LIVING BEYOND BREAST CANCER®

METASTATIC
BREAST
CANCER
SERIES

UNDERSTANDING PALLIATIVE CARE

Our mission at LBBC is to empower you to live as long as possible with the best quality of life.

Every woman deals with
metastatic breast cancer
in her own way.

You may want to talk with someone
having a similar experience or
just find out more information.

We encourage you to call our Helpline
at (888) 753-LBBC (5222) for guidance and
peer support from our trained volunteers.


Susan Beard Photography

DEAR FRIEND:

A diagnosis of metastatic breast cancer can be overwhelming. Understanding your options as you think about ongoing treatment can help you regain a sense of empowerment and control. Those options include the things you can do both within and outside your medical treatment to ensure your best possible quality of life.

This guide will help you better understand these options and the important role palliative care can play in your overall treatment plan. Although palliative care is often mistakenly associated only with end of life, it is actually just as important to your ongoing treatment as chemotherapy, hormonal therapy and surgery. Palliative care is a specialized kind of care that works with your regular, ongoing treatment to support and sustain you physically, emotionally and spiritually.

We hope this guide provides you with a broader perspective, empowering you to take an active role in your ongoing care and helping you make informed decisions that will continue to support you in living fully for as long as possible.

Warmly,

Jean A. Sachs, MSS, MLSP
CEO

LIVING BEYOND BREAST CANCER
Free Helpline
(888) 753-LBBC (5222)

Thank you to the women pictured in this brochure. They are LBBC volunteers whose lives have been affected by breast cancer.

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I

Looking at Palliative Care

Palliative care may be a new term, or it may be familiar to you. For some, it feels positive. But for others, it can be scary, because so many people associate it with the end of life.

Doctors and researchers define **palliative care** as specialized medical care focused on providing relief from the symptoms, pain and stress of serious illness, whatever the diagnosis. This includes considering your values, preferences and needs, as well as those of your family and loved ones. Palliative care providers treat the physical symptoms of illness, while also addressing sources of social, emotional and spiritual distress.

Palliative care begins the moment of diagnosis. It includes all the things you do to sustain and support yourself in ensuring your best possible quality of life. Palliative care is not about preparing for the end of life. It is about empowering yourself to live the fullest possible life right now.

Some examples of palliative care are:

- Medicines to manage pain and other symptoms
- Pain management through complementary and integrative medicine
- Surgery to manage symptoms
- Emotional support through counseling and community
- Physical support through diet and exercise
- Social support through family and friends
- Spiritual support through prayer, meditation or other activities

You might react negatively to the idea of palliative care if someone introduces it and you are not ready to think about it. Reading this guide can help you learn more about what palliative care might mean for your treatment, and how you may or may not integrate it into your treatment plan.

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Why Palliative Care Matters

Palliative care is one part of a whole approach to treatment that takes into account all aspects of your life—physical, emotional, social and spiritual—as it supports your overall wellness. Your treatment becomes not just about your medical care, but also about the total care of your body, mind and spirit. Studies show those who include palliative care in ongoing cancer treatment not only enjoy better quality of life, but also may live longer.

Metastatic breast cancer may make you feel your body has betrayed you, affecting how you see yourself and feel about your body. It might lead you to think of yourself only as someone who is ill. Palliative care can help you see yourself differently, as someone who is facing a great challenge to her health, but is not defined by illness.

Approaching your experience of breast cancer from a place of wellness rather than a place of sickness can be of great benefit. Palliative measures that support a healthy body, like proper nutrition, fitness and other mind-body practices, can enhance feelings of physical wellness and support your emotional health.

Metastatic breast cancer may bring up feelings of anger, grief, fear and anxiety. Finding ways to cope is important to your overall emotional wellness, and you can approach that in many different ways. You might seek out resources that support you, such as support groups, volunteer activities, counseling, psychotherapy, or faith-based or spiritual organizations.

Staying connected to family, friends and community is also important. You may back away from relationships and activities you once enjoyed, increasing feelings of loneliness and isolation. This can make it difficult for the people around you to lend support. Maintaining relationships, and possibly developing new ones, will help support and sustain you in your treatment and in general.

> “The very first thing to understand about palliative care is that it is not hospice care.”

Things that inspire you, like reading, gardening or walking in the woods, can be just as important to your overall sense of wellness as chemotherapy, hormonal therapy and pre- and post-surgical care. These activities and experiences touch us and inspire us at a very deep, human level. They feed us in a way that is special and memorable.

What You Should Know

Palliative care is not hospice care

The very first thing to understand about palliative care is that it is not hospice care. **Hospice care** is specialized medical care that includes medicine and treatment to manage symptoms, control side effects and promote comfort toward the end of life. **Palliative care** is the everyday medical and self-care you undertake to ensure you have the best possible quality of life right now.

While hospice care always includes palliative care, choosing palliative care is not a sign that you are giving up or moving toward hospice care. Palliative care supports and sustains you in living well in the present moment. Hospice care is a later consideration that addresses your changing physical, emotional, social and spiritual needs toward the end of life.

> “You are not your disease, even though it can sometimes feel that way. Your disease does not define you.”

Palliative and hospice care teams are similar, but the role each plays in your treatment is different. A palliative care team has specialists that include palliative care doctors, nurses and social workers who work with your regular doctor to support you in ongoing treatment. Massage therapists, pharmacists, nutritionists and spiritual care professionals may also be part of your palliative care team. Hospice care team professionals also work with your regular healthcare team, providing similar physical, emotional and spiritual support, but focus more on the transition to end of life.

