

TALKING ABC/MBC

Because speaking together can really help.

my time
our time



 NOVARTIS

Listening to one another

What's so hard about having a conversation? A lot actually.

When advanced and metastatic breast cancer (ABC/MBC) happens, it can feel like we don't know where to start. The most difficult conversations we have are with the people who mean the most to us. Everyone can be in shock, whether you have received a diagnosis, or whether you are a loved one or friend of a person who has. The emotions weighing down on you can make conversations harder. To the point where you might avoid having them at all.

But that's a real shame. Because we know that talking about how you're feeling can bring you closer together and make you stronger. We're all human. We all make mistakes. But being human also means we have the potential to love, support and make life beautiful for the people we care about. The words we use and what we say is a big part of that.

That's why Novartis organised a meeting in 2018, with women who had different experiences of breast cancer. They travelled from all over the world, to share what they thought would make talking about ABC/MBC better for everyone.

Everything you'll read in this guide comes from them. Their hopes are in these pages and we hope their words are useful to you, to listen to one another and to understand each other.



SEEING IT FROM BOTH SIDES

When emotions are running high, it makes speaking about ABC/MBC difficult. Here, we'll take a look at some of the common words and phrases used to speak about ABC/MBC and how each person in the conversation may be feeling. Hopefully you'll see opportunities to make your conversations more open as a result.



Best friend talking over coffee in a cafe:

Person living with ABC/MBC is thinking/saying:

"How did your treatment go? You've finished your chemotherapy now, so you'll get better right?"

"I have metastatic breast cancer. I'm never going to be healed. Do you know anything about this at all?"

In this situation it's really hard for a person with ABC/MBC because their friend doesn't understand that treatment will never fully treat them. What the friend in this example could do is learn about what ABC/MBC really means for their friend, what treatment is realistically going to be able to do for them before assuming they will get better. Or they could ask an open question, such as "How is everything going?". **This will help the person living with ABC/MBC feel like their friend understands what they are going through.**

Person living with ABC/MBC is thinking/saying:

Friend who is there to listen, sat with the person in a park:

"I feel like if I'm not winning the battle against MBC, I will never be a 'survivor', it must be that I'm a failure. At least that's what I'm reading and seeing everywhere."

"No way. The battle was never down to you to fight. That's not the way I see it. You are an amazing person with life left to live, not a survivor or failure!"

Sometimes in the news, we can see words like 'battling' cancer and 'surviving' cancer. This can feel upsetting to someone with ABC/MBC because they will never win their battle with ABC/MBC. It's just not how ABC/MBC works. **Letting your friend who has ABC/MBC know that you don't see them in this way is empowering.**

Colleague who has come over to the house with a gift:

Person living with ABC/MBC is thinking/saying:

“Oh, you should feel lucky, it’s only breast cancer. I know loads of people who have had that. Why can’t they operate to take it out?”

“Metastatic cancer means that the cancer has spread. It’s not possible. If it was that easy, believe me it would be fixed.”

Explaining that the cancer has spread around the body can be emotionally hard for a person with ABC/MBC. The question from their colleague also trivialises their condition. **By knowing what the word metastatic means, those around a person living with ABC/MBC can make sure they aren’t repeating and correcting everyone all the time.**

Family member (e.g. cousin) that is in the house:

Person living with ABC/MBC, who is in their pyjamas with a cup of tea and doesn’t feel very well that morning:

“So how are you feeling?”

“Actually, I’ve been up and down. Maybe you can have a read of my blog. I’m quite tired and it upsets me and it is exhausting to keep repeating how I’m feeling. I hope that’s okay, if you really want to know.”

