

ASSOCIATION
OF COMMUNITY
CANCER CENTERS

METASTATIC BREAST CANCER



EFFECTIVE PRINCIPLES IN ACTION

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Introduction

The prognosis, treatment, and management of metastatic breast cancer have significantly improved over the past decade. Recent treatment advances have allowed many patients to live considerably longer; however, specific support and resources tailored to meet the unique needs and challenges faced by individuals with metastatic breast cancer have not been integrated into practice at the same pace. Although resources for metastatic breast cancer are currently available, an environmental scan conducted by the Association of Community Cancer Centers (ACCC) for its ongoing Metastatic Breast Cancer project suggests that institutional, systemic processes for the provision of support and resources to address the specific needs of patients with metastatic disease is lacking or, at best, provided on an ad-hoc basis. Consequently, patients living with metastatic breast cancer often do not receive adequate information and tailored support so that they can fully understand their diagnosis and participate in the shared decision-making process.

In 2016 ACCC launched its Metastatic Breast Cancer project to better understand the challenges facing this patient population in terms of education and support needs and to better equip patients to participate in shared decision-making and their own care. To lay the foundation for this project, in addition to the environmental scan, ACCC conducted focus groups with several ACCC member programs that have successfully created and implemented resources specifically for their patients with metastatic breast cancer. This work led to the identification of six key support principles, which ACCC published as a workbook titled, *Metastatic Breast Cancer: Effective Principles & Practices in Patient Support*.

These six principles provide a framework for cancer programs to guide implementation of their own support services for this high-need patient group:

-  **EMPOWER THE PATIENT**
Provide easily digestible educational resources to patients with metastatic breast cancer that arm them with knowledge about their diagnosis and management options, enabling them to become stewards of their own care
-  **REFRAME THE CONVERSATION**
Communicate realistic expectations and goals of care with patients in a way that inspires hope, allowing them to think about their disease in a new light
-  **REDUCE PATIENT ISOLATION**
Connect patients with others who are coping with metastatic breast cancer to share information, guidance, inspiration, and solace, creating systems of emotional and psychological support
-  **OFFER LOGISTICAL SUPPORT AT THE CANCER PROGRAM**
Minimize the difficulties encountered by patients with metastatic breast cancer by providing logistical support to help restore balance among work demands, household/family responsibilities, cancer treatments, medical bills/insurance forms, and medical appointments
-  **CONNECT PATIENTS WITH SUPPORT IN THE COMMUNITY**
Educate patients with metastatic breast cancer about the services and support that is available within their community
-  **COLLABORATE IN THE INTEREST OF PATIENTS**
Collaboration among multidisciplinary team members to share ideas, information, and best practices to improve the care delivered to patients with metastatic breast cancer

