MY BROADCAST COMPANION:

TALKING ABOUT LIVING WITH METASTATIC BREAST CANCER

ADVICE TO SUPPORT PEOPLE LIVING WITH INCURABLE BREAST CANCER, AND THOSE AROUND THEM, TO HAVE MORE OPEN CONVERSATIONS ABOUT THE THINGS THAT MATTER MOST.

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> “I WAS DIAGNOSED WITH **METASTATIC BREAST CANCER** MORE THAN EIGHT YEARS AGO, SO I’VE BEEN TALKING ABOUT THIS DISEASE FOR A LONG TIME NOW. TO ANYONE JUST STARTING THIS JOURNEY, I WOULD SAY: **BE OPEN AND TELL THOSE AROUND YOU HOW YOU ARE THINKING AND FEELING.**”

Jean, MBC patient living in the UK.

My BroadCast Companion is a guide that has been developed to help people living with metastatic breast cancer (MBC) and those around them – including friends and family – to break the silence that can come with a diagnosis of MBC.

By talking to people living with MBC, we have learned that they often struggle to have the conversations they want to have, even with those they are closest to. Some topics, including intimacy, finances, and end-of-life care were especially difficult to talk about. Emotions, fears and worries about upsetting people can be barriers to having tricky but important conversations.[1,2]

This guide has been written with input from people living with MBC and experts involved in caring for those with MBC, in order to share tips and advice to make having difficult conversations easier. We hope that reading this guide will help you and your loved ones to talk openly and share your thoughts and feelings as you continue your journey with MBC.

This guide will look at:

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Words – your MBC glossary

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Communication – what makes a good (or not-so-good) conversation

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Advice – six difficult topics

FRIENDS AND FAMILY

If you are close to someone who is living with MBC, reading this guide may help you understand more about their disease and how to support them. Look out for tips and advice where you see the symbol in the top right of this box.

WORDS

YOUR MBC GLOSSARY

How can you explain that your cancer is different to primary breast cancer? How can you make people understand that treatment that may have cured *other* people's cancer won't cure you?

The words used to describe MBC can feel like a foreign language – one that you may be familiar with but that some friends and family can struggle to grasp. Our research showed that people found different terms useful to describe their disease and their experiences.[1,2,3]

- Doctors, nurses and other people with MBC usually use the term 'metastatic breast cancer' but friends and family might not understand what this means.
- Some people living with MBC find it useful to describe their cancer as 'manageable but not curable' or 'incurable' rather than using terms like 'terminal'. Although this might be difficult, it can help people around you to understand that you are having treatment for your cancer, but you don't expect it to be cured.

MBC GLOSSARY

You may hear several different ways of describing that breast cancer has spread to other parts of the body, and the disease is no longer curable. All the phrases below mean the same thing:

- **Metastatic breast cancer**
- **Stage 4 cancer**
- **Secondary cancer**
- **Advanced cancer**
- **Terminal cancer** (often only used at the end stages of the disease)

COMMUNICATION

WHAT MAKES A GOOD (OR NOT-SO-GOOD) CONVERSATION?

A diagnosis of MBC can leave you facing a lot of questions: who do you want to tell and when? What plans do you need to make? These are issues that will affect those around you, and that you probably want to discuss.

In our research, people living with MBC told us that they valued open, honest conversations that enabled them to be themselves and say what was on their mind. They struggled when other people's emotional reactions meant that they couldn't say what they wanted to say.[2,3]

The box below summarises some of the key elements of a good and a not-so-good conversation.

GOOD CONVERSATIONS...

- Are open – allowing you say what you want to say
- Are calm and don't let emotional reactions stop you from feeling able to open up
- Remind you who you really are and what the diagnosis has not changed

NOT-SO-GOOD CONVERSATIONS...

