



Out From the Shadows

The Reality of Living with Metastatic Breast Cancer

Picture features Emma, mother-of-two, Melbourne, living with metastatic breast cancer

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Foreword



I see my patients go through a range of emotions when they learn they have breast cancer. It's a diagnosis where fear and anxiety take a firm hold – and for those with metastatic breast cancer (mBC), these emotions are amplified as they face a future managing an unrelenting cancer. With mBC there is no end date for treatment and care. And with a 5-year survival rate of just 32%,¹ they talk about the need to make every day count.

While survival remains low, it has improved significantly thanks to advances in treatment and care. People with mBC are living longer, but they do so from the shadows, rarely visible and barely heard.

It is time now to make urgent changes – counting them in cancer registries so we see them, providing platforms so their challenging stories can be heard, building quality information to guide them, and creating support and care that meets their specific needs.

I am one of many passionate individuals, along with several organisations, who have been working to improve the lives of those with mBC – their quality of life and survival outcomes. It is a complex area, but progress is slower than many of us would like.

From my perspective, giving the community information with clear direction and guidance on where the next test and treatment may be coming from is absolutely essential to bring hope to people's lives. Specific support and care, tailored to the stage of their cancer, and access to psychosocial services is also imperative to meet their evolving needs.

I welcome '**Out From the Shadows – The Reality of Living with Metastatic Breast Cancer**', which summarises the latest evidence in mBC and provides recommendations on what we must do today to shed light on and build greater understanding of this challenging condition, to bring a brighter tomorrow. I hope you find it an insightful and powerful discussion.

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Out From the Shadows – The Reality of Living with Metastatic Breast Cancer

Executive Summary

Awareness of breast cancer and the need for action on this challenging disease has come a very long way over the past two decades. Tireless efforts of advocacy and the now iconic colour pink has elevated breast cancer to one of our most visible diseases, and in doing so, has played a critical role in improving the outcomes of those living with this disease.

The 5-year survival rate for breast cancer overall, has improved significantly, rising from 77% in 1989–1993 to 92% in 2014–2018.² For those diagnosed with early-stage breast cancer, the potential to be cured may be possible.³

For those with advanced or metastatic breast cancer (mBC), 5-year survival rates have doubled to 32%, thanks to the availability of new therapies that slow disease progression and control symptoms.¹ But this remains far too low. Their breast cancer has not been solved, not clearly visible or distinguishable, there is still a long way to go.

It's estimated more than 10,500 Australians are living with mBC.⁴

Metastatic breast cancer is currently an incurable, invasive cancer that has spread from the breast to other parts of the body.⁵ It comes with never-ending treatment, poor survival rates and a sense of invisibility.

It is time now to bring those with mBC 'out from the shadows' by capturing the impact of their disease, acknowledging them, and providing better support to meet their unique needs.

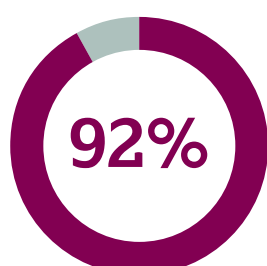
Organisations at the forefront of breast cancer advocacy have been actively working to address the unmet needs of Australians with mBC for years. While improvements are underway, more is required, and momentum needs to be accelerated.

“The messages of hopefulness from early-stage breast cancer activities still align with me – because I am a fighter, I still apply the same optimism. I’m going to keep going but with a different form of optimism.”

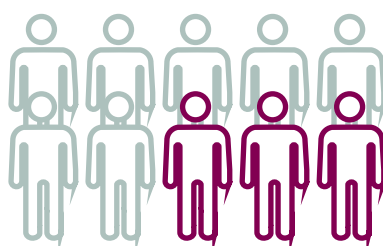
- Cassie, 36, living with mBC

Out From the Shadows – The Reality of Living with Metastatic Breast Cancer reviews current local and international evidence, to unearth critical gaps and inequities facing Australians living with mBC, and how their general invisibility in the healthcare system and community impacts them and their families.

