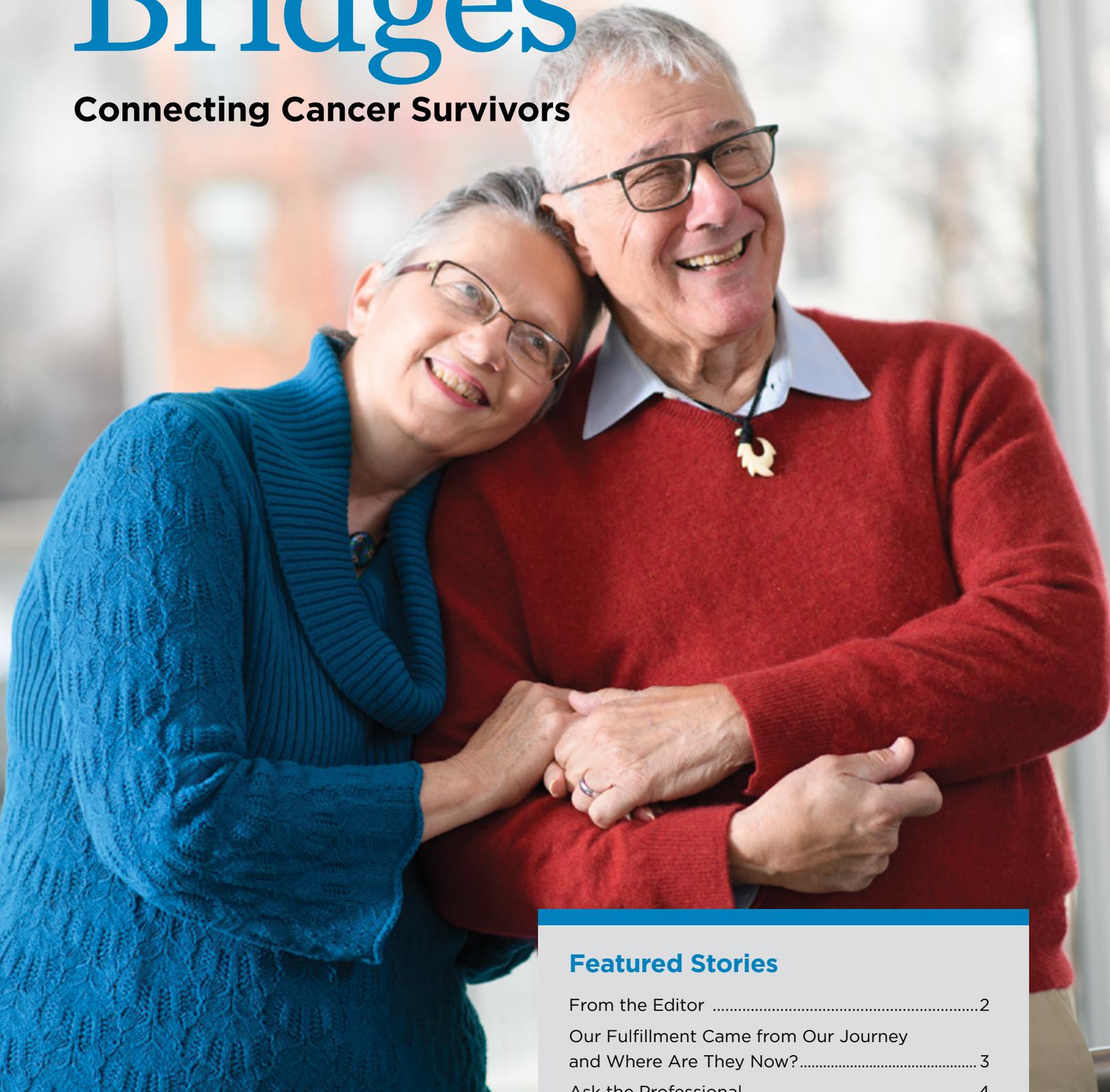


Celebrating  
Ten Years!

Summer 2018, Vol. 41

# Bridges

Connecting Cancer Survivors



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Memorial Sloan Kettering  
Cancer Center

## From the Editor

By Eileen F. Gould



Left to right: Larissa Regala, Eileen Gould, and Alexandria Woodside.

