keep lymph fluid from leaving the area, and result in fluid build-up that causes swelling in the arm, hand or other areas.



#### What is lymphedema?

**Lymphedema** usually develops within 3 years of breast surgery and can occur immediately after surgery or many years after treatment. Fortunately, most survivors don't get lymphedema.





Source: National Cancer Institute.

Some lymph nodes (axillary nodes in the underarm area (axilla) may be removed during breast cancer surgery. Modern surgery removes fewer axillary nodes than in the past.

As a result:

- ✓ Lymphedema is less common now than in the past.
- ✓ The cases that occur are less severe in terms of the impact on movement and the way the arm looks.



Images courtesy of Stanley G. Rockson, MD, Allan and Tina Neill Professor of Lymphatic Research and Medicine, Stanford School of Medicine.



## What are the symptoms of lymphedema?

If you notice early signs of lymphedema, talk with your doctor. Some common symptoms may include:

- Swelling in the arm or hand (you may notice a tighter fit of rings or watches)
- Feelings of tightness, heaviness or fullness in the arm or hand
- Feelings of tightness in the skin or a thickening of the skin
- Pain or redness in the arm or hand



## **Tips that may reduce the risk of injury or infection to the arm:**

We do not know how to prevent lymphedema. Injury or infection to the arm may trigger it. It is a good idea to take steps to reduce the risk of injury or infection. The tips below have not been proven in clinical trials but may work for some people.

- 1 Treat infections**  
of the at-risk arm and hand right away.
- 2 Wear gloves**  
when doing house or garden work.
- 3 Keep skin clean**  
clean and well-moisturized.
- 4 Use the opposite arm**  
when having blood drawn, getting injections or having blood pressure taken.
- 5 Avoid sunburn**  
and excess heat from saunas, hot baths, tanning and other sources.
- 6 Do not cut**  
the nail cuticles of the at-risk hand.
- 7 Use insect repellent**  
when outdoors.
- 8 Avoid injuries,**  
including scratches and bruises, to the at-risk arm.
- 9 Rest the at-risk arm**  
in an elevated position (above the heart or shoulder).



## How is lymphedema treated?

Complex decongestive therapy can help to improve movement and reduce pain and swelling in the affected arm.

The goal of this therapy is to decrease swelling and infection related to lymphedema through a combination of:

- Skin and nail care
- Compression bandages or sleeves (these apply pressure around the arm and help push lymph fluid out of the arm)
- Exercises (closing and opening a fist, for example)
- Manual lymphatic drainage (a special type of massage)
- Physical therapy

Other treatments include exercise, weight loss, surgery and use of a compression device (a pump connected to a sleeve that inflates and deflates to apply pressure to the arm). New treatments for lymphedema, such as laser therapy, are under study.

### RESOURCES ON LYMPHEDEMA:



*Instituto Arte de Viver Bem:*  
<http://www.artedeviverbem.org.br/2015/linfedema-apos-cirurgia-de-cancer-de-mama-2/>



*Instituto Oncoguia: Prevenção do Linfedema:*  
<http://www.oncoguia.org.br/conteudo/linfedema/88/5/>



## QUALITY OF LIFE AFTER TREATMENT

Now that you've undergone treatment, it is important to be vigilant about changes in your overall health, as well as symptoms like fatigue, loss of appetite, weakness and stress. Schedule regular visits with your healthcare provider and write down any changes you notice so that you don't forget to discuss with your doctor.

“Quality of life” describes your overall well-being, including:

- 1 Mental and physical health
- 2 Ability to perform daily roles
- 3 Sexual function
- 4 Pain, fatigue and other side effects of treatment or symptoms of the breast cancer.

Managing side effects and other issues that have a negative impact on your quality of life is an important part of breast cancer care.

### 1 Mental and physical health

Worrying about your situation, your relationship with family members and even your employment can contribute to chronic stress, anxiety and depression. Feeling overwhelmed with emotions may cause you to lose sleep, cut back on exercises and eat unhealthily.

#### Talking to a psychologist

Some people find it helpful to talk to a psychologist who can teach you relaxation exercises, meditation and other approaches without the use of medicines.

