

# metastatic breast cancer

Effective Principles & Practices in Patient Support



**Reframe  
the  
Conversation**

Association of Community Cancer Centers  
This publication is a benefit of membership.

**ACCC**  
Association of Community Cancer Centers

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The Association of Community Cancer Centers (ACCC) is the leading advocacy and education organization for the multidisciplinary cancer care team. Approximately 23,000 cancer care professionals from 2,500 hospitals and practices nationwide are affiliated with ACCC. Providing a national forum for addressing issues that affect community cancer programs, ACCC is recognized as the premier provider of resources for the entire oncology care team. Our members include medical and radiation oncologists, surgeons, cancer program administrators and medical directors, senior hospital executives, practice managers, pharmacists, oncology nurses, radiation therapists, social workers, and cancer program data managers. Not a member? Join today at [acc-cancer.org/membership](http://acc-cancer.org/membership) or email: [membership@acc-cancer.org](mailto:membership@acc-cancer.org).

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# INTRODUCTION

The hard, decades-long work of many in the breast cancer community, including both care providers and patients, has resulted in huge gains in breast cancer awareness and early detection efforts nationwide. These efforts have helped to validate the experiences of a sizable population of breast cancer patients and survivors—a group who, for many years, did not feel understood. Additionally, these efforts have educated the public about the disease itself, encouraging people to get regular mammograms as a means of prevention. Despite these substantial successes, amplified conversations around breast cancer have simultaneously led to a perception that all breast cancer can be prevented and/or cured. While this narrative largely reflects the experiences of those living with early stage breast cancer, it contradicts the equally valid experiences of those living with advanced, stage IV, or metastatic breast cancer—a chronic, incurable disease with no clear prevention strategy.

Recognizing this disparity, a number of dedicated members of the oncology community have made significant efforts to provide specific support to these metastatic breast cancer patients. However, an environmental scan of these efforts, commissioned by ACCC, suggested that this work is rarely rooted in institutional, systemic processes, and is instead provided on an ad-hoc basis. Consequently, the support experienced by the majority of patients with metastatic breast cancer is uneven at best and absent at worst. Despite this lack of institutional processes, providers who treat patients with metastatic breast cancer agree that new resources and behaviors to help these patients have emerged. Alongside this progress, there is also consensus among oncology professionals that there needs to be a stronger focus on the unique needs of this patient population.

## Two components informed this research

### 1 Environmental Scan of Metastatic Breast Cancer Patient Support

In April and May of 2016, ACCC commissioned an environmental scan, which combined primary and secondary research to highlight existing systems and approaches that effectively support patients with metastatic breast cancer. The scan included a review of key studies to understand the gaps and recent innovations that exist within patient support of this patient population and 16 phone interviews with notable leaders in the care and support of metastatic breast cancer patients. These individuals consisted of members of the ACCC Metastatic Breast Cancer Advisory Committee in addition to referrals from committee members. Referrals were specifically comprised of individuals whom advisory committee members identified as offering an important perspective on metastatic breast cancer patient support during their phone interviews.



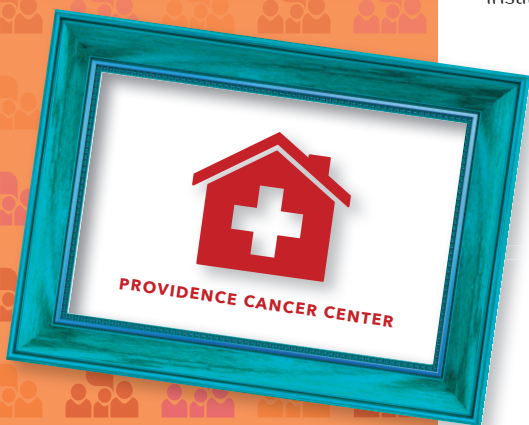
### 2 Interviews with Staff & Patients from Three Model Programs

In August and September of 2016, phone interviews were conducted with staff and patients from the three community cancer programs discussed below. Similar to the environmental scan, individuals across a range of disciplines were interviewed in order to obtain a holistic view of metastatic breast cancer patient care.

This workbook features three model programs for metastatic breast cancer patient support in the United States. These three community cancer programs provide thorough, consistent, integrated support for metastatic breast cancer patients at the institutional level:

- **Gibbs Cancer Center**, Spartanburg, South Carolina. Participants included: Chad Dingman (director of the Center for Integrative Medicine and Oncology Support), Rebecca Robertson (clinical nurse navigator), Dr. Stephan Corso (medical oncologist), Carter S. (patient), and Leslie M. (patient).
- **Providence Cancer Center**, Portland, Oregon. Participants included: Dr. Ali Conlin (director of the Breast Cancer Program, medical oncologist), Heather Hill (head of Palliative Care), Krista Nelson (oncology social worker), April S. (patient), and Linda M. (patient).
- **Sanford Cancer Center**, Fargo, South Dakota. Participants included: Dr. Chery Hysjulien (psychologist), Dr. Preston Steen (medical oncologist in Palliative Care); Dr. Shelby Terstriep (medical oncologist), Lori J. (patient), and Vicky W. (patient).

Using these three model programs, the workbook illustrates how real-world cancer teams working with metastatic breast cancer patients offer effective support and resources, despite the considerable challenges and barriers that they face. Additionally, the workbook uses the six effective practice principles that emerged from the environmental scan as a framework for highlighting where and how these cancer programs have managed to be successful. The workbook will help to spur imaginative thinking and constructive dialogue within community cancer programs looking to improve their support of this overlooked patient population. Fill out the worksheet at the end of the workbook to see how the six effective principles are embodied at your cancer program, how your cancer program is successfully meeting the needs of metastatic breast cancer patients, and how to identify opportunities for improvement.



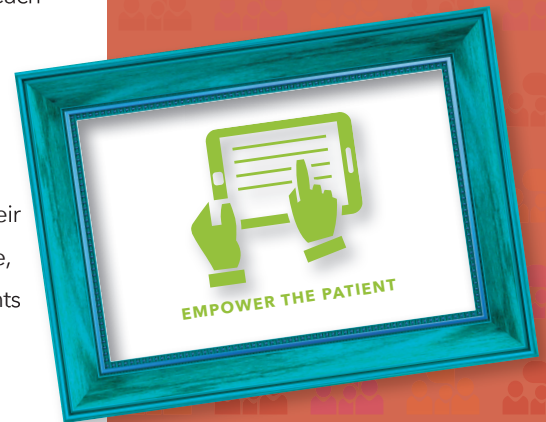
# EFFECTIVE PRINCIPLES IN METASTATIC BREAST CANCER PATIENT SUPPORT

The six effective practice principles identified by the environmental scan characterize the existing systems and approaches that are truly meeting the needs of patients with metastatic breast cancer. For the purposes of this workbook, these principles are used as a framework for examining three successful models of metastatic breast cancer patient support. While all three community cancer programs embody multiple principles, this workbook highlights three principles at each site, calling out the most innovative aspects at each program.

