Revising *Frankly Speaking About Cancer: Metastatic Breast Cancer* Book

M. Claire Saxton MBA*, Maria Gonzalo MS*, Jenny Karubian MA, Sheri Walters BSW MPH*, Amelia Robert MPH*, Alexandra K. Zaleta PhD*****

***Cancer Support Community, Washington, DC**
****Ready To Launch Research, Los Angeles, CA**
*****Cancer Support Community, Research and Training Institute, Philadelphia, PA**

Background

In 2006, the Cancer Support Community (CSC) launched its *Frankly Speaking About Cancer: Metastatic Breast Cancer (MBC)* patient education program. This program raises awareness among patients and caregivers about MBC, current treatment options, managing side effects, psychosocial impacts, and fostering an open dialogue with their health care team. Since launching the *Frankly Speaking About Cancer: MBC* program in 2006, more than 3,800 people have attended our workshops. We have also distributed over 77,000 educational books and worksheets and over 392,000 page views have been recorded for the MBC content on our website. Survey findings from program participants show that 96% would recommend the program to others.

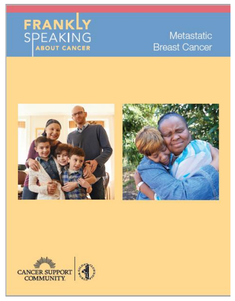
Aims

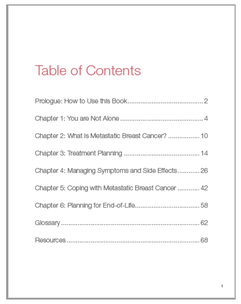
In 2018, CSC revised and enhanced its MBC educational book with patient and caregiver input to ensure it meets their needs. The revised book also provides additional resources on getting support, finances, and information for patients and caregivers.

Methods

- CSC leveraged findings from MBC patients enrolled in our Cancer Experience Registry® online research initiative as well as feedback from experts on our MBC Advisory Board, to update the *Frankly Speaking About Cancer* educational book for people affected by MBC.
- Questions were asked during a focus group and an online discussion board to review the revised book. In total, 24 women with MBC provided feedback.
- The final updates and enhancements made to the book were based on the feedback received.

Revised MBC Book





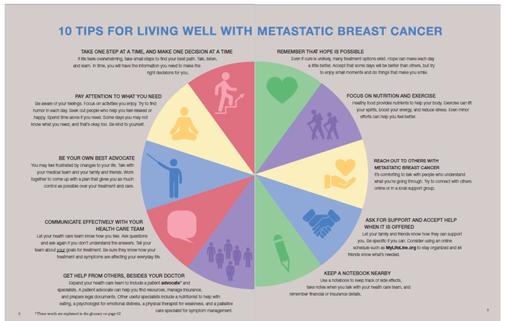
The first draft of the revised book was reviewed by research participants, who provided feedback about:

- ease of understanding;
- utility for treatment decision-making and communicating with the health care team;
- reactions to specific sections and resources included in the book; and suggestions for improvement.

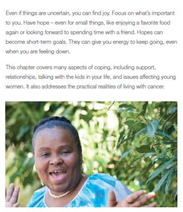
Participants Feedback

Participants reported that the information provided in the book was easy to understand, and believed that the way the information is displayed supported the messages, in particular:

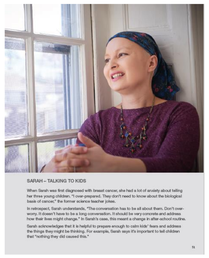
- The "10 Tips for Living Well with MBC" graphic in chapter 1 was very well received. Participants want to receive tips and advice on how to live with the disease.



- Patients emphasized the need to receive emotional assurance and support and value the testimonials of people living with MBC throughout the book.



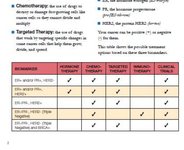
"You need to readjust your thinking, and develop a new skill set as you move forward. Accept that this is what you're going to be living with. Accept the inexplicable."
—Felicia

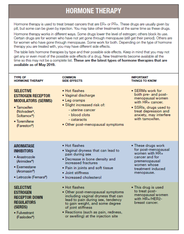


"With metastatic cancer, I think it was really hard for the kids to understand that the cancer isn't going to go away. Coming to terms with that was really hard, and there were emotional ups and downs. I've been really thankful for the CSC children and teen support group and parent support group, because through that they have met other kids that they can talk to that actually understand. I think our kids really have gotten a lot out of it."
—Joana

"As a caregiver, we also have to think about ourselves. Felicia may not know this, but there may be times that I really can't answer her call at that time, because I could be going through something. But when I am mentally, physically, emotionally, and spiritually prepared, I'm calling her and giving her what it is that I can give."
—Vicki, long distance caregiver for Felicia

- The book includes an insert that covers treatment options for MBC. Participants thought that the treatment insert is an excellent addition to the book, though they pointed out the need to address non-pharmaceutical approaches.



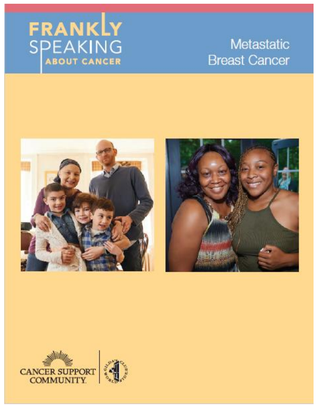


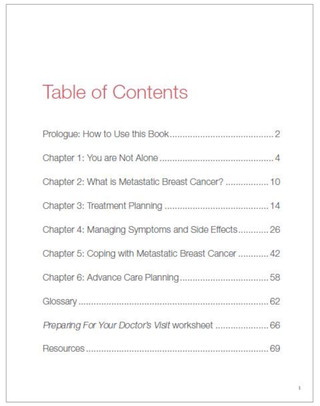
Suggestions for Improvement

- Participants suggested the need to include more in-depth information about the financial implications of a MBC diagnosis and treatment and had several suggestions for additional financial resources to be included.
- Participants pointed out the need to address and add more information about non-pharmaceutical and holistic health approaches,
- Participants suggested adding pictures of younger women with MBC; these groups are less common but need to be addressed in some way to personalize the book for them, too.

Final MBC Book

CSC implemented the feedback received and updated the MBC book.





Conclusion

Overall patients found the *FSAC: MBC* book to be useful and informative for all of those that have received a MBC diagnosis and their loved ones.

These findings suggest that the enhanced *FSAC: MBC* book can serve as a unique asset in the realm of cancer patient education, as it covers both cancer treatment and quality of life issues in a manner intended to empower individuals and their families to work in partnership with their health care team and be active participants in their treatment decisions.

CSC distributes the *FSAC: MBC* book at no charge to MBC patients and caregivers via its internal network of more than 50 affiliates worldwide, the www.CancerSupportCommunity.org webpage, the *Frankly Speaking About Cancer* radio show, and partner patient advocacy groups. We also work to make health care providers and patient navigators aware of this educational book so they may help make it available to those impacted by a MBC diagnosis.

Acknowledgments

This project was made possible with generous support from Lilly Oncology.

CANCER EXPERIENCE REGISTRY
A PROGRAM of the CANCER SUPPORT COMMUNITY

The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers.

- The Registry is for all cancer survivors and caregivers and also includes 13 disease-specific surveys.
- Findings contribute toward advancing research, health care and policy.
- Over 14,000 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org