Thriving with an MBC Diagnosis
Understanding the impact of metastatic breast cancer on daily life.
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Introduction
Breast cancer is the most common cancer among women in the U.S.\textsuperscript{1} Progress in treatment and early detection has led to improved survival for people of a variety of ages and races, and with all stages of breast cancer.\textsuperscript{2} In fact, there are more than 3.5 million breast cancer survivors in the U.S. (more than any other group of cancer survivors).\textsuperscript{3}

What most people are not aware of is that nearly 30 percent of these people will have a recurrence, and some may have cancer that has metastasized.\textsuperscript{4}

Metastatic breast cancer (MBC) is an incurable form of breast cancer that has spread to other parts of the body.\textsuperscript{5} It is often complex and unpredictable. Despite advancements in treatment, 113 women and men die from MBC every day.\textsuperscript{6} For people living with MBC, the disease creates significant daily challenges that their family and friends don’t always understand.
02 Overview
Understanding what it’s like to live with MBC

To generate more understanding and support for the women and men living with MBC, Lilly created the More for MBC initiative, a national movement aimed at bringing more awareness, more research and more solutions to support people living with MBC, and the communities that surround them.

The More for MBC initiative seeks to foster more dialogue about the disease between the MBC community and the media, healthcare professionals (HCPs), loved ones and the early-stage breast cancer community alike. Additionally, the initiative seeks to provide more education on current treatment options to empower people living with MBC to take an active role in their healthcare decisions, as well as identify more solutions to address the daily challenges that people living with the disease face with this difficult diagnosis.
Understanding what it’s like to live with MBC  (Cont’d)

As part of the More for MBC initiative, Lilly, in partnership with leaders of the MBC community, commissioned a national survey to understand the unique emotional, social and physical challenges people living with MBC face daily. Three target groups — people living with MBC, friends and family, and HCPs — were included in the survey to get a comprehensive understanding of the impact of MBC on the daily lives of people living with MBC and the communities that surround them. Lilly surveyed 297 patients, 200 caregivers, 201 oncologists and 150 oncology nurses.

The survey uncovered the stark realities of dealing with MBC — both for the people who have the disease as well as their loved ones. The diagnosis takes an immense toll on their lives and their ability to fully engage in daily activities and passions they enjoy.

Additionally, the survey revealed gaps in conversation and needs that exist between people living with MBC, their loved ones and their treatment teams.
03

Survey Findings: Daily Impact
People living with MBC are living longer, but that comes with a substantial emotional impact and daily strain on them as well as the people who love and support them. People living with MBC spend nearly half of their time (47 percent) on things related to their cancer in a typical week – spanning both mental and physical burdens – and are reconciling with how their lives have changed since their diagnosis. MBC threatens their ability to be there for their family and to maintain the sense of control and normalcy they desire to thrive and live fully in the moment.

When asked to identify the TOP THREE MBC-RELATED ACTIVITIES they spend the most time doing, people living with MBC reported:

- Thinking about the impact of diagnosis on family: 39%
- Thinking about the financial impact of MBC: 38%
- Thinking about the disease itself: 37%

Total n=297
All that time spent on MBC leads to a feeling of missing out on key parts of life for people living with MBC. In particular, people living with MBC identified having missed out on the following due to their cancer:

- Participating in everyday activities: 62%
- Ability to travel: 57%
- Progressing in my career: 55%
- Attending important events with my friends and family: 52%
- Maintaining an existing romantic relationship: 37%
- Keeping in touch with friends and family: 32%
- Developing a new romantic relationship: 29%

Life Events Missed Out on Due to MBC Diagnosis
Total (n=297)
Many people living with MBC are used to being the strong one in the family. They’re often the one who keeps everything together. They don’t want to burden friends and family with their worries, which can leave them feeling isolated. Nearly half (48 percent) say it’s hard to talk to those closest to them about their MBC diagnosis. But at the same time, they wish they had more support. Meanwhile, their loved ones want to be able to do more.