## PRINCIPLE NUMBER

### 1 Empower the Patient

Given the terminal nature of metastatic breast cancer, patients often feel that their disease has stripped them of control. Life goals may start to feel less achievable, and because life expectancies are highly variable from person to person, patients with metastatic breast cancer may feel even less equipped to navigate conversations with their family, friends, and co-workers. One way to help these patients to navigate the complexity and confusion surrounding their disease is to help them regain a sense of control and make their own decisions as confidently as possible. Empowerment, in turn, facilitates patients' abilities to live their lives as they want to, within the limits imposed by their illness. In order to do this successfully, oncology providers must clearly communicate information to their metastatic breast cancer patients in a way that does not heavily rely on medicalized, academic, scientific, or complex language. Instead, effective communication requires striking a balance between honesty and hope—allowing patients with metastatic breast cancer to fully understand their reality and therefore decide how they want to move forward.



## PRINCIPLE NUMBER

### 2 Reframe the Conversation

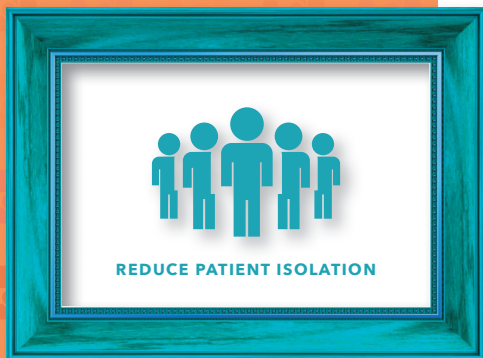
Given how patients with metastatic breast cancer often feel excluded from the dominant breast cancer narrative, there is a significant lack of understanding of the unique issues around this patient population. The majority of the public relies on their understanding of early breast cancer to navigate conversations with metastatic breast cancer patients, resulting in these patients often citing feelings of guilt and shame. Women with metastatic breast cancer can be made to feel as if their diagnosis is the result of inadequate self-care and prevention—even though there is little understanding as to how and why breast cancer becomes metastatic. Additionally, when diagnosed with metastatic breast cancer, many patients perceive the incurable nature of the disease as an immediate death sentence. Communication that is clear, yet also offers a source of hope, allows these patients to understand and even think about their disease in a new way.



**PRINCIPLE NUMBER**

**3 Reduce Patient Isolation**

Across disciplines, social support is understood to be a key source of psychological and even physical relief throughout the experience of patients with metastatic breast cancer. Breast cancer’s dominant narrative of early detection and survivorship, in combination with the difficulty and relative rarity of the disease, can cause patients to feel that they are going through this disease alone. There are very few individuals who understand metastatic breast cancer and even fewer who can personally relate to living with the disease. As a result, many patients actively seek social support at some point after diagnosis to talk about their experiences living with metastatic breast cancer in addition to work, relationship, family, and parenting issues. Social support can come in a variety of forms, such as retreats, in-person support groups, phone support groups, online support groups, mentorship programs, and even relationships with cancer care providers. Although general resources can be beneficial when support is personalized based on individual circumstances, it is problematic in social spaces that assume shared experiences and needs. It is therefore critical to create and identify metastatic breast cancer-specific spaces for these patients to share their experiences and build community—ultimately creating systems of emotional support for these patients.



**PRINCIPLE NUMBER**

**4 Offer Logistical Support at the Cancer Program**

The emotional stress of living with metastatic breast cancer produces additional difficulty for patients when they are faced with challenges that they are not informationally or emotionally equipped to handle. Even when resources are available at the cancer program, patients often struggle to access and/or use them. Logistical support that recognizes metastatic breast cancer patients need help in areas such as clinical trials and finances, elevates their experiences and minimizes their stress. Additionally, by spending less time trying to understand logistics, metastatic breast cancer patients can focus on the important facets of their lives, such as their families, extracurricular activities, and work.



# EFFECTIVE PRINCIPLES IN METASTATIC BREAST CANCER PATIENT SUPPORT *continued*

## PRINCIPLE NUMBER

### 5 Connect Patients with Support in the Community

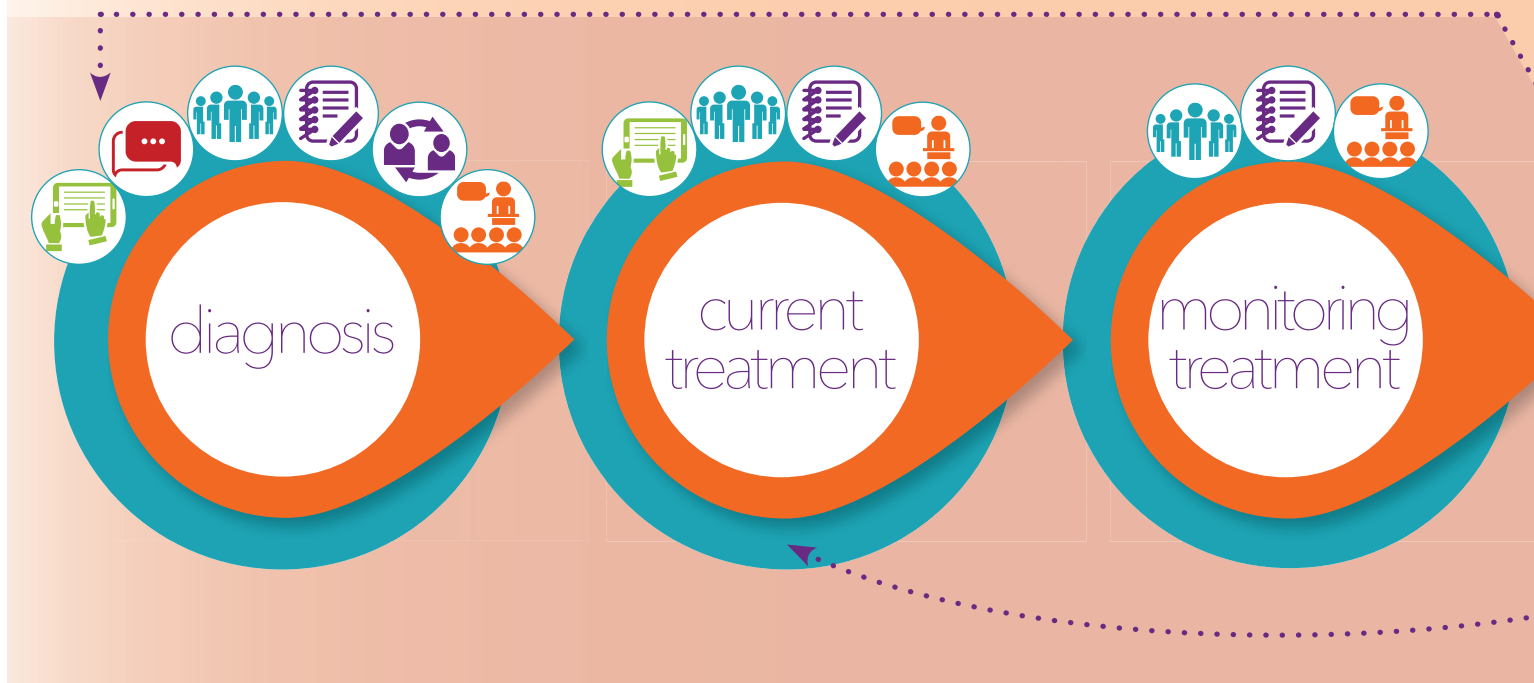
While it is important for cancer programs to offer logistical and social support to patients, it is simply not feasible for programs to provide all the needed services and support for this unique patient population. So, in addition to internal programmatic support, cancer programs must be aware of and educate metastatic breast cancer patients about resources and support available in their communities. A number of cancer programs are finding success by developing and using a referral system, but it does place additional pressure on oncology providers to know when and where to refer patients. A more effective way to create awareness is to put systems in place that allow patients with metastatic breast cancer immediate access to information about support offered both at the cancer program and within the community, maximizing efficiency and raising awareness of all available resources.