- Put up barriers between you and the people you care about and want to talk to
- Make you feel like you can't say what you want to say
- Avoid or ignore the situation
- Include comparisons between other experiences or other cancers

What you and your friends and family can do to have good conversations

Everyone is different and there is no magic formula for making these conversations less difficult. There are a few things that you and those around you can do to lay the ground work for better conversations:

YOU:

- Don't feel like you have to rush into talking about everything at once – be kind to yourself and wait until you really feel ready.
- Plan ahead by thinking through the questions you think people will ask you and deciding how you will answer them. This may relieve the pressure when you are talking to people who may feel shocked or upset.
- Try to be clear and factual about what you want and need, even if you are talking about a difficult topic like end-of-life care.

FRIENDS AND FAMILY:

- Try to keep your emotions in check, and avoid a situation in which the person with MBC feels like they have to console you.
- Give them space and time to talk about things, even if it's difficult for both of you.
- Take your cues from the person with MBC.
- Treat them as you would have done before their diagnosis – their situation might be different but they're still the same person.
- Don't assume you understand how they feel and what they want and need. Ask them.
- Take time to familiarise yourself with MBC to ensure that they don't feel like you are fully relying on them for all information. National health websites or national/local patient groups are good places to go for further information.
- Sometimes support can be shown without words – through body and facial expressions.
- Choose your words carefully – volunteer to be there if they need to talk.

WHAT NOT TO SAY

There are no rules on what you should and shouldn't say to someone who's been diagnosed with MBC, but people living with this condition have told us that there are a few things they can find difficult to deal with:[2,3]

- People other than their doctors telling them to try different treatments. Try to avoid offering advice on 'new' or 'alternative' treatment options as, to a person with MBC, it can feel like you are undermining the faith that they have put in their consultant.
- Feeling that they can't talk openly because of a friend or family member's fears.
- People avoiding talking about their diagnosis or not asking any questions.
- People saying that they look 'well', as it can be a reminder that they are not well. Taking the focus off their health by saying "You look nice" or "That dress really suits you" may be a better compliment.
- People saying that they know how they feel if they don't have MBC or have not had cancer.

Occasionally, humour helps, so you should be comfortable in taking the lead from them.

ADVICE

SIX DIFFICULT TOPICS

Our research with women living with MBC uncovered six topics that can be especially difficult to talk about.[1,3] Below are some tips that may help make these conversations easier.

1

‘I have MBC’: Talking to people about your diagnosis.

Whether it’s family, friends or people you are meeting for the first time, telling others about your diagnosis can be daunting. Here are some tips from the people we spoke to:

- Think about who you tell and in what order, as this can keep your stress levels to a minimum and help you to manage your emotions. Telling parents and children can be particularly hard.
- Many people don’t understand the difference between a diagnosis of MBC and one of primary breast cancer. Explaining that you have ‘advanced’ or ‘secondary’ cancer that has spread to other parts of your body and which can be treated but cannot be cured, may help people to understand what you are dealing with. You may find the glossary on page 2 useful.
- Be prepared for people to respond with a whole range of emotions – for example anger, sorrow and disbelief.
- Be prepared for people to ask all sorts of questions, some of which you may not be ready for, or find too emotional to answer. It may be useful to point them in the direction of support groups which provide information for the friends/families of people living with MBC.

TALKING ABOUT A LOVED ONE’S DIAGNOSIS

- Showing your loved one that you are comfortable in speaking about their diagnosis may reassure and comfort them.
- Patient support groups often provide resources which can help you to learn more about their diagnosis and avoid overloading your loved one with questions.

TALKING TO CHILDREN

It's natural to want to protect children from anything that could upset them but it's usually best to be honest and open. Try to use simple, clear language that is appropriate for the child's age. For a young child, you could think about saying something like: 'I'm having treatment to help stop the cancer growing, but it won't make it go away.' If the child likes stories, you could also make up a story to help them to understand your diagnosis.

If you have children, you should also consider telling their school or parents of their close friends, so they can look out for your child and be aware if their behaviour changes.

2

‘I’m still me’: Talking to people about how living with MBC is affecting your sense of identity.

