

A guide to
understanding
**Metastatic
Breast Cancer**

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Staying hopeful with a diagnosis of metastatic breast cancer

Hearing that you have metastatic breast cancer, or mBC, can be devastating. You may be feeling overwhelmed right now. You may have questions but don't know where to look for the answers. This guide is designed to be your resource for answers to some of the most common questions about mBC.

Inside, you'll find:

- Helpful information about mBC
- Treatment options
- What to expect along the way
- Ways to manage the day to day

As you come to terms with your diagnosis, it's okay to cry; take deep breaths, and let yourself be embraced by family and friends.

Although there is still no cure, people with mBC are living longer, fuller lives than ever before.

Whether you were previously diagnosed with early breast cancer, or this is your first diagnosis, remember: you are not alone.

More than

168,000

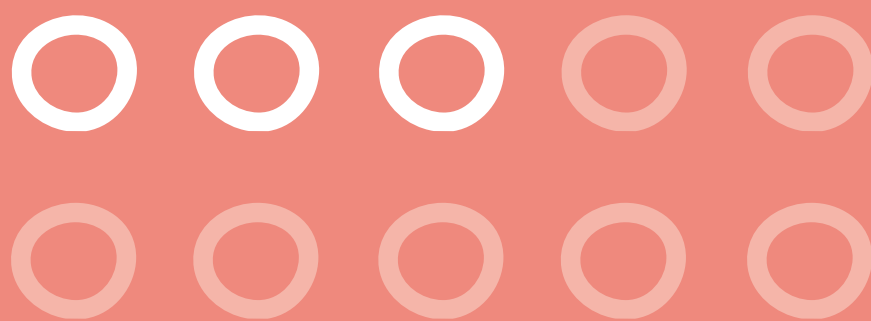
people in the
United States

are living with mBC

You're not alone, about

3 *in* 10

people with early stage
breast cancer will
eventually develop
metastatic disease



Up to 6% of people

diagnosed with breast cancer for
the first time are diagnosed with
stage 4 cancer. **This is called de
novo mBC.**

1

COMING TO TERMS WITH YOUR DIAGNOSIS



COMING TO TERMS WITH YOUR DIAGNOSIS

Stay informed. Stay supported.

In the first few weeks after diagnosis, many people feel flooded with information. They may also feel a range of emotions.

Right now, you might be stuck with a lot of waiting—for appointments, test results, and treatment options. It can be frustrating and scary, but you can use this time to gather information and collect your thoughts.

COMING TO TERMS WITH YOUR DIAGNOSIS

Here are some tips:

Research one subject at a time

A good way to manage your online search is to focus on one subject at a time. Be sure to use reliable websites. A good rule of thumb is to look for sites ending in .org and .gov (like [cancer.gov](https://www.cancer.gov) or [cancersupportcommunity.org](https://www.cancersupportcommunity.org)). You can also ask a member of your health care team where to find reliable information.

Take notes

Keep a notebook handy. You may want to write down questions as you think of them when you're between visits. Some of the information you receive from your doctor may be difficult to grasp. Consider bringing a trusted family member or friend to support you and to help take notes.



Remember, you are not a statistic

Many people want to hear the latest statistics for mBC. Statistics represent the general population. They do not take your specific situation into consideration. Everyone's journey with mBC is unique.

COMING TO TERMS WITH YOUR DIAGNOSIS

Sharing your diagnosis with family and friends

Figuring out where to start is often the hardest part of telling loved ones that you're sick. No two conversations are the same. Here are some ideas to help you think about where to begin.



COMING TO TERMS WITH YOUR DIAGNOSIS

Discussing your diagnosis with...

A partner

- **Ask** if they'd like to join you at medical appointments
- **Understand** that they may have different ways of coping with your diagnosis
- **Be clear** about your needs and recognize that they may change over time
- **Find out** what your partner needs. This is a difficult time for both of you
- **Make time** for the two of you to be alone, outside of doctor visits
- **Prepare** for potential symptoms or side effects that may affect your sexual relationship
- **Get help** from a counselor if you feel it would be good for your relationship



Children or grandchildren

- **Adapt** what you say depending on their age. Use simple language that they can understand
- **Comfort** younger children by letting them know that they can't "catch" what you have and that they didn't do anything to cause your illness
- **Explain** that you want to keep the daily routine as normal as possible, but let them know about things that may change
- **Let them know** about any expected changes in your energy level or behavior