Palliative care adds to treatment

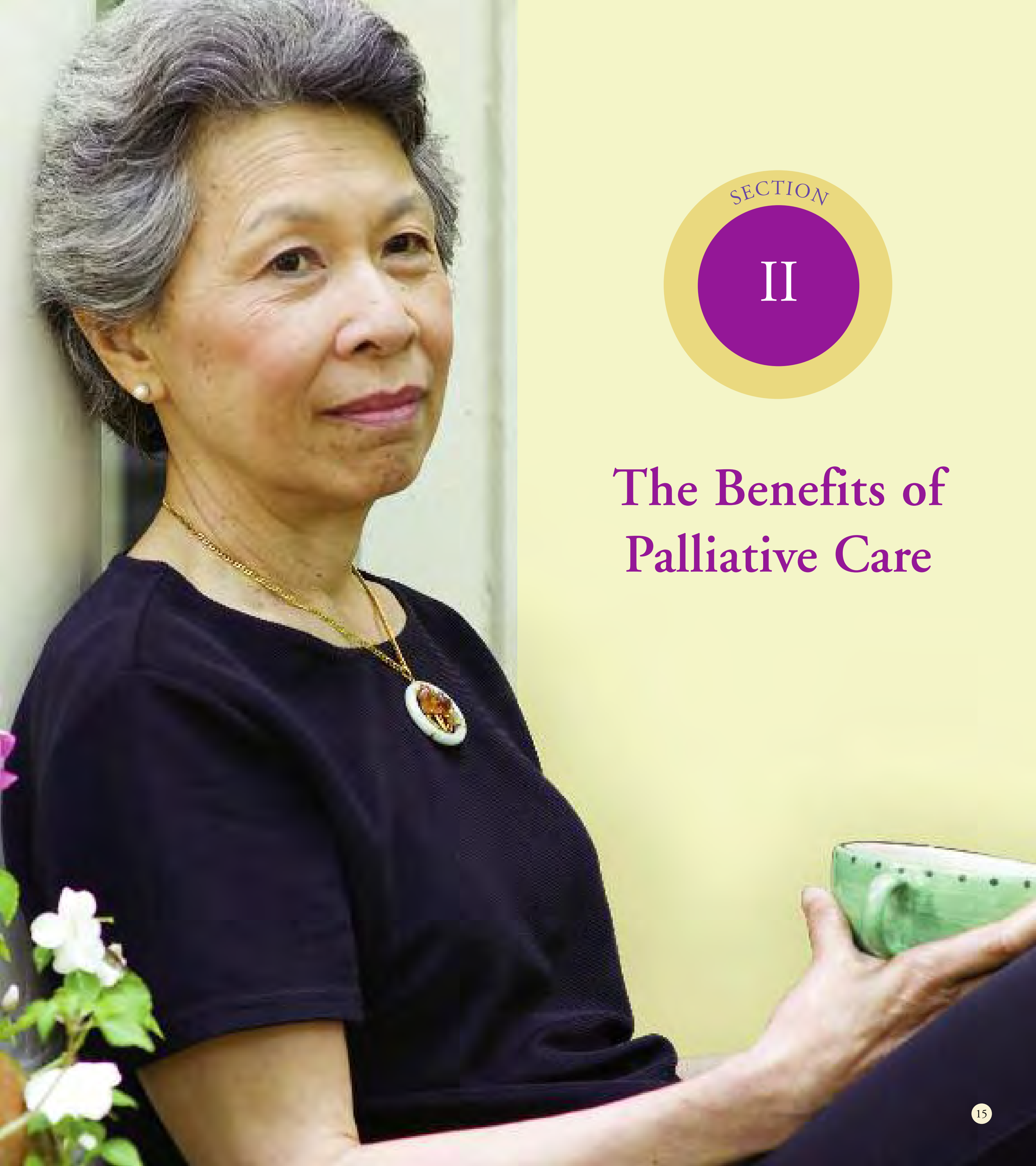
Palliative care does not replace your regular care. It adds to the treatment you already receive. Medically, this can include pain management, treatments or procedures that relieve symptoms of illness or side effects of treatment. It also includes measures that help to maintain and improve your quality of life by supporting your physical, social, emotional and spiritual well-being.

Things that you do for yourself, like exercising, meditating or maintaining an active social life, are called **self-care**. They are as important to your well-being as the treatment and medical palliative procedures you may choose to receive. These activities keep you connected, and aid you in keeping some sense of routine and order in your day-to-day activities. They can also help you manage any loneliness and isolation you may feel, bringing more joy into your daily living.

Palliative care is about living

You are not your disease, even though it can sometimes feel that way. Your disease does not define you. Before your breast cancer diagnosis, you were a whole person with a whole life. While that life may not have been perfect, you may have felt a greater sense of normalcy and control.

The profound challenge of metastatic breast cancer may cause you to change certain aspects of your day-to-day activities. But there are things you can do to prevent breast cancer from completely disrupting your life. Palliative care allows you to continue living your life, while helping you manage any new challenges or limitations. Your self-care also supports and sustains you in living life fully and completely.



SECTION

II

The Benefits of Palliative Care

Relieving the Impact of Illness

The goal of palliative care is to relieve distress you may feel connected to metastatic breast cancer, while supporting the best possible quality of life for you, your caregivers and your family.

For you, it helps lessen the direct physical and emotional stresses of metastatic breast cancer. For your caregivers and family, palliative care can address some of their concerns about your daily comfort and well-being, while also providing practical and emotional support to cope with the challenges of your ongoing treatment.

