

How to talk to others about your breast cancer

Whether you have had a recurrence, or this is your first diagnosis of breast cancer, sharing the news with family and friends can be difficult.

Telling others about your diagnosis is a personal choice. There is no one right time or way to do it. Who you tell, what and how much you share, and when you share it, are all up to you.

Some people may feel more comfortable talking openly about their diagnosis, while others choose to tell only the closest people in their lives.





The Moments That Count campaign has been developed and funded by Novartis Pharmaceuticals UK Limited. It has been created in collaboration with breast cancer patients whose knowledge and insights have informed the content and direction for the campaign.

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MOMENTS that COUNT

How people may react to learning about a diagnosis

Think about how you felt when you first learned you had breast cancer. You may have felt sad, angry, scared, shocked, or confused. Your family and friends will probably have many of the same emotions. Mental health matters, so try to allow yourself to acknowledge your emotions as it can help you to come to terms with your cancer. Similarly, it might take some time for the news to sink in for who you choose to tell. Some people handle the news better than others and often coming to terms with it takes time.

- They may struggle with finding the right words, and say something awkward and unhelpful
- They may say nothing at all because they are afraid of saying the wrong thing
- They may not want to show that they are scared/worried for the patient's sake

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Getting ready to talk

Before telling others about your diagnosis, think about the who, what, and when of your communication. Mapping these things out in advance can make each step feel more doable.

Who to tell:

- Decide who you want to share your diagnosis with
- Prioritise who you tell. You may want to start with people who are closest to you, such as your partner or spouse, parents, children, then, your good friends. If you are currently employed, you may also want to consider who you would want to tell at your workplace.

What to share:

- Think about what you want them to know before telling someone you have breast cancer. You might want to explain what kind of cancer you have and which treatments you might need
- If you are uncomfortable with certain questions, a response such as "I would rather not talk about it right now" or "I would prefer not to go into details right now" will direct the conversation to areas you are comfortable discussing
- Think about who you are talking to when planning what to say. The way you tell your partner, for example, will likely be different from the way you explain cancer to a child.

How and when to tell them

- Some people are ready to talk about their diagnosis sooner than others. Only you can decide when the time is right.
- Determine whether you want to share the news in person, over the phone or video call. Try to have a private, quiet conversation when neither of you will be interrupted and you both have time to talk.
- If you feel overwhelmed by having to tell people who may need to know or who you want to know about your diagnosis, you can ask someone you trust to tell them for you.

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Practical tips for talking about breast cancer

Here are some tips for talking with the important people in your life about your breast cancer diagnosis. Your spouse or partner will likely be the first person you tell or talk with about your diagnosis.

- Ask them to go with you to an upcoming appointment with your doctor Learning about breast cancer and its treatments will help them understand what to expect.
- Give them time to adjust They may be as overwhelmed and frightened by the news of your cancer as you were.
- Let them know what you need

If you want your spouse or partner to take an active role or you would prefer to take care of everything yourself, let them know. Your needs may change over time.

Ask them what they need

Talk to your spouse or partner about what they need to feel supported and take care of themselves. Let them know that it is important that they continue to make time for doing activities they enjoy.

Discuss possible shifts in roles

You may not be able to take care of your family and home the way you used to – at least on some days. Think about what assistance you might need now or in the future, then ask family members, friends, and neighbours for help.

• Talk about possible changes in your sexual relationship

Breast cancer and its treatment can affect you both physically and emotionally. Be open and honest with your partner about what you are feeling.

Get professional help if you need it

If you are having trouble communicating, a therapist, a counsellor, or social worker can help you and your partner through difficult conversations.