The overall **5-year survival** rate for breast cancer² is



But only **3 in 10** with metastatic breast cancer will survive for 5 years¹



It's estimated more than

10,500

Australians are living with mBC⁴

Prioritising metastatic breast cancer

There is universal agreement across the breast cancer community that more needs to be done to address the inequities experienced by people with mBC. While we have moved beyond the starting line, far more is required to bring mBC out of the shadows and onto a more positive path forward.

A review of the evidence and commentary indicates a number of priorities are required to tackle mBC head-on, with **visibility, voice and support** the most pressing areas to address:



1. VISIBILITY - Place mBC in the spotlight

- Develop dedicated mBC platforms to make this community comfortable and confident to discuss living with incurable breast cancer
- Provide people with mBC better access to existing breast cancer platforms to improve community awareness
- Build a deeper understanding of the mBC community's specific needs – including those from specific communities with unique experiences



2. VOICE - Empower Australians through tailored information

- Include mBC stories and needs in all breast cancer information
- Actively support people with mBC to receive information on new developments in management and treatments and how they can access them
- Establish stage-specific mBC peer support and facilitated groups to provide active support and information sharing through their disease



3. SUPPORT - Build dedicated mBC support services

- Invest in dedicated mBC care providers including more mBC nurses, psychologists and counsellors to support the growing number of Australians facing breast cancer treatment for the rest of their lives

Cassie's Story



“When I was told I had metastatic breast cancer four years ago, my whole world changed in an instant. The emotions that washed over me and my husband were overwhelming, leaving us feeling worried and uncertain about the future. The reality hit me that I might have to find a way to explain my grim prognosis to my 3-year-old daughter. I felt lost and completely unprepared for what was to come.

What struck me in particular was the contrast between the experiences of those with early-stage breast cancer compared to metastatic breast cancer. Women with early breast cancer often have many options and a sense of hope that comes from the potential of remission. In contrast, those with metastatic breast cancer are often viewed as beyond help, placed at the bottom of priority lists, with the odds stacked against us.

Nowadays, when I tell people about my diagnosis, I often struggle with their lack of understanding about the differences between early and metastatic breast cancer. Colleagues and friends often ask me when I'll be in remission or if the disease will stop. But remission is like a mythical unicorn in our world, and I'm constantly haunted by the thought of cancer.

Recognising the unique challenges and experiences of people like me with metastatic breast cancer as a separate group could bring huge benefits. We are more than our diagnosis; many of us continue to work and contribute to society, despite the physical and emotional toll of our condition. It's about creating a more hopeful and informed future, not only for ourselves, but for the generations to come.”

Cassie is 36 and from Newcastle, NSW.

Understanding metastatic breast cancer

Breast cancer is currently the most commonly diagnosed cancer among women and the second most common cause of cancer death among women in Australia.¹ For those with mBC, the survival rate remains unacceptably low. Two in three with mBC will not survive beyond five years.¹

Advanced, secondary, stage IV and metastatic are all terms that refer to invasive breast cancer that has spread from the breast to other parts of the body.⁶ For some, they may be diagnosed as metastatic cancer from the start, but for others, their cancer has come back.⁷

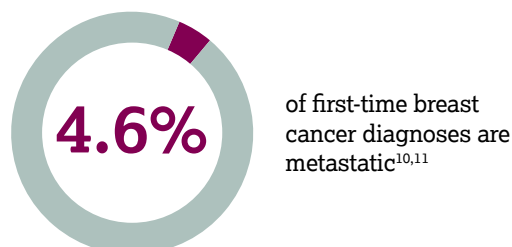
Metastatic covers a wide range of different disease states. Someone with mBC can have well-controlled bone metastasis and potentially have years to live; it also includes someone whose cancer has spread to several organs who may have just a few months to live.⁸ The impact of metastatic cancer is broad and complex.

“Having mBC is like being a long-distance runner, that feeling of being alone. All the support has gone away.”

