

FINDING THE RIGHT WORDS IN ADVANCED AND METASTATIC BREAST CANCER (ABC/MBC)

Real people. Real communication.
Making a real difference.

my time
our time



 NOVARTIS

What do we mean when we say, 'finding the right words'?

Hello. Welcome. Thanks for picking up this guide. It will give you a glimpse into what your metastatic breast cancer (ABC/MBC) patients are thinking and feeling behind closed doors. When they leave the consultation room, what runs through their mind for hours afterwards? What do they wish they'd said or asked? What do they wish they'd heard? Could something have been said better? And what did they really feel on the inside?

You'll know all too well that when talking to patients about their health, the power of every word can be magnified. Feelings hang on every sentence. Heart rate can soar with every bit of news. This is especially true in ABC/MBC. One word, or even the way a word is said, can have a big impact. The words we communicate with can change the way patients view and experience ABC/MBC.

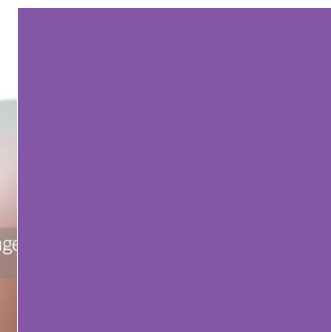
In 2018, Novartis brought together women with varied experiences and stages of breast cancer, including ABC/MBC, to explore this potential to make a real difference. The patients travelled from Germany, Austria, Israel, Spain, Belgium and Romania. They shared their experiences and observations

about the language of ABC/MBC, which revealed that miscommunication and misunderstanding can be common.

Everything you'll read in this guide came from what the women had to say. They all expressed their hope for better communication in as a result of sharing their experiences with Novartis and ultimately, you too.

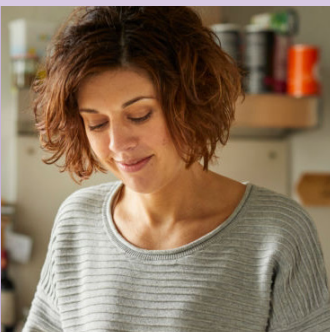
The journey to understand what the women had to say starts by asking whether the words we use to describe ABC/MBC are right. Then we look at the patient journey, identifying the points they felt were important for effective communication. Finally, we'll explore their views on how to make a difficult conversation feel so much better for a patient.

We really hope this helps you in the psychological as well as the clinical support you provide.



HITTING THE RIGHT SPOT

Are we hitting the right spot with our words? There isn't a clear answer to this question in ABC/MBC. Being diagnosed with ABC/MBC is very different to having breast cancer at any other stage. It comes with its own unique, messy feelings. Let's try to unpack some of the words that cause a bit of controversy.



Am I 'advanced' or metastatic?

Even though the differences in the staging are clear, metastatic (stage IV) patients commonly get referred to as being part of the broader 'advanced breast cancer group'. Although this is well-intentioned, to help all advanced patients feel included and part of a big community, some patients feel the term is not specific enough. Some ABC/MBC patients like the term 'metastatic' because it represents their disease and means that it's easier to explain the biology of ABC/MBC as 'spreading' through the body. The term 'metastatic' can be scary, but only because it confronts people with the idea of death. Ultimately though, this idea is the reality that has to be faced to understand what patients are going through. It's key to make sure your patient understands the difference.

Am I really on a 'journey'?

The word 'journey' has very different meanings in different languages. For example, in German it's a pleasant experience, which doesn't fit with ABC/MBC at all. However, in Hebrew it involves the good and the bad moments along a path and therefore is a better fit with ABC/MBC. Do patients feel like it's a journey? It depends on their interpretation personally. When using the term 'journey', think about whether it is appropriate for the patient and whether it is right for the stage they are in.

If I lose the 'battle', is it my fault?

