



*A Journey of Courage and Hope*

## PLANNING A METASTATIC BREAST CANCER RETREAT

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# Planning Brochure



*Pictures are for illustrative purposes only — not actual patients or retreat locations.*

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**This kit only provides some considerations for planning purposes and does not necessarily take into account all requirements. Each organization planning these retreats is responsible for ensuring it complies with all applicable state, federal, and local laws and regulations, including HIPAA.**

## INTRODUCTION

*A Journey of Courage and Hope: Metastatic Breast Cancer Retreat Planning and Resource Kit* will help you navigate through the steps needed to establish your own metastatic breast cancer retreat. Your kit, brought to you by Pfizer Oncology and working with Lillie Shockney, RN, BS, MAS, HON-ONN-CG, provides the information you will need to organize retreats for women with metastatic breast cancer and their spouses, friends, or caregivers.

Each program requires similar planning with variations that address the differing needs of the participants. Use this Planning Brochure to decide which type of program you want to design, create a vision for that program, and bring that vision to life.

Through a metastatic breast cancer retreat, you will experience the stories of how metastatic breast cancer changes lives as it progresses. Anticipate embracing the strength and courage of each individual, being present for the participants, and being hopeful with them in this stage of their journey. Also, plan to take away lessons that you can incorporate into the support and guidance you provide to future patients dealing with metastatic breast cancer.

### BE OPEN TO AN EXPERIENCE

Facilitating a metastatic breast cancer retreat is an opportunity for a life-affirming experience for all involved. The retreat is about personal stories of survival and renewal, loss and change, and despair and hope. Promote the group members' compassion for one another and seek their unique perspective as they process these concepts. Sharing their personal stories and insights, the participants validate their own strength and learn from each other. It can be very rewarding to help enlighten participants to their own wisdom.

## 1. CONDUCT A NEEDS ASSESSMENT

Start by collecting information within your organization to identify the needs of a new program and determine what type of retreat to conduct. Information may include:

- Statistics for the metastatic breast cancer population treated at your facility (e.g., how many patients are married vs. single to help decide between a couples or female caregiver retreat; where the majority of patients live to help decide between a virtual or in-person retreat, etc.)
- Established programs in your area
- Identified needs of participants

This information may also be helpful in applying for a grant and to impress upon your leadership the importance of the program for your patients.

**Additional resources to review:** *Retreat Program Rationale section (Planning Brochure), 12 Facts Everyone Should Know About Metastatic Breast Cancer (Appendix).*

## 2. SET GOALS

As with any program, goals and objectives provide direction, focus, and the basis for evaluation of the program's success. Carefully consider the goals and objectives of the retreat as they relate to planning and evaluation. Use evidence-based information in addition to the needs and requests of potential participants when setting goals for your retreat program. Goals and objectives must be clearly stated and measurable. They will be shared with funding sources, staff, and participants.

*See sample goals on the right.*

## What type of retreat will you host?

- Women with metastatic breast cancer (attending as an individual without family or a friend)
- Women with metastatic breast cancer and the women who support them (female caregivers)
- Couples (women with metastatic breast cancer and their spouse/partner)

Retreat Type	Rationale
3-Day	The benefit offered by a weekend, overnight retreat program is that it allows time for the group to connect, with the participants getting to know one another and establishing trust. Once a cohesive group has formed, they will move surprisingly quickly toward sharing and forming bonds. The group process also requires time to prepare for closing and departure.
1-Day	Women more recently diagnosed with Stage IV breast cancer, as well as women whose disease has remained stable since their Stage IV diagnosis (e.g., disease has not metastasized further to additional sites of the body), are a better fit for a 1-day retreat. Instead of delving into end-of-life issues, a 1-day program aims to revitalize each participants' outlook and help them realize that, despite their disease, they can still lead fulfilling lives.
Virtual	As an alternative to in-person retreats, this option may be fitting for patients who are physically unable (due to health or other constraints such as external circumstances) to travel to and be present for a typical retreat. This option also may require less planning, funding, and staff. Content may be similar to in-person retreats but consider shorter sessions hosted on video conferencing platforms.