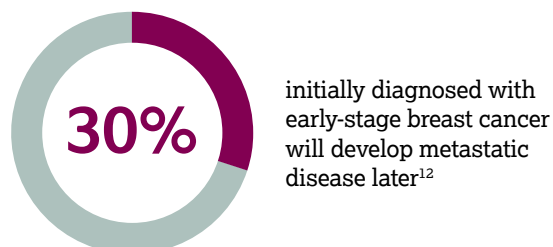
– Professor Jane Turner, Discipline of Psychiatry, School of Medicine, BCNA Feeling Invisible Webcast⁹

It is estimated in 2022, around 20,640 Australians were diagnosed with breast cancer, with around 949 of those people (4.6%) receiving a metastatic (stage 4) diagnosis.^{10,11} This figure reflects only those whose first breast cancer diagnosis was metastatic. It does not include almost 30% of those diagnosed with early-stage breast cancer who then go on to develop metastatic disease at a later time.¹²

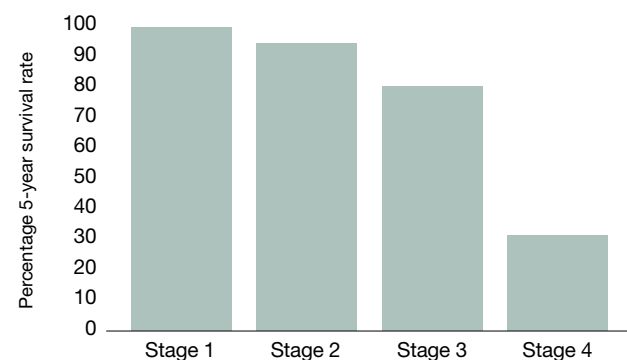
Initial metastatic diagnoses



Developing metastatic disease at a later stage



5-year breast cancer survival rate for women by stage at diagnosis



Under significant pressure

“More recognition for mBC would make us feel like we’re still alive and existing. I probably won’t ever be cured – you have an incurable disease. But you can’t let it take over your life.”

– Emma, 36, living with mBC (featured on front page)

For Australians with mBC, the psychological pressure of living with an incurable cancer can be significant and unrelenting. There can be no going back to ‘normal’. They live under the constant risk of disease progression – leading to feelings of anxiety, being overwhelmed, and a sense of isolation.⁸

There are also significant financial pressures. As treatment costs may increase, income typically decreases, with many people requiring time off work during treatment or help with daily living. This may mean reduced hours or giving up work altogether for periods of time.¹³

Access to financial information relating to specific treatment is a central contributor to financial stress. For example, understanding and making decisions about treatments that may or may not be available via the Pharmaceutical Benefit Scheme (PBS) is particularly important to support financial planning.

The range of emotions and pressures felt by Australians with mBC also extends to their family and support network. This ripple effect can be exhausting, particularly for partners who sometimes experience higher levels of stress than the person diagnosed with cancer.¹⁴

More on Emma



Emma is 36 and lives in Melbourne with her partner and daughters (aged between 9 -12 years old). Emma was diagnosed with mBC on World Metastatic Breast Cancer Awareness Day, 13 October 2021, after finding a lump in her breast weeks earlier. The diagnosis was a shock to her and her family. Emma is actively receiving ongoing treatment and wants others to be more aware of mBC.

Identifying the gaps

Despite the significant burden of mBC, there are critical gaps that must be addressed to improve the lives of those living with this incurable and life-limiting disease and their loved ones.

1. Invisibility: the biggest hurdle

“Many people don’t fully understand what mBC is. Increased awareness and recognition would do more than just acknowledge our challenges; it would bring a sense of presence and understanding, reminding us that we are still very much an integral part of this world – with stories that matter and voices that deserve to be heard.”