#### Staying active

Physical activity and eating a healthy diet is also very important as you begin to reconnect with your body, improve your mobility and work through any physical limitations you may have.

Exercising your body also exercises your mind, and can help:

- ✓ Improve sexuality
- ✓ Reduce depression
- ✓ Improve body image
- ✓ Reduce fatigue and stress
- ✓ Reduce anxiety

Talk to your health care provider about resources like physical and occupational therapy and personal training that might be helpful to you.

## 2 Finding normalcy again

Do not try to force yourself to resume life the exact same way it was before. Your mind and body have gone through a transformation and there is nothing wrong with taking the time you need to readjust.

### Leaning on family and friends

As you transition out of treatment and into a process of recovery, support from family and friends can make a big difference. Other ways to engage your family and friends:

- ✓ Attend support group meetings together to share and learn from others' experiences.
- ✓ When you feel ready, participate in outings, special events and arrange a dinner with close friends.

“ I've discovered in my darkest hours, that “what lies within” me is **tenacity**, an unexplainable **sense of humor**, **resilience**, a liberating **boldness** that I did not have before, and a **joyful** presence and **courage**. In the words of John Wayne, “Courage is being scared to death, but saddling up anyway”. So, I persevere in the “**saddle**” of cancer and it too will be “**a tiny matter**” one day soon!

Renee Wilson, Survivor



## **Self-esteem and self-image**

Breast cancer treatment can cause weight changes, hair loss, and surgical scars that may leave you feeling less attractive and less confident. Tips to help you regain your confidence:

- 1 Be compassionate to yourself.**  
Avoid being hyper critical and do the things that you truly enjoy.
- 2 Set small, achievable goals,**  
like putting on lipstick at least 3 times a week or dressing up in your favorite ensembles at least once a week.
- 3 Use accessories**  
such as stylish hats, wigs and scarves to add an extra feminine touch.
- 4 Surround yourself**  
with people who appreciate you.
- 5 Don't compare yourself**  
to others or how you used to be. You've come this far because you appreciate life. Embrace the now.

### **RESOURCES FOR WIGS AND PROSTHESIS:**

 *Associação dos Voluntários a Serviço da Oncologia em Sergipe (Avosos):*  
<http://www.avosos.org.br/>

 *Fundação Laço Rosa:*  
<http://www.fundacaolacorosa.com/>

## **Financial Assistance**

After treatment, you might realize some expenses associated with lymphedema care and supplies, durable medical equipment, transportation, prosthesis and wigs, or even childcare and/or eldercare to help you as you establish a new sense of normalcy. Talk to your social worker about where you may be able to find some free and/or low-cost resources.



## Getting back to work

Many people who work at the time of their breast cancer diagnosis eventually return to work during or after treatment. The process of adjusting to the work environment can be both physically and mentally draining. Some employers are flexible while others are demanding, and the type of work you do may affect whether you are able to adjust or not.

*As you prepare to return to work, talk to your employer about options like a modified work schedule or telecommuting. Understanding that you may get tired easily or have trouble focusing can help avoid unnecessary frustration in the workplace.*



**Here are some tips to help you as you prepare your return to work:**

- ✓ Get consent from your doctor with specific details regarding prohibited activities and other issues, including cognitive issues that may limit your work.
- ✓ Understand your rights and benefits as an employee.
- ✓ Schedule a meeting with your human resources department to talk about the details of your return.
- ✓ Take short breaks to boost energy during the day.
- ✓ Use notes to remember important meetings/tasks.
- ✓ Maintain an open dialogue with your manager about expectations and your performance.
- ✓ Only share what you feel comfortable sharing with co-workers.


## 3 Sexuality and intimacy

If you are struggling with issues affecting your sexuality, you are not alone. After months of treatment, you may feel detached or disconnected from the pleasure your body once gave you. Common issues faced by breast cancer survivors include a lack of desire, problems with lubrication and orgasms.

Because problems that affect sexuality and intimacy are common and can increase over time, maintaining an open line of communication and being honest with your partner about how he/she can best show support and affection is extremely important. Health care providers such as a social worker, psychologist, sex therapist or counselor can offer support and resources.