Your life now has a new structure, and your diagnosis, treatment and future may never be far from your thoughts. It may change the way you think and feel about yourself. Here are some tips for explaining and understanding that, while some things are different, you’re still you:

- Try to be open with friends, family and partners about the changes you are experiencing and how they are affecting what you can and can’t do.
- Don’t feel that you have to pretend you’re fine – it’s okay to let people know that you’re having a bad day, that you’re feeling tired or that you’re anxious about your next scan.
- Remember to talk about the things you talked about before your diagnosis, whether that’s what your friends and family have been up to, the book you’re reading or the latest celebrity gossip.
- Holidays and celebrations are important. Try to look forward to these occasions, as this will provide something in the future for you to focus on.

YOU’RE STILL YOU, TOO

A loved one’s cancer diagnosis can make everything else seem trivial. But make sure you carry on telling them about the things that matter to you, just like you did before – this can help normalise your conversations.

3

***'There are so many things I want to do, but sometimes I need to slow down and rest'*: Talking to people about boundaries and your 'new normal'.**

After your diagnosis you may feel that there are things you don't want to do anymore or that you need to do differently.

- Explain to people that your energy levels and wellbeing can vary day-to-day. On some days you will be able to do lots while at other times you may need to rest.
- People around you may want to protect you and might think you should stay at home and rest even when you feel fine to go out. You may have to explain that doing what you want to do won't cause you any harm.
- Don't fall into the trap of feeling that you're letting people down – dealing with MBC isn't easy and people's expectations of what you will and won't do may need to change. This isn't your fault.
- Set clear boundaries and tell people why you are setting them: 'I can't commit to seeing you regularly because I may not always feel up to it. I'll let you know when I can visit.'
- Don't avoid talking about uncomfortable but important changes, whether that is discussing intimacy with your partner or cancelling plans with a friend because you want to spend time with your family instead.

ASKING SPECIFIC QUESTIONS

People living with MBC can feel better or worse depending on how their disease is affecting them and where they are in their treatment cycles. You might find it helpful to ask them how their energy levels are, or whether they would like to join you for a trip out or a walk.

4

‘We can’t just ignore the financial side of things’: Talking about money and how MBC can affect finances for you and your family.

Being diagnosed with MBC can have an impact on finances for you and your family. You might not be able to work as much as you used to – or at all – and you might also worry about how your family will cope financially after your death.

- If you’re worrying about finances, try to discuss this with your family and be open about your concerns. This might be something your loved ones find painful to discuss – or money might be the last thing on their minds – but it is important to make time for these conversations.
- Some patient support groups have useful information and resources about the financial side of living with cancer which you could look at together. There may even be some local support groups in your area.
- Depending on your circumstances and where you live, you and your family may be able to access some financial support. Are there any state benefits you are entitled to? Alternatively, could you apply for any grants or other assistance from patient support groups?
- On a practical level, you might find it reassuring to put your financial affairs in order and make sure that you have written a will.

MONEY MATTERS

- Talking about money can be difficult even at the best of times, but finances are an important part of family life so it is important not to avoid these conversations.
- Getting familiar with some of the financial advice and benefits that might be available to people living with MBC and their families could help to alleviate what can be a major source of worry.
- You might want to talk to your loved one about your family’s longer-term finances so you can make a plan together for how you will manage after they are gone.

5 *‘My work is important to me’*: Talking about whether you will continue to work while living with MBC.

If you were working before you were diagnosed with MBC, you may want or need to carry on – perhaps doing fewer days or hours to make it manageable. Alternatively, you may want or need to step away from work completely.

- This is something you will probably want to discuss with those close to you as well as your employer or colleagues.
- Continuing to work might be helpful for your physical and mental wellbeing, as well as enabling you to continue to earn money.
- Consider whether it may be possible to agree a flexible working arrangement with your employer.
- It may be useful to know your rights before talking to your employer about work. Your local patient groups may be able to provide guidance.

