



Talking with Teens about Breast Cancer

A Family Discussion Guide

Introduction

Talking about breast cancer with your teenager may seem overwhelming and frightening, but it can also be empowering and liberating for both of you. This guide is designed to help you establish and maintain open and honest communication with your teen about breast cancer. It is divided into three main sections: **Before Treatment**, **During Treatment**, and **After Treatment**. It is structured this way because many women facing breast cancer find that their thoughts and feelings change as they transition from one phase of their cancer experience to the next. Your teen may feel the same way. We hope this guide will be helpful to you and your family.

Before Treatment Begins

Sharing the News of Your Diagnosis

Teens are observant and may already sense that something is wrong, perhaps from an increase in whispered conversations, an influx of phone calls, and adults leaving the room to have private discussions. If you are preparing to tell your teen the news of your diagnosis for the first time, it is helpful to designate a time to talk, and to have a general idea of what you will tell them. Although you may be tempted to talk to your teen as soon as you receive your diagnosis, it is important to remember that you will likely be feeling a variety of heightened emotions, which may impact how you share the news. Your teen will follow your lead; it is ok to show emotion as you share the news, but it is important to have processed it yourself first. Expect a range of emotions, and assure your teen there are no *wrong* or *bad* feelings (what are we trying to say here? That everyone responds differently).

If they already know about your diagnosis, it may be helpful to determine what your teen already knows and what they would like to know. Given limited information, they will try to fill in the blanks themselves, often turning to the Internet.



This can lead to dangerous misconceptions and worsening fears. Encourage your teen to ask questions. It is helpful to use language that adults would use when communicating about cancer. It is important to be honest, but it is not necessary to share all the intricate details of your cancer experience. Share what you are comfortable with, and what seems appropriate. You know your teen best- although this guide provides suggestions for talking to your teen, it is important that you approach these conversations in a way that works best for you.

Faced with a breast cancer diagnosis, women often feel that fear of the unknown is far worse than fear of physical pain. As you prepare for treatment to begin, you may feel no longer in control of your life. This feeling is normal given the situation, and it can be emotionally overwhelming and frightening. Your teen may feel scared, angry or frustrated by their lack of control over the situation, too, and by their inability to help “fix” the situation. They may even feel lonely or neglected as you understandably focus your attention on your treatment. Such feelings are normal, so try to be open about your changing emotions and communicate this your teenager. This will help your teen understand that their emotions may evolve, too.

If you have additional concerns about how to talk to your teen, it may be helpful for you to discuss this with a professional. Ask to meet with an oncology social worker if one is available to you at your treatment center, or seek out assistance from a counselor in your community. Additional resources are listed at the end of this document, as well.

Clearing Up Misconceptions

Upon diagnosis, there are many misconceptions teens may have about breast cancer. The following are common misconceptions and some facts to help you and your teen clear up any confusion:

- ***Breast cancer can be spread from person to person***
Cancer cannot be passed from one person to another. It is absolutely fine to continue hugging and kissing your teens (if they'll let you!).
- ***Everyone with breast cancer dies from it***
There are several types of breast cancer and several stages as well. Some are considered curable, while others are treated and managed as a chronic illness that never fully goes away. It is important to remember that there are many effective treatments for breast



cancer, including surgery, radiation, chemotherapy, hormone therapies, and biological therapies. Your children may be familiar with these treatments from popular media or personal experience. Take this opportunity to discuss their understanding of the treatments you are undergoing.

Build Understanding with Facts

Sharing illustrations and online resources can help you explain exactly what is going on inside and outside your body. It may be helpful to explain how cancer starts and how breast cancer is diagnosed. Older teens may bring some of their own understanding of biology, chemistry, and anatomy and physiology to the discussion!

It is important that your teen understands that what they read about cancer online, see on TV, or hear about from friends is not necessarily true, and does not reflect the same course for every breast cancer patient. Your treatment will be tailored to your specific needs.

For more detailed information to help guide your discussion of the science of cancer, please see Concepts, Tests, and Treatments, which begins on page 5. There you will find more information about:

- Diagnostic tools, such as mammography and MRI
- Precision medicine, including chemotherapy and radiation



During Treatment

Adjusting To the Journey

As you progress through treatment, some changes in your body and physical appearance may be more noticeable. Explain to your teen that they may see you experience hair loss and physical changes, but assure them that you are still the same person. Although undergoing treatment for cancer brings its own set of challenges, women sometimes feel emotionally best during this phase of treatment. It is a time when you and your doctor are working actively to combat your breast cancer. This may give you a greater feeling of autonomy and control.