A central aim of palliative care is to relieve the pain, discomfort and other possible symptoms you may have as a result of metastatic disease or its treatment. These may include shortness of breath, nausea, vomiting, fatigue, decreased mental alertness and, of course, physical pain. For many women, pain management is the most important part of palliative care.

Understanding pain

Pain is one of the most feared symptoms and side effects connected with any illness, especially ongoing illness. Like many things in life, it is hard to know how to handle something when you are unsure what to expect. Different people react to pain differently, and the pain you feel as very intense may feel like very little to someone else. Using palliative care to address pain can enhance the way you cope, and impact your overall treatment plan.

The part of the body that allows you to feel things physically is called **nerve tissue**. When nerves are stimulated, they send a message to the brain that tells you something is hot or cold, soft or hard, rough or smooth and so on. Stimulation that is extreme or uncomfortable prompts what we experience as **pain**.

There are different categories of pain. **Superficial somatic pain** is outside the body, on the skin or in places we can reach, like inside the nose or ears. It is sharp, well defined and clearly located, like a minor cut or a burn. **Visceral pain** is deep in the bones, muscles, ligaments and **tendons**, the tissue that connects the bones. It is dull, aching and not very localized. **Neuropathic pain** includes sensations, such as burning, tingling or stabbing, that often result from injury or damage to nerves.

There are also different kinds of pain. **Acute pain** is pain that is happening right now. **Intermittent pain** comes and goes. **Chronic pain** might increase and decrease in intensity over time, but it is always there and never really goes away. Another kind of pain you may have if you had one or both breasts removed is **phantom pain**, or pain in parts of the body that are no longer there. This type of pain is rare with breast cancer, but it is treatable, if it should happen.

Describing your pain level is **subjective**, meaning your experience is unique to you. This makes measuring pain difficult. Doctors and other medical providers use a subjective pain scale to measure your pain.

It might look something like this:

- 0–1 No pain
- 2–3 Mild pain
- 4–5 Discomforting—moderate pain
- 6–7 Distressing—severe pain
- 8–9 Intense—very severe pain
- 10 Unbearable pain

When you describe your pain, your doctor uses the same pain scale repeatedly, so your medical team can track your pain over time. Tell your team what kind of pain you have—acute, intermittent or chronic. It is common to have more than one kind of pain, or to experience chronic pain that intensifies with movement or other activities.

Managing pain

If you feel pain, you should not hesitate to speak with your medical team. Pain can interfere with your treatment, affecting recovery from surgery and disrupting sleep. It can disrupt mood and diminish your appetite and interest in activities. Pain can affect your ability to concentrate and work, as well as the quality of your relationships.

Try to describe any patterns of increasing or decreasing pain you notice during treatment cycles or daily activities. Learning to describe your pain using tools such as a pain scale, or finding words to describe your pain, like "prickly," "burning," "stabbing" or "numb," is one more aspect of self-care that helps make palliative care more effective.

Pain treatment

Although cancer-related pain cannot always be completely relieved, it is possible to use different methods to treat and lessen pain. These include prescription and non-prescription medicines, anesthetics and anesthetic procedures, palliative surgery and radiation therapy. These methods can be used strictly for reducing pain, although they may address other symptoms and side effects as well.

Complementary approaches, like relaxation techniques, meditation, movement therapies, acupuncture and massage therapies, may supplement your medical pain control methods. These techniques can help relieve acute pain, acute post-treatment pain, intermittent pain, some forms of chronic pain and even phantom pain.

> “The goal of palliative care is to relieve the distress you may feel, while supporting the best possible quality of life for you, your caregivers and your family.”

