

Development of an information film for friends & family of patients with MBC

BP52 ABC7-Internationa Consensus Conference 2023

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1) Background: Many people are unsure how best to support family members or friends who have secondary/ advanced / metastatic breast cancer. To help we produced a 25min film "They just don't know what to say or do" based on research data from the LIMBER (LIving with Metastatic Breast CancER) survey^a.

2) We collated quotes from the LIMBER survey that were given in response to these questions :-

What did family & friends do that was helpful and what was not so helpful?

3) Steering group (inc. 2 patient reps, 1 clinician) chose quotes reflecting different themes i.e.

- Understanding the diagnosis
- Dealing with family & friends' emotions & reactions
- Useful family & friends' responses & practical help •

4) Worked with director to construct the storyboard

 Auditioned, rehearsed & filmed actors who gave voice to the LIMBER quotes. They played 5 characters representative of the LIMBER survey participants

• Steering group then reviewed the filming, chose which quotes should be used and helped design topics for the interview with the patient representative



Unhelpful well-meaning advice



5) Filmed & edited the conversation between Lesley Stephen & Prof Fallowfield about :-

6) Draft film shared with steering group for feedback prior to user testing

- Recruited 27 volunteers (8 men; 19 women) via social media/ word of mouth
- Volunteers viewed the film on various devices:- phone / tablet / computer

- The experience of living with ABC/MBC, and insight regarding the LIMBER survey participant quotes
- Worked with production team to interweave the

conversation & quotes into appropriate sections

Created & recorded an introductory voiceover

7) Volunteers gave feedback on the content & usefulness of the film

- There was overwhelming endorsement for it
 - They felt they had learned new information.
 - Thought the film length appropriate



A guide for the friends and family of patients with advanced breast cancer

• Especially valued the interview with the patient

8) Impact to date

- Final film version has been shared widely with
 - **UK & International Charities**
- Was featured on UK TV news channel
- Is freely available on YouTube

Acknowledgements Gilead UK & Ireland Fellowship Programme & BCRF for funding film. Make2ndsCount for funding LIMBER, survey participants, patients with ABC & their families & friends. Reference (a) Fallowfield L, et al. Sup Care Ca. 2023; 31 (8):459.