*Please note that content included in this kit has been planned for in-person retreats but can be adapted for virtual retreats as necessary.*

### Sample Retreat Goals

1. The program will be a retreat experience that provides women with metastatic breast cancer an opportunity to get away from their everyday routine and replace it with time for discussion, support, information, and reflection
2. Identify the issues related to dealing with metastatic breast cancer for a woman and her family
3. Connect with others dealing with metastatic breast cancer as a means of finding strength and information
4. The program will be a personal experience of discovery

### 3. ESTABLISH PROGRAM CONTENT

The retreat program is based on the themes of loss and change, hope over despair, and finding strength and meaning in one's struggle. Such themes are presented along with an opportunity for individuals and/or couples to interact, share feelings, and connect. Activities are varied, and content may include the following:



**Facilitated group discussion** focuses on each participant's journey with cancer treatment, personal coping (and/or lack of coping), and specific issues identified within each group

*For more information please see the retreat discussion facilitation videos.*



**Informal discussion** time is included in the program so that participants have an opportunity to connect with one another



In a **question-and-answer session**, a medical oncologist answers questions and discusses metastatic breast cancer research, treatments, and clinical trials



A session of **yoga and relaxation** is provided for those interested



**Massage therapy sessions** provide treatment for stress release and comfort



The oncology chaplain leads a group discussion on **spirituality**, which includes defining hope and finding meaning



Using literature (poetry and essays) and metaphor, a **closing program** provides a theme for memory sharing and storytelling for life's journey

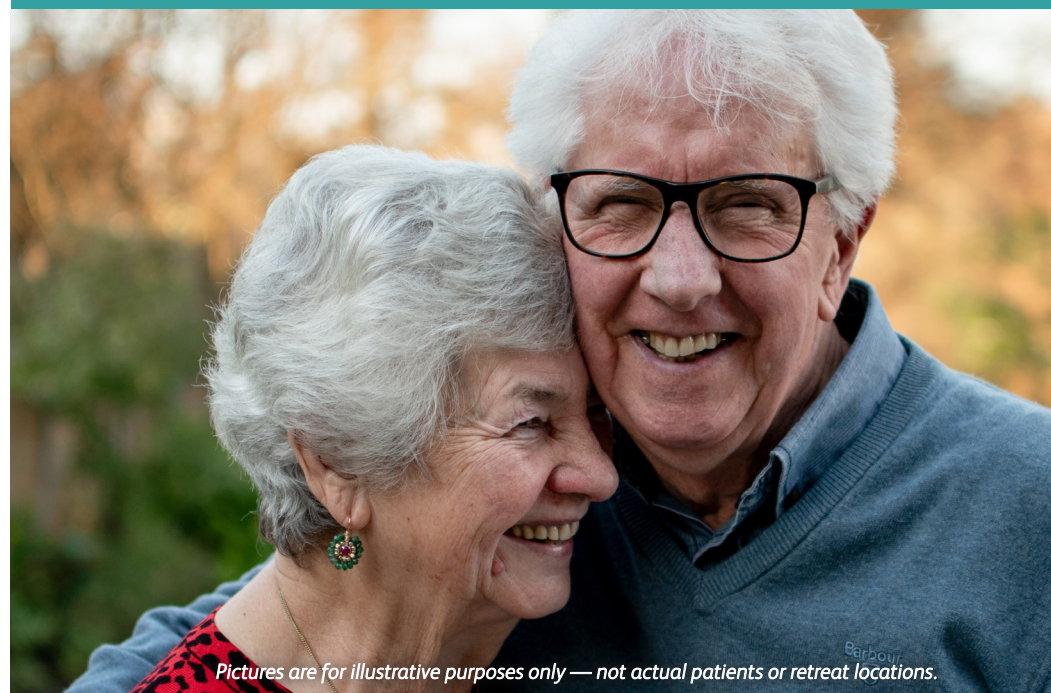
**Additional resources to review:** For more information on program content, please see the *Program Agendas and Activity Planning Ideas* section.

*As the weekend progressed, I was amazed by the transformation of the couples' dialogue and behavior. We started with one woman, J, telling me as she entered the building Friday how angry she was. You could see the anger in her eyes and her body was taut. Another woman, K, sat in our first meeting describing her fear of what lay ahead, expressing personal beliefs that would later be dispelled for her and her husband. K had a downcast look, a fearfulness that was palpable. The couples came together as strangers making their first impressions on each other, uncertain of what lay ahead for the weekend.*

*As the program progressed, the 2 women had a different posture. J actually looked relaxed seated in the group on Sunday morning. It was then that J said to K, "Look at how you are sitting straighter, looking stronger." The retreat became a safe place to share these observations.*

*It was as if they had a sense of newly found inner strength. The retreat took them away from the usual routine and thinking and provided an opportunity to rediscover themselves despite their struggles.*

— A retreat facilitator



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## 4a.