## COMMUNICATION PROCESS MAP

### *Metastatic Breast Cancer*

### LIFE PLANNING ISSUES:





PRINCIPLE NUMBER

## 6 Collaborate in the Interest of Patients

The success of these effective practices is contingent on the oncology providers to activate them. Cancer care teams that are the most equipped to engage in effective practices are ones that have internally fostered a culture that encourages multidisciplinary collaboration. Teams working with metastatic breast cancer patients need to understand that it will take multiple individuals to improve patients' overall experience—and the most effective and efficient way to do this is to work together. Ideally, cancer care teams working with metastatic breast cancer patients will be multidisciplinary, and they will understand how each team member brings value to the patients and their families. This partnership requires the institution to encourage collaboration, and all cancer care team members to educate one another on how they can add value and where in the metastatic breast cancer patient experience they are most helpful. A culture of active communication between team members helps identify where practices can be made more efficient and where improvements may be needed.



*Advanced Directives | Legacy Planning | End of Life Issues*



treatment failure



hospice

### Metastatic Breast Cancer Support Principles Key

-  **1 Empower the Patient**
-  **2 Reframe the Conversation**
-  **3 Reduce Patient Isolation**
-  **4 Offer Logistical Support at the Cancer Program**
-  **5 Connect Patients with Support in the Community**
-  **6 Collaborate in the Interest of Patients**

## GIBBS CANCER CENTER

Residents of Spartanburg, South Carolina are proud to have Gibbs Cancer Center in their community. As one of the few world-class cancer centers in its region, Gibbs stands out to its patients for its extensive research efforts, its in-house tumor board that creates personalized treatment plans for new patients, and its palliative care—or supportive care—support throughout the entirety of patients' experiences. Above all, by having its care and support services share the same physical space, Gibbs offers patients with metastatic breast cancer a one-stop shop for all of their care and treatment. This feature is particularly important as many patients drive long distances to receive their care at Gibbs. A cancer program that embraces the community it works in, Gibbs provides exceptional support for its metastatic breast cancer patients.

Given its location in the nation's Bible Belt, Gibbs' patients tend to be more religious, more conservative, and more skeptical of mental health services than the average patient. Specifically, the skepticism surrounding mental health services highlights an existing barrier that Gibbs faces when looking to provide comprehensive care for patients with metastatic breast cancer. Gibbs is also still working to find systematic solutions for moving discussions about advance directives and legacy planning earlier in the metastatic breast cancer patient experience. This process has proven to be difficult given many patients' fears about the implications of discussing advance directives. Last, Gibbs is proactively working to find a way to electronically identify early breast cancer patients who later transition to metastatic breast cancer. Gibbs' current system flags new breast cancer patients for healthcare providers; however, the system does not account for existing patients whose conditions develop into new diagnoses. Flagging metastatic breast cancer patients will consequently help the Gibbs' team provide more nuanced care to these patients, as it will ensure that no patients are left to navigate their disease without the knowledge of the available resources Gibbs has to offer—both within the cancer program and out in the community.

In light of these challenges, Gibbs is proactively identifying ways to better support its population of metastatic breast cancer patients. The key piece to this team's success is its commitment to and understanding of its patients. Frequently, this understanding manifests in the team tailoring its communication styles and outreach materials to resonate with individual metastatic breast cancer patients, helping these patients feel uniquely cared for. Gibbs also excels in its efforts to systematize its successful techniques in patient care and support, maximizing efficiency while providing consistent care.



metastatic  
breast  
cancer



## PRINCIPLE NUMBER 2

### Reframe the Conversation

Clear, candid communication is a best practice for relationships between healthcare providers and patients. While this type of communication is important for most, if not all, patient relationships, honest communication is a necessity for patients with metastatic breast cancer. When healthcare providers use overly technical medical language with metastatic breast cancer patients, it muddies the implications of the disease, leading many patients to misunderstand the information and unconsciously put up barriers to effective support. The Gibbs team is exceptional in its communication because it relays important information to metastatic breast cancer patients in a way that patients will not only understand, but also embrace. Below are specific examples of how Gibbs puts this principle to work at its cancer program.

#### Using a Metaphor to Explain Metastatic Breast Cancer Diagnosis

Stephen Corso, MD, a medical oncologist at Gibbs, uses a metaphor to help his patients with metastatic breast cancer fully grasp the implications of their diagnosis in a way that is clear and honest, but still hopeful. Using a metaphor of a map, Dr. Corso tells metastatic breast cancer patients to think of life as a journey with a beginning and an end—one that starts in South Carolina and ends in California. While all people have California as their end destination, Dr. Corso explains that patients diagnosed with metastatic breast cancer will arrive to California sooner than expected. He also explains that he wants his patients to enjoy the ride to California, encouraging them to continue with their lives with dignity—helping patients see that a metastatic breast cancer diagnosis is not an immediate death sentence. The map metaphor also provides a helpful way to talk about death without overtly focusing on the topic. As his patients' conditions change, Dr. Corso uses the metaphor again to explain how close his patients are to "California."

