

Letter from Dr. Lin

EARLY IN MY TRAINING, A SENIOR physician shared with me that he always strived to help patients “hope for the best, but prepare for the worst.” It’s a tricky balance, and can change over time. In this issue of the EMBRACE newsletter, you will be able to read about new drugs approved by the FDA within the past few years for treatment of metastatic breast cancer, and how researchers and patients at Dana-Farber have been involved in some of the key clinical trials leading to their development. At the same time, having a cancer diagnosis brings many important questions to the table. How will you feel physically? What can be done to manage symptoms related either to your cancer or your treatment? What are some strategies to cope emotionally? When should you ask for help and what resources are available? Many patients also have questions about how to designate a health care proxy, what is involved in creating a living will, and how to communicate their wishes for medical care.

I hope that you will find this issue to be thought-provoking. Perhaps it will prompt discussions between you and family members and with your health care team. We all understand that living with metastatic breast cancer can sometimes feel like riding a roller coaster, but as health care providers, we don’t want you to worry in silence, and we promise to accompany you on this journey every step of the way.

Warm regards,
Nancy Lin




The power of palliative care

MISCONCEPTIONS ABOUND ABOUT PALLIATIVE CARE. WHAT IS IT, EXACTLY? WHO SHOULD BE GETTING IT? AND WHEN?


PALLIATIVE CARE IS ABOUT HELP AND SUPPORT.

Quite simply, palliative care provides an extra layer of help and support for patients concerned about quality-of-life issues. Palliative care also provides support for questions and decisions about end-of-life care.

IT IS AVAILABLE AT EVERY STAGE OF ILLNESS.

Palliative care is available from diagnosis through treatment and into the final stages of life. A 2010 study of advanced lung cancer patients found that the use of palliative care from the beginning of treatment resulted in better outcomes, including decreased depression, and that it even lengthened survival.

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EMBRACE at-a-glance

ENROLLMENT

With our increasing EMBRACE enrollment, we are getting close to our goal of approaching every patient at DFCI who is diagnosed with metastatic breast cancer and offering the opportunity to participate in the EMBRACE study.

TUMOR SUBTYPES

There are three major subtypes of breast cancer that your doctor considers in choosing the appropriate treatments for you:

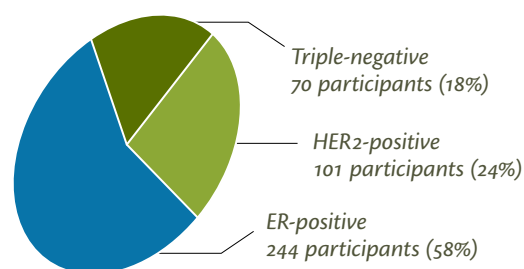
- Estrogen receptor (ER)-positive breast cancer is estrogen and/or progesterone receptor positive, and HER2-negative
- HER2-positive breast cancer is HER2-positive and can be either estrogen receptor positive or negative
- Triple-negative breast cancer is negative for the estrogen receptor, progesterone receptor, and HER2

If you have questions about which subtype of breast cancer you have, talk to your doctor.

Number of EMBRACE participants



Tumor subtypes of EMBRACE participants for whom we have data



Newly approved treatments for metastatic breast cancer

OVER THE PAST THREE YEARS, THANKS TO THE MANY PATIENTS WHO HAVE PARTICIPATED IN CLINICAL TRIALS, FOUR NEW DRUGS HAVE BEEN APPROVED FOR TREATMENT OF METASTATIC BREAST CANCER. MANY MORE DRUGS CONTINUE TO BE STUDIED IN CLINICAL TRIALS FOR FUTURE BREAKTHROUGHS.

Eribulin (Halaven) is a chemotherapy drug that is typically given intravenously for two weeks in a row followed by a one-week break. Eribulin was studied in a phase 3 clinical trial with patients who had received at least two prior chemotherapy treatments for advanced breast cancer. Patients with any breast cancer subtype (hormone receptor-positive, triple-negative, or HER2-positive) were allowed to enroll. In the study, eribulin was compared to “treatment of provider choice,” meaning that patients who were not assigned eribulin were able to receive standard chemotherapy or other treatment as recommended by their doctor. On average, patients who received eribulin lived longer than patients who received standard treatment. Side effects included low blood counts and neuropathy. The FDA approved eribulin in November 2010.

Everolimus (Afinitor) blocks a pathway (mTOR) that may help cancers become resistant to hormonal

therapies. The combination of exemestane (Aromasin) and everolimus was compared to exemestane by itself in a phase 3 clinical trial that enrolled patients with hormone-receptor positive breast cancer. Patients who received the combination treatment experienced a longer time period before their tumors grew—about a five- to six-month difference compared to patients who received exemestane on its own. Side effects included mouth sores, tiredness, rash, and diarrhea. The FDA approved everolimus in August 2012. This combination is an option for patients whose tumors have gotten worse through other hormonal treatments.