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Young children

- Tell them they did not cause the cancer by their behaviour or thoughts, and that they cannot "catch" cancer from you¹
- Use simple words

You may want to use a doll or stuffed animal to show your children where the cancer is located in your body.¹

- Ask your children if they have questions about what will happen now that you have cancer Answer only when they ask.
- Attention spans at this age are short
 Keep conversations brief. Be prepared to talk more at another time.¹
- Be direct
 Do not be afraid to use the word "cancer".¹
- Be positive, but realistic

Reassure them without making promises about the future. Let them know that your doctors and nurses are doing all they can for you.³

Teenage children

- Tell them they did not cause the cancer by their behaviour or thoughts, and that they cannot "catch" cancer from you¹
- Provide more details than you would to young children Share most of the facts about your cancer diagnosis and treatment plan. Details can include the name of the cancer and the basics of your treatment plan. Choose a quiet place to talk where you will not be interrupted. Allow enough time for your teen to understand the information and ask questions.¹
- Encourage them to express their feelings² Whether that is sadness, anger, fear, or confusion.
- **Give them permission to keep life as normal as possible** Let them know that they should continue to focus on their schoolwork and other activities and spend time with their friends. Tell them it is still okay to have fun.
- Ask if they understand what you are telling them and if they have questions If you do not know the answer to a question, it is OK to say you do not know.²

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Adult children²

If you have adult children, your relationship with them may change. You may:

- Ask them to help with making health care decisions, managing bills, or taking care of your home
- Ask them to explain medical information
- Need them to go with you to the doctor or pick up medicines
- Turn to them for emotional support
- Need their help with physical care

Other relatives and friends

• Be prepared to accept and ask for help

One of the first things many people ask when they learn someone they care about has cancer is if there is anything they can do to help. Have some specific suggestions in mind, such as helping with running errands or childcare.

• Do not take anyone's reaction personally

You will probably talk to some people who do not respond the way you want or expect them to. This is not your fault; it is because they do not know how to cope with you having breast cancer. It may help to tell only family and friends who can give you the kind of support you need.

• Let them know how you prefer to be in touch

After you share your breast cancer diagnosis, you may find yourself overwhelmed with calls and visits from family and friends who want to check in on you. If so, you may want to:

- Use e-mail or social networks to post regular updates on how you are doing. Or, consider assigning a person to keep everyone up to date
- Screen your calls and return them at the end of the week or ask a family member or friend to return them
- Limit visits to 1 or 2 days or evenings per week

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People at work

- If you work, you may be wondering if or how to share your diagnosis of breast cancer with your employer. You may want to consider telling your employer if:
 - You may need time off for doctor visits or because you do not feel well
 - You are eligible to take sick leave
 - You are applying for a new position
 - If you think your condition may affect your performance or if you feel it is important for them to know
- If you do decide to tell your employer, here are some things that may help make the discussion easier:
 - Understand how breast cancer and its treatment will affect your work
 Before you go to your employer, talk with your doctor about what to expect. That way, you will be prepared to discuss your treatment schedule and any accommodations you might need, such as flexible work arrangements.
 - Talk to your Human Resources (HR) department

Once you have told your boss, they will probably need to communicate the information to the HR department. You may also want to go directly to your HR representative to learn more about company policies and your rights in the workplace.

- Keep a record

Employers are usually supportive of employees with cancer, but this is not always true. It is a good idea to keep track of discussions you have with your boss or HR department.

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References

- 1. Dana Farber Cancer Institute. For parents: talking with children about cancer. For Patients and Families. https://www.dana-farber.org/for-patients-and-families/care-and-treatment/support-services-and-amenities/family-connections/for-the-patient/talking-with-children-about-cancer/ [Last accessed: May 2023]
- 2. National Cancer Institute. Talking To your Children About Cancer. https://www.cancer.gov/about-cancer/coping/ adjusting-to-cancer/talk-to-children [Last accessed: May 2023]
- 3. BreastCancer.Org. Talking to Young children. https://www.breastcancer.org/tips/telling_family/young_kids [Last accessed: May 2023]

Reporting of side effects

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at https://yellowcard.mhra.gov.uk/

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