Through this metaphor, Dr. Corso effectively navigates a difficult conversation with his metastatic breast cancer patients—a conversation where he needs patients to know that the disease will undoubtedly shorten their life. This conversation is important for metastatic breast cancer patients to not only have an accurate understanding of the implications of the disease, but also to encourage them to start planning their future. In a death-averse society, the use of the map metaphor at diagnosis integrates the concept of death and palliative care early on without putting unnecessary weight on the end of the journey. Dr. Corso's technique helps his patients maintain their dignity as they continue living with metastatic breast cancer.

### **Sensitive, Integrated Introduction of Palliative Care**

As a result of Dr. Corso's use of the map metaphor at the time of diagnosis, metastatic breast cancer patients already have an understanding that palliative care can improve their quality of life throughout the "journey." This early introduction helps metastatic breast cancer patients get comfortable with the idea of palliative care, which is often stigmatized due to the false perception that palliative care only occurs after the decision to stop treatment and patients are nearing the end of their life. Additionally, the metaphor embeds the reality that Gibbs will be integrating palliative care from the start of the metastatic breast cancer patient experience as a means of pain management.

Knowing that there are existing negative associations with the words "palliative care," Gibbs uses a different term. When naming its palliative care program, Gibbs deliberately titled it the "Outpatient Support Clinic." This decision has allowed the Gibbs team to break down one of the barriers to metastatic breast cancer patient support. Even more, this decision reflects the Gibbs team's ability to recognize where they might encounter resistance to patient support and as a result, proactively think of ways to work to overcome this resistance.

#### **THE PATIENT'S PERSPECTIVE**

"My doctor is a good listener,  
but I also think he's realistic.  
He doesn't paint any unrealistic pictures.  
But he also won't project;  
he doesn't have a crystal ball.  
He said, 'Don't put anything off,'  
and I thought that  
was very realistic."

**LESLIE M., Gibbs Patient**

#### **THE PATIENT'S PERSPECTIVE**

"I am very aware that it will  
take my life,  
but my doctor never speaks in those  
terms with me . . .  
He never looks at the negative aspects.  
He stays positive like I do."

**CARTER S., Gibbs Patient**

Carter and Leslie's praises of their medical oncologists at Gibbs speak to the personalized approach the Gibbs team uses to communicate important, and oftentimes difficult, information. While Carter responds well to positivity, Leslie prefers a more candid approach. Each oncologist has been successful in gauging the unique needs of their patients and adapting their communication style to the patients' learning style. The staff at Gibbs calibrates their approach for metastatic breast cancer patients to help meet their personal needs.



## PRINCIPLE NUMBER 5

### Connect Patients with Support in the Community

The available resources and support at a community cancer program are a crucial piece to effective support; however, equally—if not more—important is a cancer program’s ability to connect its patients with external resources available in the community. Putting in place a system and procedures to connect patients with these resources can help members of the cancer care team keep current on both internal (those offered at the cancer program) and external (those found in the community) resources, reducing the risk of patients falling through the cracks. This is the approach that Gibbs uses to educate its metastatic breast cancer patients.

Specifically, Gibbs encourages patients to tell team members what they need, but also understands that providers must first help metastatic breast cancer patients understand what resources are available and the value of each. Without this education, metastatic breast cancer patients may be less likely to articulate or even identify their own needs. Below are specific examples of how Gibbs puts this principle to work at its cancer program.

#### Partnering with Patients

Understanding that no cancer program can offer all the supportive care services and resources needed by metastatic breast cancer patients, Gibbs invests considerable effort in developing resources that connect metastatic breast cancer patients to both internal and external services. This connection minimizes the danger that metastatic breast cancer patients will go through their time at Gibbs without the knowledge of existing support resources. Simultaneously, it also increases metastatic breast cancer patients’ confidence in Gibbs’ care.

For example, one metastatic breast cancer patient, Leslie, uses what she describes as a “librarian-researcher” who helps patients learn more about any aspect of their disease, whether it be questions about symptoms, psychological support, or even nutrition. After patients approach this Gibbs staff member with their questions, he scans his own databases to pull relevant information that will help patients. His presence reduces the time that many metastatic breast cancer patients spend researching on their own and helps patients understand that Gibbs wants to be a partner to them throughout their experience.

Additionally, Gibbs offers two specific breast cancer nurse navigators. Rebecca Robertson, one of Gibbs’ nurse navigators, explains that the two navigators work with all breast cancer patients to position themselves as go-to resources for any questions the patients might have. By giving metastatic breast cancer patients their contact information and frequently checking-in with them either in-person or on the phone, the two navigators act as mediators between the patient and Gibbs. When these navigators are able to answer patient questions, they do so immediately, and when they cannot, they quickly work to introduce metastatic breast cancer patients to someone who can help.

### Visually Presenting Resources at Diagnosis

Even when cancer care teams make patients aware of available resources and support, oftentimes, the emotional state of metastatic breast cancer patients clouds their decisions to use these services or causes patients to forget about the offerings entirely. For this reason, it is critical for cancer care teams to develop and use an effective process to communicate the full array of support services that metastatic breast cancer patients have available to them—both within the cancer program and out in the community. Gibbs does this with a carefully designed packet that outlines all of the support services available to metastatic breast cancer patients. Every patient receives this packet at the time of diagnosis. In the packet, there is a panel card that educates patients about diagnosis and treatment, including pictures of the Gibbs cancer care team. Next to the photos of staff members are descriptions of their roles, the “role” each staff member plays for the metastatic breast cancer patient, and how to contact them. Gibbs encourages metastatic breast cancer patients to take the packet home with them, allowing patients to revisit the documents throughout their experience—instead of expecting patients to recall information that was given to them verbally.

#### THE PATIENT'S PERSPECTIVE

“You get a packet and a folder of comprehensive services, so I’ve kept that and filed it away because I need that. But if there’s something that I don’t understand about these services or if I need to know more about them, I can turn to my nurse navigator.”

**LESLIE M., Gibbs Patient**

Because Gibbs has developed a process and invested resources to help metastatic breast cancer patients locate and identify support services, these patients are aware of the internal and external support services available to them, improving the patient care experience.

#### THE PATIENT'S PERSPECTIVE

“Gibbs stays on top of what’s going on in the rest of the country—the latest developments. I don’t have to fly to New York or Houston; I can get my treatment right here where I live.”

**CARTER S., Gibbs Patient**



## PRINCIPLE NUMBER 6

### Collaborate in the Interest of Patients

Gibbs' exemplary level of care for its metastatic breast cancer patients is a direct result of the team's proactive efforts to internalize successful techniques and programs that elevate metastatic breast cancer patient support at the institution. By taking responsibility to spread best practices and successful models of support, Gibbs commits itself to providing comprehensive metastatic breast cancer patient care at an institutional level. Below are specific examples of how Gibbs puts this principle to work at its cancer program.