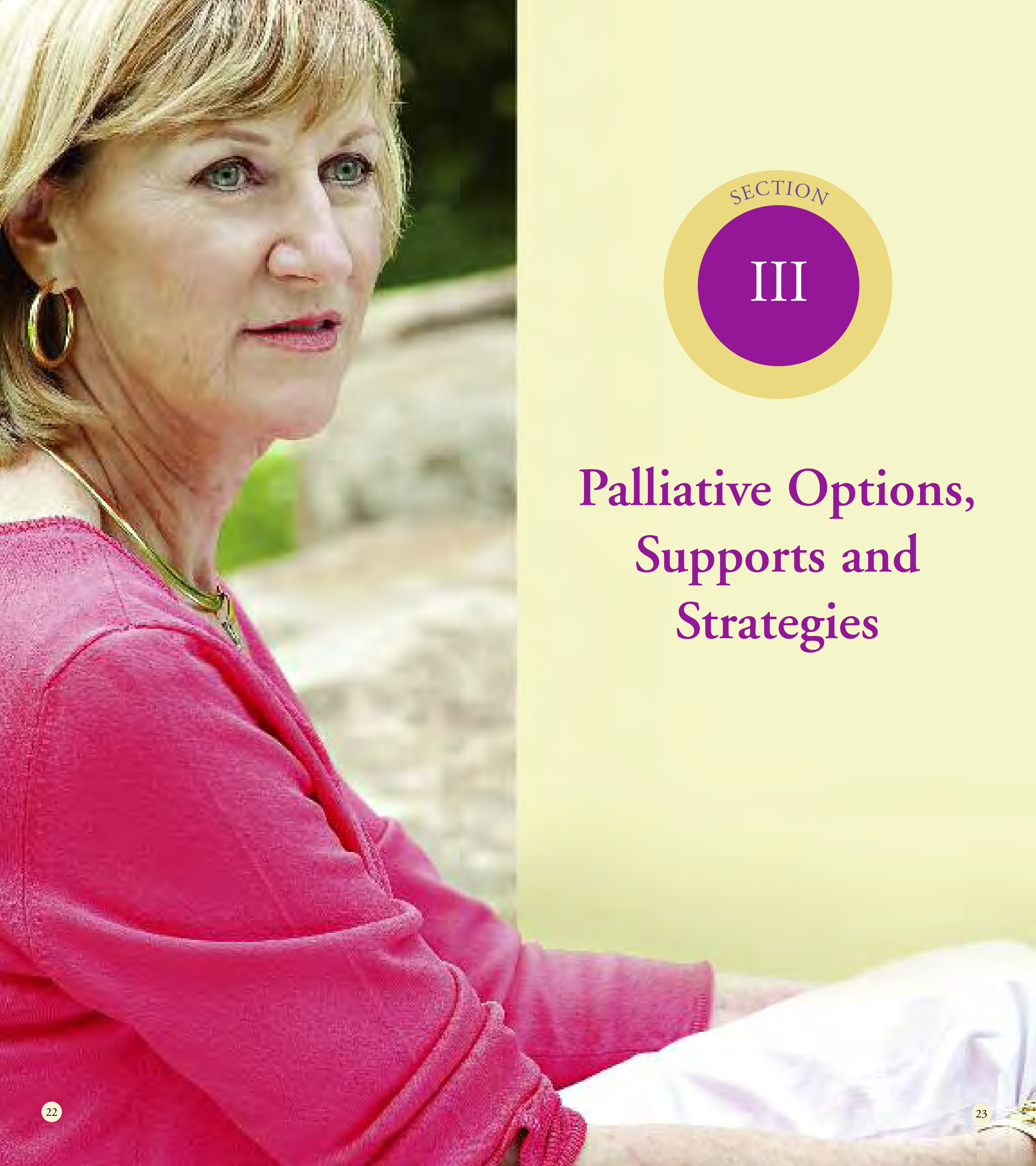
Managing symptoms and side effects

You may have side effects from treatment or symptoms from the cancer itself. Palliative care can help lessen the effects of both.

Many things you do to manage pain can be applied to other symptoms and side effects of metastatic breast cancer. This might be something as simple as taking an over-the-counter medicine to fend off a headache. You can try relaxation techniques, hypnosis, mindfulness and guided medication practices, physical therapy or nutritional supplements. You might also include regular exercise or body work, like therapeutic massage. Always speak with your care team about which over-the-counter medicines and supplements are safe for you.

Providing emotional support

Emotional support is an important part of managing pain. Short-term psychotherapy, structured support and other methods can help you develop useful coping skills and strategies. If counseling and support groups do not suit you, you may find relief from spiritual or religious communities, social groups or other activities and organizations.



SECTION

III

Palliative Options, Supports and Strategies

Palliative care typically uses a team approach that includes a palliative doctor, nurses, social workers and other professionals, like massage therapists, pharmacists, nutritionists, spiritual care professionals and others.

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Palliative Care Team

Palliative care specialists provide the support you need as you, your caregivers and your loved ones face the many challenges of living with metastatic disease. The difference between your palliative care specialists and your other doctors is where and how they focus their attention. Your palliative care specialists concentrate on preventing and alleviating physical and emotional discomfort, helping to improve your overall quality of life. Your other doctors, while also concerned about your quality of life, focus more on your general health and directly treating the breast cancer.

Your palliative care specialist works closely with your regular medical team, prescribing treatments to control pain and other uncomfortable symptoms, assisting with difficult medical decisions and coordinating care with your other doctors. The palliative team takes into account your unique needs, concerns and goals for ongoing care and treatment.

In addition to your palliative doctor or nurse practitioner, members of your palliative care team might include nurses, social workers, spiritual care professionals, pharmacists or other medical providers on the hospital or care center staff. These people can also help you and your loved ones find emotional and spiritual support. You will come into contact with some of these people as a matter of course, and others you may have to seek out through your regular medical team, your palliative care team or even on your own.

Your care team can guide you in finding specialized providers like massage therapists, nutritionists, acupuncturists, psychologists, psychiatrists and spiritual care professionals outside the hospital or care center. Typically, a social worker or patient navigator can provide information on resources in your community.

Depending on where you live and the services available to you, you may not have direct access to a doctor who specializes in palliative care. In this case, your primary doctor or members of your care team can help you find outside professionals and work with them to develop your plan for palliative care.

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Medicines

Pain medications

Your doctor can prescribe pain-relieving medicines, called **analgesics**, for cancer-related pain, based on the degree of that pain. For many types of mild to moderate pain, over-the-counter medicines like acetaminophen (Tylenol) and nonsteroidal anti-inflammatory drugs like aspirin and ibuprofen (Advil) can provide relief from muscle and bone pain, as well as pain caused by **incisions** (cuts).

For moderate to severe pain, opioids can be combined with analgesics like acetaminophen, aspirin or ibuprofen. Your doctor may call the medications given along with opioids in combination treatment **adjuvant analgesics**. Opioids can be prescribed at any stage of treatment, even starting at your diagnosis.

Potent, fast-acting opioids help relieve **breakthrough pain**, which is pain that comes through despite other long-acting medications you take to control your pain. These medicines are usually given along with medicine taken regularly for persistent pain.

Addiction, dependence and tolerance

Many women with metastatic breast cancer worry about becoming addicted to pain medicines. **Addiction** has particular features like craving, misuse, compulsive use and using medicines when you don't actually have pain. Although you may have to regularly take medicine to control your pain, it is very unlikely that you will become addicted. If you have a history of addiction, this could be of concern; your team can assist you with your more complex pain and symptom management needs.

