

EDUCATE, ADVOCATE FOR, EMPOWER, SUPPORT

MY LIFE

METASTATIC YOUNG (MY)
LIVING IN FOCUS EMPOWERED (LIFE)



FOCUSING ON MEETING
THE NEEDS OF YOUNG
WOMEN LIVING WITH
METASTATIC BREAST
CANCER, DIAGNOSED
UNDER THE AGE OF
45 YEARS OLD



THIS GUIDEBOOK IS PROVIDED THROUGH
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DEAR YOUNG WARRIORS:

We know that getting diagnosed with metastatic breast cancer (MBC) is a lot to handle. We all want a breast cancer diagnosis to end with the words "cancer free". Our goal in creating this guidebook is to give you resources to help you understand and make educated decisions as you decide what to do next; to help you know that you have a voice and empower you to use it to engage your healthcare team going forward; to connect you with resources; and to share the perspectives of other young women living with MBC.

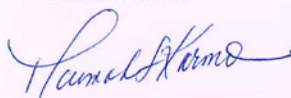
We also want you to know that we "see" you. Your feelings and stories are very real, as are the fears and challenges you experience. We view your bravery in the face of your diagnosis with the utmost respect and look forward to supporting you, as you navigate this path.

The content in this guidebook was created with the support of young women diagnosed with metastatic breast cancer and reviewed by young women - just like you. The guidebook's sections are separated into four areas: Learning about Metastatic Breast Cancer, Advocacy, Empowerment and Resources.

Thank you for trusting us on this journey. We look forward to helping you navigate your diagnosis, and helping you to become even stronger, more empowered and live an even more fearless life going forward, with us by your side.

Blessings, hope and with much love,

Maima H Karmo



If you'd like to share your thoughts about this guidebook or would like more information, email mylife@tigerlilyfoundation.org or visit www.tigerlilyfoundation.org. You can also reach us at (888) 580-6253.



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MY LIFE. MY LEGACY. MY WORDS.

The Metastatic Young (MY) Living in Focus Empowered (LIFE) Program is one of the most important initiatives we have ever embarked on. As an organization, Tigerlily Foundation's mission is to educate, advocate, empower and support young women, during one of the most critical times of their lives. In addition, it is important to us to remind young women that they are beautiful, strong and can be transformed by their experience with breast cancer. Our President and Founder, Maimah Karmo, holds a core belief, which is that even though breast cancer and other challenges happen upon us, the key questions to ask ourselves is this, "Why are we here and what is our soul here to do?" With that in mind, we want to ensure that our programs not only provide you with the educational information that you need, but we also want to inspire you to think about how your warrior spirit can rise up and live even more passionately and purposefully. You're a warrior. You know this. As you navigate this journey, ask yourself why you're here and what is it that you're here to do. What is the meaning of your life? What is the legacy you'll leave behind? How will you use your words and actions to change your world as a whole?

As we developed the MY LIFE program offerings, our goal was to ensure that we offered initiatives for young women with Metastatic Breast Cancer (MBC), with input by young women with MBC. We wanted to give you what YOU need. To ensure that we did this, we launched a national survey to get the viewpoints of young women living with MBC. The top needs expressed were **for Targeted Programs - just for you; Better Communication (perceptions of MBC, with healthcare team, recognition of this population); more education of MBC and accessibility to information, resources and stories; programmatic support to help you through day-to-day life; engagement in advocacy events; more and better clinical trials, and research.** Based on this feedback, we have enhanced our MY LIFE program offerings, to include more than eight different ways to receive educational information, additional ways to connect with other MBC peers, ways to share information with the general public, ensure YOU are at the table when it comes to advocacy, and to make sure that your voices are heard.

Special Thanks to the following "metsters" for their feedback into developing this guidebook. Your strength, fearlessness, honesty and determination are boundless. Thanks to your inputs, we are able to provide this educational guidebook (and other really cool initiatives) to other young women living with metastatic breast cancer.

Beth Caldwell
Leslie Falduto

Jen Campisano
Mandi Hudson

Beth Fairchild
Josie Ivey



Also, a special thanks to Eisai for providing support for this guidebook.

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LEARNING ABOUT METASTATIC BREAST CANCER



“KNOWING AS
MUCH AS
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DRIVER’S SEAT,
AND ENABLES
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CHOICES.”

METASTATIC BREAST CANCER FACTS

Metastatic breast cancer is breast cancer that has spread beyond breast tissue and the surrounding lymph nodes to form tumors in other parts of the body such as bones, brain, liver, and lungs. Metastatic breast cancer is also known as Stage IV or advanced breast cancer. Stage IV breast cancer is diagnosed in about 6-10% of newly diagnosed breast cancer patients. Individuals with an initial diagnosis of Stage IV breast cancer have an average 5-year survival rate of 26%. That said, many people live for years or even decades with Stage IV breast cancer with a good quality of life; it is estimated that approximately 155,000 people in the United States are currently living with metastatic breast cancer. While many young women can live a long time with the disease, it is important to note that no one knows how long an individual can live with metastatic breast cancer, so it is important to make treatment decisions that consider quality of life. About 20 to 30% of all breast cancers that are originally localized within the breast become metastatic.

WHERE CAN BREAST CANCER METASTASIZE?

Breast cancer can come back can come back:
a) as a local recurrence - site of the original diagnosis; b) as a regional recurrence - lymph nodes (armpit or collarbone) near original diagnosis; c) as a metastatic/distant recurrence - a part of the body not close to the original occurrence (lungs, bones, brain).

BEING DIAGNOSED WITH METASTATIC BREAST CANCER

Being diagnosed with metastatic breast cancer is overwhelming. You have lots of questions and will want to make treatment decisions that are right for you. Before you do anything else, breathe, then make a plan; and know that you're not alone. Also, if you'd like to get a second opinion, then do so. There are many other young women that live with metastatic breast cancer. Approximately 150,000 women and men live with metastatic breast cancer. Your life will change and you'll have to learn more medical terms, have additional tests and you'll be seeing your doctors more. It's a lot to handle, but you'll adapt. Breathe again. Put your hand over your heart and feel your heartbeat. You can do this.