COMING TO TERMS WITH YOUR DIAGNOSIS

Discussing your diagnosis with... (continued)

Family and friends

- **Write down** what you think would be helpful for them to know
- **Designate** a trusted friend or family member to help you share the news with others
- **Have someone close to you** at your side for support
- **Use a website**, such as [CaringBridge.org](https://www.caringbridge.org), which is designed to help people in difficult situations keep friends and family informed and updated



Employer and co-workers

Telling your manager or co-workers about your personal health is a choice. You have a legal right to keep it private. However, if you want to take advantage of certain laws that protect employees, you may need to give your employer some information.

- **The Family and Medical Leave Act** allows eligible employees to take up to 12 weeks of unpaid, job-protected leave in a 12-month period
- **To get this benefit**, you simply need to say that you will be unable to perform your job functions
- Learn more about this law at [dol.gov/whd/fmla](https://www.dol.gov/whd/fmla)

COMING TO TERMS WITH YOUR DIAGNOSIS

Finding the right words

Children

"I haven't been feeling well lately, and the doctor was able to tell us why."

"There's something called cancer inside my body, and it's making me sick."

"Remember when I had breast cancer? Now it has spread to another place in my body."



COMING TO TERMS WITH YOUR DIAGNOSIS

Finding the right words (continued)

Adults

"My breast cancer came back. It's metastatic, which means it has spread throughout my body. I'll be heading down a different treatment path this time. I will need extra support during this time with managing appointments and care."

"My breast cancer is back and has traveled to another organ. This time it's stage 4. They call it metastatic."

"There's no cure for metastatic breast cancer. The doctors are going to help me slow down the growth and spread of the cancer as long as possible."

"There was nothing wrong with my last treatment. Cancer returning is something that's always a possibility."

See pages 33 through 37
for resources to help
you with these difficult
conversations

THE FACTS

ABOUT METASTATIC BREAST CANCER



THE FACTS

ABOUT METASTATIC BREAST CANCER

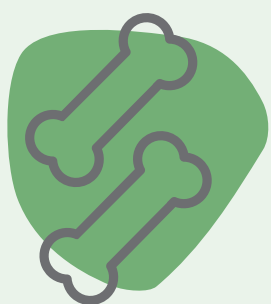
Understanding mBC

Metastatic breast cancer, or mBC, means that the cancer cells have spread beyond the breast tissue to other parts of the body. This is when breast cancer is considered stage 4.

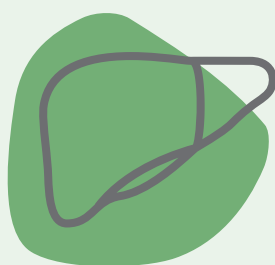
mBC can be

- 1 Early breast cancer that returns after initial treatment
- 2 Cancer that is metastatic from the beginning, called de novo mBC

Breast cancer most commonly spreads to the...



bones



liver



lungs



It can also spread to the brain or other organs.

THE FACTS

ABOUT METASTATIC BREAST CANCER

Recurrence

In most cases, mBC is a recurrence, or the return, of an earlier-stage breast cancer. If this is the case, you're familiar with treating cancer, and your disease may have gone into remission. But, with mBC, it's not currently possible to "cure" the cancer.

The good news is that there are treatments that can help delay the progression, or slow the growth, of your disease. And although it's not common, there are rare instances where the disease becomes undetectable. This is called no evidence of disease, or NED.

Treatment

The goals of your treatment will be different as well. For early stage breast cancer, we know that the goal is to reach remission. With mBC, treatment focuses on:

- Stopping or slowing the growth of cancer
- Managing any symptoms or side effects
- Living with the highest quality of life possible



THE FACTS

ABOUT METASTATIC BREAST CANCER

Determining your type of mBC

Four different kinds of tests may be needed to determine the type of mBC you have



1 Biopsy

Your doctor will first remove a sample of your tissue or cancer cells. The sample is sent to a doctor called a pathologist who tests samples of tissue to help identify diseases. A **confirming biopsy** may be taken from an additional tissue sample.