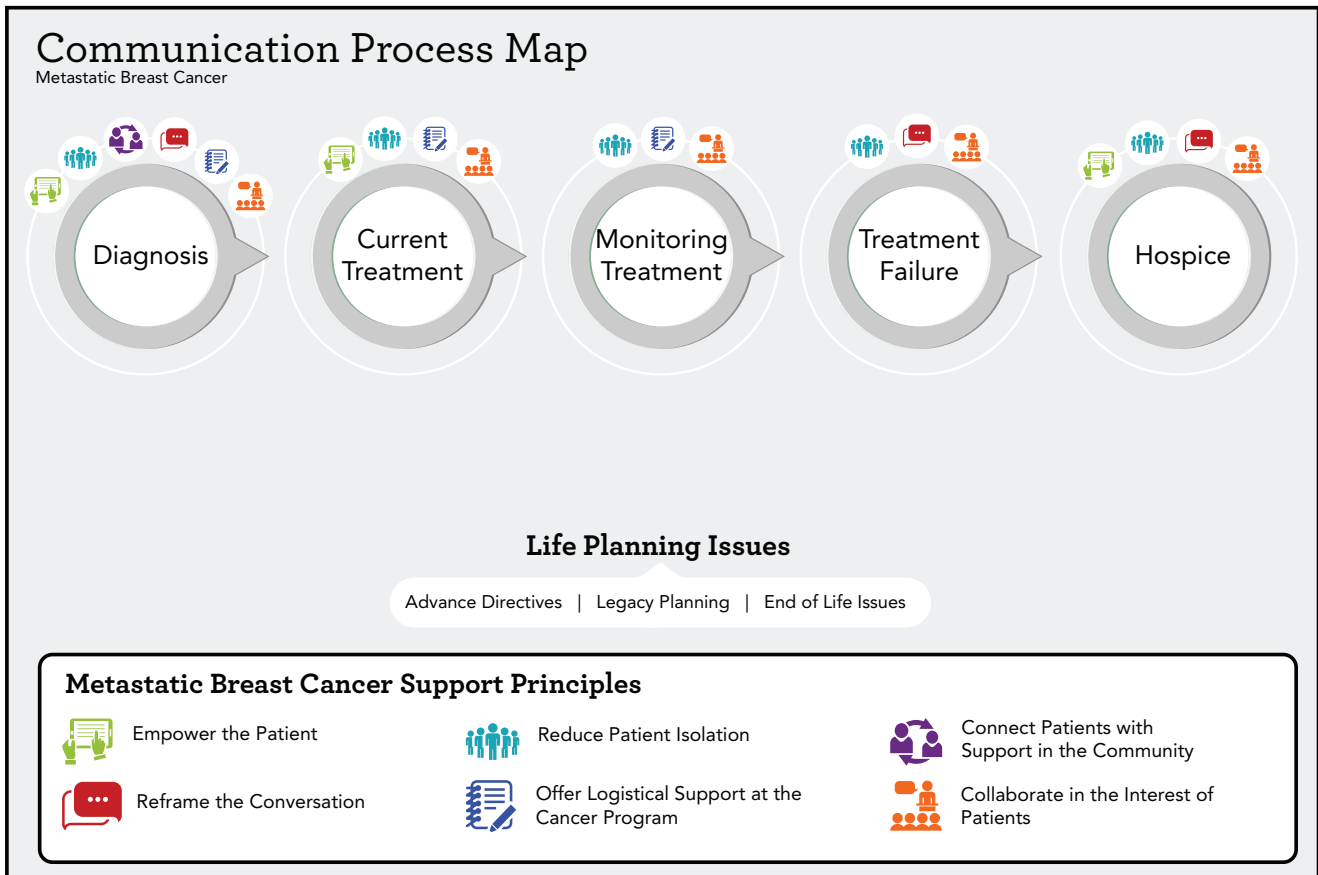


FIGURE 1. Communication Process Map

These principles bring patient-centeredness to the forefront of care for metastatic disease, with effective patient-provider communication at its core. Because communication needs and preferences can change across the disease course, resources must address the full spectrum of the care-delivery system. Figure 1 maps out the communication process across the disease trajectory and ties the principles and practices into specific phases of the metastatic breast cancer journey. ACCC has created an interactive online resource comprised of curated tools and resources, developed by leading patient advocacy groups and medical associations, and vetted by healthcare providers and leading oncology organizations. These materials are aggregated along the path outlined in the Communication Process Map and are linked with the six principles for effective support of patients with metastatic breast cancer. Using this online repository, healthcare providers can quickly locate applicable resources at specific touchpoints throughout the patient’s care journey, addressing communications with various members of the multidisciplinary team for key interactions.

The online resource and the *Metastatic Breast Cancer: Effective Principles & Practices in Patient Support* workbook (both available at accc-cancer.org/metastaticbreastcancer) present actionable steps for incorporating effective communication tools into the routine workflows and processes of cancer programs in the community setting.

For perspective on how the six effective principles may be integrated into practice, in 2017, ACCC followed up with three Cancer Program Members that have prioritized advancing patient-centered care for their patients living with metastatic breast cancer. These programs vary considerably in size and scope—from a cancer center dedicated solely to caring for metastatic breast cancer patients, to a large health system providing unique support services and extensive clinical trial access, to a recently opened cancer center that brings the oncology services together in one location for the first time in the community. Site visits and focused interviews with cancer center staff explored successes achieved, challenges, and opportunities remaining for these programs in serving their patients with metastatic disease.

The Koontz Center for Advanced Breast Cancer

SAINT LUKE'S HEALTH SYSTEM KANSAS CITY, MISSOURI

Saint Luke's Koontz Center for Advanced Breast Cancer, located in Kansas City, opened its doors on October 13, 2016. The center focuses on quality, research, genetics, immunotherapy, and clinical trials. A full menu of support services for metastatic breast cancer patients is embedded within the clinic: behavioral health, nutrition, physical therapy, exercise, social workers (including financial navigators), pastoral care, and genetic-testing staff.

The staff members at Saint Luke's Koontz Center for Advanced Breast Cancer are experienced in caring for patients with metastatic breast cancer. With a quality-focused mission to improve the outcomes and quality of life for patients with metastatic breast cancer, the center offers a dual approach to care that combines access to the latest clinical trials, medical research, and treatment options with integrative supportive therapies such as nutritional planning, exercise physiology, yoga, acupuncture, behavioral health, and spiritual support.



GETTING TO KNOW THE PATIENT

The Koontz Center understands that patients may feel overwhelmed after receiving a diagnosis of metastatic breast cancer and be unsure about next steps. Staff at the Koontz Center provide tools that empower patients to become active members of the care team and address patients' quality of life. Some of these tools are discussed below.