## We are celebrating the tenth anniversary of *Bridges*, a newsletter for and about cancer survivors.

We are celebrating the tenth anniversary of *Bridges*, a newsletter for and about cancer survivors. What started as an idea for a volunteer project has developed into an award-winning publication. *Bridges* has published 40 issues so far. All told, this includes approximately 160 patient stories and 40 Ask the Professional and Ask the Survivor articles. We thank all of the patients and caregivers who have shared their stories of hope and survival with our readers. We also appreciate all the experts who have offered their wealth of knowledge and expertise on the topics that survivors face post-treatment. The newsletter has more than 3,300 online subscribers. We print 8,000 copies of each issue, distributing them to all of the MSK locations in three states.

In addition to all of those who have submitted stories and articles during

the last ten years, this newsletter would not be possible without the efforts of the stellar editorial staff. We thank the senior designer Larissa Regala, MSK photographer Rick Dewitt, and the current managing editor, Alexandria Woodside. All of their talents, as well as those of the two previous managing editors, Katie Decker and Meghan Newcomer, have been part of this collaborative effort. Furthermore, we benefit from a very dedicated Advisory Committee. The advice and time of these staff, patients, caregivers, and volunteers are greatly appreciated in preparing the newsletter.

After ten years, there are some visual changes with *Bridges*. This new era starts with this issue. We hope the design will streamline the newsletter for easier reading. We thank the creative team for their suggestions. We also want to thank past committee

member Duane Bailey-Castro for allowing us to use his beautiful Brooklyn Bridge photo all these years.

I started as patient editor in 2008. At that time I was a 30-year survivor of Hodgkin lymphoma and breast cancer. Having been first diagnosed at age 21, I have encountered the multiple late effects of treatment. I envisioned the newsletter as a publication for those facing cancer, so they would know there were others who had been down the same path, had completed treatment, and could share their experiences with those newly diagnosed. As I write this 40th editorial, I am now a cancer patient again. I was recently diagnosed with non-Hodgkin lymphoma and am undergoing treatment. The lesson learned is that the definition of being a cancer survivor has certainly changed over the last ten years since starting *Bridges*.

It can mean different things to different people. According to the National Cancer Institute, “an individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life.” One of the biggest differences from when I was first diagnosed and now: No one talked about cancer then, certainly not young adults. There were no forums to do so. Today, there are many programs at MSK for patients to discuss their cancer experience. We have the *Bridges* newsletter, writing programs like *Visible Ink*, and in-person and virtual online support groups. I am now both a cancer survivor and a cancer patient as I travel the World of Cancer again at MSK. I continue to be grateful to be a patient at this premier institution. I look forward to sharing many more stories and articles of hope and survival in *Bridges* and continuing my role as patient editor.

# Our Fulfillment Came from Our Journey

By Karen May and John Marra

After 28 years of marriage, couples counseling, and relationship workshops, Karen May and John Marra thought their relationship was pretty strong. However, in December 2016, Karen was diagnosed with breast cancer, and they went from being a couple consisting of Karen and John to being a patient and caretaker. They quickly realized that the communication skills on which they had built their marriage would now truly be tested.

Right away, death was the proverbial elephant in the room that no one mentioned but both of them thought about. Karen was in shock over the uncertainty of this huge unknown. John spent weeks trapped inside

thoughts that all started with “When she dies ... .” Thankfully, their medical providers at MSK assured them that since the cancer had been caught before it metastasized to other organs, their road would be long but not fatal. They shifted to hope.

They made a conscious decision to try to think about health, especially as it applied to their relationship. They did this by challenging themselves to think beyond health as an individual matter and ask, “What might ‘couple health’ look like?” The draining effect of chemotherapy on Karen’s energy,



Karen May was diagnosed with breast cancer just as she was looking forward to retiring from her IT career. Her husband, John Marra, was by her side and caring for her the whole time. They love traveling together and have several trips planned in the near future. They are part of several groups that focus on relationships and growth.

mobility, and appetite meant that their new normal became a life in which Karen, the patient, went through all the treatments and what they did to her body, and John, the caretaker, did all the other work — cooking, cleaning, laundry, shopping, driving.

■ *Continued on page 5*

## Where Are They Now?

By Teresa Levitch



My achievements are modest. I now fancy myself as a writer. My writing was chosen to be performed at a *Visible Ink* live performance at MSK. Some other work has been published. I am proud to be a member of the Patient-Centered Outcome Research Network Cardiovascular Health Collaborative. I won a full scholarship to the conference in New Orleans.