#### Spreading Reframing Techniques

To improve communication with metastatic breast cancer patients, Dr. Corso shares his approach to discussing death with these patients with other staff members at Gibbs. Without forcing his colleagues to use his map metaphor, he stresses the importance of being candid with metastatic breast cancer patients in a way that still gives them hope. What could have been one oncologist's successful communication technique has instead become a starting point for further educating others on the team, helping to provide a more consistent patient experience.

#### Advocating for Resources to Improve Patient Support

Just as Dr. Corso shares his philosophies for improving communication with other staff members, Gibbs team members who work with metastatic breast cancer patients advocate internally for resources and services that will better their patients' experiences. In the specific case of palliative care services, Chad Dingman, director of the Center for Integrative Medicine and Oncology Support, explains that as a non-revenue generating part of the institution, it is crucial for him to demonstrate to the higher-level administration how the Outpatient Support Clinic adds value. To do this, Chad and other members of the team make an effort to build relationships with staff within the institution—educating them about their services and the benefits they offer patients and providers. Additionally, his staff uses survey results to help quantitatively validate the positive impact these support services have had on patient satisfaction. Presenting the institution with data displays concrete evidence of why metastatic breast cancer patient support resources should continue to be a priority for the cancer program. This return on investment (ROI) not only serves to justify continued support and funding of these services, but can also inspire the institution to continue to invest in additional non-revenue generating services and resources that address the needs of metastatic breast cancer patients.

Both Leslie and Carter explain that they have no doubts that they are receiving the best level of care at Gibbs. Part of the reason that metastatic breast cancer patients display this level of confidence in Gibbs' care is because patients feel that they are receiving treatment and support from a unified, well-run team. In addition, Gibbs' metastatic breast cancer patients articulate that the care feels consistently strong throughout the entirety of the experience—and this is a testament to the entire team's constant commitment to learn from and teach one another.

# PROVIDENCE CANCER CENTER


In Portland, Oregon, Providence Cancer Center is known for its Family Support Program and commitment to working with underserved populations, including metastatic breast cancer patients. In its efforts to care for the whole person, Providence believes that care should serve both patients and families. Additionally, Providence is home to a strong integrative medicine program with offerings such as naturopathy and acupuncture. Providence's support of the families of metastatic breast cancer patients and emphasis on treating the whole person, not just the disease, reflects its comprehensive approach to care—and its physical space supports this approach, with all of its current supportive care services available in one location.

Providence recognizes patient needs that are still unmet, and is working to grow its programs to address them. It strives to provide more metastatic breast cancer-specific support to its patients, for example, through the creation of a metastatic breast cancer-specific support group. Providence is also looking to identify a process that delicately introduces the idea of advance directives earlier in the experience, helping patients with metastatic breast cancer plan ahead and take control of their futures without minimizing their hope. Its cancer care team also hopes to differentiate support for patients who have been diagnosed with metastatic breast cancer at first diagnosis from those whose disease has progressed (patients who have transitioned to metastatic breast cancer) to further personalize the patient experience. These identified areas of improvement display Providence's dedication to extending beyond what is traditionally expected of care providers—serving metastatic breast cancer patients in a deeply holistic, progressive way.

## PRINCIPLE NUMBER 3

### Reduce Patient Isolation

Providence offers emotional support beyond the standard parameters of many medical institutions. Instead of exclusively focusing on treating the disease, Providence looks to treat patients with metastatic breast cancer and their families as one cohesive unit—with each family member receiving equal support. By doing so, Providence recognizes that other aspects of patients' lives can affect their quality of life. Providence understands that the quality of life of patients with metastatic breast cancer impacts their state of being and state of mind—directly affecting their health. The team's interpretation of emotional support transcends standard practices of patient care by including families of metastatic breast cancer patients in treatment planning and shared decision-making. Following are specific examples of how Providence puts this principle to work at its cancer program.



metastatic  
breast  
cancer



REDUCE PATIENT ISOLATION





### Comprehensive Family Support Program

When living with metastatic breast cancer, patients do not know how the disease will impact their life span. This uncertainty often generates stress and anxiety for the people who care about them the most. When their loved ones show signs of sadness about their disease, patients with metastatic breast cancer can become even more emotionally distressed. These patients are often not in a position to support and counsel family members about their own diagnosis; distress can also compromise family members' ability to support patients effectively.

Providence's Family Support Program is a resource that allows the families of patients with metastatic breast cancer to get complimentary emotional support from professionals. By offering support to families, the program helps metastatic breast cancer patients by caring for some of their most important sources for support. Serving hundreds of families, Krista Nelson, an oncology social worker at Providence, explains that the support group holds sessions each month that are 90 minutes in length. Each session consists of three groups that run concurrently, divided by age (children, teenagers, and adults), allowing family members at different life stages to find community in other people in similar situations.

### Communicating a Team Effort

Providence also provides emotional support to its metastatic breast cancer patients by positioning itself as a partner in, rather than provider of, care. Ali Conlin, MD, a medical oncologist at Providence, makes it clear to her patients at diagnosis of metastatic breast cancer that they are a team and that they will make decisions together. This shared decision-making communicates to metastatic breast cancer patients that throughout their time at Providence, they will have someone to turn to and someone to help them make difficult decisions.

Providence's nurse navigators also display a collaborative approach to decision-making. In their work with metastatic breast cancer patients, nurse navigators explain to patients that they are go-to resources for any questions or concerns and can be reached anytime by phone.

Linda and April, two metastatic breast cancer patients at Providence, identify the cancer program's approach to metastatic breast cancer patient support as collaborative. The numerous resources that the patients use and the relationships that they develop with Providence providers are primary drivers for their excitement and passion for the cancer program. April explains that having a team that she knows cares about her family and knows about her life helps to "take the edge off," especially when she walks into a place where she often does not want to be. She notes that her husband has used more of the emotional support services than she has—recalling that he went to see a social worker at Providence when he was struggling to process her diagnosis, illustrating Providence's belief that family support is vital to delivering effective metastatic breast cancer patient support.

# PROVIDENCE CANCER CENTER

*continued*

## THE PATIENT'S PERSPECTIVE

"I never slipped through the cracks. Providence's mission statement matches what they do. Everybody is a team, and it's like a beautiful chain of people that really care."

LINDA M., Providence Patient

## THE PATIENT'S PERSPECTIVE

"You can call her [the navigator] for anything, and if she doesn't know the answer, she'll find out.

You don't waste your time as a patient trying to find a phone number or figuring out stuff by yourself. The nurse navigator can really be a liaison to everything."