The Koontz Center is committed to engaging with patients from the start. When patients first contact the center, they receive a call from a nurse coordinator within 24 hours. Patients are then sent new patient packets that include questionnaires to help the center learn more about each individual. The questionnaires cover topics such as sleep-related impairment, physical function, fatigue, pain, spiritual well-being, distress levels, and nutrition. For

instance, a needs assessment questionnaire developed by social work staff asks whether patients need assistance in areas such as transportation, home help, and navigating insurance coverage, as well as, whether they need psychosocial support in areas such as managing stress and coping with their disease. Also included in the new patient packet is a questionnaire that serves as a screening tool for genetic counseling. In addition to providing valuable information that the cancer center can use to tailor support strategies for the patient, the questionnaires offer an opportunity for patients to evaluate how they are currently feeling, including their overall physical health and emotional well-being.



OFFER LOGISTICAL SUPPORT AT THE CANCER PROGRAM

These questionnaires also help streamline access to supportive care services. As an example, the social worker will review the patient's questionnaire and prepare an information packet based on needs identified through the patient's responses. During their first meeting, she is able to provide this customized information to the patient. Packets often include information about local/community resources and agencies that can assist with logistical concerns related to cancer treatment. For instance, due to frequent office visits and treatment demands, metastatic breast cancer patients may need to access transportation and home-care services; however, patients are often unaware of resources available in their community. By providing these resources from the start, the social worker helps smooth the patient's access to treatment.

Although many patients expect to speak with providers during their clinic visits, they often do not ask or are unaware of the various types of support available to them. A social worker can synthesize a vast amount of information to connect patients or their family members with support groups; identify organizations that can offer financial, transportation, or home-care assistance; help patients navigate the Family and Medical Leave Act (FMLA); address questions regarding Social Security; offer counseling services; and manage end-of-life issues. Thus, the questionnaire responses help clinicians to reframe the conversation by

focusing not only on the disease but also on the whole patient, identifying specific topics that warrant further discussion, and tailoring treatment plans to meet the individual patient's needs and preferences.

Another way that the Koontz Center empowers patients and strives to improve the patient experience is by encouraging them to contact the center with any questions or concerns and providing multiple contact options. For example, patients can email staff through a HIPAA-protected portal, or they can directly contact St. Luke's Cancer Institute Medical Director Timothy J. Pluard, MD, by calling his cell phone or by email.

STARTING THE DIALOGUE

From that first patient encounter, Koontz Cancer Center is attentive to the patient's perspective and acutely aware of the impact a provider's words can have on a patient. In an interview conducted for this project, a Koontz Center patient described her experience. She explained that when her previous provider presented the devastating news of her metastatic breast cancer diagnosis, she was told that her disease was incurable but manageable. In contrast, during her initial visit to the Koontz Center, her metastatic disease was described as treatable but not curable. For this patient, the words used by her provider made all the difference. She shared that being encouraged to view metastatic breast cancer as akin to diabetes—a chronic, treatable disease that people live with and learn how to manage—felt as if a weight had been lifted off her shoulders.

VISITING THE CENTER

The Koontz Center schedules no more than two new patients on one day. During their first three-hour comprehensive visit, patients meet with various disciplines based upon their needs

assessment/patient survey. For example, patients will meet with an extensive multidisciplinary team comprised of the radiation oncologist, medical oncologist, plastic surgeon, genetic counselor, and pathologist, as well as a social worker, nutritionist, behavioral health nurse, and survivorship coordinator.

Then, the team members including the medical oncologist, social worker, nutritionist, behavioral health nurse, and survivorship coordinator meet to discuss their interactions with the patient. This team approach offers the opportunity for the team to share feedback on their individual interactions with each patient. Often team members will each identify something unique about the patient that had not been discovered by anyone else.

At the end of the initial visit, patients have a final consultation with their team and receive a customized treatment plan designed specifically for them.

Patients may be overwhelmed by their diagnosis and/or the amount of medical information they receive during their appointments and as a result retain only a small percentage of information discussed. Staff members at the Koontz Center know that a diagnosis of metastatic disease affects both the patient and family members, so the patient's family is encouraged to join the consultation, participate, and ask questions. A web conferencing option is also available for family members who are unable to join in person. Treatment consultations at the Koontz Center are also recorded so that patients can receive a video that they can review at home and share with family and friends.

DESIGNING PROCESSES AROUND PATIENTS

The staff at Koontz Center strive to make each visit seamless for their patients. On arrival, patients receive a schedule from the receptionist that outlines who they will meet with that day. Patients are escorted to an examination room and the scheduled specialists come to the patient, rather than the patient having to move to a series of separate rooms or offices. Patients leave their examination room only to travel to high-tech consultation rooms or to receive chemotherapy treatments.

Dr. Pluard has a medical assistant accompany him during patient visits to document the patient-provider conversation, record the patient's history, and transcribe the physical examination findings into the electronic medical record (EMR). This process frees Dr. Pluard to focus exclusively on his conversation with the patient.

The full team meets weekly to discuss patients who are currently in the center's database to ensure patients are following up with care as needed. The clinical coordinator uses spreadsheets to track this information and reports to staff.