Another concern is **drug dependence**, of which there are two kinds: physiological and psychological. **Physiological dependence** means that you have gotten used to taking a particular medicine or substance. There is the potential for physiological dependence with anything you put in your body over a long period of time, even caffeine or sugar.

Although it varies from person to person, physiological dependence generally means when you stop taking something, you will have a brief, unpleasant reaction. This is not a sign of addiction; it just means you should stop taking that medicine more gradually. **Psychological dependence** is when you believe you need something, but you really don't. This kind of thinking might lead to addiction in some cases, but, without a history of addictive behavior, it is very unlikely.

You might also be concerned about **drug tolerance**, which is a little different from drug dependence. Drug tolerance means your body gets used to a medicine and you may need more and more of it over time to feel its effect, or you may need a different medicine to get the same effect. This can happen with any medicine you take over a long period of time. Your doctors always take drug tolerance into account, because there is no reason to wait until pain is severe to increase how much medicine you take for it.

Concerns over drug dependence, addiction and drug tolerance are some of the biggest obstacles to the medical treatment of pain. These concerns are often not just yours, but also those of your friends and loved ones. It is important for all of you to understand how your pain is being treated. Speak with your regular doctor, as well as the members of your palliative care team, to address everyone's concerns.

Other medications

Several other types of medicine provide relief for cancer-related pain. Antidepressants, anticonvulsants and steroids are better known for treating other conditions. Many are now used in combination with other medications to treat pain, with excellent results.

Anesthetics or nerve blocks

For acute and some chronic pain, trigger point injections and nerve blocks provide short-term relief. **Trigger point injections** can help relieve pain in the chest wall that is common after any breast surgery. A **nerve block** is a local anesthetic put directly into the nerve causing pain. An **anesthetic** is a medicine that relieves pain by reducing or removing feeling.

Nerve blocks work best for pain that occurs in a limited area, involving one or two specific nerves. For more widespread pain, it is possible to interrupt pain signals using one of two kinds of pumps that deliver medicine continuously to large areas. An **epidural pump** sends medicine to areas just outside the outer part of the spinal cord, and an **intrathecal pump** sends medicine to the area around the **spinal cord**, the pathway that sends sensation or feeling from the nerves to the brain. Blocking this pathway with medicine prevents pain signals from reaching the brain.

Surgery

Most cancer-related pain is effectively managed with medicines. In rare cases, they prove inadequate, or side effects become a problem. Surgeons can interrupt pain pathways by implanting medicine-delivery devices, like epidural and intrathecal pumps, or stimulating nerve fibers that inhibit pain.

Complementary and Integrative Therapies

Integrative medicine combines conventional medical treatment with **complementary therapies**, striking a balance between treating physical illness and sustaining overall physical and emotional wellness. Complementary practices focus on you as a whole person. They may be used alongside medicines and other treatments.

Some palliative care programs include complementary therapies as part of treatment, but many do not. If your hospital or care center offers these options, you may consider exploring them. If they don’t, you may ask your regular doctors, palliative care specialists or other members of your care team to recommend complementary therapies that support your medical palliative care program. In some cases, members of your team may know how to integrate specific complementary therapies into your medical treatment.

> “It is important for all of you to understand how your pain is being treated.”

Mind-body practices

Complementary and integrative therapies that include movement help you reconnect with your body, supporting and sustaining your physical and emotional health. Yoga, yoga therapy, Tai Chi and Qigong can help you manage treatment side effects, relieve stress and reduce anxiety and pain.

There are many different kinds of mind-body practices. If you choose to include these practices in your treatment plan, first explore which is best suited to your needs, your temperament and your physical abilities. Ask your providers to help you decide.

Meditation

Like mind-body practices, meditation has different techniques and styles. You might think meditation means sitting with your legs crossed for hours. You would likely be surprised to find out there are meditation and mindfulness techniques that involve standing, walking and even running! Meditation and mindfulness training also provide stress relief, and help you feel grounded in your day-to-day activities.

Body work

Another integrative therapy, **acupuncture**, involves putting tiny needles into the skin at various points around the body to stimulate muscles and nerves. Acupuncture does not hurt, and it has been used as a regular medical practice in Asia for thousands of years. Typically, it is used to relieve fatigue, manage pain, treat symptoms of nausea and vomiting, reduce stress and control medicine-related hot flashes for women in all stages of breast cancer.

Therapeutic massage relieves stress, promotes relaxation, reduces muscular tension and helps soften scar tissue that results from surgery. It also provides an opportunity for non-sexual human contact that studies show promotes emotional well-being.

Spiritual Support

Spirituality is complex. Many people associate it with religion, but religion is just one part of spirituality and sometimes isn’t part of it at all. For some, spirituality means connecting to a higher sense of purpose, or searching for meaning in life. For others it may mean enjoying the things that touch and inspire us at a very deep, human level.

Your palliative care team can guide you to spiritual or pastoral counseling, or direct you to groups outside the hospital that might suit your personal exploration. This part of palliative care involves getting and staying connected to yourself, in whatever way feels most comfortable.

SECTION

IV

Quality of Life

When you consider medicine just one part of a whole approach to treatment, you will begin to see other ways to care for yourself. Consider your quality of life in four big categories: physical, emotional, social and spiritual. Both kinds of palliative care—medical and self-care—include these four things, which impact your quality of life.

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The Four Parts of Quality of Life

Physical

Managing pain and other symptoms and side effects of treatment is often the most important part of ensuring quality of life. But rediscovering a connection to your body that you may have lost after diagnosis can help you regain your sense of personal independence and self-reliance.