APRIL S., Providence Patient

## PRINCIPLE NUMBER 4

### Offer Logistical Support at the Cancer Program

As a community cancer program that treats patients with lower socioeconomic status, Providence acknowledges that the presence of navigational resources can be the difference between metastatic breast cancer patients who receive high-quality care and those who are not able to access the care they need. With patients' busy schedules, time is not a resource that patients with metastatic breast cancer often have, let alone a resource that they want to use to research clinical trials or calculate their finances. To address this reality, Providence invests in non-revenue generating resources that are critical to meeting the supportive care needs of metastatic breast cancer patients. Below are specific examples of how Providence puts this principle to work at its cancer program.

#### Support from Research Nurses

Working under Dr. Conlin, Providence has two research nurses to specifically help metastatic breast cancer patients navigate clinical trials. A part of the patient experience that often creates confusion, the clinical trials landscape is one that challenges metastatic breast cancer patients who lack the necessary information to determine whether or not they qualify for trials. When these patients are unable to locate clinical trials they are eligible for, they can become less hopeful and frustrated with what appears to be limited care options. As a result, these dedicated research nurses, who help run clinical trials, educate patients with metastatic breast cancer about the risks and rewards of participation, and assist patients in locating and understanding clinical trials. Their presence has also had a positive effect on Providence's patient trial enrollment numbers. With an estimated 13 percent of patients enrolled in clinical trials, Providence sits almost 10 percent higher than the national average—validating the value of these resources ([medscape.com/viewarticle/77662](https://www.medscape.com/viewarticle/77662)).



#### THE PATIENT'S PERSPECTIVE

“They had a resource center,  
which was brand new at the time.

I went in and thought  
not only do they have computers to  
educate ourselves, books, and beyond,  
but they had hats if you're losing your hair,  
a whole wig shop.

They've got everything in-house . . .  
I felt like there was no end to my resources.”

**LINDA M., Providence Patient**

#### Free Drop-In Childcare

Because metastatic breast cancer can be found in younger patients, many are parents with young children who need to be supervised during appointments. Acknowledging this reality, as a part of its family support program, Providence offers free drop-in childcare to its patients. Complimentary childcare eliminates what is often a source of financial stress. Providence's decision to offer this service displays not only its dedication to improving patient care, but also its commitment to meeting the needs of underserved patients.

The support that Linda and April describe is thorough and deliberate. They feel cared for, understood, and accounted for, which can be rare for metastatic breast cancer patients. Providence displays an authentic understanding of the unique needs and concerns of these patients and is able to address them with tangible patient resources.

#### PRINCIPLE NUMBER 5

### Connect Patients with Support in the Community

Providence's success in providing holistic care to its patients with metastatic breast cancer is due to its ability to connect patients to both internal and external services. Instead of relying on patients with metastatic breast cancer to independently identify their needs, Providence understands that these patients need to know what resources are available to them *before* they can decide where they need assistance. To educate metastatic breast cancer patients about services available in-house and out in the community, Providence creates materials and spaces that can serve as a one-stop shop for resources, minimizing the time patients must spend locating resources. Below are specific examples of how Providence puts this principle to work at its cancer program.

#### “Living Well” Booklet

When patients are first diagnosed with metastatic breast cancer, Providence provides them with a “Living Well” booklet. The booklet contains tips for living with cancer, in addition to a comprehensive list of all resources—both those offered at the cancer program and those available in the community. The “Living Well” booklet educates metastatic breast cancer patients about the resources available to them, allowing patients the opportunity to revisit the information at any time throughout their treatment.

#### Comprehensive Resource Center

In addition to the “Living Well” booklet, Providence also has an on-site resource center that is available to all patients. Providing patients with books and computers, the resource center is a designated space for metastatic breast cancer patients to get answers to their questions. More than just offering informational support, the center also provides resources that address patients' emotional concerns. Linda, a Providence patient, recalls a wig shop inside of the resource center for patients who had undergone chemotherapy. Thus, the resources within the center speak to a thorough understanding of the needs of patients with metastatic breast cancer.

Through written materials, educated staff, and a brick-and-mortar resource center, Providence makes it clear what support services are available and where to locate them. This level of clarity and proactivity makes patients with metastatic breast cancer feel better equipped to manage their disease, as well as more confident in their care providers.

# SANFORD CANCER CENTER

Located in Fargo, North Dakota, Sanford Cancer Center offers state-of-the-art cancer treatment for metastatic breast cancer patients—many who travel long distances to receive care. The cancer program prides itself on its cutting-edge research, strong participation in clinical trials, integrative pain and symptom management services, and holistic psychological and social support.

Sanford's achievements have not come without significant challenges. The cancer care team is still looking for ways to address a shortage of physical space, which is needed to continue to grow their pain and symptom management services. Sanford is also navigating a way to break down internal barriers to embedding integrative medicine throughout the metastatic breast cancer patient experience.

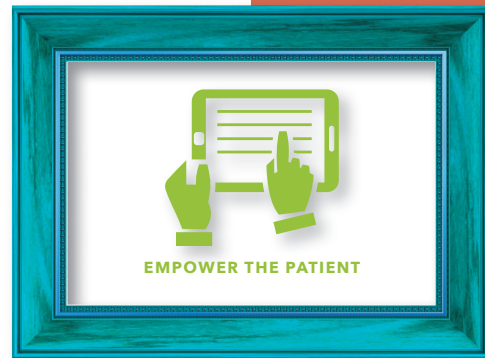
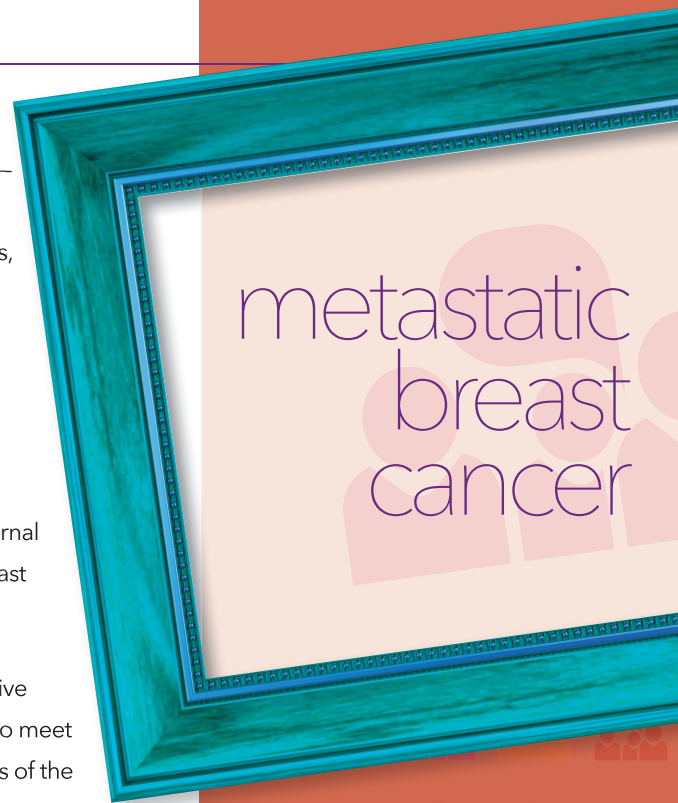
One factor that makes Sanford successful is its acknowledgment that effective patient care is inextricably linked to patients' quality of life. Sanford strives to meet the needs of metastatic breast cancer patients not just within the perimeters of the cancer center, but also to elevate patients' emotional and functional experience throughout their everyday lives. Support from Sanford goes beyond the traditional standards of medical care and is made available to patients remotely, at every point throughout their experience.