COMPREHENSIVE CARE

The treatment of metastatic breast cancer includes two goals: prolonging survival and improving quality of life by treating cancer-related symptoms. Therefore, the staff at the Koontz Center believe in more than treating just the cancer—the team is dedicated to caring for the whole person. The center uses the most advanced genomics, immunotherapy, and clinical trials in combination with clinically proven integrative therapies, such as emotional counseling, nutrition analysis, and exercise physiology.

Considering the complexity of this holistic approach, nurse navigators at the Koontz Center are vital to both patients and care team members. For those patients newly diagnosed with breast cancer, nurse navigators work to optimize care coordination by quickly scheduling any additional testing and following up on results. In addition, navigators offer a free monthly educational seminar for all newly diagnosed patients. Throughout the course of treatment, nurse navigators are a consistent resource for patients and their families, serving as educators and advocates, and helping patients understand their diagnosis and treatment options. During the patient's treatment, navigators help to resolve care-related issues and coordinate services with other members of the care team such as clergy, counselors, and nutritionists, as the need arises.

The center's survivorship coordinator assists patients with resources to maintain their highest level of function and independence, including support for physical improvement,

emotional health, and social well-being—all free of charge. Patients and family members can also access the services of a clinical psychologist who specializes in behavioral health to help with the diagnosis of metastatic disease.



PSYCHOLOGICAL HEALTH

Receiving a diagnosis of metastatic breast cancer can result in psychological symptoms including distress, fear, anxiety, and depression. Along the course of treatment, patients are often confronted with new challenges including the impact of living with a metastatic disease on personal relationships, chronic fatigue, anxiety about their symptoms and/or treatment, facing end-of-life and mortality. The Koontz Center has a full-time psychologist on staff to help patients cope with the physical, emotional, and psychosocial distress associated with metastatic disease.

She provides cognitive behavioral therapy, deep-breathing training, mindfulness techniques, and guided imagery to help patients who are experiencing psychological distress. For patients experiencing feelings of isolation or stigmatization, the Koontz Center psychologist helps to normalize and validate these emotions by presenting research that shows what they are feeling is common in individuals with metastatic breast cancer. To empower patients and encourage them to become active members of their care team and to minimize any anxiety they might feel about voicing their questions/concerns, she conducts role-playing exercises with patients to demonstrate how they can initiate these conversations with their healthcare providers. Along the continuum of care, she also supports patients in talking about their post-death wishes, exploring how planning may be helpful to friends and family, eliminating some of the feelings of guilt they may experience following a loved one's death.



SPIRITUAL HEALTH

Living with metastatic breast cancer is stressful and can have a profound effect on various aspects of a person's life including their spirituality. Some may struggle to find meaning, purpose, and value in their life or feel they have lost love, peace, and connectedness, which can affect their

spiritual needs or cause spiritual distress. Patients' spiritual health can often go unaddressed; however, at the Koontz Center, it is an essential part of patient care. The staff chaplain at St. Luke's Health System also serves as the spiritual health provider at the Koontz Center. In conversation with the patient, he explores and assesses the patient's understanding of their personal spirituality, reflects on how their spirituality has been influenced by their diagnosis/treatment journey, discusses spiritual resources and practices, and considers how their healthcare providers can best support their spiritual needs. His approach in talking with patients about their spiritual issues is ecumenical and focused on the mind-body-spirit connection. He also includes narratives of each interaction with patients in their chart notes.



FOCUS ON RESEARCH

The Koontz Center has its own research infrastructure, including six research nurses; two of whom are dedicated to working with patients to ensure they are aware of their clinical trial options and help them navigate through trial information and eligibility criteria.

Individuals contacting the center about open trials they've viewed on the Koontz Center's website are first screened by a practice manager. Those patients who are eligible candidates for a trial must visit the Koontz Center and meet with Dr. Pluard. After this initial meeting, a research nurse and staff members work with the patient to obtain pre-authorizations for treatment. At the time of publication, 16 trials are ongoing at the center.

In some instances, patients who are interested in participating in a clinical trial must travel long distances from neighboring states to the Koontz Center. Previously, the travel distance had been a barrier to trial participation for these patients. However, to address this challenge Dr. Pluard created a process to collaborate with patients'

local oncologists: he will discuss trials that are an appropriate match for patients with their primary oncologist and develop a treatment plan so that patients can participate under the guidance of the local oncologist. This spares the patient the travel burden and provides the opportunity for more patients to participate in trials.