### RESOURCES ON SEXUALITY AND INTIMACY:

 *Femama: Batalhadoras:*  
<http://www.batalhadoras.org.br/artigo/261/o-impacto-do-cancer-de-mama-na-sexualidade#.WyVAFqczrIV>

 *Instituto Oncoguia: Sexualidade apos o cancer:*  
<http://www.oncoguia.org.br/conteudo/o-corpo-e-a-sexualidade-apos-o-cancer-de-mama/1378/266/>



*reflection moment*

# you persevere



“

If you can't fly, then run,  
if you can't run, then walk,  
if you can't walk, then crawl,  
but whatever you do,  
you have to keep moving forward.

”

Martin Luther King Jr.

# R

## RAQUEL'S STORY

*I'm Raquel  
and I  
survived  
twice.*



### about me

Two months after getting married to the love of my life, I was diagnosed with Stage 2 breast cancer in my right breast. Because it was small, and the lymph nodes were negative, I had a lumpectomy and axillary dissection with radiation treatments. I worked full-time during treatment and had support from my spouse and friends.

Nearly three years later, when I started feeling normal again, my doctor tells me during a regular checkup that I had another lump, now in my left breast. Once the test results came back positive for malignant cancer it was as if the sky had fallen! I was devastated and frightened.

### what I thought...

Over the next few weeks, I went to several doctors to make sure the diagnosis was accurate. Before me, my mother, my sister and my grandmother all had breast cancer. In the back of my mind, I somehow always feared that the cancer would come back one day. Reflecting on the impact of this second diagnosis on my family, I decided on a mastectomy without reconstruction.

*My spouse said that I was much more than my two breasts and that he loved me for being simply me.*

# B

## BREAST CANCER RECURRENCE

When breast cancer comes back after treatment, doctors call it a recurrence or recurrent breast cancer. Breast cancer can recur at the original site (called **local recurrence**) or return and spread to other parts of the body (called **metastasis**).

Finding out that breast cancer has come back can cause feelings of shock, anger, sadness, and fear. You might feel more cautious, guarded, and less hopeful than ever before. You may be disappointed in your body and your cancer care team.

Many issues and questions come with cancer recurrence like Why me? Could I have done something to prevent the recurrence? This section offers you some tips on how to overcome the challenges associated with breast cancer recurrence.



My **mission** in life is not merely to **survive**,  
but to **thrive**; and to do so with some  
**passion**, some **compassion**,  
some **humor**, and some **style**.

Maya Angelou



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### LOCAL RECURRENCE

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Breast cancer that occurs at the original site is usually found on a mammogram, during a physical exam by a health care provider or when you notice a change. It is normally treated in the same way as the first breast cancer.



### Local recurrence after lumpectomy

If you had breast conserving surgery (lumpectomy) the first time, the second treatment will usually involve a mastectomy and may also include chemotherapy, hormone therapy and/or targeted therapy.



### Local recurrence after mastectomy

Even though the entire breast is removed in a mastectomy, breast cancer can still return to the chest area. The more lymph nodes with cancer at the time of the mastectomy, the higher the chances of breast cancer recurrence.

Local recurrence after a mastectomy is usually treated with surgery followed by radiation therapy (if radiation therapy wasn't part of the initial treatment), but may also include chemotherapy, hormone therapy and/or targeted therapy.

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## METASTASIS

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Metastasis is usually found when symptoms are reported during follow-up office visits with your health care provider. Common symptoms:

Shortness of breath • Weight loss • Bone pain

Depending on your symptoms, some follow-up tests may include:



Blood tests (including tumor marker tests)



Imaging tests (such as bone scans, CT scans, PET scans and chest X-rays)



A tissue biopsy (to check if a suspicious finding is a recurrence of breast cancer)

### Pain management for metastasis

Metastatic breast cancer can cause pain in the areas where the cancer has spread. It's important to control any pain as it can interfere with daily life and make other side effects, such as fatigue, seem worse.