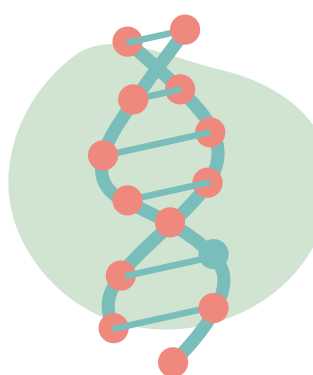
2 Blood tests

There are three types of blood tests used to determine subtype: **complete blood count**, or **CBC**, **serum chemistry**, and a **blood tumor marker test**.



3 Imaging tests

Imaging tests are used to locate where the cancer has spread: **Bone scans** and **positron emission tomography (PET)**, **computerized tomography (CT)** or **computerized axial tomography (CAT)**, and **magnetic resonance imaging (MRI)** scans are examples of imaging tests.



4 Genomic tests

Genomic tests look at a cancer's DNA to help customize treatment. This is called **personalized medicine**, or **precision medicine**. The treatments used are called targeted therapies. These test results will let your doctor know whether targeted therapy is an option for your type of cancer.

THE FACTS

ABOUT METASTATIC BREAST CANCER

Understanding your test results



Subtype
(eg, HR+, HER2+)



**Location
within
the body**



Growth rate



**Treatment
course**

Your doctor uses your test results to determine which treatments may be right for treating your specific cancer.

For help understanding your pathology report, visit [breastcancer.org](https://www.breastcancer.org) and download the Pathology Report Booklet or talk to your doctor.

To learn more about your type of mBC, visit [cancersupportcommunity.org](https://www.cancersupportcommunity.org)

To learn more about personalized medicine, go to [cancer.org](https://www.cancer.org) or [komen.org](https://www.komen.org)

THE FACTS

ABOUT METASTATIC BREAST CANCER

The different subtypes of mBC

Know your cancer subtype. A subtype is a way of grouping cancer based on what fuels its growth. Breast cancer subtypes are based on two things:

1 Hormone-receptor, or HR, status:

Your cancer grows with the help of hormones. A plus sign (+) after HR means that your cancer cells have hormone (estrogen and progesterone) receptors. A minus sign (–) means that your cancer cells don't have hormone receptors.

HR+ mBC is often treated with hormone therapies. Hormone therapy aims to slow the growth of cancer by keeping hormones and cancer cells from binding together.

2 Human epidermal growth factor 2 (HER2) status

HER2 is a normal protein in the cell, but a plus sign (+) after HER2 means that your cancer cells have too much HER2. A minus sign (–) after HER2 means that your cancer cells have a small amount of HER2 or none at all.

The proteins and receptors found on your cancer cells determine how your cancer may respond to different treatments. **Knowing your subtype helps you and your doctor decide on treatment options for you.**

If your cancer has recurred, your subtype may have changed since your first diagnosis. It's important to get a biopsy, if possible.

THE FACTS

ABOUT METASTATIC BREAST CANCER

Four subtypes of breast cancer

1 HR+, HER2–

HR+, HER2– cancer cells have hormone receptors but make small amounts of HER2 protein or none at all.

2 HR+, HER2+

HR+, HER2+ cancer cells have hormone receptors and make large amounts of HER2 protein. This type of breast cancer is also called triple-positive.

3 HR–, HER2+

HR–, HER2+ cancer cells don't have hormone receptors but do make large amounts of HER2 protein.

4 Triple-negative (HR–, HER2–)

Triple-negative cancer cells don't have hormone receptors for estrogen or progesterone, plus they also don't make HER2 protein.

This type of cancer grows without the help of estrogen, progesterone, or the HER2 protein, but we're still trying to learn what fuels its growth.

HR+, HER2– breast cancer is the most common subtype of breast cancer.
70% of all breast cancers are HR+, HER2–.

3

FINDING THE RIGHT TREATMENT



FINDING THE RIGHT TREATMENT

Treatments for mBC

Stage 4 mBC is treatable, but it can't yet be cured. If you were treated for early stage breast cancer before, it may feel different this time. That's because treatment for mBC is meant to go on for a longer period of time. This is unlike early breast cancer treatment, which can be short term.

The goal of mBC treatment is to reduce the amount of cancer in your body and to slow its spread. There are two approaches to treating mBC.



SYSTEMIC THERAPIES

treat the entire body by moving through the bloodstream.