FOSTERING RESPITE FOR FAMILIES AND CAREGIVERS

The diagnosis of metastatic breast cancer and often lengthy treatment journey can affect relationships between patients and spouses/partners. With this in mind, the Koontz Center created The Journey of Courage and Hope for Couples, a retreat for women living with metastatic breast cancer and their spouses/partners. This intensive weekend retreat, led by a psychologist and a breast navigator, is designed to help patients and their partners address the realities of living with metastatic disease and provide an opportunity to experience mutual healing and renewal. The free retreat includes meals and two nights' lodging and offers group discussions and planned activities such as yoga, labyrinth walks, and massage in a relaxed setting. The program has received a positive response from participating spouses. As a result of this feedback, the Koontz Center has added a new support group for spouses of patients with metastatic breast cancer and now also offers patients' spouses/partners the opportunity to speak with the center's psychologist.

Providence Cancer Institute, Providence Health & Services

PORTLAND, OREGON

Providence Cancer Institute provides comprehensive, compassionate care locally and throughout the state to cancer patients including those with metastatic breast cancer. The cancer institute is part of Providence Health & Services in Oregon, a not-for-profit Catholic network of hospitals, care centers, health plans, physicians, clinics, home healthcare, and affiliated services.

The cancer institute's approach to care involves collaboration among oncologists along the care continuum from diagnosis through treatment; access to advanced cancer therapies including clinical trials; integrative services, nurse navigators, counseling and support services; and education provided in an established resource room. Providence Cancer Institute is featured in the ACCC *Metastatic Breast Cancer: Effective Principles & Practices in Patient Support* workbook. Since publication of the workbook, Providence Cancer Institute has continued its efforts to advance delivery of patient-centered care to individuals with metastatic breast cancer. Currently, Providence is exploring establishing a support group specifically for metastatic breast cancer patients and differentiating support services for patients with metastatic disease from those provided to newly diagnosed early-stage breast cancer.

WELL-BEING DURING TREATMENT & BEYOND

When patients are first diagnosed with metastatic breast cancer, they receive a 32-page booklet titled, "Living Well Through Cancer Treatment and Beyond." This internally developed publication features local resources and support programs for all cancers. It also explores steps that patients living with metastatic disease can take to promote healing, reduce side effects, and maintain their health during treatment. Included are evidence-based tips on nutrition, exercising, and reducing stress to help patients live well while undergoing cancer treatment and beyond. The booklet describes how the team at Providence Cancer Institute is available to help patients throughout their journey, with chapters on addressing intimacy issues, sleeping well, obtaining support for family members and patients, and enrolling in clinical trials.

COMPREHENSIVE RESOURCES

Providence Cancer Institute offers a host of practical resources and services to assist patients living with metastatic disease. For many patients and family members, arranging child care during appointments and clinic visits can be an added burden. Providence Cancer Institute has an area called My Little Waiting Room® that provides complimentary drop-in child care for children of patients

who are attending medical appointments and those of family members who are visiting a patient. This resource is helpful for patients with metastatic breast cancer who have young children requiring supervision during their cancer care. The Providence Guest House, which offers nearby affordable housing for out-of-town patients and visitors, is also available.

One of the institute's most-used resources is the Jill Lematta Learning Center, which has an extensive library of cancer-related reference materials—all of which have been reviewed by oncologists and deemed useful and accurate. Patients and their families can learn about all levels of disease management as well as the latest treatment advances, empowering them with the information and confidence to become more active participants in their care. The learning center, staffed by trained resource specialists, stocks free brochures about different educational programs and support groups, provides dolls so children can reenact situations or express feelings more easily, and keeps pillows on hand to be used under seatbelts by patients who have had reconstructive surgery.

ROBUST SOCIAL WORK SERVICES

Social workers are a critically important part of the care team at Providence Cancer Institute. Many patients living with advanced breast cancer experience anxiety and/or depression. The social work team screens every patient for depression and distress. Incorporation of the National Comprehensive Cancer Network (NCCN) distress screening tool into routine practice has allowed the Providence Cancer Institute to provide personalized psychosocial care for patients and connect them with resources that can minimize symptoms of depression. To optimize screening, the cancer institute customized its screening tool to include additional questions related to anxiety and to gauge interest in clinical trial enrollment. The additional information for inclusion in the screening tool was reviewed by local clinicians and approved by the cancer institute's internal review board. Although the approval process for the customized tool took three years, Providence has found the results to be well worth the effort. The tool is administered via an iPad, and the responses are immediately uploaded to the patient's elec-

tronic health record so that referrals can be made as needed. To streamline the referral process, one social worker is designated to review the screening results daily and ensure that referrals are issued appropriately. All patients with a positive screening result are assessed and referred for appropriate services.



SUPPORT GROUP DEVELOPMENT

Providence Cancer Institute's social work team actively collaborates with social workers, both in other health systems and in the community, to reduce redundancy and strengthen existing resources. Providence social workers meet quarterly with social workers from facilities in the area to stay updated on the various programs that different groups are offering and to create efficiencies. As an example, the social workers realized that because there were so many support groups, they were duplicating their efforts. Therefore, they decided to reduce the number of support groups and focus on strengthening those remaining. They came together to develop a curriculum that included stories, educational tools, and strategies—going beyond the typical support group offerings. To better meet patient needs, they also created a support group for those living with advanced cancer as well as a breast cancer education and support group.