# USE YOUR RESOURCES - SECURE FUNDING

### SECURE FUNDING

Planning a budget for your retreat will be important to understand your funding goal. Retreat costs may include lodging, meals, conference rooms, facility fees, program materials and supplies, honorariums, and salary support, to name a few. To offset costs, one must be optimistic and look to funding through patient advocacy grants, patient education grants, philanthropic funding, or an oncology center's patient education or survivorship budget, if one exists. After the retreat, consider sending thank you notes to those that provided funding for your retreat.

Since these are metastatic breast cancer retreats, participants **should not be asked for a registration fee**. It is felt that for those dealing with metastatic breast cancer and ongoing treatment, it is not appropriate to request a participant fee. Consider other options for securing retreat funding.



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## SAMPLE BUDGET ITEMS



**Lodging/Meals & Snacks/Meeting Rooms**



**Supplies:** Brochures/printing, office supplies, books and journals, pearl bracelets, cards, tote bags



**Mailing:** Brochures, participants' confirmation/information



**Retreat Coordinator Salary**



**Secretary Salary**



**Volunteer's Acknowledgement (x3)**



**Yoga Instructor Professional Fee**



**Travel Reimbursement Volunteer/Facilitator**

**These are sample budget items. Your organization can adapt budget items based on your own needs.**

## 4b. USE YOUR RESOURCES - RECRUIT STAFF

### RECRUIT STAFF

Look to your center's staff to provide expertise, program development, group facilitation, and helping hands. The retreat leader needs to know the abilities of the staff and be willing to delegate.



#### Retreat Staff May Include:

- Health professionals such as oncology nurses, nurse navigators, and physicians
- Select staff from community organizations, the medical center, and the breast center volunteer team
- Additional roles such as social workers, oncology chaplains, and specialists



#### Staff Responsibilities & Expectations:

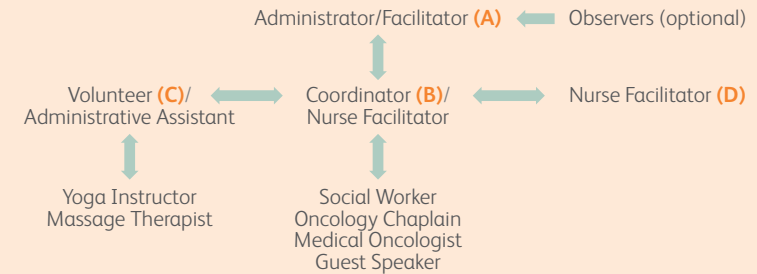
- Maintain open and direct communication among staff
- Must be prepared to deal with the intensity of the retreat
- Understand the objectives, program content, and expectations of each role before the retreat takes place
- Plan for debriefing to occur during and after the retreat

*Independent practitioners interested in replicating the program may also be present as observers. These observers should apply in advance, pay for their lodging in full, and be limited in number to maintain group dynamics.*

At least 3 program facilitators should be present and available throughout the event for 10 participants and their guests. Staff members should be assigned specific tasks such as managing logistics (working with the staff of the facility, securing rooms, assisting with the flow of the agenda, etc.), session recording, and session facilitation. The facilitators are also available to participants for 1-on-1 support throughout the event if needed.

Certain activities and specialty topics require additional staff to be present for a particular session. Examples include a Q&A session with a medical oncologist or oncology research scientist, a discussion on spirituality and hope with an oncology chaplain, and massage sessions with oncology-certified massage therapists.

### EXAMPLES OF RETREAT STAFF ROLES



A recommended retreat staff is made up of 3 nurses and a volunteer. Each member has multiple roles. The administrative director (A) secures funding, approves the budget, and collaborates with the facilitators to establish goals and objectives as well as plan the program content.

The coordinator (B) then further develops the program, taking the lead in organizing and overseeing the event with the assistance of the other facilitators.

It is an enormous advantage to have a trusted and very capable volunteer (C) who deals with the retreat center throughout the program (reserves lodging and conference rooms, secures and reviews the contract, interacts with facility staff, and contacts the massage therapist and yoga instructor). An administrative assistant takes care of paperwork and calls from the center.

Putting 1 facilitator (D) in charge of registration also provides a source of contact and information for participants prior to the retreat. This facilitator also collects the evaluations from participants once the retreat has ended.