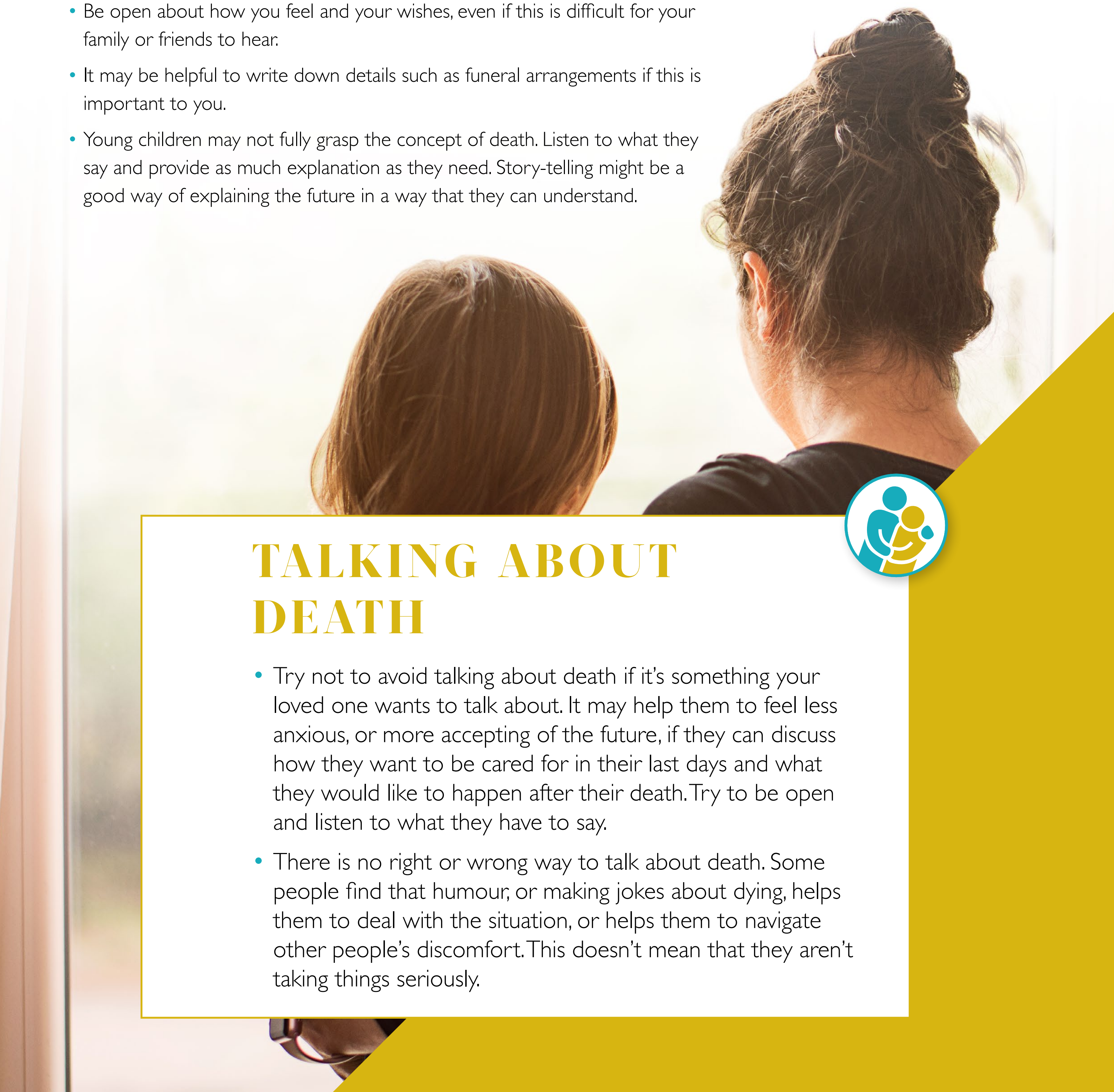
SUPPORTING A LOVED ONE THROUGH WORKING WITH MBC

- There may be some support you can offer your loved one so they can continue working, for example offering to drive them to work or helping out with childcare if you are able.
- Taking the time to talk through the practicalities of them continuing to work, and the different options available, might also be helpful.

6 *'I want to plan ahead'*: Talking about end-of-life care and after death.