Systemic therapies include:

Chemotherapy

Chemotherapy aims to damage cancer cells so they can't divide and multiply. It can also damage healthy cells. Chemotherapy is often given along with hormone therapies or targeted treatments. Together, they can help stop the cancer from growing. It can be given through an IV drip or in a pill.

Hormone therapies

Hormone therapies are designed specifically to treat hormone receptor-positive, or HR+, breast cancer. They target the hormones estrogen and progesterone or the receptors they bind to. Many hormone therapies are pills that can be taken at home.

FINDING THE RIGHT TREATMENT

Targeted therapies

Unlike chemotherapy, targeted therapies are designed to interfere with proteins and processes that impact cancer cell growth. However, they can still affect healthy cells in the body. Many targeted therapies come in pill form and can be taken at home.

To see whether you are a good candidate for a targeted therapy, your doctor will look at the features of your cancer. This includes your subtype, as discussed in Chapter 2. An example of targeted therapy is a CDK4/6 inhibitor, which you could be given if you if you have HR+, HER2– disease. CDK4 and CDK6 are proteins that cause cancer cells to grow.



LOCAL TREATMENTS

focus on one area, usually in or around tumors.

Local treatments are less common options for mBC and include:

Surgery

Surgery may be recommended when an area of cancer hasn't grown for some time. It can also help to ease or prevent symptoms and side effects.

Radiation therapy

By destroying cancer cells, radiation therapy can shrink tumors. It can also alleviate symptoms and ease pain caused by the cancer. It can be a good option to treat mBC that has spread to the brain.

Deciding on a treatment

Don't be afraid to ask questions when discussing treatment options with your doctor. Even better, write down any questions you may have and bring them to your appointment. The more prepared you are, the better the conversation with your doctor.



What to ask when considering treatment options

- Why are you recommending this type of treatment?
- What are the potential benefits of this treatment?
- Does it work alone or with other treatments?
- How is this treatment given, and how often?
- What are the possible side effects? Are there ways to prevent or manage them?
- How much will this affect my day-to-day life?
- How do I take it, and can I take it at home or if I travel?
- Did people who took this treatment in clinical trials live longer than the people who didn't take it?
- How will you know if this treatment is working for me?

FINDING THE RIGHT TREATMENT

Getting a second opinion

It's common for people with cancer to ask for a second opinion. Your oncologist may be connected with a larger cancer center and know other doctors who specialize in breast cancer.

You can also contact an institution or center you would like a second opinion from and make your own appointment.

You should check with your insurance company before scheduling an appointment with another oncologist. Understanding the costs associated with your care is important.

Advances in treatment

There have been advancements in treatment that apply science and technology to treat cancer more effectively. There may be treatment options for you that you haven't heard of before.

It is crucial to make an informed decision about your treatment plan. **Talk to your doctor.** Don't hesitate to seek a second opinion or explore new treatment options.

FINDING THE RIGHT TREATMENT

Managing side effects

One of the goals of your treatment may be to give you the best possible quality of life. If your side effects are getting in the way of that goal, say something to your doctor. Some people turn to supportive care or complementary care, such as meditation and yoga, to help cope with side effects.

It's common to experience some side effects from your treatment. The good news is that there are things you can do to help manage them.

Before choosing a treatment

- Discuss possible side effects with your doctor
- Ask if any of the side effects can be prevented or managed, and how
- Discuss what kind of things you should report to your doctor
- Consider how the potential side effects would affect your lifestyle



FINDING THE RIGHT TREATMENT

What to do if you experience side effects while on treatment

- Before starting a medication, ask whether it has any side effects of its own
- Call your doctor's office at the earliest sign of a side effect
- Ask whether there are any complementary or supportive care methods you could try to manage your side effects

Some side effects may not be easy to manage. If you have trouble managing certain side effects, your doctor may modify your treatment plan.

Supportive medications can help control or prevent side effects such as pain, nausea, fatigue, or depression caused by your disease or treatment. Talk to your doctor about how you're feeling physically and emotionally. You and your doctor can work together on managing or preventing side effects.

Share a list of any medications you are already taking with your care team to help prevent or manage side effects. It's important to make sure that all your medications work safely together. This includes sharing any herbal supplements or vitamins you may be taking.