Additionally, there are several areas family and friends believe their loved ones with MBC could use more support, despite the significant amount of time they spend with them.
MBC takes over family and friends’ lives too

Family and friends of people living with MBC spend over half of the typical week (56 percent) doing things related to their loved one’s MBC. Even still, many wish they could do more and wish their loved ones with MBC would talk to them about other ways they could help.

- 61% of care partners that wish their loved one would talk to them more about what they can do to best support
- 49% wish their loved one would talk to them more about fears about what will happen to loved one
- 47% want their loved one to talk to them about the emotions about their diagnosis

80% of family and friends surveyed say they too have been very impacted by the MBC diagnosis.

85% of family and friends say they exhibit a new mental or emotional health condition themselves.

62% feel comfortable sharing their emotions.

*If you have experienced a new or worsened mental health condition, it’s important to speak with a doctor about the symptoms you are having.
04

Survey Findings:
Mental Health
Mental health conditions following an MBC diagnosis are widespread and recognized by both people living with MBC and HCPs. People living with MBC may be hesitant to mention it to their doctor.
MBC takes toll on mental health of people living with the disease

Dealing with the daily stressors of MBC can take a significant emotional and mental toll on people living with MBC.* The following are emotional / mental health conditions people living with MBC say their diagnosis may have created or worsened:

- 90% of people living with MBC experience a new or worsened emotional issue
- 52% of people living with MBC say their MBC diagnosis created or worsened feelings of loneliness or isolation
- 36% of patients require mental health support, according to HCPs (n=351)
- 61% suffer from anxiety over their MBC diagnosis
- 56% struggle with depression
- 56% report frequent bouts of insomnia

*If you have experienced a new or worsened mental health condition following an MBC diagnosis, it’s important to speak with a doctor about the symptoms you are having.
There is an emotional and mental health impact on care partners

Family and friends also experience emotional and mental health conditions that may have been a result of a loved one’s MBC diagnosis, though less frequently than the patients themselves.

- 85% of family and friends experience a new or worsened emotional issue since their loved one’s diagnosis.
- 68% of family and friends say they are worried they are not strong enough to handle everything their loved one with MBC needs from them.
- 64% of family and friends say they are not sure where they can turn for support during this time.

- 59% suffer from anxiety.
- 45% struggle with depression.
- 36% report chronic stress.

*If you have experienced a new or worsened mental health condition, it’s important to speak with a doctor about the symptoms you are having.*
Survey Findings: Relationships
85 percent of people living with MBC put more importance on having a meaningful relationship with family since being diagnosed with MBC.
Involvement in important life events changes after MBC diagnosis

Family and friends perceive people living with MBC to be much more involved with important life events, while people living with MBC say they are less involved.

This decreased involvement is a source of dissatisfaction for many people living with MBC.

Satisfaction with current LEVEL OF INVOLVEMENT (people living with MBC)

48%

dissatisfied

42%
satisfied
MBC impacts existing and future relationships differently

For the majority of people living with MBC, as well as spouses and significant others who were in a relationship at the time of the MBC diagnosis, the diagnosis either had no effect or strengthened their romantic relationship. However, patients who are single anticipate their diagnosis being prohibitive to finding a partner.

MBC diagnosis’s impact on relationships
Among those in a relationship at the time of diagnosis

MBC’s impact on future relationships
Among people living with MBC who are currently single
Total (n=106)
People living with MBC continue to have a desire to serve – both the people around them and their communities alike. They remain resolute in being able to fully engage in daily activities and the passions they enjoy, as well as being strong and present for their loved ones.

