



Pink Hope Metastatic Cancer Roundtable Summary

‘Hope is a really good thing.’

BACKGROUND

The Pink Hope Metastatic Cancer Roundtable aimed to help Pink Hope ascertain what we could do to better support women living with metastatic breast or ovarian cancer. The roundtable focused on the five key areas that were identified in patient focus groups held earlier in 2022:

- Treatment
- Data, research and trials
- Testing (tumours and re-testing)
- Communication and language
- Support, supportive care and resources



‘It’s like stage 4 now needs a whole new reshaping.’

(Quote from roundtable patient participant)



ROUNDTABLE

In early 2022 and before the roundtable, Pink Hope facilitated three patient focus groups involving women with metastatic breast or ovarian cancer and one focus group with healthcare professionals who care for women with metastatic breast or ovarian cancer.

The Pink Hope Metastatic Cancer Roundtable discussion took place in October 2022. Two separate sessions were facilitated by Pink Hope staff, involving 13 participants. The intent of the roundtable was to further explore the key topics identified in the earlier focus groups.

Participants in the roundtable included patients, healthcare professionals and an accredited oncology social worker. All patient participants had been diagnosed with metastatic breast cancer. They identified as having breast cancer that was treatable, not curable. The term metastatic was used frequently in the discussions and has been used within this report. The healthcare professionals included medical and allied health professionals: oncologists, a breast surgeon, breast care nurses, an ovarian cancer nurse, a clinical psychologist and an exercise physiologist.

Key words collected from patient participants throughout the roundtable convey the essence of their experience living with metastatic breast cancer in Australia:

Alienated, isolated, disconnected, unheard, underrepresented, excluded, invisible, lack, limbo, nothing, not seen, lonely, forgotten, shameful, unclear, lost.



SUMMARY

The Roundtable was set up to discuss Metastatic Breast Cancer (mBC) and Metastatic Ovarian Cancer (mOC). The discussions were predominantly about mBC, representing the lived experience of participating patients and the specialties of participating professionals.

There were themes and topics which attracted more attention, passion and time; these are listed below:

- The specific supportive care needs for metastatic patients compared with early-stage cancer patients. This includes addressing disparities between different cancer types and that metastatic patients will never be 'post-treatment', yet don't need end-of-life care. Government assistance schemes don't recognise treatable but incurable mBC as a chronic disease.
- There is a lack of reliable data being collected for metastatic patients and restrictive research practices that exclude metastatic patients.
- Many aspects of the healthcare system have not caught up with the advances in science and medicine.
- People with metastatic cancer are living longer with treatable but incurable cancer, so patients need a system (including treatment options) that supports them, with timeliness being the most important factor.
- The need for specifically trained metastatic care nurses.
- Metastatic patients feel invisible because they often fall outside the 'checkboxes' for support, financial assistance, research or a particular patient pathway.
- The need for metastatic peer support groups.
- Reframing 'end-of-life care' and 'palliative care' to supporting people with a chronic illness.

Overall, participants called for:

- An organisation solely dedicated to mBC advocacy and education that brings the community together and is not a subset of other organisations.



QUOTES FROM ROUNDTABLE PATIENT PARTICIPANTS

“They told me how to die with this.
They told me how to be sick with this.
But no one told me how to live with this.

“I’m not in palliative care. So, what’s that period? The gap? I’m just in this limbo. I don’t tick any boxes.

“I think of it myself as having a chronic condition and I don’t care if that’s full of hope. That’s what I want.