# D

## DEALING WITH BREAST CANCER RECURRENCE

Reliving the emotions that come along with a breast cancer diagnosis for a second time can be extremely difficult. It is normal to place blame, feel angry, and contemplate death.



Here are some tips to help you address your emotions:

- 1 Placing blame.**  
You might be thinking about what could've possibly gone wrong with the prior treatment that caused you to get breast cancer again. It is good to have a clear discussion with your doctor and express your feelings in a constructive way to ensure that there is a good level of trust to help you focus on your new treatment.
- 2 Anger.**  
Feeling angry and upset about a cancer recurrence is completely normal. Ask your doctor if you should seek the help of a therapist or counselor to help ease these feelings.
- 3 Depression and anxiety.**  
Some degree of depression and anxiety might be common in people who are coping with breast cancer recurrence but this can be resolved by seeking treatment, improving your physical symptoms, and using coping skills to boost your mood.
- 4 Self-doubt.**  
Doubting your past treatment decisions or lifestyle choices either during or after your previous treatment will not help you go forward. Do your best not to look backward and instead to focus on what you can do to get better from today on.
- 5 Dealing with a fear of death.**  
Death is a painful prospect, one that calls for thoughtful processing and even preparation. Talk with your health care provider to determine your true risk of death and hopefully establish a treatment plan that you are optimistic about.



*Successful treatment of the breast cancer recurrence demands that you overcome fears, anxiety and negative emotions that may negatively affect your treatment.*

Think of the positives:

- ✓ You know more today than you knew the first time you were diagnosed.
- ✓ Your loved ones have gone through this with you and are more conscientious of how and when they can be of assistance.
- ✓ You know your health care team and should feel comfortable discussing your situation and gathering detailed information to help you make the best treatment decisions for you.



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Breast cancer touches the lives of millions each year. In this guide Angela, Maitê, Fernanda and Raquel shared their personal experiences and the impact breast cancer had on their lives. They taught us that it's when you least expect it that a storm comes through to make a mess of the life we began planning even as a young child. When certainties are made uncertain, and the future takes an uncharted course. That moment when everything seems out of control is the moment when prayer, positivity and love uncover the strength and hope that lies within. This is when you realize that cancer does not define you, and never will.

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# GLOSSARY

## **Adjuvant (systemic) therapy**

Treatment given after surgery and radiation to treat breast cancer that may have spread to other parts of the body. It may include chemotherapy, targeted therapy and/or hormone therapy.

## **Alternative therapy**

Therapies used instead of standard treatments. They are different from integrative and complementary therapies, which are used in addition to standard treatments.

## **Axillary lymph nodes**

Lymph nodes in the underarm area. Lymph nodes are small groups of immune cells that filter lymph fluid within the lymphatic system.

## **Aromatase inhibitor**

Hormone therapy drugs that lower estrogen levels in the body by blocking aromatase, an enzyme that converts other hormones into estrogen. Aromatase inhibitors are used to treat postmenopausal women with hormone-receptor positive breast cancer.

## **Benign**

Non-cancerous.

## **Biopsy**

Removal of tissue or cells to be tested for cancer cells.

## **BRCA1 and BRCA2 gene mutation (Breast Cancer genes)**

A mutation (change) in one gene can increase a person's risk of breast, ovarian and certain other cancers.

## **Chemotherapy**

The use of drugs to kill cancer cells.

## **Clinical breast exam**

A physical exam done by a health care provider to check the look and feel of the breasts and underarm for any lumps or changes.

## **Clinical trials**

Research with people who volunteer to take part in a study. These studies usually test the benefits of possible new ways to prevent, detect, diagnose or treat disease.

## **Complementary therapies (integrative therapies)**

Therapies (such as acupuncture or massage) used in addition to standard medical treatments. Complementary therapies are not used to treat cancer, but they may help improve quality of life and relieve some side effects of treatment or the cancer itself. When complementary therapies are combined with standard medical care, they are often called integrative therapies.

## **Cysts**

Fluid-filled sacs that are almost always benign.