Did I not fight hard enough? Was there some way I could have 'won' my battle with cancer? No is the answer for ABC/MBC

patients. By describing the journey with cancer as a 'battle' it puts the success of the fight on the patient's will, as if their strength determines their survival. Should we consider a battle lost as the patient failing the therapy or the therapy failing the patient? Or has the tumour or the patient progressed? Such divisive, combative terms make ABC/MBC patients understandably feel that they are 'losing' at something everyone else around them is winning at.

If I'm not a 'survivor', am I a failure?

By saying that people have 'survived' cancer, it makes those with ABC/MBC who are not going to be in remission feel like failures. Do they become a 'survivor' from day one of their cancer diagnosis? Or will they never be a survivor at all, always destined to fail? It isn't clear. This isn't helped by the use of this word in a sensationalised way in the media, which can make those with ABC/MBC feel uncomfortable.

SO HOW DO WE HELP?

Being aware of how these terms could make a patient feel is useful. Also, communicating in an open way can help to find out what terms your patient feels most comfortable with. Listening to the words the patient uses themselves and mimicking them is an important part of doing this too.

THE JOURNEY THROUGH
A PATIENT'S EYES

The way we see a patient's journey with ABC/MBC is usually around where they are at in their treatment. But this isn't necessarily how your patient will be thinking about their journey. For them, it's about what they feel.



The Clinical Journey

- 1. Before ABC/MBC
- 2. Initial diagnosis
- 3. Making treatment decisions
- 4. Continual management

The Emotional Journey

(but the journey can be a bit more complicated)

1. The weight of disappointment

When patients are diagnosed with ABC/MBC, they are in different emotional places. An early breast cancer patient who has progressed has experienced more disappointment compared to someone with an initial ABC/MBC diagnosis. For them, it can feel like a slap in the face.

2. Understanding there's no way back

Take the obvious but really important fact that if you've got ABC/MBC you don't have a chance to go back to how it was before, unlike early breast cancer.

There is a period of shock, learning and eventual understanding that is different for everyone. Patients feel that they are not able to step back into their old lives anymore and that life with ABC/MBC will never be the same again.



3. Accepting and owning it

Accepting the situation is a process and involves working out resources available to you and what can be done. Readjusting happens gradually after that and is a continual process of acceptance.

4. Connecting to combat loneliness

After a time there is a need to connect and look for help and support from others. Patients need to feel that they aren't alone.

5. Coping never stops

Coping with diagnosis, then with treatment decisions and potential relapses means adapting continually.

6. Recognising relapse

The second and third relapse brings a new wave of emotions and there is a lack of appreciation that feelings might be different at each relapse.

SO HOW DO WE HELP?

By recognising where a patient is emotionally, it will help you to ask the right questions build trust, helping to ease the decision-making process.



TIME FOR SOME REAL TALK

What makes a conversation feel so much better for people with ABC/MBC?

We asked, and they told us.

1. Hope is fundamental

Hope is the one thing that must be kept alive for people with ABC/MBC. Hope for better treatments and hope to live in the time they have left. Hope that it isn't all bad from this point on.

Never kill hope, as that's not your job. Equally, giving false hope is bad. Finding that balance between the honesty and optimism is essential.

2. Understand it's hard to understand

Hearing words such as 'metastatic' is hard. Sometimes people block words out in shock or don't understand what words such as this mean. Becoming frustrated with a patient belittles them in these situations.

Explaining that it is difficult to understand shocking words like 'metastatic' and acknowledging how a patient may need some time to process what is happening will help them. Repeating and explaining in simple terms, with drawings, will help them to gain an understanding.

3. It shouldn't be numerical

Giving your patient a numerical estimate, say of around 2–4 years or months doesn't help them, because a ticking clock starts in their head. It causes panic. Bluntly stating numerical time left is not a positive use of language.

Explain the nature of terminal without giving exact numbers for survival. It means they have a chronic illness. Mentioning that there are good treatments available and coming up in the future to prolong life and improve quality of life is a good approach.