In this situation, the family member sometimes doesn’t actually want to hear that the person with ABC/MBC is feeling really low, is in a lot of pain and is struggling. The person with ABC/MBC knows that too and will often just say “Yes I’m fine” to avoid awkwardness around sharing how they really feel. Some people find that writing blog entries which their family and friends can read helps, because they don’t then have to keep repeating themselves and the people around them will get to understand how they feel. **For family members, have time and be prepared to hear exactly how the person with ABC/MBC is feeling before you ask, so they can really open up, whether it’s good or bad.**

Colleague at work, in the office:

Person with ABC/MBC who has just received a diagnosis:

“You need to think positive! I’ve been reading loads of tips for you.”

“I’m not convinced that is going to fix it.”

This is a classic scenario in which someone feels that they are helping, encouraging the person with ABC/MBC to think positive. In actual fact, this makes it sound like by following tips the ABC/MBC will magically disappear, or that there is a simple solution to solve it. It’s not the case and can make someone with ABC/MBC feel angry and belittled. **A better question to ask would be about how the person is feeling and really listening, rather than telling them to do things, read tips, or think positively.**



MAKING IT BETTER

There are some things to bear in mind or do that can make conversations about ABC/MBC feel so much better. Here are some examples. We hope you will find them useful.



SHARING DIFFICULT NEWS WITH FAMILY AND FRIENDS

Person living with ABC/MBC would like:

What you can do:

<p>Telling family, friends and everyone else in your personal life about bad news is difficult. Whether this is about a diagnosis, or a relapse, bottling up emotions and hiding them from the people who love you the most won't make you feel good.</p>	<p>The best thing you can do is to listen, give the person living with ABC/MBC space to speak about how they feel. It's okay to cry, to express that you are upset, as long as you support one another in the conversation.</p>
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You're stronger together, supporting and listening to one another when bad news happens.

TALKING ABOUT TUMOURS

Person living with ABC/MBC would like:

What you can do:

<p>It may be helpful to think about the tumour as a separate thing from you, because the tumour isn't part of who you are and ABC/MBC hasn't taken over your identity. You're still you.</p>	<p>Speaking about the tumour getting worse is much better than saying that they as a person are getting worse. This means you still see them as a person, without the tumour.</p>
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The tumour has got worse, not you.

CONNECTING AND SHARING ONLINE

Person living with ABC/MBC would like:

It can feel like ABC/MBC is a lonely place. At first, no one really understands as much as you do about what ABC/MBC means. It's often useful to reach out for support from other people who have ABC/MBC, as they have gone through exactly what you're going through. Online forums and social media can be a fantastic tool to connect with people.

What you can do:

It's hard to support someone going through ABC/MBC. There are support networks that exist and other people who are going through the same thing as you. Have a look online to see if connecting with others affected by ABC/MBC, or reading their stories can help you understand your role in supporting your friend or family member with ABC/MBC.

You're not alone and you can reach out to people.

TWO IS COMPANY, THREE'S A CROWD

Person living with ABC/MBC would like:

It's really important to feel that you get the most from appointments with your doctor, or nurse. So it may help to invite someone you trust along too, as a lot of the time information can be forgotten when you're worried. You'll feel more reassured if someone else was hearing the same things.

What you can do:

Make sure to go along to appointments and listen to what the doctor or nurse is saying. Sometimes shock makes our minds go blank, so it will be good to have you there to remember to ask important questions and to write down anything important to remember.

Two heads are better than one – especially at appointments.

LIFE IS FULL OF EMOTIONS

Person living with ABC/MBC would like:

The emotions you'll feel with ABC/MBC will almost certainly change. There can be shock at first, then acceptance and understanding. These emotions can come in different orders. There could be anger and disappointment, or tears of joy. There are no set rules and your experience is going to be unique to you. The main thing is that you can express how you feel, because feelings these things makes us human.

What you can do:

Your friend or loved one with ABC/MBC is going to be feeling lots of different emotions. Feeling sad, or angry, or happy is okay. For them and for you. What matters is that you can sense how they are feeling and communicate with them, to listen and support whatever it is they feel at that time.

Emotions are what you both have – to cry at and to laugh at, and everything in-between.