4

TIPS FOR HEALTHY LIVING

WITH METASTATIC BREAST CANCER



TIPS FOR HEALTHY LIVING WITH METASTATIC BREAST CANCER

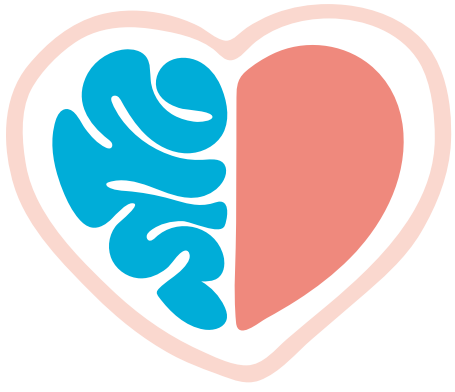
Treating all of you

Cancer treatment can affect more than the cancer. Every part of your body can be affected at different times. It may be a lot to think about right now. Just know that your **mind, body, and spirit** all need to be treated with care.

To be matched with another person living with mBC, call the breast cancer helpline, SHARE, at 1-844-275-7427.

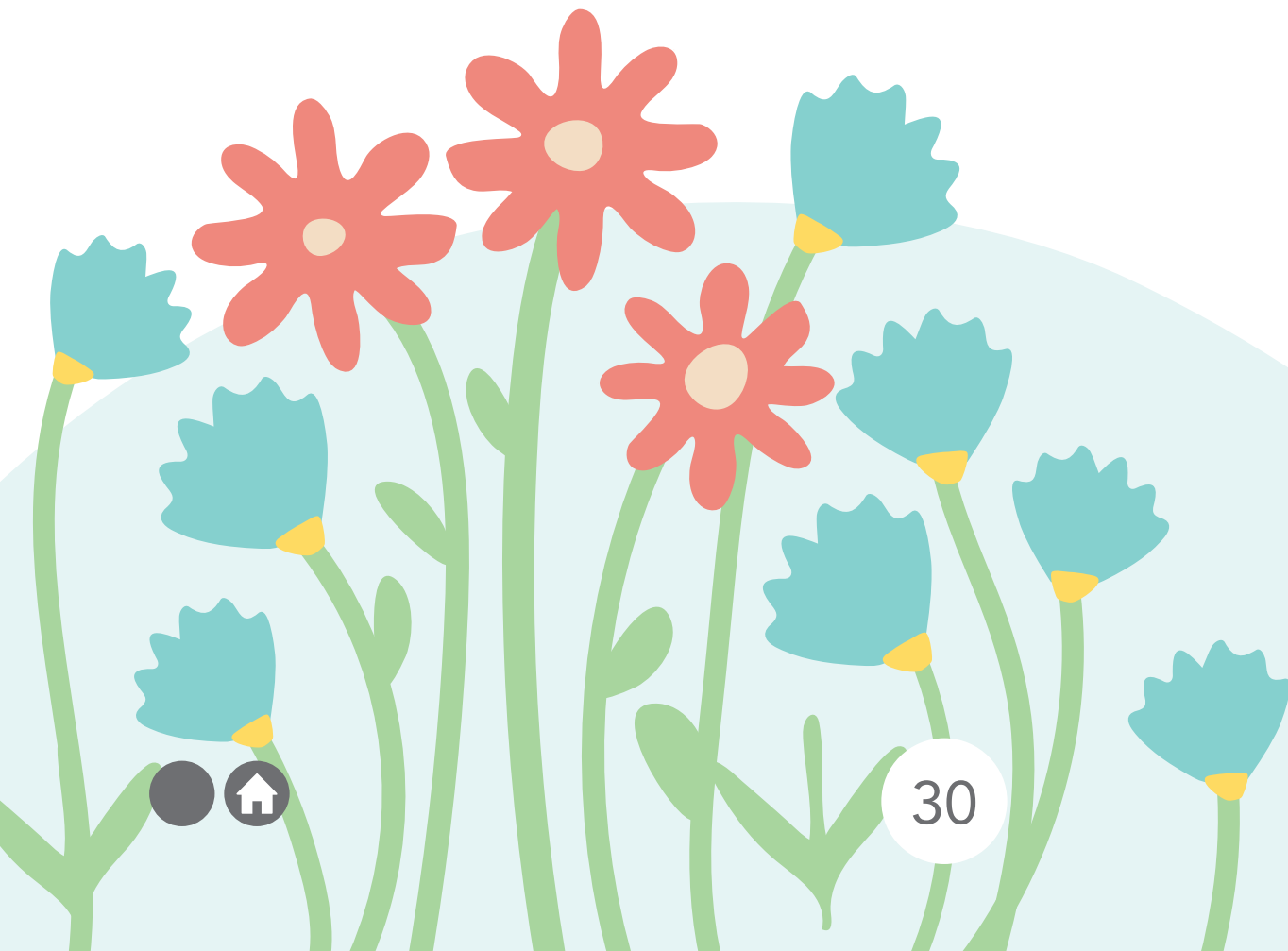
To speak to a trained peer counselor or find counseling resources, call Pink Aid at 1-844-746-5243.