There are many ways to reconnect to your body. Even simple exercise, like taking a short walk, can make you feel better physically, which, in turn, impacts your emotional well-being. More strenuous exercise, like yoga or weight lifting, has also been shown to help manage the ongoing effects of treatment.

Studies show that just 30 minutes of exercise can positively affect your mood for as much as 12 hours. Palliative measures that support a strong body can help you feel more resilient and resolved to maintain your overall health.

Emotional

The stress of living with metastatic disease can be taxing. You may feel disconnected, or even isolated, as you integrate treatment into your life. Breast cancer can also make you feel you have no control over what's happening around you and what's happening to you.

Thinking about metastatic breast cancer as something that is part of your self-concept but does not define you can be very helpful for your emotional well-being. Reserving a special time each day for thinking about cancer and its treatment can sometimes be helpful.

Private counseling and psychotherapy, as well support groups, are places to find support and understanding with women who share your experience. If these services do not appeal to you or make you uncomfortable, there are many other places to seek emotional support.

Consider what inspires you and explore it with others who share your interest. Look into taking art classes, joining a book club or getting involved in charitable organizations. What is most important is staying engaged in your life, or finding new ways to engage in your life now that you must also manage the challenges of metastatic disease.

Social

The social challenges of living with an ongoing illness are considerable. You may find people do not understand you or immediately respond to you. Very often people you expected to count on distance themselves because they are fearful or feel vulnerable themselves. Others whom you expected to be sensitive to your needs might make rude or inappropriate comments.

Most people genuinely care, but they may not understand the seriousness of your diagnosis and how it affects you. They may be afraid, or simply not know what to say or how to help. Sometimes being aware of these things can help you be more understanding toward those who act in ways that feel insensitive or uncaring.

Maintaining your social connections and developing new ones is essential for managing feelings of loneliness and isolation. Just as important is recognizing which relationships are helpful and which might not be as supportive. This means setting strong boundaries with certain people. It also means making judgments about which relationships feed you socially, emotionally and maybe even spiritually.

Consider making a list of what you feel you can expect from various people in your life. This way, you have an idea of how others might act or react, and you can respond accordingly. It can also help to have a few stock phrases or responses ready to aid you in gently disengaging from people who are rude, inappropriate or even unintentionally hurtful.

Spiritual

Spirituality is anything you do that touches you deeply and feeds you in a way that is more profound than a simple emotional reaction. Many find this in religion and a connection with God, or a higher power. For others, it is finding a higher sense of purpose and connection to a deeper human experience. Some find this sort of bond in nature or through art, music or engaging in community. You may now find exploring these experiences in a larger way helps you support yourself and your self-care.

> “Exploring things that touch you deeply and feed you in a profound way helps you support yourself and your self-care.”

SECTION

V

Feelings About Palliative Care

Your emotions about palliative care can be every bit as complex as those you felt, or are feeling, at your initial diagnosis. Two of the strongest may be fear and anxiety. Before today, you may have thought that accepting palliative care marked the beginning of the end of your life. Others supporting you may also view palliative care negatively.

The decision to integrate palliative care into your overall treatment plan may change your perspective, and that of those around you. Your attitude and the actions you take will make it easier for your family, friends, caregivers and even your healthcare team to become more receptive to the idea that you are using palliative measures to support and sustain yourself, not prepare for the end of life.

Your range of emotions as you journey through breast cancer can be broad and complex. Keep in mind that all your feelings and reactions are valid. Finding new ways to cope can help you manage your emotions more effectively. Palliative care can be part of this process.

If your initial reaction to palliative care is negative, you are not alone. Most people mistakenly equate palliative care with the end of life, which is something very few people consider. Hopefully, you will give yourself time to understand how palliative care can help you. As you learn more about it, you may feel more positive about the ways you are helping to improve your life and your care.

Family and Friends

When you discuss palliative care, your loved ones may feel you're "giving up." Make it very clear that you feel palliative care can support and sustain you, giving you the best quality of life and extending your life for as long as possible. Explaining your reasons may help them understand you are making a positive, proactive choice.

Some conversations about palliative care are likely to be very difficult. People may react negatively or disagree with your choices. Try to understand that your loved ones may react this way because they fear losing you. Anything that magnifies that fear will be difficult for them.

Some family members or friends may simply reject palliative care, no matter what you say. Bear in mind that your treatment is your own, and that your decisions need to focus on what is best for you. Your health and well-being are more important than their emotional comfort. Although it may at first feel uncomfortable to you, doing what you feel is best for you promotes your self-care.

Children

It is difficult to predict how children of any age will respond to the news you have metastatic breast cancer. Young children may not understand what's happening to you. They will understand that you're sick and cannot do everything you used to do. This is because they experience these changes directly. Very young children may believe they somehow caused the cancer. Older or adult children may retreat or, on the other hand, overinvest in your treatment.

Conversations with children are likely to be among the most difficult you will have around your illness and treatment. Every situation is different, but remember that children's reactions are about their fear of losing you. They may respond negatively to your decisions around palliative care because they associate it with preparing for the end of life. Your optimism could go a long way to influence their reactions. The counseling and support afforded to you through palliative programs can help you navigate the often complex nature of these relationships.

Co-workers

How much you share with co-workers can be complex. You may wish to be quite frank, or to share nothing at all. If you are continuing to work, make sure you check your employee handbook or consult Human Resources to understand exactly how much and to whom you must disclose your circumstances.

> "Your optimism can go a long way to influence the concerns and reactions of those around you."

> “It is not your responsibility to manage the feelings and reactions of those around you.”

Often we establish very close relationships with co-workers. We can also establish relationships that seem close, but when considered more directly, are different than first thought. While it is important to establish a circle of support, bear in mind it is supposed to support you. It should not drain you, or intrude upon your life.