How much you want to think and talk about what you want to happen in the last days of your life and after your death is entirely up to you. For some people, making plans about end-of-life care, funeral arrangements and family life after their death help them to worry less and feel more in control. Others prefer to take things day-by-day.

- There's no right or wrong time to talk about end-of-life care, the transition from active to palliative care or, what will happen after you pass away – wait until you are ready to have this conversation.
- Be open about how you feel and your wishes, even if this is difficult for your family or friends to hear.
- It may be helpful to write down details such as funeral arrangements if this is important to you.
- Young children may not fully grasp the concept of death. Listen to what they say and provide as much explanation as they need. Story-telling might be a good way of explaining the future in a way that they can understand.



TALKING ABOUT DEATH

- Try not to avoid talking about death if it's something your loved one wants to talk about. It may help them to feel less anxious, or more accepting of the future, if they can discuss how they want to be cared for in their last days and what they would like to happen after their death. Try to be open and listen to what they have to say.
- There is no right or wrong way to talk about death. Some people find that humour, or making jokes about dying, helps them to deal with the situation, or helps them to navigate other people's discomfort. This doesn't mean that they aren't taking things seriously.

PASS IT ON

If you have found this guide useful, please consider passing it on to someone else it could help. This might be members of your family, friends or someone else living with MBC.

The **FurtherMore.life** website is a useful place to find more information about people's experiences of living with MBC. It includes videos, information and advice, all designed to help people with MBC and their families to navigate life after diagnosis.

Join the conversation

Let us know what you think – use **#MyBroadCast** to share your experiences of talking about MBC on social media.

About this guide

In 2018, Eisai Europe Ltd. launched a campaign called FurtherMore with the aim of giving women living with MBC opportunities to share their experiences. Part of this campaign was a report called 'MBC Radio Silence' which revealed, based on survey data, that many women feel isolated and confused after being diagnosed with MBC. This booklet is one of the ways that Eisai Europe Ltd hopes to support women by helping them to feel less isolated, through better conversations that can help to end the MBC Radio Silence.

To develop this guide, we:

- Conducted in-depth social listening across forums, blogs, Twitter and Facebook to examine the language used around MBC in conversations online.[1]
- Interviewed 11 MBC patients across seven countries – Australia, France, Germany, Italy, Singapore, Spain and the UK.[3]
- Held steering committee consultations with healthcare professionals and patient advocates:[2]
  - **Dr. Elisabeth Andritsch (Austria)** – President of the Austrian Platform of Psycho-oncology and member of the International Psycho-oncology Society (IPOS).
  - **Dr. Victoria Harmer (UK)** – a Macmillan Consultant Nurse (breast) at Imperial College Healthcare NHS Trust, and trustee for the charity Against Breast Cancer.
  - **Jean Robinson (UK)** – a patient with metastatic breast cancer.
  - **Dr. Fatima Cardoso (Portugal)** – Director of the Breast Unit of the Champalimaud Clinical Center and chair of the Advanced Breast Cancer International Consensus Guidelines Conference (ABC) and of the ABC Global Alliance.
  - **Dr. Ana Casas (Spain)** – Breast Cancer Consultant and Tutorial Professor at University Hospital Virgen del Rocio (HUVR), President of Spanish patient advocacy group Actitud frente al cancer.
  - **Dr. Cristian Ochoa Arnedo (Spain)** – Coordinator of the Psychosocial Committee at the Catalan Institute of Oncology, Professor at the University of Barcelona and OnCommun Project Director.

If you have any comments or questions about this guide, please contact Eisai Europe Ltd on emea-comms@eisai.net.

Dedicated to Sarah Lloyd, whose honest and candid insights of living with metastatic breast cancer, were integral to the development of this guide.

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1. Pulsar Market Research. Metastatic Breast Cancer (MBC): A social insight report. July 2019
2. Eisai Europe Ltd. My BroadCast steering committee report. December 2019
3. Shift Behavioural Insights. Conversations about MBC: The Patient's Perspective. September 2019