TESTS FOR METASTATIC BREAST CANCER

Before being diagnosed and after your diagnosis, you'll have to do a series of tests to help you and your doctors understand what type of breast cancer it is, the aggression levels, and where the cancer has metastasized to. Your physicians will need to gather your scans/imaging reports, lab tests, pathology reports, biopsy, surgical and physical exams to be able to figure out what your situation is and how to treat it.

You'll need to have a variety of tests to throughout your treatment, to include ultrasound, mammogram, xray, PET scan, CT scan, MRI, bone scan, genetic test and blood work. Physicians also might have you take a tumor or blood marker test to look for specific tumor cells - this helps them to make a proper diagnosis and to monitor disease progression. Make sure to always keep records of all documents, tests, scans and doctor visits.

At every doctor visit, take your journal and/or take someone with you to help take notes as well - and for support.

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MANAGING YOUR RECORDS AND HEALTH INFORMATION

You'll have a lot of information coming at you and you want to make sure you keep track of it. Also, it's a lot to take in. Make sure to: 1) Have a folder where you keep all your records; 2) keep a journal of notes of all your health information - you can do this via handwritten or voice recorder notes; 3) keep a journal of how you feel and make sure to include a list of all your doctor's contact information.

TREATMENT OPTIONS FOR METASTATIC BREAST CANCER

Metastatic breast cancer is not curable, but it is treatable. You can live with it for a long time, but having metastatic breast cancer means you will live with it for the rest of your life. Treatment options are based on the characteristics of the tumors and can include cancer cell-killing chemotherapy, medicines that target specific genes to slow or stop cancer cell growth, and hormone therapy to stop cancer cells that are growing in response to the hormones estrogen and progesterone. Your physician's goal will be to manage and control the cancer by slowing disease progression and trying to minimize treatment symptoms and side effects, while helping you have a good quality of life.

Some patients wonder why treatment for metastatic breast cancer is not as aggressive as what is given to patients with early stage breast cancer. The reason is that early stage breast cancer treatment is for a short time and metastatic breast cancer is for a longer period of time and the goal of treatment is to manage the cancer long-term. Aggressive treatments might be too toxic or if you have had breast cancer before, your body may be resistant or have adapted to some treatments.

Some patients can be on a treatment regimen for a long time and other patients may have to change treatments more often. Everyone's body reacts differently. Sometimes certain treatments are tough and leave you feeling unable to have the quality of life you want, feeling sick, tired or in pain. It is important to communicate with your doctor how you're feeling and whether you need to change treatment plans. In some cases, you may want to talk with your physician about clinical trials.

TALKING WITH YOUR MEDICAL TEAM

When you are first diagnosed with metastatic or advanced breast cancer, you may have a lot of questions. Some questions to ask your medical team include treatment options and goals, information about diet and nutrition, exercise goals, managing pain, and resources and support groups available in your local community. If you have more questions after your first visit, call your doctor's office or make another appointment to discuss issues and questions. As you work with your medical team to put together a treatment plan, you may have questions or concerns about side effects. Don't hesitate to talk to your medical team about side effects or any other concern that you may have. It is important to make treatment decisions that work best to slow or stop cancer growth. Also let your medical team know what side effects you want to avoid.

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TALKING WITH YOUR MEDICAL TEAM

When you are first diagnosed with metastatic or advanced breast cancer, you may have a lot of questions. Some questions to ask your medical team include treatment options and goals, information about diet and nutrition, exercise goals, managing pain, fertility, potential impact on your work and finances, resources and support groups available in your local community. If you have more questions after your first visit, call your doctor's office or make another appointment to discuss issues and questions. As you work with your medical team to put together a treatment plan, you may have questions or concerns about side effects. Don't hesitate to talk to your medical team about side effects or any other concern that you may have. It is important to make treatment decisions that work best to slow or stop cancer growth. Also let your medical team know what side effects you want to avoid.

Some patients need "treatment breaks" or may lower the dose of the medication to lessen side effects. A lot of cancer treatment centers also offer palliative care to help patients better their quality

of life. Palliative care teams help you balance emotional, mental-physical changes. In the case where you want to stop treatment altogether, they can help you navigate that decision and give you options that help your quality of life.

MANAGING YOUR MEDICAL RECORDS

There may be many different medical professionals caring for you including your primary care physician, medical oncologist, radiation oncologist, surgeon, therapists, and others. Each of these professionals are keeping a record of your care. However, keeping your own records with information about your medications, surgeries, treatments, treatment schedules, imaging reports, pathology reports, and other details of your care is a good idea for several reasons. Having your complete health history allows you and your caregivers to be active participants in making decisions about your care. Also, in case of emergency, all of your information will be in one place. Computer flash drives or hard drives can be a good place to store records, as can a 3-ring binder or file folders. To make keeping track of information easier, you could also take a recording device with you to doctor appointments, using your phone or other device; and make sure to label the recording, so you can keep track of visits and find information easily. This will save time if you forget information, and also is a great tool to share with caregivers who cannot attend appointments or treatments with you.

Consider keeping your health information in a secure online area (Google Docs, Dropbox or other online storage), so that people you trust can access them easily. This also helps to lessen the chances of losing information. Ask someone on your support team to help with the task of uploading documents for you. Choose one system that you think will be easiest for you and your caregivers to keep all of your information in one place and up to date.

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LIVING WITH METASTATIC BREAST CANCER

Living with a condition like metastatic breast cancer can be very emotionally and physically draining. You may have trouble sleeping. You may be very concerned about the future, worrying if your treatments are going to work, or worrying if you will have painful side effects. All of these concerns are normal. Talk to your medical team about ways to help you with these feelings. Pain management may be an important aspect of your care. Your medical team wants to know what pain you are experiencing, so that they can help reduce your pain.