### PEOPLE LIVING WITH MBC & THEIR RELATIONSHIPS (SINCE DIAGNOSIS)

**Total (n=297)**

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
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<tr>
<td>67%</td>
<td>say it’s more important now to be a good friend</td>
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<tr>
<td>66%</td>
<td>put less importance on possessions</td>
</tr>
<tr>
<td>60%</td>
<td>put less importance on what others think of them</td>
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Survey Findings: Career
MBC interrupts career goals for people living with MBC and their loved ones

Career issues affect people living with MBC, as well as those closest to them. About four in 10 people living with MBC currently work. Eighty percent of those individuals say it’s important to continue working, but 43 percent of people living with MBC who work are fearful they may lose their job or be unable to work.
MBC interrupts career goals for people living with MBC and their loved ones (Cont’d)

- 17% of friends and family have had to quit a job.
- 43% of people living with MBC have had to quit a job.

- 28% of people living with MBC have needed flexible hours.
- 60% of friends and family have needed flexible hours.

- 39% of friends and family have had difficulty completing their work.
- 20% of people living with MBC have had difficulty completing their work.

- 22% of people living with MBC have had to work fewer hours.
- 44% of friends and family have had to work fewer hours.

- 15% of people living with MBC haven’t been promoted/advanced.
- 21% of friends and family haven’t been promoted/advanced.
Survey Findings: Healthcare Professionals
HCPs want to help beyond treatment

Nearly half (45 percent) of oncologists say they want to learn more about the impact of MBC on mental health. In fact, roughly 59 percent of oncologists reported that they may not be as aware of when their patients need mental health support, and only 40 percent said they are aware of the current research being done to understand the mental health impact of an MBC diagnosis. (n=201)

90% of people living with MBC have experienced a mental or emotional health condition (n=297)

40% of oncologists are aware of research being done on the impact of MBC on mental health (n=201)

45% of oncologists are interested in learning more about MBC impact on mental health (n=201)

55% of oncologists would like to provide patients with additional mental health support if needed (n=201)

79% of oncology nurses are interested in learning more about MBC impact on mental health (n=150)
HCPs may not be aware of how eager their patients are to have information about the treatment options available to them. **82 percent of people living with MBC** are very interested in knowing about all potential treatment options, while **80 percent of oncologists** were not aware that patients wanted this additional information.
HCPs want to know more about current treatments and want patients to know their options.
Doctors discuss participation in clinical trials with patients throughout their journey, but even though 45 percent discuss it at initial MBC diagnosis and 57 percent after progression on multiple lines of therapy, HCPs estimate that they refer 11 percent of patients to trials.

**KEY BARRIERS TO CLINICAL TRIAL REFERRALS INCLUDE:**

Total (n=201)

- **Distance to Trial Location**: 61%
- **Burdens of Trial Participation**: 46%
- **Concerns About Delays in Trial Initiation**: 43%
Survey Findings: Public Perceptions
People living with MBC are passionate about doing more for MBC

MBC is often left out of the general breast cancer conversation. More needs to be done to elevate understanding and awareness of MBC. Since being diagnosed, over half of people living with MBC believe that advocacy, fundraising and supportive initiatives are more important.

- 81% say advocating for research is more important now (than before diagnosis)
- 78% say there is not enough focus on MBC during Breast Cancer Awareness Month
- 69% say fundraising for MBC has become more important
- 61% say there is not enough support for people living with MBC compared to other people living with breast cancer

Total n=297
Among people living with MBC, 81 percent say most people cannot tell they have MBC, and 67 percent wish the phrase “you don’t look sick” would be taken out of the MBC conversation.
Doing #MoreForMBC
Doing more for people living with MBC, their loved ones and their HCPs through #MoreForMBC.

Through its More for MBC initiative, Lilly hopes to increase dialogue and empower communities by building awareness for MBC, driving research efforts and bringing tangible solutions to help all who are impacted by MBC.
More awareness

(through education)

We seek to elevate understanding of the daily impact of MBC by driving education to dispel common misconceptions about the disease, like how people living with MBC may not appear to have cancer, or highlighting the language that should be used to describe their experiences.

How we’ll do it:

AMPLIFY
the voices of people living with MBC.

EMPOWER
people living with MBC to take a more active role in their care.

IMPROVE
awareness of newly approved treatment options.