TWO NEW DRUGS SPECIFICALLY FOR PATIENTS WITH HER2-POSITIVE BREAST CANCER

Pertuzumab (Perjeta) is an antibody treatment that works with trastuzumab (Herceptin) and chemotherapy. In a phase 3 clinical trial, patients who received pertuzumab, trastuzumab, and docetaxel (a chemotherapy drug) experienced a longer period of disease control compared to patients who received trastuzumab and docetaxel without pertuzumab, and also lived longer. It is important to note that this trial was limited to patients who had not yet received any other chemotherapy for advanced breast cancer. The FDA approved pertuzumab in June 2012.

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Meet:

Douglas Brandoff, MD

Director, Adult Palliative Care Clinic

How does DFCI's adult palliative care clinic director feel about his work? His answer comes easily: "I love what I do," says Douglas Brandoff, MD.

Brandoff is one of several clinicians who see patients in the adult palliative care clinic. His charge? To "listen, explore, validate, and intervene" as needed for a patient. Palliative care clinicians work closely with a patient's care team to provide expertise managing symptoms at any stage of illness and to offer guidance in coping with uncertainty.

Brandoff found his way to palliative care during a hematology/medical oncology fellowship at Brown University, where he "felt drawn to the human experience of patients living with cancer," and wanted specialty-level expertise to manage symptoms and psychosocial distress. As part of his training, he worked with hospice nurses who provided home-based care for cancer patients, and he conducted research on end-of-life care issues. This experience inspired him to pursue a palliative care fellowship at Massachusetts General Hospital. He has been on-staff at DFCI since 2006, and carries board certification in hospice and palliative medicine, medical oncology, and hematology. "My oncology background helps me understand the issues patients face," he says. "I speak the language, so I can work together with patients and their care teams to address the human impact of cancer."

Brandoff's favorite aspects of his work include helping people feel more physically comfortable and creating a bond that encourages patients to share their hopes, goals, and fears. He also enjoys learning about patients' backgrounds, personal interests, and "what brings them purpose, meaning, and excitement."

His challenges include persistent misconceptions about palliative care—such as that merely thinking about death and dying will make it happen sooner, or bring about severe depression. "We can discuss these issues in a way that not only preserves hope, but alleviates many fears patients have around cancer."

When asked whether his work is depressing, he points out the rewards of helping people in times of great need and vulnerability. He also has the satisfaction of seeing a patient's empowerment after developing a plan to manage their symptoms and cope with the uncertainty of a cancer diagnosis.

Health care proxy

HAVE YOU COMPLETED YOUR HEALTH CARE PROXY FORM? IF NOT, HERE IS A QUICK INTRODUCTION TO WHY THIS LITTLE FORM IS SO IMPORTANT.

WHAT IS A HEALTH CARE PROXY FORM?

It is a simple legal document that allows people 18 and older to name someone they trust to speak for them if they can't make medical decisions on their own. The person you identify on the form is your "health care proxy."

WHO SHOULD FILL OUT A HEALTH CARE PROXY FORM?

Everyone! At DFCI, we believe that everyone should have a health care proxy, no matter what their health status is. Having a proxy helps ensure that your wishes will be followed for your care.

WHAT IF I DON'T LIVE IN MASSACHUSETTS?

Even if you don't live in Massachusetts, if you receive your care at DFCI you can still use the form to designate your proxy.

BUT I ALREADY HAVE A POWER OF ATTORNEY; I DON'T NEED A PROXY, RIGHT?

You should still have a health care proxy. The form is the preferred legal document in Massachusetts to identify whom you want to make medical decisions if you can't make them yourself.

WHERE DO I GET A FORM, AND WHAT DO I DO WITH IT AFTER I FILL IT OUT?

Anyone on your care team can give you a form. Once you've filled it out, keep the original and give a copy to a member of your DFCI care team, who will add it to your medical record.

WHAT IF I CHANGE MY MIND ABOUT WHOM I CHOOSE AS MY HEALTHCARE "AGENT"?

You can change or cancel your proxy at any time by filling out a new form and giving it to your DFCI care team.

WHAT IF I DON'T KNOW WHO TO PICK?

Think about who you would trust to make medical decisions for you if you couldn't speak for yourself (for example, if you were temporarily unconscious). A proxy is usually a relative or close friend, but could be any competent adult, apart from someone who works at the facility where you get care (according to Massachusetts law).

I'D RATHER NOT DO THIS RIGHT NOW—IT'S UPSETTING TO THINK ABOUT!

We understand that thinking ahead can be difficult, but it may help you decide what health care choices are best for you, and it can spark important conversations with loved ones about what you want. Making your wishes known in advance can give you a sense of security and confidence that your wishes will be respected.

I HAVE QUESTIONS ABOUT THE FORM; WHOM SHOULD I ASK?