The coordinated effort is ongoing. The roles during the event are noted on the staff agenda. With assistance, the coordinator ensures that the program objectives are being met as patients arrive, calls those who are not present, greets the guest speakers and facilitators, etc. One facilitator takes charge of evaluations as needed. Meanwhile, the volunteer is working with supplies, room assignments, copies, etc.

## 4c.

# USE YOUR RESOURCES - RESERVE A LOCATION

### RESERVE A LOCATION

Finding a location that meets the program objectives and needs of participants is a crucial step. The setting should be a comfortable and safe place, and it needs to be held away from the cancer center. Select a facility that accommodates a weekend program with lodging, meals, meeting space, and handicap accessibility. Most importantly, select a site that offers the right atmosphere. A location like a retreat center set away from the hospital and hectic life plays into the purpose of “retreating” — of finding time away from the day-to-day routine and pursuing activities that focus on self and healing. A location that is serene and peaceful promotes the program goals to focus on self in an environment conducive to respite and relaxation. To maintain the serenity, consider encouraging participants to remain “unplugged” from phones and other electronics throughout the retreat.

A retreat center, an inn, or a college campus (on break) are possible facilities. Look for meeting space that is comfortable and spacious but not so big that participants will feel lost inside it. An intimate space should allow for all participants to hear and see one another. Consider the seating with the goal of accommodating those in pain (upholstered chairs and sofas for lying down have been invaluable to those with bone metastases). Liability insurance should be the facility’s responsibility.

#### A Note on Virtual Retreats

**The information in this section is specific to in-person retreats. However, many of the suggestions can be adapted to a virtual environment; for example, recommending that patients try to find a peaceful, private environment with no distractions when attending a virtual retreat.**

### Amenities to Seek Out:

- Tranquil environment
- Private sleeping rooms and baths (keep in mind you need twice as many rooms for attendees when conducting the patient/female caregiver retreat)
- Heat and air conditioning throughout the facilities that can be adjusted
- Handicapped accessible sleeping rooms, conference rooms, and dining areas
- Close proximity between sleeping rooms and areas where the retreat activities take place, to minimize the amount of walking necessary
- Very comfortable chairs and sofas in the conference rooms where most of the retreat activities take place
- Outside walking grounds- ideal with paved foot paths, a labyrinth, garden area, pond or lake, chairs outside for patients to sit in when tired when walking, no sounds of traffic on highways, lots of trees is preferable, a true sense of serenity and tranquility
- Good quality food for 3 nutritious meals a day. Able to cater to special needs diets like gluten free or low sodium
- Snacks and water always available and within easy reach during the Retreat sessions
- Small conference rooms where massage therapists can set up their tables and massage chair and be still close enough to the conference rooms so the patient has a short distance to walk

### Before Booking the Facility:

- Find out what other activities are going to be happening there at the same time. Remember, you need a quiet environment
- Ask about the cancellation policies
- Know how far away hospitals and emergency care centers are
- If this is a religiously affiliated retreat center, and many are, make patients aware that religion is NOT part of the retreat program
- Ask to speak with prior clients who have held some type of “quiet” multi-day event there as references
- Meet with the manager of the retreat center and explain the purpose of and meaning behind the retreat. They will likely have never hosted such a program before and may be moved or inspired. Forming a relationship with this individual may be beneficial for hosting future retreats

**Do NOT choose entertainment-focused resorts including hotels and spa facilities**

## 5a. RECRUIT PARTICIPANTS - PARTICIPANTS

### PARTICIPANTS

Who can participate? >>>

Women who have been diagnosed with Stage IV breast cancer

How many times can a participant attend? >>>

It is recommended that participants attend no more than once

What is the size of the retreat groups? >>>

The number of participants should be limited to 10 couples for the couples retreat. Other retreats may vary slightly in size but the goal is to keep the group small so discussion is more intimate and manageable (typically no more than 12 women)

What are the requirements for attending? >>>

Participants need to be able to endure the duration of the program. The status of the patient may change leading up to the retreat so it is a good idea to have a waitlist

What are participant expectations? >>>

Participants should be willing to attend a group event, be interested in the content, and be open to sharing. They should understand that this is not a spa weekend, but rather a planned program that addresses living with metastatic breast cancer

Retreat materials have been created with a female patient audience in mind. However, your organization can adapt these materials to best fit your own patients and participants.