Your teen may feel better if they have opportunities to help you. There are many ways they can help and contribute to your recovery. This can include helping out with household tasks and chores, as well as spending time with you. For example, ask them to help out with making dinner, or clean up the kitchen after a meal. Spending time together can include things like watching a movie or planning a day trip to a place you both enjoy, if you are feeling up to it. There may be many times during your treatment when you and your teen feel powerless. Helping each other in small ways will assist both of you to work through those feelings together.

It is important to keep up with household rules and routines as much as possible. Children of all ages respond well to structure, consistency and limit-setting. When possible, try to maintain a sense of normalcy at home.

If you notice a change in your teen's behavior, this could be an indication that they are struggling with anxiety or depression. Signs may include, but are not limited to: increased risk-taking behaviors, uncontrolled anger, decline in academic performance, or withdrawing from friends or activities. It may be helpful at this time to communicate your concerns to your teen, and propose several different ways for them to gain support. This may include joining a peer support group, talking to a trusted relative, or meeting with an oncology social worker or counselor. Give your teen the freedom to choose what they feel would work best.



After Treatment

Processing Your Journey

The ending of treatment can bring up different emotions. When you are finished with active treatment, you will begin to process what has occurred. When you reach this phase of your journey, you may feel happiness and relief. However, you may also experience fear, sadness, and grief. This may lead to confusion or guilt for not feeling happier. It is common to feel all these things simultaneously. When friends and family express happiness that you completed treatment, you may feel pressure to reflect these same feelings. It is important to be honest with yourself, and your teen, about your mixed emotions. This is a very normal part of the process.

Understanding Your Follow-Up Care

Once you have completed active treatment, you will continue to follow up with your medical team, which may include your medical oncologist, radiation oncologist and surgical oncologist. This may involve several visits per year, as well as any testing deemed necessary by your physicians. Explaining this to your teen will help them understand the continuing monitoring process of your health.

Your teen may also be wondering if they are going to get breast cancer, especially if they are female. It is important to keep in mind that only 5%-10% of breast cancer diagnoses are known to be hereditary. Most inherited cases of breast cancer are associated with two abnormal genes. These genes are known as BRCA1 (BReast CAncer gene one) and BRCA2 (BReast CAncer gene two). The BRCA genes which everyone has repair cell damage and ensure the normal growth of breast cells. Sometimes, these genes contain abnormalities that are passed down. In that situation, the risk of breast cancer increases. However, having an abnormal BRCA1 or BRCA2 does not mean you will definitely get breast cancer.

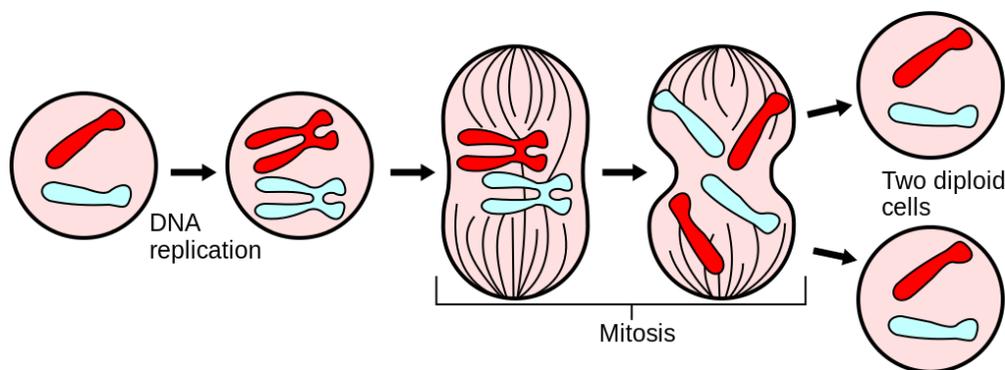
Cancer Genetic Counselors discuss a patient's specific cancer risk factors and family history of cancer. They provide education, risk assessment, and genetic counseling. The information is based on a patient's family history, medical factors, environmental factors, reproductive history and lifestyle choices. Patients learn about different risk factors for cancer, the inheritance of cancer risk, genetic testing, and management options through a genetic counselor. Talk to your oncologist to determine whether a consult with a Cancer Genetic Counselor is appropriate for you.



Concepts, Tests, and Treatments

Concepts

Your teen may want to know what cancer is and how it begins. You may want to use the mitotic process as a way to explain how cancer can develop. *Mitosis is typically helpful for our bodies. It is the type of cell division used for growth and repair. Mitosis produces two cells that are identical to each other. This enables our wounds to heal, and new cells to grow and develop.*



Explain that sometimes mitosis becomes uncontrolled and cells continue to replicate. If a damaged cell continues to replicate, cancer cells will form lumps or tumors. They can then spread further in the body.