It may be very hard for you to talk to your friends and family about your metastatic breast cancer diagnosis. Open, honest communication with your spouse or partner about needs—yours and theirs—is very important. It's also important to involve them in your medical care as much as possible. A professional such as a psychologist or social worker can help if you are having communication or relationship issues.

You can also create a list of your daily routines, responsibilities, appointments and treatments, to allow your support team to know where and how to best help you. Make sure to include activities you enjoy, for example, time for meditation, yoga and fulfilling hobbies, travel. Perhaps, "map out" a "week in the life of", or month or so, if possible, to best help yourself and those who want to help you along the way.

Also, take time to familiarize yourself with the world of metastatic breast cancer and the many amazing people within it. There are countless numbers of support groups that you can find through internet searches and social media. They are filled with men and women across the world, ready to welcome you, love you and support you. Through these groups you will make new friends, become well educated, connected, supported and empowered by those who can relate to you near and far. Join one or multiple groups, create connections, get involved in advocating or volunteering in some way. What better way to change your perspective on things than to become involved in the big picture. You will quickly begin to see that "you are not alone".

MANAGING SIDE EFFECTS

There will be side effects of your treatment and it is important to communicate them to your doctor. Some side effects are short-term and others are ongoing. Long-term treatment is associated with more side effects. Side effects can include bone pain, chemobrain, hair loss, fatigue, depression, anxiety, heart issues, mouth sores, neuropathy, and menopause. Side effects are also treatment specific, meaning that they vary depending on what treatment regimen or medication you have. Side effects can be challenging, but there are ways to lessen and/or prevent them. Talk to your doctor about ways to manage side effects - through medication or complementary treatments.

CLINICAL TRIALS

Clinical trials are human research studies that determine if a medicine, treatment, or medical device is safe and effective. New medicines and treatments are tested in a series of clinical trials. Joining a clinical trial may be an option for you. To join a clinical trial, you have to meet certain criteria such as type of tumor or cancer stage; ask your medical team if there is a trial near you that would be appropriate. The advantages of a clinical trial include access to the newest treatments and careful monitoring of your condition. The disadvantages include side effects, the possibility that the medicines or treatments may not work, and additional trips to the hospital or clinic.

Once you become a part of a clinical trial, your physician will let you know whether you will still be cared for at your local center or if you'll have to travel. A clinical trial coordinator will help you manage the important details. Again, make sure to communicate with your physician about side effects. It is important to note that clinical trials don't mean you're giving up - it just means that you're exploring every option. Also, make sure to talk with your patient navigator or coordinator if the costs of the trial or travel, check-ups and scans become too expensive. Various advocacy groups offer resources to help you cover costs. Visit our resource page for a list.

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There are several websites with a search function to find clinical trials that may be a good fit for you:

https://www.breastcancertrials.org/bct_nation/home.seam

<https://www.clinicaltrials.gov/>

<http://www.cancertrialshelp.org/cancer-trial-search/>

<http://sarahcannon.com/clinical-trials/index.dot>

<http://mbcn.org/education/category/metastatic-trial-search>

ALTERNATIVE TREATMENT OPTIONS

Complementary medicine can help reduce stress, relieve treatment side effects, and improve your quality of life. Complementary therapies could include acupuncture, aromatherapy, art therapy, journaling, massage, meditation, music therapy, reiki, support groups, tai chi, yoga and many others. Talk to your medical team if you'd like to try some complementary therapies. They may have recommendations to make about providers and groups in your area. Some complimentary treatments are partially covered by insurance companies, while others, like journaling and support groups, are free.

GENETIC TESTING

About 10% of breast cancers are hereditary breast cancers, caused by genetic changes that are passed on from generation to generation. Changes in the BRCA1 and BRCA2 genes are responsible for most hereditary breast cancer. You and other family members can see a genetics counselor to determine if you have changes in these genes. Information from the genetic tests can be used to customize a treatment plan for you.

WANT TO HELP?

Getting more educated about MBC helps you work better with your healthcare team and make decisions that are right for you. Now, you're also in a position to educate others. You can join our efforts to educate more young women about MBC by engaging in our Twitter chats, podcasts, blogs sharing our social media information or by joining our MY LIFE Advisory Committee. Email mylife@tigerlilyfoundation.org to find out about other ways to become an advocate.

OUR PERSPECTIVE

September 11, 2008 I found THE lump under my left armpit. Terrified, and with a gut feeling that it wasn't good, I called my OB-GYN. She immediately



got me an appointment for a mammogram and breast ultrasound. Nothing showed up on either, except four large lymph nodes. After a lymph node biopsy, it was confirmed I had breast cancer; and after my MRI, it was confirmed that I had three tumors in my left breast. I was 31, extremely healthy, with no family history of breast cancer, married for three years - we had just moved to Chicago with our then almost two year old son.

I underwent A/C chemo, bilateral mastectomy, reconstruction, blood transfusions, Taxol, radiation to my chest wall, Herceptin and Tamoxifen. June of 2009 we moved to Austin. I completed my Herceptin there, continued Tamoxifen, and had clear scans in April 2010. In November of 2010, I ran my first half marathon. In August of 2011, I ran my second half marathon. In August of 2012 I went off Tamoxifen for six months to try and conceive. On September 14, 2012, he was born. I got back on Tamoxifen six weeks after his birth and began running, taking tennis lessons, and kick-boxing classes. I felt the best I had ever felt. I was healthy, I had my two sons, and life was great.

September 7, 2013 I was working a shift in the Neonatal ICU. I didn't feel right. The Neo and labor and delivery charge nurse checked my blood pressure and blood sugar. Both were normal. Later that afternoon, I still felt really bad. I went to the door to get out of the locked unit, and I couldn't remember how to open the door. I knew it was a door, but couldn't remember how to open it. When I finally got out, the L&D charge nurse saw me, ran to get a wheelchair, and brought me down to the ED. My right leg was convulsing and I was in so much pain. By the time they got me to the back (minutes later) I had a tonic-clonic seizure. The MRI revealed a 2.5-3cm tumor between the two hemispheres of my brain.