Mind

- **Connecting with other people living with breast cancer** can help you feel less alone and more understood. You may find it helps to learn about how others manage day-to-day challenges
- **Consider joining a local or online support group.** Talking with other people living with mBC can help you feel confident in your ability to manage day-to-day while living with cancer
- **Talking to a counselor or therapist** can help you explore your feelings and thoughts in a judgement-free environment and develop coping skills. You may want to choose someone with experience in counseling people with mBC. If you don't like the first person you see, try someone else. Keep going until you find someone you feel comfortable with



TIPS FOR HEALTHY LIVING WITH METASTATIC BREAST CANCER



Body

It can be difficult to exercise and eat healthy when you're experiencing fatigue, depression, nausea, changes in taste and smell, or other side effects, but there are things you can do that can help.

- **Exercise can help ease side effects.** Movement, like walking, swimming, yoga, dance, and strength and aerobic training, can help you feel better mentally and physically and even improve your sleep
- **A nutritious diet can also help you manage side effects and improve how you feel.** Ask your health care team if they can help you create healthy meal plans
- **Although some women still find sex to be a positive experience, others may find it difficult.** It's important to communicate openly and honestly with your partner. Discuss what's comfortable for both of you and what's not. Whatever your situation, maintaining some form of intimacy can improve your emotional health and quality of life. Your health care team can refer you to a counselor with expertise in this area

Always check with your doctor before starting a new diet or exercise routine.



Spirit

- **Whether you find spiritual support from your religion, your community, or a passion such as art or volunteering**, a connection to something bigger can help alleviate anxiety
- **Speak with a spiritual advisor or counselor** to help guide you through all of the emotions you are feeling
- **Contact** your local religious organizations, holistic wellness centers, hospitals, or treatment center to find the support you need