## 5b. RECRUIT PARTICIPANTS - RAISING AWARENESS AND RECRUITMENT

### RAISING AWARENESS AND RECRUITMENT

A written description in the form of a brochure can be personally handed to patients or mailed/emailed to individuals, departments, and outside facilities and support groups. Develop a list of contacts (medical offices, support groups, wellness communities, oncology nurse navigators consortium, breast centers) in the community to share the brochure with. Recruitment may also include your organization's website, social media, publications, or other means of your choosing. Reaching out to the community and ensuring a diverse group of participants is an important goal for any program.

**Additional resources to review:** For more information on the role of brochures, including templates that you can format to promote your future retreats, please see the Appendix.



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## 5c.

## RECRUIT PARTICIPANTS - REGISTRATION

### REGISTRATION

Once a woman decides to join the program, a registration form needs to be completed and submitted to the retreat coordinator. This form, which is part of the brochure, requests basic information. Additional personal information will be obtained from participants once registered via a **phone interview** or an additional registration form. Obtaining information on mobility, dietary needs, and past and current treatment will assist with planning for the needs of participants. In addition to sample brochures, sample registration forms are provided in the Appendix.

In place of paper registration, an online site can easily secure the registration. There are sites that will serve this purpose for no fee. Provide a link to the registration web page on your center's website or website calendar and include the registration URL on the brochure.

To ensure full attendance, it is recommended that you maintain a waitlist. Because of the nature of metastatic breast cancer and disease progression, participants may need to cancel registration closer to the date. Those on the waitlist will be able to fill the openings.

**Ensure patient privacy is appropriately maintained during the registration process.**

## SAMPLE PHONE INTERVIEW REGISTRATION QUESTIONS:



- **Basic Information:** Can you tell me your:
  - Name
  - Age
  - Contact information
- **Disease and Treatment Information:**
  - Where are you being treated?
  - When were you originally diagnosed?
  - What kind of breast cancer do you have?
  - Where has the cancer spread?
  - What treatment are you receiving?
- **Family and Caregiver Information:**
  - Marital status?
  - Do you have any children?
  - Who (if applicable) will be accompanying you on this retreat?
  - Can you confirm they are available and willing to attend the retreat?
- **Physical Abilities and Restrictions:**
  - What is your level of physical ability?
  - Do you need a handicapped accessible room?
  - What are your dietary restrictions?
- **Retreat:**
  - Have you ever attended a retreat in the past?
  - What are your retreat expectations?
- **Virtual Retreat (if Relevant):**
  - Do you have access to a computer with internet connection or a smartphone?
  - Are you comfortable using video conferencing technology?

## 6. PROGRAM EVALUATION

### PURPOSE OF EVALUATION

Program evaluation is a crucial part of event planning. An evaluation is a process or a tool that allows critical assessment of a program or plan. Evaluations are used to find out how well a program, practice, or policy works.

The purpose of a retreat evaluation is to determine if the retreat:

- Achieved the goals and objectives of the program
- Met the needs and influenced the perspective of participants
- Helped the staff improve in their roles

Critical evaluation of the program, the participants' experience, and the staff and their roles determines the effectiveness of the program. Moving forward, a program that is determined to be effective is validated as beneficial and appropriate, while one that needs improvement in specific areas can be altered.

Sample surveys to be taken at the beginning and end of the retreat, as well as a 3-month post-retreat evaluation are included in the Appendix.

Ensure patient privacy is appropriately maintained during the evaluation process.

### DATA CAN BE COLLECTED VIA:



#### In Person

Experience has determined that there is a better chance of achieving 100% return of retreat surveys if they are completed in person at the event



#### Online

Use of an online survey allows for information to be obtained and analyzed quickly



#### Mail/Email

Evaluations can be sent, completed, and mailed via email and mail. Note that this method does not allow for anonymity

### INFORMAL EVALUATION

Being open to informal evaluations from participants and staff throughout the weekend is crucial to address concerns or adjust topics. Facilitators and volunteers are present to listen to and interpret participants' comments and concerns (refer to the Staff Debriefing section in the Program Agendas). Assessing and responding are critical to the individuals' needs, as well as to the group dynamics.

### ANALYZE THE RESULTS

Analyzing the information obtained on questionnaires will help determine to what degree the program was effective in meeting its goals and objectives, as well as assessing its impact on participants. The results will provide information for funding sources to justify their support. The information will direct future planning and funding for retreats.

The staff's thoughts and impressions also help guide future retreat planning. Taking time to assess what went well and what needs improvement is essential. Meet with the staff to ascertain their ideas and impressions. A group that owns the program will want to continue to help it evolve and improve.

Remember that you cannot manage what you do not measure.



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