Metastatic breast cancer was confirmed after my craniotomy on September 11, 2013. Late September, it was confirmed that I had mets to my right lung, one in my spine as well. I underwent brain radiation, a bilateral Salpingo-oophorectomy, and chemotherapy. I had to go to physical therapy to work on my proprioception and build strength back up on my right side. I continue with Herceptin, Perjeta, and Anastrozole to this day. I am currently NED (no evidence of disease). My lung, spine, and brain mets are gone. I am now dedicating a lot of my free time to advocating for metastatic breast cancer research and patient support.

- Leslie Falduto



TIP

CONSIDER MAKING
A FRIEND OR
FAMILY MEMBER
YOUR ADVOCACY
WARRIOR BUDDY,
SOMEONE YOU CAN
TALK THROUGH
ISSUES WITH.

MY LIFE - BE YOUR OWN BEST ADVOCATE

KNOW WHAT YOUR RIGHTS ARE

It is important to know your rights when it comes to your insurance, work leave or potential discrimination. It is illegal for an employer to discriminate against an employee because of a serious illness, such as cancer. If you feel that you have been discriminated against in the workplace because of your metastatic breast cancer, you can take action. Keep a record of the examples of the discrimination, and consider talking to your supervisor, company Human Resources department, and possibly a discrimination lawyer.

DISABILITY

You may want to take a leave of absence from your job during part or all of your breast cancer treatment.

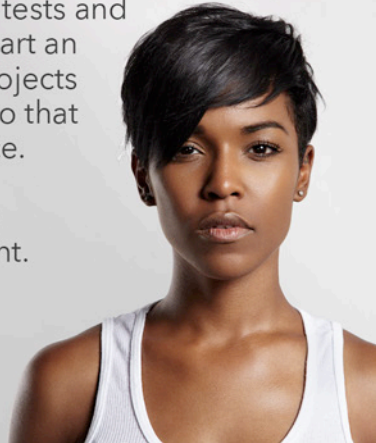
If you have worked full-time at a company that has 50 or more employees for at least one year, you are covered by the federal Family and Medical Leave Act (FMLA) for up to 12 weeks of unpaid medical leave, with no loss of job or benefits. Contact your employer's Human Resources department to find out more about short-term (often 3-6 months) disability policies, which pay a percentage of your paycheck even if you are not able to work, such as during an illness. Long-term disability (longer than 6 months) may be right for you if you want to take a long-term leave of absence from work and focus on your treatment and recovery, however, you may not receive your paycheck or benefits during this time.

INSURANCE

If you have health insurance, your policy will probably cover many of the expenses associated with your tests, diagnosis, and treatment. Make sure that you know what policy you have and what is covered. You can look this up on your company's Human Resources website or call your health insurance company and ask them to send you a summary of your benefits. It's a good idea to keep insurance paperwork, receipts, copies of claims that you have submitted, bills, and other paperwork related to your healthcare costs in a 3-ring binder or folder.

WORK

Talk to your medical team if you'd like to keep working during your treatment. It may be possible to schedule tests and treatments around your work schedule. Start an electronic or paper calendar with work projects and deadlines and your treatment dates so that you have all of this information in one place. It's important to stay flexible—you may experience side effects and might need to work less hours than usual during treatment. Having a backup plan, such as being able to work from home and/or delegate essential tasks to coworkers, is a good idea.



OUR PERSPECTIVE

My name is Adrian McClenney a Metastatic (Stage 4) Breast Cancer Survivor. On May 19, 2011 I was diagnosed with stage 3 Inflammatory Breast Cancer, a rare but aggressive form of breast cancer.

My treatment regimen consisted of 16 cycles of chemotherapy treatments, A Double bilateral mastectomy and 37 treatments of radiation treatments. I have also had a full hysterectomy performed. I was misdiagnosed for months, before being properly diagnosed. Inflammatory breast cancer rarely shows up on mammograms. I am grateful for being persistent and demanding attention. My breast went from a little red itchy spot to a very painful itchy swollen hot breast. I had a big knot underneath my arm where the cancer had spread to my lymph nodes. I could barely lift my arms, carrying my purse was a big challenge. I would try and cook and found myself dropping bowls and pots. I knew something was wrong and I needed attention quickly.

I am now the Author of two books Pink Lifesaver and also Pink Sunshine. I am also a Co-author of two other books. I love using my story to educate other women about the importance of breast health and advocacy.

Things are sometimes a little rough but I push through. I am grateful for a very supportive family and loving friends that really makes a difference while going through a journey as breast cancer. I am now living with metastatic breast cancer, but I vow to educate, advocate, live and love loudly. There is no cure for metastatic breast cancer but I believe in miracles. If I can leave you with anything today it would simply be alive every day, beautiful, because you are.

- Adrian McClenney





MY LIFE – BE EMPOWERED

FAMILY

Think about how you want to tell family members about your diagnosis. Will you share the news in person, on the phone, via FaceTime or Skype? Would you prefer to send a group text or a group email to all family members, and then follow up with individuals at a later time? When people hear your news, they may ask you what they can do to help. Make a list of tasks that your family members could do (meal preparation, household chores, transportation for you or other family members). Perhaps a family member could coordinate a web page on a site such as CaringBridge.org to provide family and friends with updates; you may find it draining to continually provide updates to concerned family and friends.

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TIP

TO KEEP EVERYONE UPDATED, CHOOSE A COMMUNICATION METHOD THAT CAN PROVIDE UPDATES TO EVERYONE AT ONCE; OR DESIGNATE ONE PERSON TO POST UPDATES FOR YOU REGULARLY.