## **Ductal carcinoma in situ (DCIS)**

A non-invasive breast cancer that begins in the milk ducts of the breast, but has not invaded nearby breast tissue. Also called stage 0 or pre-invasive breast carcinoma.



**Estrogen**

A female hormone produced by the ovaries and adrenal glands that is important to reproduction. Some cancers need estrogen to grow.

**Fibrocystic condition (fibrocystic changes)**

A general term used to describe a benign breast condition that may cause painful cysts or lumpy breasts.

**HER2/neu**

A protein that appears in high numbers on the surface of the breast cancer cells of about 15 to 20 percent of breast cancer tumors. Tumors with high levels of HER2/neu can be treated with the targeted therapy drug trastuzumab (Herceptin).

**Hormone receptors**

Specific proteins found on some cancer cells. Hormones in the body attach to these proteins. A high number of hormone receptors on a breast cancer cell often means that the cancer cell needs the hormone to grow.

**Hormone therapy**

Treatment that works by keeping cancer cells with hormone receptors from getting the hormones they need to grow.

**Invasive breast cancer**

Cancer that has spread from the original location (milk ducts or lobules) into the surrounding breast tissue and possibly into the lymph nodes. Invasive ductal cancer begins in the milk ducts. Invasive lobular cancer begins in the lobules of the breast.

**Lobular carcinoma in situ (LCIS)**

A condition where abnormal cells grow in the lobules of the breast. LCIS increases the risk of breast cancer.

**Lumpectomy (breast conserving surgery)**

Surgery that removes only part of the breast — the part containing and closely surrounding the tumor.

**Lymphedema**

Swelling due to poor draining of lymph fluid that can occur after surgery to remove lymph nodes or after radiation to the area. It most often occurs in the upper limbs (arm, hands, fingers), but can occur in other parts of the body.

**Malignant**

Cancerous.

**Mammogram**

An X-ray image of the breast. Mammography is the best screening tool used today to find breast cancer early.

**Mastectomy**

Surgical removal of the entire breast. Depending on the procedure, it may also include removal of the lining of the chest muscles and some of the lymph nodes in the underarm area.

**Menopausal hormone use (menopausal hormone therapy; hormone replacement therapy)**

The use of hormone pills that contain estrogen (with or without progestin) to ease symptoms of menopause.

**Metastasis**

The spread of cancer from the breast to other parts of the body (most often the lungs, liver, bones or brain).

**Neoadjuvant therapy**

Chemotherapy or hormone therapy given before surgery to shrink a tumor.

**Oncologist**

A specialized doctor who treats people with cancer.

**Palliative care**

The combination of symptom and pain management therapies used to comfort and support those with a life-threatening illness.

**Progesterone**

A natural hormone made by the body that is important in menstrual cycles and pregnancy.

**Progestin**

Any substance (laboratory-made or natural) that has some or all of the effects of progesterone in the body. It is used in birth control pills, menopausal hormone therapy and other types of hormone treatment.

**Prognosis**

The chance of recovery (survival).

**Prosthesis (breast)**

An artificial breast form that can be worn under clothing after a mastectomy.

**Radiation therapy (radiotherapy)**

Treatment using high energy X-rays to destroy cancer cells.

**Reconstructive surgery (breast reconstruction)**

Plastic surgery to restore the look and feel of the breast after mastectomy.

**Recurrence (relapse)**

**Return of cancer**

Local recurrence is the return of cancer to the same breast or the same side chest wall. Distant recurrence (metastasis) is the return of cancer that has spread to other parts of the body, such as the lungs, liver, bones or brain.

**Risk factor**

A factor that increases or decreases a person's chances of getting breast cancer.

**Stages of cancer**

A numbering system (from 0 to IV) that indicates the extent of cancer within the body. It is used to help determine treatment options and prognosis.

**Targeted therapy**

Drug therapies designed to attack specific molecular agents or pathways involved in the development of cancer.

**Triple negative breast cancer**

Cancer that is Estrogen receptor-negative (ER-negative), Progesterone receptor-negative (PR-negative) and HER2- negative.

**Tumor**

An abnormal growth or mass of tissue which may be benign or malignant.

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