ONLINE VIDEO SUPPORT GROUP

In early 2018, Providence Cancer Institute founded the first-of-its-kind group in Portland specifically for those living with advanced (metastatic, stage IV) cancer. This group complements the cancer institute's in-person advanced cancer support group that meets on opposite weeks and also includes a parallel caregiver group. The online patient group meets virtually from the comfort of their home. Participants can join from their smart phone, tablet, or computer and can connect with others around the challenges of

living with advanced disease. The oncology social work team is also looking to expand to offer a group for caregivers.



FAMILY SUPPORT GROUP

Because a diagnosis of metastatic breast cancer affects all family members, Providence Cancer Institute created a Family Support Group, which meets monthly. This group connects families affected by metastatic breast cancer, helping to reduce family and patient isolation. Facilitated by approximately 10 staff members and volunteers, many of whom are licensed social workers, the meetings include a family-style pizza meal. Anywhere from 20 to 60 family members attend the support group, which is organized by participant age so that staff can deliver age-appropriate support.

The Family Support Group pays particular attention to children, developing specific age-appropriate approaches for participants. Art is used as a modality to communicate about cancer. For example, the children and teens create hope flags (i.e., writing their hope down on small flags that are tied to a rope so that the wind can carry their hopes to heaven) to help communicate the things they are hopeful for. The teens are not allowed to bring cell phones, and many of them spend time playing music, including in a drum circle. Meetings include a twinkle session in which young group members discuss their feelings and how they are coping. Other children who feel the same way use "jazz hands" (referred to as "twinkles") to express the shared feeling. In the event that a parent passes away, the children in the group make a bereavement package for the child who has lost a parent; the support group also sets up fundraising for the family using services such as youcaring.com and the Cancer Support Community's MyLifeLine.org.



HELP WITH DIFFICULT CONVERSATIONS

The social workers at Providence Cancer Institute are also integral in helping patients with difficult conversations, including end-of-life discussions. A resource to support staff used within Providence Health System's Institute for Human Caring under the leadership of Ira Byock, MD, is the *Serious*

Illness Conversation Guide developed by Ariadne Labs. End-of-life conversations are documented in the patient's electronic health record, which notifies the social workers if a follow-up discussion is needed and helps physicians navigate treatment decisions based on the patient's preferences and goals.

When patients express concerns about reducing the stress on loved ones, social workers may utilize tools such as "Death: Items to Consider" and "Preparing for Your Own Death Checklist." Taking care of practical considerations, such as preparing lists of important items like passwords, insurance and pension policies, account numbers, will location, and funeral/memorial information, may be an empowering process for some patients.

COORDINATED FOCUS ON CLINICAL TRIAL ENROLLMENT

At Providence Cancer Institute, due to the dedicated research and clinical staff, patient trial enrollment is higher than the national average. The 51-member clinical trial team includes research nurses, clinical nurse supervisors, and laboratory assistants and research scientists. Providence has approximately 7 to 10 ongoing clinical trials specific to metastatic breast cancer at any time.

Two expert research nurse supervisors have implemented a process to screen all patients with metastatic breast cancer for trial eligibility at the start of their cancer journey with the institute. The research nurses are copied on all metastatic breast cancer referrals so that they can identify patients who may be appropriate for a study. This process alleviates the burden and frustrations that patients with metastatic breast cancer face in navigating the complex clinical trial landscape by themselves. The clinical research nurse specialists (CRNs) educate patients about the benefits and disadvantages to trial participation. Once a patient has enrolled in a trial, a CRN sees the patient at each visit, reviews all laboratory work, checks up on appointments, and follows up on side effects. As a result, clinical research nurse specialists often establish strong bonds with these patients.

Since 1993, cancer immunotherapy has been the main area of investigation for the Earle A. Chiles Research Institute located in the Providence Cancer Institute. The research institute offers approximately 10 clinical trials examining the efficacy of therapies including immunotherapy in individuals with metastatic breast cancer.

Cowell Family Cancer Center Munson Healthcare

TRAVERSE CITY, MICHIGAN

Before the Cowell Family Cancer Center (CFCC) opened its doors in April 2016, the local community had only two oncology offices and one radiation center. Today, Traverse City and the surrounding area have a cancer center that focuses on a holistic approach to caring for patients with metastatic breast cancer—focusing on body, mind, and spirit. Patients come to CFCC from all over Northern Michigan, with some traveling more than 200 miles.

CONNECTING PATIENTS WITH NURSE NAVIGATORS

On receiving a diagnosis of metastatic breast cancer, patients often experience high levels of anxiety. Appointment wait times can increase patient distress. CFCC strives to mitigate this by reaching out to ensure patients with metastatic breast cancer are scheduled to visit the cancer center within two weeks of diagnosis.