CAREGIVERS

It is normal for spouses/partners of those with breast cancer to feel many emotions such as anger, anxiety, discouragement, and fear for the future. Many treatment facilities offer support groups for co-survivors, and there are many blogs, telephone hotlines, and social media groups focused on supporting those who are caring for breast cancer survivors. The Cancer Support Community has a good list of tips for caregivers and links to other resources.

TALKING TO CHILDREN

Children and teens feel many of the same emotions as spouses and partners. Some families try to protect children by not telling them too many details. No matter what their age, children can sense family stress. Talk to your medical team about how and what to tell your children about your cancer. At the end of the day, what and how you tell your children is up to you. What matters most is that they feel that they are still connected with you, they don't feel left in the dark and that they feel that they are able to support you -whatever you decide that to be.

Reassure your children that it's normal to feel sad, mad, scared, or upset. Tell them about any possible changes in your appearance and/or family routines. Answer their questions when they feel comfortable asking them. There are many local, regional, and national support groups for children and teens with parents who are living with cancer. Your children may find it helpful to connect with peers who are experiencing similar emotions.

DATING

Being single and dating can be challenging even without having metastatic breast cancer. When you tell someone you're dating that you have metastatic breast cancer is up to you. In the end, honesty is often the best policy; consider sharing information about your diagnosis, treatment, and side effects with your partner once you're ready to do so.

MANAGING YOUR EMOTIONAL, SPIRITUAL, MENTAL SELF

Learning that you have metastatic breast cancer can be overwhelming at first. Eventually you will find “a new normal”. Make the time to nurture your emotional, spiritual self. Depending on your practices, connect or re-connect with a religious congregation. Try meditation or daily yoga. Pray - often. Start a new hobby or take up an old favorite, like crocheting or knitting, reading, drawing or painting. Join a support group or social network. Take a class at your local community college. Make a vision board and map out your life - this is the time that you can purposefully design life - just as you want it to be.

PAIN MANAGEMENT

Controlling pain is a crucial part of treatment for individuals with metastatic breast cancer, in order to improve quality of life. It is important to find the right combination of medication for pain control, while limiting side effects.

Make sure to tell your health care provider about any pain or discomfort you experience, as soon as it starts. Typically, the causes of pain are easier to treat when the symptoms first appear, so don't wait until the pain becomes more severe before talking to your provider and getting treatment; doing so can make it harder to control and may require more medication. Different individuals experience pain differently, as no person is the same and no cancer is the same. To ensure that your provider can offer you the best pain management, it is important to explain exactly what you are feeling and experiencing.

Palliative medicine is a medical specialty focusing on giving patients relief from the symptoms and stress of a serious illnesses. Your provider may refer you to a palliative care specialist who treats pain and helps patients maintain the best quality of life possible.

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THE TOUGH STUFF

Because there is no cure for metastatic breast cancer, there will be a time when treatments are not successful or you decide to stop treatment because of severe side effects. Think about what kind of medical care you want to have at the end of your life and who you would like to make decisions about your medical care if you are not able to. A Living Will is a document that lists your choices for medical care such as if you want machines to keep your kidneys and lungs functioning, if you want cardiopulmonary resuscitation (CPR) if your heart stops beating, if you want to receive nourishment through a feeding tube if you aren't able to swallow foods, and if you want to withhold food or fluids. A Medical Power of Attorney is a document that lets you list whom you would like to make decisions about your medical care if you are not able to. Once you have prepared and signed a Living Will and/or a Medical Power of Attorney, make copies and give them to your family members and your medical team. Make a few extra copies for your medical records folder.

When or if you decide to stop treatment, you will still receive medical care to help reduce your pain and maintain a good quality of life. This is called palliative care. Hospice care provides support to you and your family at the end of your life. The goal of hospice is to make your quality of life the best it can be in the time that you have left. Hospice care can be provided at your home, at a hospice facility, or in a hospital. Clergy, counselors, home health aides, nurses, and social workers often work together to provide hospice care.

You may decide to preplan or even prepay your funeral or memorial service. Some details to consider are what kind of service, any particular music or hymns, and your preferences in terms of your physical remains (cremation, burial location, donating your body to the medical community). Write your wishes down and save them either on paper or electronically for your loved ones.

SAYING "SEE YOU LATER" TO FRIENDS AND FAMILY

So, this is the part that no one likes to talk about. Life is a wonderful blessing, and at Tigerlily Foundation, we like to believe that it never ends, and that we transition from a physical, to a spiritual form, and that we can be with our loved ones in a different way. So, transitioning can be looked at as a "see you later" and a new beginning. There are a lot of unknowns, and it isn't to say goodbye for you or your loved ones. So, here is an approach: 1) Live your life now like you never have before - be open, vulnerable, live out loud, love as wide as you can; 2) Make a bucket list and DO IT; 4) Make a list of your favorite memories with your parents, siblings, children, grandchildren and special friends and share your thoughts with them either in writing or by recording video messages to them. If you have children, consider recording advice for them for the future. Tell them how much you love them. If you enjoy scrapbooking, put together a photo book for loved ones of your favorite holidays, travels, or other good times together.

Also, before the time comes, begin a dialogue with your family, including your children about what they are thinking and feeling. Explore the option of adopting a pet or planting a tree together, so they can nurture it, watch it grow and sit under. Leaving your family with happy, living reminders are a great way they can feel close to you, or to help them soften the fear of you "leaving them".

CELEBRATING LIFE

It is challenging not to brood about the past or worry about the future, but as much as possible, try to be present and live in the moment. Consider keeping a gratitude journal and taking time to savor the "little" things in life, like a beautiful sunrise, the ritual of brewing tea, and the changing colors of the seasons. Make time for favorite hobbies and visits with cherished family and friends. Enjoy every breath. Put your hand on your heart - hold it there and "feel" your heart beat. Take in every sight and sound. Enjoy the touch - of heat and cold, hugs, kisses, textures - take it all in. Above all, say all that needs to be said. Laugh. Do it all. Live.