People you consider close to you may distance themselves because they feel sharing in your story is too personal. Others who have not previously been close may prove to be strong allies. And still others may become overinvested. Learning to set boundaries with members of your circle of support is important for both your physical and emotional well-being.

Your Healthcare Team

Your relationship with your healthcare team can be complex. On the one hand, your providers are likely to keep a certain professional distance. On the other, they interact with you—sometimes daily—and may know a great deal about you, your family and your life.

It is inevitable that you and members of your medical care team may become close. Their job is to recommend treatment that is in your best interest, but at times their connection to you may cause them to react emotionally to changes in your health. It is not your responsibility to manage their reactions, but it can be helpful to keep in mind that, despite their role, they are human. Their perspective on palliative care might be influenced by their own ideas and experiences with it, and what they feel it might mean for you.

If you feel members of your healthcare team are reacting emotionally to your decisions, talk with them. You might say something like, “Everyone here is always so concerned about how I feel, but it seems like you’re feeling something I can’t quite put my finger on. I’m wondering if you’d like to share it with me.”

SECTION

VI

Grief, Loss and Acceptance

It is normal to grieve the life you once knew. Metastatic breast cancer has likely brought some disruptions and limitations into your life. These changes may provoke feelings of fear and uncertainty, as well as anger and betrayal. They can also raise many questions, like "Why me?" or "What did I do to deserve this?"

One part of working through these feelings is recognizing that you are not to blame. You are entitled to feel your situation is unfair and you don't deserve it, but you did not do anything to bring it on.

The emotional and spiritual support afforded by palliative care, both within and outside your medical treatment, may help you release anger, fear, grief or feelings of betrayal. By allowing for change, rather than fighting it, you can release distress and work toward an outlook that allows you to move forward with your life.

The urgency you may feel over limited time can be a cause of anxiety and grieving, not only for you, but for those around you. Everyone's time is limited but, despite constant reminders, all of us tend to cling to a sense of our own immortality. Prayer, meditation and mindfulness practices can help you acknowledge your mortality, easing your sense of loss. After all, just as you are not alone in your illness, you also are not alone in your need to consider the end of life. The difference is that metastatic breast cancer has forced you to face those considerations directly. This can be an obstacle, or you can use it as a tool to find a renewed sense of value and vitality in your daily life.

Moving from grief and loss to acceptance is one of the greatest emotional challenges of metastatic breast cancer. Grief is a normal part of mourning any loss. Feeling like you've lost the life you once knew, or the opportunity to explore your expectations for the future, might feel in some ways like you've lost yourself. But you are not lost: you're still here. The acceptance that is part of grieving does not mean resigning yourself to your fate. It means making a commitment to live the best possible life you can right now.

Palliative care, whether it addresses pain, symptoms and side effects, or provides the emotional, social or spiritual support you may need, can sustain you in your commitment to live a life of quality and purpose for as long as possible.

> "Metastatic breast cancer may force you to consider your own mortality—this can be an obstacle, or you can use it as a tool to find a renewed sense of value and vitality in your daily life."

SECTION

VII

Paying for Palliative Care

Depending on where you live, paying for palliative care, as well as hospice care, can be different. In some areas, palliative and hospice services are paid for by the state or commonwealth in which you live. This isn't the case everywhere, and the social worker or patient navigator on your palliative care team can help you explore your options.

Many insurance companies consider palliative care, sometimes called **concurrent care**, part of regular medical treatment. They will often cover most or all the cost for services provided by the palliative program at your hospital or care center.

Government programs, like Medicare and Medicaid, have guidelines around paying for palliative and hospice care at the official website for Medicare, **medicare.gov**. Many private agencies offer information packets on their websites about paying for palliative services.

Palliative services outside the hospital or care center, like therapeutic massage, acupuncture or yoga therapy, may or may not be paid for by insurance. This will be specific to your coverage. Your medical team can help you sort this out.

“Acceptance does not mean resigning yourself to your fate. It means making a commitment to live the best possible life you can right now.”

SECTION

VIII

Hospice Care

Preparing for the end of life is something few people want to consider, but it is something we all must face. Just as palliative care provides you with physical, emotional and spiritual support throughout treatment, hospice care can provide you with that same support as you transition to the end of life.

You and your loved ones may feel angry, hopeless or desperate if hospice care is offered as the next step in your treatment process. This is a normal reaction to the prospect of any loss, particularly the loss of ourselves. Palliative care offers a bridge from your ongoing medical treatment to this specialized form of care that focuses on your unique needs for physical, emotional and spiritual comfort in the last months of life.

> "Just as palliative care provides you with physical, emotional and spiritual support throughout treatment, hospice care can provide you with that same support as you transition to the end of life."

Hospice care is provided by a team of professionals that includes a hospice doctor and regular nursing staff. Other team members might include a psychologist, social worker, chaplain or spiritual care professional, pharmacist, nutritionist and physical therapist.

Continuing to work with your regular medical team and palliative care professionals, the hospice care team helps with your changing medical needs and activities of daily living, like bathing and eating. They also support the emotional and spiritual needs of you and your loved ones, like caregiver stress, grief and fear of dying.

A more complete discussion of hospice care is beyond the scope of this guide. By choosing palliative care now, you empower yourself and your family to have the hard conversations about bridging your needs later as you transition toward the end of life. Hospice care can give you and the people in your life a greater sense of control, and help improve the chances you will get what you want, in addition to supporting your loved ones, during this time.

LBBC extends thanks to those individuals who volunteered their time and expertise in the production of this guide.

