

Exploring the support needs of women **Living with Metastatic Breast cancer**: a qualitative analysis of the LIMBER survey

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Introduction

- In the UK, around 67,000 people are living with metastatic breast cancer (MBC)
- Their experiences differ from those with early stage breast cancer (EBC). Previous work showed many have informational gaps and unmet support needs
- Alongside people with lived experience, we designed an online survey exploring views, perceptions and experiences of women living with MBC
- As part of the survey, people were asked for free text comments which were analysed thematically

Survey sections – online for 3 months



Survey demographics

- Completed by 143 women
- Average age was 52 years with a range of 20 - 77
- Predominantly white (90%)
- Over half had higher education (51%)
- Majority were partnered (82%)
- A third (33%) were employed
- A third (33%) had an initial diagnosis of MBC
- Just over a third (38%) had been living with MBC for 2 years or more

Free text comments

- Respondents were encouraged to leave comments to 11 questions about:
 - **Friends and family (F&F)** – what they had or hadn’t done which was helpful/unhelpful, and information F&F should have
 - **Healthcare professionals (HCPs)** – what they had or hadn’t done which was helpful/unhelpful, areas to discuss and helpful lifestyle considerations
 - **Information needs** – what respondents wished they had known before diagnosis, what was unclear about treatment, why they didn’t join a trial and their advice to others
- Say keep positive. Some of the hardest things are managing other peoples emotions.*

My first oncologist suggested using Maggie's, who have been a massive help since my diagnosis.

I wish I'd known about MBC full stop. Had no idea it existed. I thought if it came back it would be just in the breast

Thematic analysis

- Two researchers undertook a process of thematic analysis
- A structure of 7 themes and 26 sub-themes was developed based on the data
- This structure was discussed with our lived experience advisors to ensure it remained salient and representative
- Themes centered around support from the healthcare system, social support, knowledge & information, and outlook and wellbeing

Themes & examples

1 Healthcare professionals	2 Systems & processes	3 Friends & family	4 Reaction from others	5 Knowledge & info	6 Wellbeing	7 Outlook & goals
<ul style="list-style-type: none">• Accessibility• Clinical compassion• GP support• Communication style• Shared decision making	<ul style="list-style-type: none">• Perceived gaps• Practical elements	<ul style="list-style-type: none">• Empathy• Availability• Knowledge• Practical support and advice	<ul style="list-style-type: none">• Minimizing• Pity• Privacy and intrusiveness	<ul style="list-style-type: none">• Information sources• Patient knowledge• Peer support• Signposting• Support for F&F	<ul style="list-style-type: none">• Lifestyle• Mental health and emotional wellbeing• Symptom management	<ul style="list-style-type: none">• Adjustment and outlook• Advocacy• Normality and value alignment• Positivity
<p><i>Clinics seem too busy and health professionals don't have the time to talk. Just the physical pain and symptoms are dealt with</i></p>	<p><i>Oncologist who treated me for primary disease should have told me about red flag symptoms for metastatic disease</i></p>	<p><i>Saying things like "you can beat this" (no, no I can't it's terminal, it's never going away)</i></p>	<p><i>After the initial shock, not being treated as a cancer victim and pity looks was really important to me</i></p>	<p><i>Don't Google it, get information from recognised resources</i></p>	<p><i>Would love to hear more about nutrition but no one is interested in this area and I think it's a massive opportunity being missed</i></p>	<p><i>Friends also don't talk to me about their issues ...but its so important to feel normal and its not all about my cancer when we meet</i></p>

Next Steps

- Produced a film to help F&F, called ‘They just don’t know what to say or do’, now available via YouTube, the SHORE-C website and this QR code
- Ongoing work to develop an educational training programme for HCPs engaged in discussion with patients and their families
- Further work proposed to generate patient materials using co-design methods
- Quantitative work has been published, qualitative findings are being prepared for publication – available via DOI: 10.1007/s00520-023-07928-8