MY LIFE – RESOURCES

There are a variety of resources that provide information about diagnosis/treatment, complementary and alternative medicine, clinical trials, legal resources, financial assistance, , transportation, retreats, housecleaning services, and resources for caregivers and children. We provide a list below

DIAGNOSIS/TREATMENT

AdvancedBC.org
American Cancer Society (Cancer.org)
BCMets.org
BrainMets.org
BreastCancer.org
Cancer.gov
Cancer Support Community (CancerSupportCommunity.org)
Komen (Komen.org)
Living Beyond Breast Cancer (LBBC.org)
Metastatic Breast Cancer Network (MBCN.org)
Metastasis Research Society (Metastasis-Research.org)
Metavivor.org
MetUp.org
National Cancer Institute (Cancer.gov)
Young Survival Coalition (YoungSurvival.org)



CAREGIVERS

Caregiver Action Network (CaregiverAction.org)
My Lifeline (MyLifeLine.org)

CLINICAL TRIALS

BreastCancer.gov/clinicaltrials
BreastCancerTrials.org
Cancer.gov/clinicaltrials
ClinicalTrials.gov
ClinicalTrialsHelp.org

COMPLEMENTARY/ALTERNATIVE MEDICINE

Annie Appleseed (AnnieAppleseedProject.org)
National Center for Complimentary and Alternative Medicine
(nccih.nih.gov)

OTHER

Cancer and Careers (CancerAndCareers.org)
Meal Train (MealTrain.com)

OUR PERSPECTIVE

"This looks like cancer," the radiologist told me as the ultrasound technician stood over me, cold gel at the end of the wand pressing on my right breast. I suddenly felt like covering up, as if I could pull a sheet over myself and make the malignant cells disappear. The technician gave me that "I'm so sorry" look, and all I could blurt out was, "What else could it be?" Cancer wasn't supposed to happen in my life.



No one on my side of the family had ever had any type of cancer, which is probably an anomaly in itself; all of my grandparents and great-grandparents had lived into their eighties or nineties (or are still alive). People don't die in my family so much as wear out sometime around their ninetieth birthday.

I was aware of breast cancer -- who isn't these days? I'd run a couple of 5k races for the cure, but that was the extent of cancer touching my life. I'm lucky, I guess.

I didn't know the first thing about coping with a breast cancer diagnosis at the age of thirty-two. My head was spinning. I had recently become a first-time mom, so my head was spinning from that, too. The day I was diagnosed, I'd had to call my husband to make sure we had enough breast milk in the fridge to tide our son over until I could get home; my appointment was taking longer than I expected and they wanted to send me to radiology for additional tests. Even as I sat in the waiting room, watching Dr. Oz and surrounded by pamphlets on breast cancer, I didn't suspect what was coming.

As I drove home from the radiologist's office that August afternoon, I felt guilty about having to tell my husband, who had lost his dad to pancreatic cancer less than two years earlier. I worried that I'd already passed the cancer on to my son. After all, I'd been nursing him for five months out of what I now thought of as a rotten, cancer-filled breast. My doctors told me not to worry, as if that were possible. I worried I was going to die and leave my little family, but then I thought: It's breast cancer. People beat this all the time. I didn't know the first thing about it.

My husband -- a scientist and professor -- and I began reading everything we could. We learned that the average age of a breast cancer diagnosis is 61. We learned that, while rare, when cancer does strike young women, the survival rate is high. I figured: I'm healthy, so I've already got a leg up. I figured -- naively -- that the one percent or so who didn't make it must have other, underlying health issues. Maybe they didn't tolerate chemo, or were obese, or smokers. I was trying, desperately, to make sense of something frighteningly random.

I'd done yoga until I was seven-and-a-half months pregnant. I'd run two marathons. I graduated from Johns Hopkins University and law school. I'd passed the bar and planned a wedding and moved across country all in the same summer. Cancer has nothing on me, I thought, as if it were a matter of will or endurance.

Because my tumor was about the size of a walnut and as aggressive as they come, my doctors ordered a slew of follow-up scans and tests those first couple of weeks. My breast surgeon was the one who called with the results. She told me as gently as she could that there were spots in my lungs, my spleen, my chest wall, and an area outside my liver called my periportal region. I wasn't sure whether to cry or vomit. My mind was buzzing, and everything started to get dark around me as if I might lose consciousness. I wasn't able to process any of what she was saying, so I passed the phone to my husband and asked my doctor to repeat everything to him.

I had a five-month-old son and Stage IV breast cancer. As I write this, I am on my third course of chemo, a relatively new drug that specifically targets my cancer cells while leaving the rest of my body relatively unscathed. I get to keep my hair this time. And luckily, it appears to be working.

In the four-and-a-half years since my diagnosis, I have been bald twice, lost both my breasts and my fertility, and have had reconstruction surgery and five weeks of daily radiation. My nipples have been replaced by scars, and I don't know if my eyebrows will ever recover the fullness they once had. I have gotten down to no evidence of disease (NED, in cancer-speak) with every chemo, but hotspots have cropped back up as soon as chemo ends. I have scans every four months to check the status of my cancer. I worry about the day my may drugs stop working.

~ Jennifer Campisano

MY LIFE - GLOSSARY

A

Ablation

Removal or destruction of a body part or tissue or its ability to function. An ablation may be performed by surgery, hormones, drugs, radiofrequency, heat, or other methods.

Access Port

A small device implanted under the skin that allows access to your veins; sometimes called a port-a-cath.

Adjunct Therapy

Treatment used in conjunction with primary treatment, to assist the primary treatment. It is also called adjunctive therapy.

Adjuvant Therapy

Additional cancer treatment given after primary treatment to lower the risk of recurrence, which may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.

Advanced Cancer

Cancer that has spread to other places in the body.