DRIVE A DIALOGUE
that represents the real needs of people living with MBC and connect people in the community.
**More research**

Over the last few years, treatment advancements have evolved for people living with MBC. Lilly is committed to continuing research efforts that provide oncologists with the scientific insights and treatment options necessary to care for patients throughout the breast cancer care continuum – as well as move towards more individualized treatment approaches.

**How we’ll do it:**

**FUND**

evidence-based research to optimize treatment.

**IMPROVE**

therapeutic options throughout the breast cancer care continuum.

**DEVELOP**

individualized treatment approaches for patient-specific MBC characteristics.
More solutions

People living with MBC want resources and solutions to help them thrive within the daily challenges of their disease. Lilly is collaborating with the breast cancer advocacy community, leading cancer care centers, and MBC supporters to ensure it continues supporting programs and services that people living with MBC need most.

How we’ll do it:

PROVIDE
unique and useful tools that help people living with MBC manage the daily stressors of the disease and help them thrive.

PARTNER
with advocacy groups and community members on tangible programming and research needs.
To help address some of the emotional, mental and physical health needs uncovered in the *More for MBC* Survey — and through direct discussions with the community — Lilly has launched the **Thriver Movement** as part of its *More for MBC* initiative in partnership with leaders and advocates of the MBC community.

Ultimately, Lilly hopes the Thriver Movement sparks a more informed dialogue around this incurable disease, drive understanding and highlight the resilience of those living with MBC.
We’ve learned the word “Thriver” resonates with many in the MBC community more than “Survivor”—a term often associated with people living with early-stage breast cancer. While people living with MBC will live with it for the rest of their lives, they are determined to thrive and do all they can while living with this disease.

We also learned 91 percent of people living with MBC who have tried yoga find it to be helpful in managing stress. For this reason, Lilly collaborated with a yoga expert to create a unique **Thriver yoga pose and flow that can be done daily,** which is symbolic of the emotional and physical strength these women and men exude. As a reminder, it’s important to consult your healthcare provider before starting a new exercise routine.

The Thriver pose and flow represents the unstoppable spirit of women and men living with MBC, as well as the community that surrounds them.

The public is encouraged to show their support for the MBC community by posting a photo or video of the Thriver pose with the hashtag #MoreForMBC.
Learn more

Find additional resources and join the conversation on the More For MBC Facebook page.

For more information about MBC or treatment options, people living with MBC should speak with their healthcare provider.
Project overview & methodology

Three target groups (People living with MBC (patients), Friends & Family, HCPs) completed a target-specific 20-minute online survey. Multiple targets are included in this study to get a comprehensive understanding of the impact of MBC on the daily lives of people living with MBC. Separate surveys for each target allow for analysis of the gaps in conversation and needs that exist between people living with MBC, their loved ones and HCPs. Research conducted in the U.S., nationwide.

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<tr>
<th>TARGETS</th>
<th>BASE SIZES</th>
<th>FIELD DATES</th>
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<tr>
<td>People Living with MBC:</td>
<td>People Living with MBC: n=297</td>
<td>People Living with MBC: 8/7 - 9/4, 2018</td>
</tr>
<tr>
<td>Men and women with MBC</td>
<td>Care Partners: n=200</td>
<td>Care Partners: 8/7 - 8/24, 2018</td>
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<tr>
<td>Friends &amp; Family / Care Partners:</td>
<td>Oncologists: n=201</td>
<td>Oncologists: 8/14 - 8/31, 2018</td>
</tr>
<tr>
<td>Friends and family of people living with MBC</td>
<td>Oncology Nurses: n=150</td>
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<tr>
<td>Interact with person living with MBC ≥ several times a month</td>
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<td>Are ≥ somewhat familiar with cancer experience and treatment details</td>
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<tr>
<td>HCPs: Those who treat ≥ 5 patients with MBC in a month</td>
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<tr>
<td>Oncologists</td>
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<tr>
<td>Oncology Nurses (including RNs, NPs, LPNs, and Nurse Navigators)</td>
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