### Reporting Metastatic Breast Cancer

# Media Guide



Increasingly, metastatic breast cancer is making the news. This is important as increased awareness and understanding of the different stages of breast cancer will help drive better treatment and care.

This guide was designed for journalists when reporting on metastatic breast cancer, and breast cancer more generally. It was developed in consultation with members of BCNA's Metastatic Breast Cancer Lived Experience Reference Group. Metastatic breast cancer is also called stage IV (4) breast cancer, secondary breast cancer or advanced breast cancer. These terms are interchangeable and mean the same thing. In Australia, **'metastatic'** is the most commonly used term.

Metastatic breast cancer is when breast cancer has spread beyond the breast to other parts of the body, most often the bones, lungs, liver or brain. It is treatable but not currently curable and is a life-limiting disease.

Metastatic is different to other stages of breast cancer, such as early breast cancer (stages I-III) or ductal carcinoma in situ (DCIS). It is the only breast cancer that people die from.

The development of better treatments means that some people with metastatic breast cancer are living longer. Many are also experiencing improvements in their quality of life, although many challenges persist including managing pain and side effects of treatment, psychosocial impacts, financial challenges, fear of progression and coming to terms with end-of-life.

Unlike early breast cancer, treating metastatic breast cancer aims to slow the progression of the cancer and to prolong life, as opposed to curing the cancer.

Metastatic breast cancer does not discriminate. Although it predominantly affects women, men and people who are non-binary or gender diverse can also be diagnosed. It affects indigenous people, as well as people of any age, ethnicity, or socioeconomic group. This is why we use the simple term **'people with metastatic breast cancer'** to describe this group.

#### Important terms:

Term	Definition
De novo metastatic breast cancer	When metastatic breast cancer is diagnosed as someone's first breast cancer
Recurrent metastatic breast cancer	When someone's previous breast cancer returns as metastatic breast cancer
Locally advanced breast cancer	Stage III breast cancer that has spread to areas immediately surrounding the breasts such as the lymph nodes, skin, or muscle. This is different to metastatic breast cancer (stage IV), which has spread further in the body.

#### Language and representation matters

Finding the right language when reporting on metastatic breast cancer is important. Inadvertently or unconsciously, journalists can use language that offends or misrepresents the realities of living with metastatic breast cancer. This can negatively impact the progress being made raising awareness about metastatic breast cancer.

What to avoid	Try instead
"Battling metastatic breast cancer"	"Living with metastatic breast cancer"
"Lost the battle/lost the fight"	"Died of metastatic breast cancer"
"Suffering"	"The impacts/effects of metastatic breast cancer" "Managing treatment side effects"
"Terminal"	Whilst "terminal" may be appropriate in some circumstances, it is often better to describe metastatic breast cancer as "treatable but not curable" or "life-limiting." Always check with people which term is right for them.
"Journey"	"Experience"

People with metastatic breast cancer often feel excluded by the term 'survivor' because their cancer will limit their lives. Instead, you could talk about 'living as well as possible with metastatic breast cancer' as maintaining health and well-being is important, but those with metastatic breast cancer also face challenges of ongoing treatment, sideeffects and managing the progression of their cancer.

### Insinuating blame

While there are some lifestyle factors that affect a person's risk of breast cancer and recurrence, implying blame for someone for their cancer is inaccurate and can be hurtful and harmful. Saying that someone 'won the fight' against breast cancer could imply that those with metastatic breast cancer do not fight hard enough.

### **Finishing treatment**

Implying that everyone diagnosed with breast cancer will finish treatment excludes those living with metastatic breast cancer who will require ongoing treatment. This also includes language that implies people's lives will 'resume' or that they'll 'get to the other side' of cancer, as this is not the case for those with metastatic disease.

#### **Visual representation**

Metastatic breast cancer looks different for everyone and can change over time. Some people with metastatic breast cancer may look well at times and others may show more visible signs of their treatment. Hair loss is relatively uncommon except during initial chemotherapy and during some other treatments. We encourage diverse visual representation of metastatic breast cancer.

## FACTS AND FIGURES

We don't know how many people in Australia have metastatic breast cancer as stage-at-diagnosis and cancer recurrence are not recorded consistently on cancer registries in every state and territory.

BCNA's advocacy campaign to have people with metastatic breast cancer counted routinely by all Australian registries kicked off in 2022. **Discover more** about our campaign and 2023 expert roundtable in Canberra. By using the latest available modelling, at least

1**5,000** people

### **ŧŧŧŧŧŧŧ**ŧ

were living with metastatic breast cancer in Australia during 2020. This is a conservative estimate, the actual figure is likely to be higher.

### In 2023, it was predicted that around



were diagnosed overall with breast cancer (DCIS, early and metastatic).

Indigenous Australians have lower rates of diagnosis than non-Indigenous Australians. When an Indigenous person is diagnosed with breast cancer, they are more likely to die from their breast cancer than a non-Indigenous person.



More breast cancer statistics

### Engaging those with a lived experience

BCNA has a strong and engaged Metastatic Breast Cancer Lived Experience Reference Group. Their feedback included wanting their views included in media coverage of breast cancer, as they often feel excluded from breast cancer narratives.

Speaking to someone with a lived experience of metastatic breast cancer can help strengthen any story or reporting.

Please contact BCNA if you need a comment or case studies for your stories.

Call 03 9805 2540, email us at media@bcna.org.au or view our latest media releases at bcna.org.au/media-centre

In 2023, it was estimated that

**3,255 36** men

died from metastatic breast cancer.

Five-year survival rates for early breast cancer are high in Australia. However, around

### 20 PER CENT OF PEOPLE

diagnosed and treated for early breast cancer will have a breast cancer recurrence.