Angiogenesis

Blood vessel formation. Tumor angiogenesis is growth of new blood vessels that tumors need to grow, caused by the release of chemicals from the tumor.

Apoptosis

Programmed cell death - Cell death in which molecular steps in a cell leads to its death. This is how the body gets rid of unneeded or abnormal cells. The process of apoptosis may be blocked in cancer cells.

Ascites

Abnormal buildup of fluid in the abdomen that may cause swelling. In late-stage cancer, tumor cells may be found in the fluid in the abdomen. Ascites also occurs in patients with liver disease.

B

Benign

Not harmful.

Biological Therapy

Treatment to boost/restore ability of the immune system to fight cancer, infections, and other diseases. It is also used to lessen certain side effects that may be caused by some cancer treatments. Agents used in biological therapy include monoclonal antibodies, growth factors, and vaccines. These agents may also have a direct antitumor effect. Also called biological response modifier therapy, biotherapy, BRM therapy, and immunotherapy.

Biomarkers

A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease.

Bisphosphonates

A drug/substance used to treat hypercalcemia (abnormally high blood calcium) and bone pain caused by some cancers. Forms of bisphosphonates are also used to treat osteoporosis

and for bone imaging. Bisphosphonates inhibit a type of bone cell that breaks down bone. Also called diphosphonate.

Blood-brain Barrier

A network of blood vessels with closely spaced cells that makes it difficult for potentially toxic substances (such as anticancer drugs) to penetrate the blood vessel walls and enter the brain.

Bone Scan

A technique that creates bone images on computer film. A small amount of radioactive material is injected into a blood vessel and travels through the bloodstream; it collects in the bones and is detected by a scanner.

BRCA1 and BRCA2

These are genes within cells in the body that control the growth of cells. If there are changes called mutations in these genes, there is a greater chance of developing breast or ovarian cancer. These changes, or mutations, can be passed from generation to generation in a family.

C

CAM - Complementary and Alternative Medicine

Treatment are used in addition to (complementary) or instead of (alternative) standard treatments, which are not traditional treatments. They may include supplements, vitamins, herbals, teas, acupuncture, energy treatments, massages, spiritual treatment, reikki and meditation.

Chemotherapy

Systemic treatment with drugs that kill cancer cells.

Clinical Trials

Research done in humans to test a medicine or new treatment to see how well it works and if it is safe.

Chronic condition

A disease that progresses over a long period of time.

Complementary medicine

Non-medical treatments or therapies used in addition to medical treatment.

CT Scan - Computerized Tomography

These are detailed pictures of areas inside the body taken from different angles, created by a computer linked to an x-ray machine. Also called CAT scan, computed tomography scan, computerized axial tomography scan.

D

Disease-free survival

The length of time after treatment for a specific disease during which a patient survives with no evidence of the disease. Disease-free survival may be used in a clinical study or trial to help measure how well a new treatment works. Also called DFS and disease-free survival time.

Duct

The passageways that carry milk from the lobules to the nipple.

Ductal Cancer

Cancer that grows in the ducts of the breast as a mass and may later spread through the duct wall into other breast tissue.

E

Effusion

An abnormal collection of fluid in hollow spaces/between tissues of the body. For example, a pleural effusion is a collection of fluid between the two layers of membrane covering the lungs.

Estrogen

A hormone made in females by the ovaries that has effects on reproduction. Some breast cancer cells may grow in response to this hormone.

G

Gene

Coded information within cells in the body that contain instructions for cell growth and other processes.

Genetics Counselor

A medical professional who specializes in talking with patients and their families about their risks for developing diseases caused by changes in genes.

Growth factors

A substance made by the body that functions to regulate cell division and cell survival. Some growth factors are also produced in the laboratory and used in biological therapy.

H

Hand-foot Syndrome

A technique that creates bone images on computer film. A small amount of radioactive material is injected into a blood vessel and travels through the bloodstream; it collects in the bones and is detected by a scanner.

HER2/Neu

A protein involved in normal cell growth. It is found on some types of cancer cells, including breast and ovarian. Cancer cells removed from the body may be tested for the presence of HER2/neu to help decide the best type of treatment. HER2/neu is a type of receptor tyrosine kinase. Also called c-erbB-2, human EGF receptor 2, and human epidermal growth factor receptor 2.

Hormone

A chemical that is made and released by a gland in the body that affects cells or organs in another part of the body.

Hormone Receptor Status

The measure of hormone receptors on cancer cells.

Hormone Treatment

Treatment that adds, blocks, or removes hormones. For certain conditions (such as diabetes or menopause), hormones are given to adjust low hormone levels. To slow or stop the growth of certain cancers (such as prostate and breast cancer), synthetic hormones or other drugs may be given to block the body's natural hormones. Sometimes surgery is needed to remove the gland that makes a certain hormone. Also called endocrine therapy, hormonal therapy, and hormone therapy.

Hormone Therapy

Medicines that stop the action or production of hormones.

Hospice Care

Caring for the whole person at the end of their lives by supporting their emotional, physical, social, and spiritual needs.

Infiltrating/Invasive Breast Cancer

Cancer that has the ability to spread beyond the breast and nearby lymph nodes.

In situ cancer

Cancer that has not invaded the walls of the ducts or acinus. It is also called stage 0, or non-invasive, cancer.

L

Lobule

The glands that produce breast milk.

Lobular Cancer

Cancer that starts in the acinus of the lobule but does not cause scar tissue or form a mass, making it harder to find.

Local Therapy

Treatments that are directly targeted to and affect cells in and around tumors.

M

Malignant

Cancerous.

Metastasize

Spread beyond the breast or nearby lymph nodes to distant areas of the body.

Medical Oncologist

A doctor who specializes in treating cancer with medicines.

Metastatic

Cancer that has spread beyond the original location to other parts of the body.