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This brochure is designed for educational and information purposes only, as a resource to individuals affected by metastatic breast cancer. The information provided is general in nature. For answers to specific healthcare questions or concerns, you should consult your healthcare provider, as treatment for different people varies with individual circumstances. The content is not intended in any way to be a substitute for professional counseling or medical advice.

We’re always here for you through our Helpline and at lbbc.org.

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More Resources

Visit **lbbc.org** or call (610) 645-4567 to order other brochures in our *Metastatic Breast Cancer* series.

- Treatment Options for Today and Tomorrow
- Understanding Symptoms and Treatment Side Effects of Advanced Breast Cancer
- Managing Stress and Anxiety

You may also find helpful information in these brochures:

- Guide to Understanding Financial Concerns
- Guide to Understanding Lymphedema
- Frankly Speaking About Advanced Breast Cancer (written with Cancer Support Community)

Visit us today at
lbbc.org/Audiences/Metastatic-Breast-Cancer

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Help us!

If you have metastatic breast cancer, please fill out the survey below and return it in the enclosed envelope or fill it out online at **surveymonkey.com/s/PalliativeCareMBC.**

Please choose the answer that best describes how you feel about these statements.

1. After reading this guide, I better understand what palliative care is.

☐ Strongly agree
☐ Agree
☐ Undecided
☐ Disagree
☐ Strongly disagree

2. After reading this guide, I better understand the differences between palliative care and hospice care.

☐ Strongly agree
☐ Agree
☐ Undecided
☐ Disagree
☐ Strongly disagree

3. After reading this guide, I better understand how palliative care can be part of my overall treatment plan.

☐ Strongly agree
☐ Agree
☐ Undecided
☐ Disagree
☐ Strongly disagree

4. After reading this guide, I better understand how palliative care can enhance my overall quality of life.

☐ Strongly agree
☐ Agree
☐ Undecided
☐ Disagree
☐ Strongly disagree

5. After reading this guide, I feel more knowledgeable about how to proactively manage my treatment.

☐ Strongly agree
☐ Agree
☐ Undecided
☐ Disagree
☐ Strongly disagree

6. After reading this guide, I am more likely to discuss my palliative care options with my medical care providers.

☐ Strongly agree
☐ Agree
☐ Undecided
☐ Disagree
☐ Strongly disagree

7. Please rate how helpful you found each section of the guide.

	Extremely helpful		*Neither helpful or unhelpful*		*Extremely unhelpful*
I: Looking at Palliative Care	☐	☐	☐	☐	☐
II: The Benefits of Palliative Care	☐	☐	☐	☐	☐
III: Palliative Options, Supports and Strategies	☐	☐	☐	☐	☐
IV: Quality of Life	☐	☐	☐	☐	☐
V: Understanding Emotions	☐	☐	☐	☐	☐
VI: Grief and Loss	☐	☐	☐	☐	☐
VII: Paying for Palliative Care	☐	☐	☐	☐	☐
VIII: Hospice Care	☐	☐	☐	☐	☐

8. I found this guide easy to read.

☐ Strongly agree
☐ Agree
☐ Undecided
☐ Disagree
☐ Strongly disagree

9. How likely is it that you will save this guide and use it in the future?

☐ Very likely
☐ Likely
☐ Undecided
☐ Somewhat unlikely
☐ Definitely unlikely

10. After reading this guide, how likely are you to use other LBBC services?

☐ Very likely
☐ Likely
☐ Undecided
☐ Somewhat unlikely
☐ Definitely unlikely

11. When did you get this guide? *Choose all that apply.*

☐ At an appointment when I was first diagnosed with metastatic breast cancer.
☐ Not at an initial appointment, but within a year of my diagnosis with metastatic breast cancer.
☐ More than one year after my diagnosis with metastatic breast cancer.
☐ At a time I discussed adding palliative care to my treatment with my care team.
☐ At a time I considered adding hospice care to my treatment.
☐ At the time I stopped receiving metastatic breast cancer treatment.

12. When you most recently wanted information on metastatic breast cancer, where did you first look?

☐ Guides or pamphlets
☐ Cancer organization
☐ Family
☐ Friend/co-worker
☐ Healthcare provider
☐ Internet
☐ Library
☐ Magazines or newspapers
☐ Another person with cancer
☐ Telephone Information number (800 number)
☐ Other.

12a. If other, please explain:

____

____

Please tell us a little more about you!

All information is optional.

13. In what state and country do you live?__________

14. What year were you born?____________________

15. What year were you first diagnosed with <u>primary</u> (initial) breast cancer?________________

16. What year were you first diagnosed with <u>metastatic</u> breast cancer?______________________

17. Right now, are you receiving any of these treatments? *Choose all that apply.*

☐ Chemotherapy
☐ Hormonal therapy
☐ Targeted therapy (Herceptin, Avastin, etc.)
☐ Radiation therapy
☐ Other.

18. What racial or ethnic background do you most closely identify with?

☐ African-American
☐ Asian
☐ Hispanic or Latino
☐ Mixed Background
☐ Native American or Alaska Native
☐ Pacific Islander
☐ White, not Hispanic or Latino
☐ Other.

19. What is the last grade of school you completed?

☐ Some high school
☐ High school graduate/GED
☐ Some college or vocational/technical training after high school
☐ College degree
☐ Master's degree
☐ Doctorate degree

If you would like to join Living Beyond Breast Cancer's mailing list, please fill out the information below:

FIRST NAME LAST NAME

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CITY STATE ZIP CODE

COUNTRY

I would prefer to receive information from LBBC by *(choose all that apply)*:

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