- Emma, 36 (featured on front page)

Feeling invisible and overlooked is a global issue for people with mBC that can lead to a sense of isolation and perceived lack of care by those around them.⁴

These shared emotions are more common in those with mBC than early-stage breast cancer and are reflected in various campaigns and resources being developed around the world to help to bring mBC ‘out of the shadows’.¹⁵

For example, ‘Secondary. Not second rate’ from the UK’s Breast Cancer Care Group is a call for change in the way people with mBC are supported. Met Up UK, who specifically represent people living with mBC, has created ‘The Darker Side of Pink’ to build greater mBC awareness and understanding to support changes in UK policies.^{16,17}

And ‘I’m still here’ by The Breast Cancer Foundation New Zealand strives to break through the silence and amplify the voices of those who feel unnoticed.¹⁸

Commentary and discussion within the local mBC community here in Australia also reinforce they are ‘surviving’ not ‘survivors’.¹⁹ The reality does not resonate with the optimistic ‘pink’ portrayal of breast cancer.

The difficulty in finding their own story within the ‘shade of pink’ has spurred the emergence of smaller, dedicated mBC support groups across Australia that have created their own identity with messages that don’t shy away from their unique reality.

The Advanced Breast Cancer Group (QLD) has produced ‘A Darker Shade of Pink’ which reflects on the set-up of this dedicated support group and includes accounts of those living with mBC.²⁰

“We do a disservice to these women when we do not acknowledge the reality of their situation.”

- Advanced Breast Cancer Group (QLD)¹⁹

A recent roundtable discussion, hosted by Pink Hope, reinforced the need for an organisation solely dedicated to mBC advocacy and education, to bring the community together and not act as a subset of another organisation.²¹

Perceptions of invisibility are also actively reinforced when people with mBC are excluded from cancer registries – currently they are not formally counted, making them legitimately invisible to health systems and policy makers.⁴

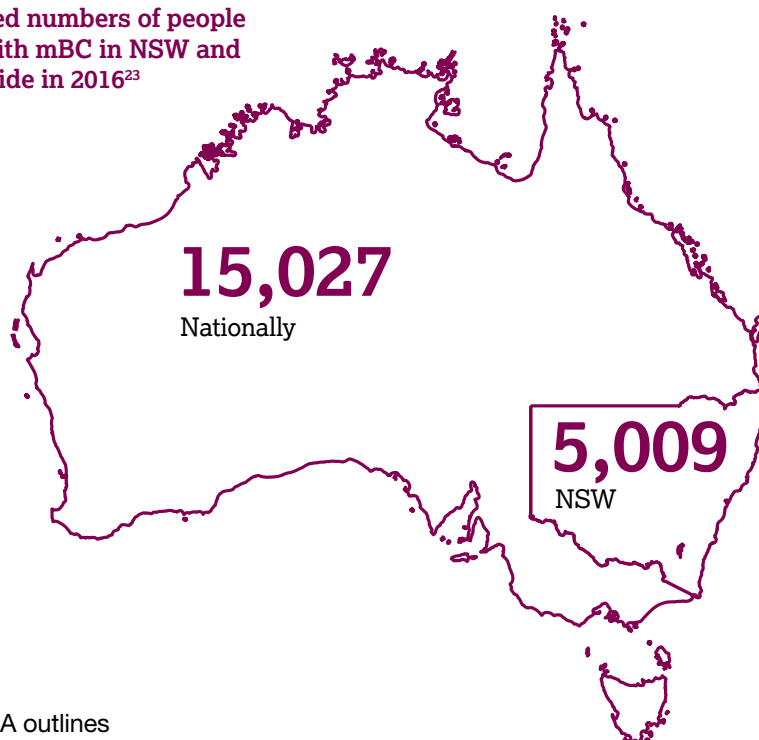
This has implications for effective disease management, as the appropriate level of funding and support can only be provided for people with mBC when accurate data is available on who they are, where they live and what their needs are.