Anyone on your care team can answer your questions. You may also speak to DFCI social workers, patient/family relations specialists, and palliative care consultants. Your care team can connect you with these resources.



Meet Sairah Mahmud

TITLE EMBRACE Clinical Research Coordinator

JOINED EMBRACE October 2012

YOU MIGHT INTERACT WITH HER Most often I interact with patients in an exam room or in infusion. I also get the opportunity to connect with patients informally all over the hospital.

FAVORITE ASPECT OF HER WORK Talking with patients. Every day I meet people who inspire me and teach me something new about life, courage, and resilience. I feel honored to be part of EMBRACE.

FUN FACT My background is very diverse. My family comes from six countries: Ireland, Mongolia, Pakistan, Turkmenistan, India, and England.

Get EMBRACE updates via email

Do we have your email address? Please share it to receive email updates. Email us at embrace@partners.org.

Thanks for another great forum!

Thank you to all our 2013 Metastatic Breast Cancer Forum participants. If you were unable to attend, you can still participate by watching the webcast at: video.dfcionline.org/accordent/MBCFONE100513 (first session) and video.dfcionline.org/accordent/MBCFTWO100513 (second session).

EMBRACE webcast

Based on your feedback at the 2012 Metastatic Breast Cancer Forum about the need for more online resources, we launched our first webcast!

TITLE Targeting Advanced Triple Negative Breast Cancer

SPEAKERS Introduction by Dr. Nancy Lin, presentation by Dr. Erica Mayer

TOPICS

- Defining triple negative breast cancer, including what makes it different from other breast cancer subtypes
- Optimizing therapy, highlighting new developments for chemotherapy and biologic targeted therapy
- Participating in clinical trials

LENGTH About 30 minutes

WATCH IT video.dfcionline.org/accordent/AdvancedTripleNegative071913

Suggestions? Please email us with suggestions for future webcasts at embrace@partners.org.

New treatments

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Trastuzumab emtansine (TDM₁, Kadcyla) is a new type of medicine in which a chemotherapy drug is attached to trastuzumab (Herceptin). The idea is that the trastuzumab will bring the drug to the HER2-positive cancer cell, where the cell will “swallow” the drug and release the chemotherapy medicine directly into the cancer cells, while sparing normal cells in the body. TDM₁ was studied in a phase 3 trial that compared it to the combination of lapatinib (Tykerb) and capecitabine (Xeloda) in patients whose cancer had worsened on trastuzumab plus a taxane (for example, Taxol or Taxotere). Patients who received TDM₁ experienced a longer period of disease control and lived longer than patients who did not receive TDM₁. In general, the side effects were notably mild, with no hair loss and minimal nausea. Some patients experienced drops in some of their blood counts, especially the platelets, and increases in liver blood tests were also noted in some patients. The FDA approved TDM₁ in February 2013.



Dana-Farber researchers and patients have been involved with the development of many of these new drugs. Many other potentially useful breast cancer drugs are in clinical trials today, and we hope these will lead to more advances in the future. While progress sometimes feels very slow, it is gratifying to see new treatments make it from the lab to clinical trials and then into standard clinical care. With your help, we are committed to accelerating this progress as much as we possibly can.

Palliative care

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DFCI’s Adult Palliative Care Clinic Director Douglas Brandoff, MD, has seen that connecting patients with the palliative care team *before* a crisis develops can proactively address likely symptoms and patient anxiety. Palliative care can also help patients explore unanswered questions about treatment, as well as a patient’s hopes, goals, and fears, and ways to address them.

PALLIATIVE CARE CAN HELP WITH PHYSICAL CHALLENGES.

The palliative care team has expertise in physical symptom management—including pain, fatigue, nausea, vomiting, constipation, diarrhea, insomnia, cough, itching, poor appetite, poor sleep, breathlessness—whatever a patient may be facing.

PALLIATIVE CARE ENHANCES YOUR EXISTING CARE TEAM.

The palliative care team doesn’t replace any doctors or a patient’s current care team; they provide a welcome supplement. Palliative care is highly collaborative; the team works and communicates with a patient’s entire care team, both behind the scenes and with the patient directly.

PALLIATIVE CARE IS NOT JUST FOR PATIENTS.

The palliative care team includes families, if a patient wishes, as part of their consultation process.

HOW CAN I CONNECT WITH PALLIATIVE CARE?

Not every DFCI patient needs a special palliative care team. DFCI oncology staff provide a primary level of assistance with many palliative care and symptom management issues. We encourage you to work with your care team, express your needs, and ask whether a palliative care consult would be right for you.

COVER PHOTO: THE PALLIATIVE CARE TEAM

From left to right:

John Halporn, Maureen Lynch, Douglas Brandoff, Deborah Whalen, Vanessa Pugh, and Bridget Scullion

EMBRACE



ENDING METASTATIC BREAST
CANCER FOR EVERYONE

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