OPENING UP CAN FEEL GOOD

Person living with ABC/MBC would like:

Sometimes it is worth setting aside some time to speak to others. To share how you feel. To also listen to how they feel. Sharing together means you acknowledge that it's okay to have feelings and that all feelings are valid.

What you can do:

Sometimes it's important to sit down and listen to each other with openness. This is so you can express any feelings that have been bottled up and you can go through them together.

At the end of a cry and a hug, you feel closer with one another.

YOUR ENVIRONMENT CAN MAKE THINGS EASIER

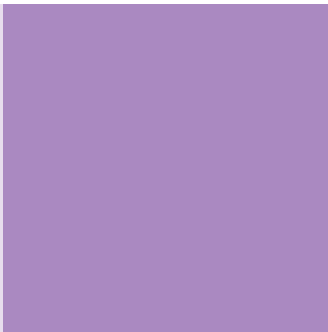
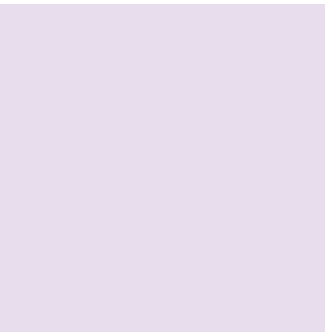
Person living with ABC/MBC would like:

What you can do:

When you tell your closest family about diagnosis, or relapse, it's never easy. But there are things you can do for you. For example, if you know your children will be upset, then pick a quiet room in your home, with time to speak for as long as is needed without outside stress. Or if you are telling someone but you know you need space to process, then consider using the telephone to add some distance and make sure you can both process what is happening. You need to think about what is best for you.

Having difficult conversations is made easier if you have space to react, breathe and say what you need to say. Make sure to be accommodating to how the person sharing the news is feeling and how they would like to do it. You also need to make sure you don't divert the conversation, or shut it down, because even though you're scared talking about it and confronting difficult emotions will help the other person too.

You'll feel better if you give yourself time and space to process bad news.



PEOPLE ARE DIFFERENT

Person living with ABC/MBC would like:

What you can do:

You need to figure out what makes you tick. Whether it's talking about ABC/MBC a lot, to process what is going on with others, or whether you'd prefer to write it down and share your story without having endless conversations.

People are different. You might deal with ABC/MBC by speaking it through to everyone and asking lots of questions, but for someone else that may be their worst nightmare. Try to gauge what a person with ABC/MBC prefers, and make sure you know how they like to express themselves.

You're both unique, so your conversations will be too.

OVERCOMING FEAR

Person living with ABC/MBC would like:

What you can do:

People don't like to think about ABC/MBC and misunderstand it a lot of the time because they are scared. It's a scary thing to think about for some people, because it makes them confront death. Be bold and encourage them to see it how you see it, to help them understand how you feel about it.

Realise that death will happen, but also that you will be ruining life if you are fearful of this to the point that it comes in between you and your friend or loved one.

The only thing darker than fear of death, is not being able to connect with your loved ones in life because of it.

Hope for better

“My wish is to take the shadow from metastatic breast cancer and bring light to us patients. There is a space for hope. A real hope. This is the right time now and the coming times I think will be much, much better.”

– Person living with ABC/MBC

If there is one message we have for you, it is to hope.

Hope that better treatments will be found for ABC/MBC. Hope that current treatments will make life with ABC/MBC better. Hope that the rest of your life with ABC/MBC will be filled with special moments. Hope that you will have meaningful conversations together. Hope that you will find strength together, even when dark times come. Hope that you will support each other and enjoy life together. Hope not to go back to how life was, but to live for the present and the future. Hope for our children's futures, and their children's futures. Hope for whatever it is that's individual to you.

**This is the most important thing.
To always hope.**





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Novartis 2019

March 2019

G-RIB-1208252

**Novartis would like to thank the women who
generously gave their time and opened
their hearts to help improve other women's
experiences in the future.**