Breast Cancer Network Australia (BCNA) has proposed short and long-term measures to incorporate mBC data into cancer registries and bring greater equity in care and outcomes.²² ‘The Time to Count People with Metastatic Breast Cancer – A Way Forward’ report, BCNA outlines an important roadmap to collect and report cancer stage and recurrence data.²²

A joint Cancer Council NSW, Daffodil Centre and University of Sydney study estimated 5,009 women were living with mBC in NSW in 2016. The Australia-wide figure is thought to be three times higher (~15,027 people), which is significantly more than existing estimates.²³

Research into mBC is also limited. The National Breast Cancer Foundation (NBCF) had only two of their 20 research projects focussed on mBC in 2022.²⁴ Only one local study has been published by NBCF on long-term breast cancer recurrence data (i.e. after 5 years), a crucial figure required to help understand the full burden of disease.²⁵

Estimated numbers of people living with mBC in NSW and nationwide in 2016²³



Quantitative and qualitative research into mBC will give evidence and insights to help not only improve the lives of Australians with this incurable form of breast cancer, but also provide the right information to educate the broader community and build their understanding of the experience.

PRIORITY

To be seen and heard for a clearer understanding of the mBC reality.

2. Voice: a lack of mBC information and connection

The complexity and longevity of mBC makes it a disease with significantly higher needs for information and supportive care than early-stage disease. Currently, information resources and Australia's health services are not designed to effectively meet these.⁴

For those living with mBC, keeping informed and up to date on the latest developments is central to their disease management and maintaining a level of hope. There is a fear connected to what is next, and understanding new treatment options and developments is important to keep the community on the front foot with information while advocating for themselves.

Concerningly, Australians with mBC cite feeling excluded from receiving information as part of their care. Some report hospital information sessions not being open to those with mBC, while others have tried to join lifestyle programs but found themselves ineligible because they had not finished treatment.²⁶

A 2017 BCNA member survey of more than 10,000 people found more than nine in ten (93%) of those with mBC needed breast cancer information (compared to 76% with earlier stage BC), but only one third (34%) with mBC received information compared to half (50%) of those with early-stage BC. A similar pattern was seen with the need for support.²⁷

The greater need for information among people with mBC is also reflected in another Australian study. It found participants' preference for talking to someone to gain information increased with the stage of disease, i.e., people with mBC preferred to speak to someone more often than those with early-stage breast cancer, rather than obtaining the information online, in written form or via an app.²⁸

The provision of stage-specific support groups for mBC Australians is now being actively called for, to give practical support and information from health professionals and others living with mBC.²⁹ Facilitated by a trained health professional, these would provide continued assistance for Australians through their disease.

Improved information sharing will empower the mBC community and support their overall wellbeing, allowing them to make better, informed decisions around their care and play a more active role in the management of their disease.

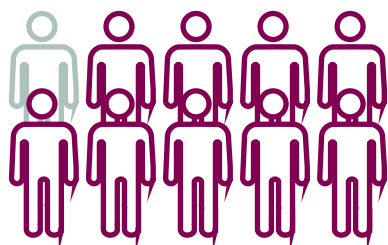
PRIORITY

Improving mBC content in breast cancer information and facilitating active sharing through stage specific groups.

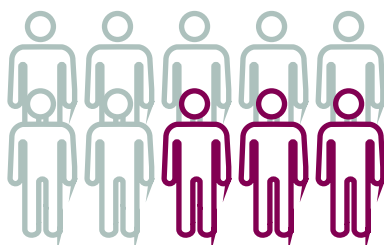
“Peer support is important as it gives you empathy. It's somewhere to go where you're understood.”