## PRINCIPLE NUMBER 1

### Empower the Patient

Beyond providing metastatic breast cancer patients with information, Sanford empowers its patients by giving them a voice within the institution. With numerous variables outside of their control, patients with metastatic breast cancer want to reclaim autonomy in their medical care through shared decision-making, and also have a lasting impact on the care of future patients.

Unlike a more traditional medical model where patients are seen as the recipients of care, Sanford fosters a symbiotic relationship with its patients. The relationship is one where the institution and the patient are learning from one another, while directly influencing, the other's actions. Sanford actively seeks the perspective of patients with metastatic breast cancer to improve the support and treatment of this patient population. While this model may be more common in individual patient-healthcare provider relationships, Sanford is remarkable in its system-wide processes to do so. Following are specific examples of how Sanford puts this principle to work at its cancer program.





### Educational Series

Sanford offers an educational series that helps patients learn more about living with cancer. While not specific to metastatic breast cancer, the series offers a wide range of information, such as managing neuropathy and stress. The series was conceived as a result of survey feedback from patients who expressed wanting more available information. Over the course of 8 years, the program has expanded into both a live series at 2 sites and a teleconference at 11 sites—with all content shared online.

The success and rapid growth of the educational series is a direct result of the value patients are receiving from it. Sanford distributes a survey at the end of each lecture to gather patient feedback about topics and speakers. Sanford then decides on topics based on a combination of survey feedback, questions that patients frequently ask staff, and postings that appear on Sanford's Facebook page.

### Fourward, Metastatic Breast Cancer Support Group

In addition to expressing how existing resources can best meet their needs, metastatic breast cancer patients at Sanford have the ability to create new resources and policies. For example, after attending Sanford's general breast cancer retreat, three patients with metastatic breast cancer came together to start Fourward, Sanford's metastatic breast cancer-specific support group. Throughout the retreat, Vicky, one of Fourward's founders, described feeling alienated from the other retreat members due to their significantly different experiences and ultimately saw the need to create a metastatic breast cancer-specific space. As a result, Vicky, along with two other metastatic breast cancer patients, worked with Sanford to create the group, and Sanford displayed a willingness to listen and put resources towards it.

During group sessions, Fourward members lead discussions and dictate the direction of group conversations. More so than in other support groups, Fourward takes a patient-led process that encourages relationship building within the group. Chery Hysjulien, PsyD, a psychologist at Sanford, serves as the group's moderator, allowing discussions to form organically in an effort to help group members acknowledge and process their own issues. This empowers metastatic breast cancer patients to take control in a space that is often structured and moderator-driven.

Because Fourward members guide the direction of the support group, their top-of-mind concerns emerge organically. Although sharing concerns is commonplace in a support group, using these conversations to shape policy is rare. Dr. Hysjulien works with Sanford to address the institutional concerns raised by the support group. For example, when metastatic breast cancer patients voiced concern about sitting in waiting rooms designated for general emergency services because of their compromised immune systems, Sanford responded by incorporating a number of private rooms for patients to wait in. Thus, Fourward is more than just a space of support for metastatic breast cancer patients, it is a vehicle to improve the patient experience.

These two examples of empowerment embody how Sanford represents a community cancer program that not only puts the needs of its patients at the center of its practices and policies, but one that has also created a system of support where the patient perspective serves as a primary driver for institutional change.

As Vicky explains, Sanford's metastatic breast cancer patients feel that their voices are heard, validated, and responded to. Because Sanford empowers its metastatic breast cancer patients with an uncharacteristic level of control in their experience, these patients express that they are dictating their own futures with an institution that wants to evolve with them. This empowerment fosters a culture of trust that metastatic breast cancer patients are grateful for.

### PRINCIPLE NUMBER 3

#### Reduce Patient Isolation

Arguably one of the strongest aspects of Sanford's support for metastatic breast cancer patients is its ability to reimagine and unpack what psychological support can mean for its patients. At many cancer programs, addressing patient isolation is a direct call for more traditional emotional support resources, such as support groups, counseling, and retreats. There is no question about the tremendous value these resources bring to the metastatic breast cancer patient experience, particularly when these resources are metastatic breast cancer-specific. However, Sanford has developed a holistic response to addressing metastatic breast cancer patient isolation. In addition to providing traditional resources, such as a metastatic breast cancer support group and a retreat, Sanford also looks for ways to embed the idea of combatting isolation throughout the care continuum. Sanford ultimately strives to provide metastatic breast cancer patients with 24/7 access to support, particularly because of the long distances many patients must commute. Below are specific examples of how Sanford puts this principle to work at its cancer program.

#### Breast Cancer Mentorship Program


Although only one year old, Sanford's mentorship program offers metastatic breast cancer patients the opportunity to help new patients navigate living with metastatic breast cancer. After the survivorship program trains metastatic breast cancer patients who have been identified as star communicators, these patients are then paired up with new patients who have opted into the program. True to its nature, Sanford gathers program feedback at each interaction in order to improve services. So far, the program has been

#### THE PATIENT'S PERSPECTIVE

“I feel like I’m an equal part of the cancer care team.”

VICKY W., Sanford Patient





well-received, and Sanford is now working to ensure that metastatic breast cancer patients who opt-in have a mentor to support them throughout the entirety of their treatment. The conception of the mentorship program signifies a progressive shift in thinking about emotional support—allowing patients, instead of staff members, to act as caregivers. This change is effective not only in providing metastatic breast cancer patients with another resource for support, but also in breaking down potential barriers to care by encouraging patients to discuss difficult concerns and questions with someone other than a healthcare provider. Additionally, the program provides metastatic breast cancer patients with the opportunity to create meaning from their challenging experience by leveraging their hard-won knowledge to help others.