To provide individualized guidance and care, *de novo* patients are paired with an oncology nurse navigator who specializes in metastatic breast cancer. All new patients meet with the navigator during their first appointment. She administers the National Comprehensive Cancer Network distress screening tool, referring those with elevated scores to support services with the cancer center's social worker.

During this visit, patients receive a patient information binder and the book, *100 Questions & Answers About Advanced & Metastatic Breast Cancer*, written by experts from Johns

Hopkins University. The book covers commonly asked questions about diagnosis, treatment, post-treatment, quality of life, and coping strategies for living with metastatic breast cancer, and provides both physician and patient perspectives on a variety of topics that cover the entire spectrum of metastatic disease. (CFCC patients diagnosed with an early-stage breast cancer also receive an information binder during their first visit. Should the breast cancer progress to metastatic disease, the patient receives the additional education and information materials at the time of diagnosis, usually from the clinic nurse with whom they've developed a strong bond.)

The patient-centered information binder is a thoroughly curated resource with practical tools and resources, including:

- Care team contact information and important telephone numbers
- An introduction to the buildings and services
- Information on how to sign up for and access the patient portal so that patients can view their laboratory results, pathology reports, and physician summaries
- Several pages to jot down any questions for their care team
- A document that patients can use to track their symptoms
- A calendar to keep track of appointments and important dates
- A medication log to track medications
- A booklet that explains how clinical trials work, the benefits and risks of taking part, and questions for patients to consider and discuss with their doctor
- Information to help in understanding health insurance terms, e.g., co-pays, co-insurance, and deductibles

- A description of palliative care
- Information related to end-of-life planning.

Recognizing the daunting economic impact that may accompany the diagnosis of cancer, CFCC has financial navigators available with whom patients can discuss any financial concerns. In addition to the binder, patients are offered shared resources from the cancer center library, such as *How Breast Cancer is Like a Dandelion*, written by Dr. Joseph Hofmeister and Dr. Erin Macray, a medical oncology team who use analogies to clarify the often-confusing breast cancer journey to metastatic disease.

The oncology nurse navigator strives to ensure that patients' questions are answered and that they have access to available resources. She reiterates to patients that their care is centered around their preferences and treatment goals, and encourages patients to be informed about metastatic breast cancer, understand the various treatment options, and the services offered at CFCC so that they can make well-informed treatment decisions.

Because the needs of individuals with metastatic breast cancer change across the disease trajectory, patients are asked to bring the binder to every appointment so that clinical staff can address specific questions or provide additional information when appropriate.

CFCC has also curated relevant national resources so that these can be easily accessed by patients. Many of these resources can be downloaded at no cost; however, some require payment to print. Among these resources are:

- "*Your Guide to the Breast Cancer Pathology Report*," from Breastcancer.org, which helps patients and their families read and understand pathology reports
- "*What You Need to Know About Breast Cancer*," from the National Cancer Institute, which provides medical information about this disease
- Tips on eating before, during, and after cancer treatments from the National Cancer Institute
- A fact sheet on breast cancer risk factors from Susan G. Komen

- Nutrition and physical activity guidelines for cancer survivors from the *CA: A Cancer Journal for Clinicians*.

FOCUS ON SOCIAL WORK

Looking ahead, the cancer center would like every patient with metastatic breast cancer to meet with a social worker at diagnosis. At present, however, the majority of patients see the social worker during a crisis. CFCC social workers are extremely knowledgeable about the many services offered at both the cancer center and in the surrounding community. For example, they work with the cancer center's financial navigators and the local community to find services for patients who are struggling to pay everyday expenses, such as utility bills. They also work with the local community to provide affordable transportation to the cancer center.

PEER-TO-PEER CONNECTIONS

Many women with metastatic breast cancer find it helpful to connect with others who are experiencing advanced disease, to share stories or advice. The CFCC social worker ensures that patients are aware of a support group for metastatic breast cancer patients. This is a small support group founded by patients seeking support from peers. After each support group meeting, the CFCC social worker emails a summary of the meeting to all participants. Because some patients with metastatic breast cancer may not feel well due to treatment or disease-related symptoms, the support group meetings run for no more than 1.5 hours. The meetings start with 45-minutes of education, such as a webinar developed by national non-profit organizations like Living Beyond Breast Cancer, or a guest speaker, followed by 45 minutes of open conversation.

In addition, the cancer center offers participation in a support group called "Come Together," which meets twice a month at CFCC. This group is facilitated by the inpatient RN educator and welcomes patients, caregivers, friends, and family members. Support is given through shared experiences. Other community resources that the social workers tap into include "Michael's Place," which provides support and advocacy for children, teens, and adults grieving the

death of a loved one, and "Making Choices Michigan," a non-profit community collaborative that offers free advanced care planning to West Michigan residents.