- BCNA Webcast, Bittersweet⁸

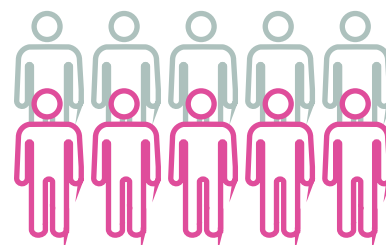
9 out of 10 living with mBC need more information about their disease¹⁵



But only 3 in 10 receive mBC information¹⁵



While 1 in 2 of those with early-stage breast cancer receive information¹⁵



3. Support: increasing nurses and psychosocial services

International guidelines recommend Australians with mBC have access to nurses experienced in mBC treatment, and Cancer Australia's 'Best Practice in Metastatic Breast Cancer' states every Australian with mBC should have access to a key contact person.³⁰ Despite this guidance, this support is not widely available, so few Australians have the opportunity to benefit from this dedicated support.²⁸

The research paper, 'Potential inequities in availability of care from breast care nurses', published in 2022 noted there is currently limited data on this topic.²⁷ So, while changes and improvements may be underway, the general findings from previous studies remain relevant.

A decade ago, a BCNA survey of women with mBC (n=582) found only half of Australians with mBC regularly saw a breast care nurse and one third had no access at all.²⁷

Since this time, the Federal Government has invested funding for more breast care nurses in the public health system as well as the McGrath Foundation, which now has 40 dedicated mBC nurses.^{31,32}

A further Federal Government funding commitment from the 2023-24 Budget means an additional 100 nurses will be recruited through the McGrath foundation, with implementation of the 'Australian Cancer Nursing and Navigation Program', described as 'the biggest investment in cancer nurses on record'.³³

Research confirms care from mBC nurses is appreciated, valued and perceived as beneficial by those living with this disease.²⁷ Continued funding of dedicated mBC nurses is essential to meet the evolving needs of this group.

Psychologists and counsellors also provide valuable support to people with mBC who are under frequent and high levels of stress – but more of these professionals are needed to meet the demands of women with mBC. The emotional isolation experienced by those with this cancer is almost universal.³⁴ They can feel that family and friends are becoming fatigued with the cancer discussion, reinforcing the need to talk to someone else.⁸

Currently Australians with mBC can access just 10 Medicare Benefits Schedule (MBS) mental health sessions per year. This number needs to be revisited to ensure Australians get the access they need for this important care. There is also insufficient resourcing in the mental health sector and additional training is needed for mental health experts to support Australians with mBC.

PRIORITY

A continuing allocation of mBC nurses and increased access to psychosocial services.

“I’m hopeful for a future with better support and more help for those of us with mBC. A future where we’re equipped with the right information to tackle each day as it comes, living our lives to the fullest.”

- Emma, 36, living with mBC (featured on front page)

“Even though I specialised in the treatment of cancer-related distress for many years before my own diagnosis, I was surprised at the intensity and extended duration of the psychological effects on me, which persist even now, well after hospital-based treatment has ended”

- Dr Charlotte Tottman, Clinical Psychologist³⁴

Timeline

2013



A decade ago, only 1 in 2 living with mBC saw a breast cancer nurse regularly²⁷



1 in 3 had no access to a breast cancer nurse²⁷

2023 - 2024



A Federal Government commitment adds an additional 100 cancer nurses³³



Those living with mBC can access 10 MBS mental health sessions per year

More is needed



Continued funding of mBC nurses is essential to meet the evolving needs of this group



More MBS mental health sessions are needed



Additional training for mental health experts to support those with mBC

Time to bring mBC ‘out of the shadows’

The discussion and evidence reinforces a clear need to step mBC out of the shadows and forge a more positive path forward for those living with the disease. Three critical areas have been identified as priorities that need to be addressed to secure renewed momentum and clear progress now in mBC.



Visibility – creating new opportunities and platforms to discuss the realities of living with incurable, life-limiting breast cancer while securing a deeper understanding of those living with mBC and their specific needs.



Voice – integrating the needs of people with mBC, or new forms of information, ensuring appropriate access to details on new developments, in order to maintain hope and facilitate stage-specific mBC information sharing and support.



Support – increasing the number of mBC nurses nationally and providing greater access to psychosocial services.

This discussion paper has been proudly supported by AstraZeneca.

AstraZeneca’s vision is to help improve the outcomes of people living with breast and contribute to the elimination of breast cancer as a cause of death.

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