4. Balance good with bad

Hearing loads of bad news isn't challenging. It can make the journey ahead appear very dark.

Let patients know some good information will balance the bad, ending with positivity. Also, this applies to their long-term journey, if they know there will be good and bad times along the way it becomes easier. It is important that they know this.

5. You are not alone

Being a patient with ABC/MBC can be a lonely place.

Directing patients to support materials and ways to connect with other ABC/MBC patients will help them to connect with one another and find support.

6. Opening up can feel good

ABC/MBC can be difficult to explain to others. People can ask questions about when a patient will be getting better, without realising the nature of a chronic, metastatic condition. This repetition to everyone around a patient can be tiring and they may not bother communicating with some people at all.



People find it hard to communicate and tell others about ABC/MBC, but by encouraging them to write their experiences down, they will have a place for others to read about their condition. It will help them come to terms with what is happening, find the right words to use and avoid constantly repeating themselves.

7. Don't deny feelings

Denying patients the space to express feelings hurts them. Things that can be useful in other conditions don't apply to ABC/MBC and can make it seem like you are underestimating and trivialising the condition. For example, the therapeutic technique of putting concerns in a mental cloud and making them go away from reality can be traumatising.

Let patients express their emotions and embrace how they feel, whether that is good or bad.

8. Those 'oh-no' phrases

Patients that hear well-meaning tips such as 'think positive' feel that it belittles the gravity of the diagnosis. This too, trivialises ABC/MBC as a condition, as it can't be solved with mental techniques and 'thinking differently'.

Do not try to solve the emotional complexity the patient feels with a simple solution, but show understanding that this is going to be difficult and empathise.

9. No going back

ABC/MBC patients are not able to step back into their normal lives. This is different to early stage breast cancer.

Help them understand that although life will be different now, it can still be full of hope.

10. People are different

Some people prefer to know everything about the details of their treatment and others prefer to know the bare minimum. What empowers one person will overwhelm another. People are different, so conversations about treatment should reflect this.

Create discussions that recognise what a patient needs and tailor language to them. Ask the right questions, listen to how they respond and understand their body language to work out what helps them. It's difficult to do this, but it makes all the difference.

11. Feeling like a number

If the clinician is reading their notes or talking to a colleague in front of a person, it can make a them feel like they are just another number on the clinician's list. It can feel dehumanising.

Making an effort to see the patient as an individual and picking up what they respond well to e.g., full eye contact when speaking, will help the interaction to feel that little bit more human.

12. Explain biology clearly

Hearing medical jargon can make anybody feel stupid. Explaining the biology that's happening inside a patient in the clearest way possible may help them to find power in understanding their condition.

Drawing what is happening on a piece of paper really helps to picture it. Finding easy ways to say what is happening, and then what a drug will do based on that, is great.

13. Deal with 'tumour' delicately

Conversations that centre on the tumour rather than the patient can make them feel like the tumour has become their identity. Equally when talking about progression, being told at relapse that they have progressed, rather than their tumour can make the cancer seem all-consuming.

Saying that the tumour has progressed, not the patient, is helpful to detach personal identity away from the tumour.

14. Advice is everything

Conversations about treatment decisions can involve moments of high tension and stress. Being asked to choose what treatment to go for next, without feeling equipped or ready to make that decision added so much unnecessary pressure. It might be that they have something that's worrying them, that they haven't expressed.

Ask whether the person in front of you has all the information they need to make that decision, but could be too afraid to ask. Don't put the pressure on them to decide if they are not well-informed. Always check that they feel comfortable with their chosen therapy.

15. Two is company, threes a crowd

Often consultations are one-on-one experiences and patients don't feel that they can bring someone with them. However, it can be hard to remember everything when hearing some shocking news.

Advising patients to bring someone to their appointments, so that the extra person can help fill in gaps which they missed during discussions is essential to help them prepare. This person can also help them cope with experiencing difficult emotions afterwards.



“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.”

– MBC Patient



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.