We do not yet know the causes of most kinds of cancer. However, some behaviors increase the risk of developing some cancers. For example, people who smoke are at a higher risk of lung cancer and people who tan are at a higher risk of skin cancer.

Diagnostic Tests

Your teens may be curious about how breast cancer is diagnosed. The tests that are used to diagnose cancer are mammogram, magnetic resonance imaging (MRI), ultrasound, and biopsy.

- **Mammogram:** A mammogram is an x-ray of breast tissue. It can reveal abnormalities in breast tissue that may indicate the presence of cancer.



Mammograms are the only diagnostic tests that are also used in routine health screenings.

- **MRI:** MRI uses a magnet, radio waves, and a computer to create hundreds of images of a part of the human body. To create an MRI of the breast, a patient lies face down on a table and the breast hangs through a hole. The patient is moved into a large tube-like machine. An MRI session takes about one hour.
- **Ultrasound:** Ultrasound machines use sound waves to create images of areas within the body. During an ultrasound, a medical professional will cover the skin with a lubricating gel and use an instrument called a transducer to direct the sound waves.
- **Biopsy:** A biopsy is a diagnostic procedure that involves removing a tissue or fluid samples from a patient. Pathologists analyze the tissue or fluid to detect cancerous cells. This is the only definitive way to diagnose the presence of cancer.

Types of Treatment

Your teen may already know something about common treatments for breast cancer. This presents an opportunity to discuss precision medicine. Precision medicine helps allow for treatment regimens that are more customized to an individual's specific cancer, as well as their unique genetic makeup, environmental factors and lifestyle. Some common precision medicine approaches include Biological Therapy, Chemotherapy, Hormone Therapy, Radiation Therapy, and Surgery. These therapies can be used very differently depending on the stage of disease.

- **Biological Therapy:** Biological therapies include immunotherapies, which are medicines that help the body's immune system fight cancer. They also include antibodies, which directly target cancer cells.
- **Chemotherapy:** Chemotherapy is used to kill cancer cells, but can also affect the growth of normal cells. It may be given as a single agent, or in combination with other types of therapies. Chemotherapy can be given in pill form, as an injection, or an infusion, depending on the particular type of medication.



- **Hormone Therapy:** This type of treatment, blocks, or lowers hormones in order to slow or stop the growth of cancer cells. Depending on the type, hormone treatment may be given in pill form, injection, or infusion.
- **Radiation Therapy:** Radiation is used only to treat the known site of cancer. It is used to shrink tumors and kill cancer cells. Breast radiation is directed only at the breast affected with cancer after the tumor has been removed by the surgeon. It can also be used to treat breast cancer that has metastasized to other areas of the body.
- **Surgery:** Breast surgery is performed by a surgeon. This can either be a lumpectomy (removal of breast lump) or mastectomy (removal of breast). A plastic surgeon may also be present for the surgery to begin the reconstruction process.

Older teens may know that genes contain the recipes for the various proteins a cell needs to stay healthy and function normally. Cancer cells from a tissue sample can be tested to see which genes are normal and abnormal. The proteins they make can also be tested. Doctors use this information to prescribe a precise treatment for each individual.



Summary

As you proceed through each phase of your treatment, it is likely that you and your teen will need similar support and even encouragement. You will both be worried at times about how you will feel physically on any given day. Your teen may have questions that they do not know how to ask. You may struggle with how to approach this difficult topic with your teen. Your diagnosis of cancer is overwhelming from the day you hear it. Once you understand and process the diagnosis, you face the challenge of talking to your teen. Your teen will likely feel so many emotions, many that will be similar to your own.

Open communication will be key for both of you to navigate your treatment. Asking questions of you, helping you, or spending time with you will help your teen feel comfortable with the treatment process that you will be experiencing. Setting schedules and keeping a sense of normalcy in your lives will also help all of you get through this in a healthy manner. Though receiving a diagnosis of breast cancer may seem daunting, you and your teen can get through it together. Together, you can always ask for help from the professionals who want to help you, as well.



Additional Resources

- **American Cancer Society:** <http://www.cancer.org/>
- **Cancer.Net:** <http://www.cancer.net/cancer-types/breast-cancer>
- **CancerCare:** CancerCare.org
- **Cancer Support Community:** <http://www.cancersupportcommunity.org/>
- **Gilda's Club:** <http://gildasclubnyc.org/>
- **National Cancer Institute:** <http://www.cancer.gov/about-cancer>
- **National Center for Complementary and Alternative Medicine, National Institutes of Health:**
<http://nccam.nih.gov/>