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SUPPORT AND RESOURCES

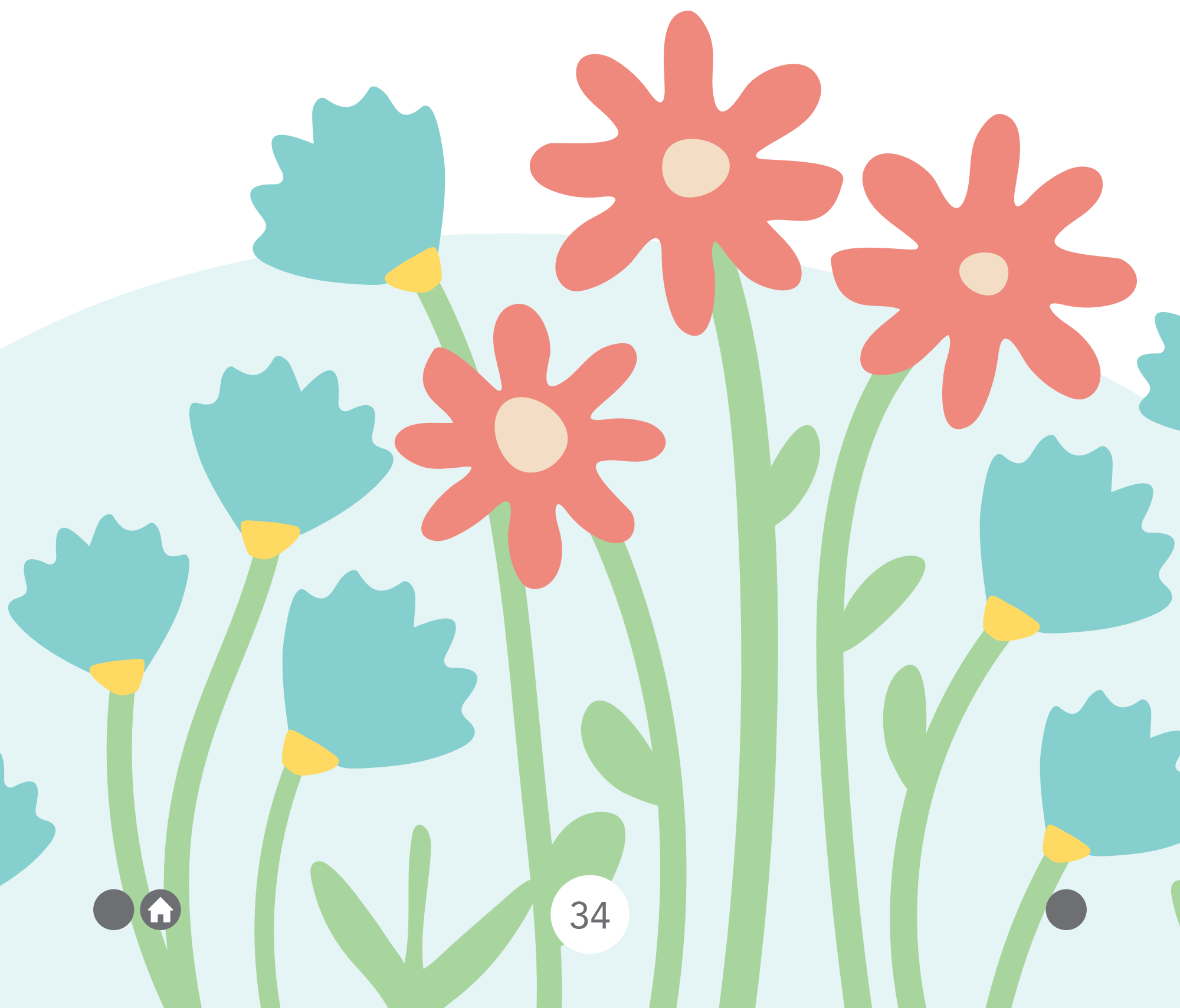


Finding the right support and resources for you

Everyone's experience with mBC is unique. How you feel, how you manage, and the type of support you need is specific to you. Getting the right support and resources can help ease the burden of living with mBC and managing treatment.

The following are support groups and resources to help you with different aspects of living with mBC. The list includes everything from understanding mBC to financial assistance, transportation assistance, support groups, and much more.

You can also ask your care team about local support services available near you.



Understanding and connecting

Breastcancer.org

www.breastcancer.org

CancerCare

www.cancercare.org/services

Cancer Support Community

www.cancersupportcommunity.org

- **Talking to kids and teens about cancer:**

www.cancersupportcommunity.org/talking-kids-teens-about-cancer

Living Beyond Breast Cancer

www.lbbc.org

- **Metastatic breast cancer information:**

www.lbbc.org/mets

Metastatic Breast Cancer Network (MBCN)

www.mbcn.org

METAvivor Research and Support

www.metavivor.org

National Cancer Institute

www.cancer.gov/types/breast

Sharsheret

www.sharsheret.org

Sisters Network Inc.

www.sistersnetworkinc.org

Susan G. Komen

www.komen.org/breast-cancer/metastatic/

Unite for HER

<https://uniteforher.org>

Young Survival Coalition

<https://youngsurvival.org>

Support and peer counseling

Cancer Support Community

www.cancersupportcommunity.org

Support Connection, Inc

www.supportconnection.org

SHARE Cancer Support

www.sharecancersupport.org

Home cleaning

Cleaning for a Reason

www.cleaningforareason.org

Preparing healthy meals

Cook for Your Life

www.cookforyourlife.org



SUPPORT AND RESOURCES

Transportation and lodging support

Air Care Alliance

www.aircarealliance.org

Joe's House

www.joeshouse.org

Support in the workplace

Cancer and Careers

www.cancerandcareers.org/en

Cancer Legal Resource Center

www.cancerlegalresources.org

Palliative care

National Cancer Institute

<https://www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-care-fact-sheet>

All organizations listed are not-for-profit and/or government agencies, and are independent from Novartis Pharmaceuticals Corporation. Novartis has no financial interest in any organization listed but may provide occasional funding support to these organizations.





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