### **Ongoing Breast Cancer Online Community**

In addition to offering a mentorship program, Sanford is also beta-testing an online community for breast cancer patients. Mentors and healthcare staff will act as moderators who can post questions, informational resources, and topics that specifically address the needs of breast cancer patients. This online community will allow metastatic breast cancer patients to converse with other breast cancer patients remotely and in their own time, while granting moderators the ability to create separate digital spaces for early breast cancer and metastatic breast cancer patients. The digital resource reflects Sanford's commitment to extending metastatic breast cancer patient support beyond the walls of the cancer center, arguably where metastatic breast cancer patients need emotional support the most. Remote, unlimited access to emotional support allows metastatic breast cancer patients to seek support more often, consistently addressing more of their needs. It is a particularly important component of a cancer program that serves patients across significant distances.

### **Staff Who Make an Extra Effort**

With the busy schedules of cancer care team members, it can sometimes be easy to forget about the small things that leave substantial, lasting impact on metastatic breast cancer patients. When possible, members of the Sanford team spontaneously check in with these patients by phone or in person during office visits. Staff members, even those at the front desk, always greet metastatic breast cancer patients by name and develop a relationship with their patients over time. Although this level of care benefits all types of patients, the nature of metastatic breast cancer often requires an extended, evolving relationship between patients and their cancer care team. Having a team that demonstrates care beyond what is expected of them is a key ingredient in building trust between metastatic breast cancer patients and their care team. Ultimately, this trust helps metastatic breast cancer patients to feel that they are not going through their disease alone.

## SANFORD CANCER CENTER *continued*

Metastatic breast cancer patients Vicky and Lori express similar sentiments about the emotional support they receive at Sanford. They describe Sanford as a team that recognizes their emotions, concerns, and questions. Sanford sees these women as more than patients—and as a result, acts as more than just a provider of medical care. These metastatic breast cancer patients vividly tell stories that demonstrate how Sanford is constantly finding ways to nurture its relationships with patients. For example, Lori describes an instance where she brought her husband to Sanford, and he immediately remarked that everyone knew who she was from the moment they had their car parked for them, exclaiming: “It’s just like walking into Cheers!” In short, the institution’s level of dedication to supporting metastatic breast cancer patients beyond what is medically required produces deep, emotional relationships with its patients.

### PRINCIPLE NUMBER 6

#### Collaborate in the Interest of Patients

When the Sanford team addresses metastatic breast cancer patients, they consistently appear to be one team. The care of patients with metastatic breast cancer requires the attention of multiple team members, often from different departments, which can lead these patients to perceive that their care is fragmented and disjointed. A unified front of quality and effective metastatic breast cancer patient care requires active internal collaboration, across disciplines. Sanford succeeds by recognizing that streamlined care requires all staff members to embody similar philosophies on support. Below are specific examples of how Sanford puts this principle to work at its cancer program.

#### Training for Nurses

Sanford offers specialized training to its nurses as a way to equip them with the necessary skills to effectively help metastatic breast cancer patients manage their symptoms. The training consists of integrative approaches such as aromatherapy, acupuncture, imagery, mindfulness, and biofeedback, all of which are a part of Sanford’s symptom management services. Dr. Hysjulien, a psychologist at Sanford, explains that the training helps nurses care for themselves, become aware of the power of Sanford’s supportive services, and ultimately understand the importance of self-care. She argues that someone is unable to care for others if they are unable to care for themselves. Embracing the idea that one must practice what they preach, Sanford shows that metastatic breast cancer patient support is most effective when institutional philosophies are embedded in all members of the care team.

### THE PATIENT’S PERSPECTIVE

“The members  
of my cancer care team  
see me as more than just  
a patient.”

VICKY W., Sanford Patient





**THE PATIENT'S PERSPECTIVE**

“I just plain like my doctor. She’s really well read, always innovative. I think she’s really honest, and it’s pretty awesome to have a doctor who will hug you and cry with you when she explains a diagnosis.”

**LORI J., Sanford Patient**

**THE PATIENT'S PERSPECTIVE**

“They have a rockin’ pain management team. I was really happy with the doctor I saw. I had never met him before, but he seemed really well-versed on my issues.”

**LORI J., Sanford Patient**

**Daily Interdisciplinary Meetings**

Sanford’s interdisciplinary cancer center team is required to hold daily meetings to discuss patients. Meetings consist of team members from different departments talking about patients’ physical symptoms, psychological states of mind, and family dynamics. Beyond helping staff better understand their patients, these meetings help ensure that metastatic breast cancer patients do not have to relive pain or trauma by repeating symptoms or stories to multiple people, ultimately delivering these patients more streamlined care.

Both Lori and Vicky articulate that they always feel that their care is coming from one unified team. Despite working with the various members of the Sanford team, these metastatic breast cancer patients do not feel that they have to repeat themselves or retell their symptoms, background, or how they are feeling emotionally. As stated above, Lori recalls a time when she was particularly impressed that a doctor she had never met before knew so much about her case. This outward-facing cohesiveness reflects Sanford’s careful and deliberate internal system of collaboration.

# SELF-ASSESSMENT TOOL

The six effective practice principles you've read about in this workbook improve support of patients with metastatic breast cancer. You've learned how three ACCC member cancer programs embody these principles in practice. Now use this tool to identify specific ways your cancer program puts these principles into practice with your metastatic breast cancer patients, including potential areas for improvement. Solicit feedback from your metastatic breast cancer patients. When you're done, share your strategies and successes with other ACCC member programs online at: [accc-cancer.org/MBCworkbook](http://accc-cancer.org/MBCworkbook).

## PRINCIPLE NUMBER 1

### Empower the Patient



My cancer program embodies this principle by:

My cancer program could improve in this area by:

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## PRINCIPLE NUMBER 2

### Reframe the Conversation



My cancer program embodies this principle by:

My cancer program could improve in this area by:

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## PRINCIPLE NUMBER 3

### Reduce Patient Isolation



My cancer program embodies this principle by:

My cancer program could improve in this area by:

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**PRINCIPLE NUMBER 4**

**Offer Logistical Support at the Cancer Program**



**My cancer program embodies this principle by:**

**My cancer program could improve in this area by:**

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**PRINCIPLE NUMBER 5**

**Connect Patients with Support in the Community**



**My cancer program embodies this principle by:**

**My cancer program could improve in this area by:**

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**PRINCIPLE NUMBER 6**

**Collaborate in the Interest of Patients**



**My cancer program embodies this principle by:**

**My cancer program could improve in this area by:**

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Continue the conversation  
about improving the care for patients  
with metastatic breast cancer at  
[acc-cancer.org/MetastaticBreastCancer](http://acc-cancer.org/MetastaticBreastCancer)

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