MRI - Magnetic Resonance Imaging

A procedure in which radio waves and a magnet linked to a computer creates detailed pictures of areas inside the body, which can show the difference between normal and diseased

Magnetic resonance imaging makes better images of organs and soft tissue than other scanning techniques, such as computed tomography (CT) or x-ray.

Median Survival Time

The time from diagnosis or treatment at which half of the patients with a disease are found to be, or expected to be alive. In a clinical trial, median survival time is one way to measure how effective a treatment is. Also called median overall survival and median survival.

Medical Oncologist

A physician specializing in diagnosing and treating cancer using chemotherapy, hormonal therapy, biological therapy, and targeted therapy. The medical oncologist may also be the main treating physician, and can also provide and/or coordinate the treatments given by other specialists.

Monoclonal antibodies

A protein made in the laboratory that can locate and bind to substances in the body, including tumor cells. Each monoclonal antibody is made to find one substance. Monoclonal antibodies are being used to treat some types of cancer and are being studied in the treatment of other types. They can be used alone or to carry drugs, toxins, or radioactive materials directly to a tumor.

N

NED

A period where tests show no evidence of disease.

Non-invasive

Cancer that stays within the ducts or lobules of the breast. Also called in situ or stage 0 cancer.

NSAID - nonsteroidal anti-inflammatory drug

A drug that decreases fever, swelling, pain, and redness.

Neuropathy

A nerve problem that causes pain, numbness, tingling, swelling, or muscle weakness in different parts of the body. It usually begins in the hands or feet and can worsen or improve over time.

O

ONJ - Osteonecrosis of the Jaw

Cancer patients taking certain bone drugs called bisphosphonates may develop bone damage in the jaw, which disrupts the blood supply to the bone, causing tiny breaks that can eventually lead to bone collapse.

Oophorectomy

Surgery to remove one or both ovaries.

Opioid

A substance used to treat moderate to severe pain. Opioids are like opiates, such as morphine and codeine, but are not made from opium.

Opioids bind to opioid receptors in the central nervous system. Opioids used to be called narcotics. An opioid is a type of alkaloid.

Osteoblastic/Osteolytic Bone Metastases

Metastatic bone lesions are also known as osteolytic, osteoblastic and mixed, and are most common where the destructive processes outstrip the laying down of new bone. Osteoblastic lesions result from new bone growth stimulated by the tumor.

Ovarian Ablation

Surgery, radiation therapy, or a drug treatment to stop the functioning of the ovaries. Also called ovarian suppression.

P

Palliative Care

Medical care given to reduce pain and maintain the best quality of life.

PARP Inhibitor

A substance that blocks an enzyme involved in functions of the cell, including repair of DNA damage, which could have been caused by normal cell actions, UV light, some anticancer drugs, and radiation used to treat cancer. This is a type of targeted therapy, that may cause cancer cells to die. Also called poly (ADP-ribose) polymerase inhibitor.

Pathology report

A profile of your test results that helps doctors figure out treatment plan.

PET Scan

A procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body. Also called positron emission tomography scan.

PICC Line

A thin, flexible tube inserted into a vein in the arm and into a larger vein in the body, used to administer chemotherapy treatment.

Placebo-controlled Studies

Clinical trials in which one group of participants does not receive the treatment being tested so that researchers can compare the new treatment against standard treatments.

Primary Diagnosis

The first diagnosis of breast cancer.

Progesterone

A hormone made in females by the ovaries that has effects on reproduction. Some breast cancer cells may grow in response to this hormone.

Progression

The course of a disease. In cancer, the growth of tumors or spread of the disease.

Progression Free Survival

The length of time during and after treatment in which a patient is living with a disease that does not get worse. Progression-free survival may be used in a clinical study or trial to help find out how well a new treatment works. Also called PFS.

Proliferation Index

A number that shows what percentage of the cancer cells are actively dividing at a given time.

Q

Quality Life

The quality of an individual's daily well-being.

R

Radiation Oncologist

A doctor who specializes in treating cancer with radiation.

Radiation Therapy

The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors.

Radiation may come from a machine outside the body (external-beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy). Systemic radiation therapy uses a radioactive substance, such as a radio-labeled monoclonal antibody, that travels in the blood to tissues throughout the body. Also called irradiation and radiotherapy.

Radiofrequency Ablation

A procedure using radio waves to heat and destroy abnormal cells. The radio waves travel through electrodes. Radiofrequency ablation may be used to treat cancer and other conditions.

Recurrent Disease

Cancer that has come back.

Regression

Decreases in the tumor size or spread of cancer.

S

Side Effect

Unwanted effect caused by medicines or treatments, including emotional and physical

Stages of Breast Cancer

These describe the extent of the cancer in the body, and is based on whether the cancer is invasive or non-invasive, tumor size, lymph node involvement, and whether or not it has spread to other body parts. Cancer staging is one of the key factors that allow healthcare providers to determine prognosis and treatment.

Staging

Performing tests to determine extent of the cancer within the body, especially whether the disease has spread from the original site to other parts of

the disease in order to plan the best treatment.

Systemic Therapy

Medicines/treatments that treat the whole body by traveling through the bloodstream.

T

Targeted Therapy

Treatment that uses drugs or other substances, such as monoclonal antibodies, to identify and attack specific cancer cells. Targeted therapy may have fewer side effects than other types of cancer treatments.

Treatment Breaks

Short breaks in treatment that allow for rest or for special events.

Tumor Marker

A substance that may be found in tumor tissue or released from a tumor into the blood or other body fluids. A high level of a tumor marker may mean that a certain type of cancer is in the body. Examples of tumor markers include CA 125 (in ovarian cancer), CA 15-3 (in breast cancer), CEA (in ovarian, lung, breast, pancreas, and gastrointestinal tract cancers), and PSA (in prostate cancer).

V

VEGF

A substance made by cells that stimulates new blood vessel formation. Also called vascular endothelial growth factor.

MY LIFE - NOTES

MY LIFE - NOTES *(CONTINUED)*

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