CARING FOR THE WHOLE PATIENT

CFCC focuses on health and wellness to treat the whole person and promote physical, emotional, mental, and spiritual healing. The center's Health and Wellness Suite includes three therapy rooms for patients, caregivers, family members, and the community. Eastern and Western therapies are available, including acupuncture, Asian bodywork such as Zen shiatsu, clinical massage, oncology massage, lymphedema massage, and body-specific massage. The Health and Wellness Suite also offers exercise, yoga, and meditation studios for patients, families, and caregivers.

INTEGRATING PALLIATIVE CARE

The palliative care team at CFCC is a relatively new but much needed group. Previously, patients with metastatic breast cancer had to travel to a separate office to receive palliative care. Today, the care teams are connected and collaborate daily.

The palliative care team is in the process of educating clinicians on integration of palliative care as a resource at any point in the disease trajectory for patients living with metastatic breast cancer. Palliative care services can provide relief from symptoms, pain, and physical and mental stress for patients and family members. The team is working on identifying triggers that would alert physicians to refer to palliative care, such as specific symptoms, high stress levels, and coping issues. The team can also help patients with metastatic breast cancer and their families navigate end-of-life issues.

When new patients come for palliative care, the team spends an extensive amount of time with the patients and their family members, sometimes up to 90 minutes. For the first and second visits, the team discusses symptom management and suggests a variety of coping methods. For example, a strong emphasis is placed on counseling for pain management. The team is also developing metrics like

tracking emergency room visits to determine how well the pain management program is working.

By the third visit, the care team starts to discuss goals of palliative care and advanced care planning. By the fourth visit, the palliative care team requests that a family member be present.



THE MULTIDISCIPLINARY TEAM WORKING TOGETHER

Additional team members are also engaged in providing services and resources to enhance the patient's well-being. For example, there are three physical therapists on the oncology service line team who strive to help patients live more comfortably. The physical therapists also spend time educating the educators; they participate in local events like Breast Cancer 101 to educate primary care physicians on physical therapy issues in patients with metastatic breast cancer. They even work in collaboration with the cancer center's financial navigators to set up partnerships with local gyms and secure reduced gym fees. Throughout the center, there is cross-department collaboration in support of patients, e.g., the financial navigators work closely with social workers and pharmacists to help patients in accessing medications or financial assistance. In short, every member of the cancer center's care team is focused on meeting the patient's needs.

Conclusion

The Koontz Cancer Center, Providence Cancer Institute, and the Cowell Family Cancer Center are each integrating effective principles to improve communication with and care for their patients with metastatic breast cancer. Each program has implemented practices that raise awareness among the care team of the unique needs of these patients and that provide support for the patient's voice. Having learned about how these cancer centers are taking action to recognize and empower patients with metastatic breast cancer, ACCC invites cancer programs and practices to:

- reflect on your current processes and procedures that support patients with metastatic breast cancer
- identify ways in which your cancer program applies the six principles identified above
- use ACCC Metastatic Breast Cancer project resources and information at acc-cancer.org/metastaticbreast-cancer as a catalyst for change
- determine what steps you can make to “reframe the conversation” so that your patients with metastatic breast cancer feel empowered, engaged, connected, and supported.

About the Metastatic Breast Cancer Project

The ACCC Metastatic Breast Cancer project is working to expand multidisciplinary team awareness of—and strategies for—effectively meeting the holistic needs of metastatic breast cancer patients, enhancing patient-provider communication, and advancing patient-centeredness of care for this patient population.

In 2016 ACCC combined primary and secondary research to identify existing systems and approaches that effectively support patients with metastatic breast cancer, including key documents to help ACCC understand the gaps and recent innovations that exist within patient support for this patient population.

The results were published in the Metastatic Breast Cancer: Effective Principles & Practices in Patient Support workbook, which includes:

- key highlights from an environmental scan conducted for this project,
- a communication process map that integrates 6 effective principles across the care continuum for the metastatic breast cancer patient, and
- real-world examples of how providers can reframe and improve the conversation between the multidisciplinary cancer care team and patients.



An online resource hub connecting curated resources for key touchpoints along the care continuum for metastatic breast cancer can be found at acc-cancer.org/MetastaticBreastCancer.

We would like to hear from you. Contact ACCC at resources@acc-cancer.org with your feedback and questions, and keep the conversation going.



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A publication from the ACCC education program, "Metastatic Breast Cancer Project." Learn more at acc-cancer.org/MetastaticBreastCancer.

The **Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the multidisciplinary cancer team. ACCC is a powerful network of 24,000 cancer care professionals from 2,100 hospitals and practices nationwide. ACCC is recognized as the premier provider of resources for the entire oncology care team. For more information visit acc-cancer.org or call 301.984.9496. Follow us on Facebook, Twitter, and LinkedIn, and read our blog, ACCCBuzz.

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