I continue to be surrounded by loved ones. The joy of my grandson’s laugh as he clings to me while my husband plays monster is indescribable. My daughters’ kind and strong natures continue to make me proud.

My husband is still the love of my life. Friends forgive my lapses of memory when I appear at their doorstep on the wrong day.

Survivorship issues continue to be a large part of my life. Fighting the pain, fatigue, and other health issues is a daily struggle. I begin to feel sorry for myself. After my pity party, I think of friends lost to cancer. I am sure they would accept my 20 years with survivorship issues without complaint. As a tribute to those who never were able to experience more time, I am reminded that I am one of the lucky ones.

## Ask the Professional:

# Communicating with Your Healthcare Team in Survivorship

By Patricia Parker, PhD



Patricia Parker is an associate attending psychologist and Director of the Communication Skills Training and Research Program at MSK. The program aims to improve communication between doctors and patients and their families. Better communication can affect a person's overall cancer experience. The program also supports research in healthcare communication. Dr. Parker's other research interests are decision-making and psycho-oncology.

## Why is communication so important?

Being diagnosed and living with cancer has many challenges for patients and their family members. This continues even after active treatment ends. People who have had cancer may have a variety of emotions. These can include fear, anxiety, and uncertainty throughout the survivorship period. Good communication between survivors, family members, and care

teams can make this experience a little easier and help survivors get the best care possible. Specifically, good communication between survivors and doctors can have many benefits. Studies have shown that when there is effective communication between cancer doctors and their patients, the patients tend to be more satisfied with their care. They feel more informed and are more likely to follow through with their treatment.

## What are the unique communication challenges during cancer survivorship?

Going from cancer patient to cancer survivor is often confusing. People may have many mixed emotions. After months of frequent visits and close care during treatment, people often have questions about moving forward. What doctor should they go to if they have symptoms or concerns? What is the frequency of follow-ups? Who monitors their follow-up care? What tests or screenings are recommended? What should they share about their cancer and treatment experience with other doctors? These answers may be given as treatment ends, but survivors often have additional questions that leave them feeling unprepared. One way to help is to make a list of questions before treatment ends and review it with your doctor or another member of the care team. Additionally, a treatment summary and care plan is often provided for survivors and their local doctor. Survivorship care plans typically have key information about the cancer, treatments, recommended screening, and other behavioral or health recommendations. This can also be shared with other care providers and help start a discussion about survivorship concerns.

■ *Continued on page 5*

Karen and John saw how, in the past, it would have been easy for either one of them to feel resentful in this situation, or that things were unfair.

Karen and John saw how, in the past, it would have been easy for either one of them to feel resentful in this situation, or that things were unfair. Instead, they found peace in the understanding that Karen was doing what she needed to do, that John was doing what he needed to do, and that their relationship was operating by fulfilling the patient and caretaker roles. There was no need to question fairness and no temptation to feel resentful because they were both all-in.

Their oncologist warned them that during chemo treatment Karen would experience the doldrums, several weeks of extra debilitating discomfort

and exhaustion. Indeed, Karen hit this phase right on schedule and found that she could do almost nothing independently. Suddenly, she needed to ask for John's help constantly, and him saying no was not an option. So John chose to be generous, fully embracing saying yes for the rest of treatment.

Karen's new dependence on John made constant requests both unavoidable and a source of guilt, since Karen felt needy, not deserving, or too demanding. This showed up in how she communicated those requests. They worked on both the language used to make requests and also the way those requests were received, so

they occurred not as favors asked for or given but rather as part of the flow of their relationship.

John and Karen can see that they started this process with a strong foundation. From the beginning of this cancer journey, they naturally spoke of the diagnosis as "our diagnosis." The appointments, the surgeries, and the outcomes were all theirs, and the impact of this was that Karen has never felt alone in this journey ... and neither has John.

Their treatment journey was completed with radiation in October, and now the next phase is concentrating on decreasing the chances of recurrence. They know they will get through it together, and they feel enormously grateful for the past, present, and future ways in which their friends and family and the work they've put into their marriage have contributed to the healing process.

### What can survivors do to get the most out of a visit with their doctor?

First, it may be useful to think about the most important questions they have ahead of time and write them down. Bringing this list of concerns to the visit and using the list to guide the conversation with the doctor is often helpful. Having questions written down will help make sure that there is time to discuss the most important issues. If survivors have specific questions ready in advance, it is better to ask them early in the visit rather than as the doctor is walking out of the room.

Every person is different. Doctors or other members of the care team may not know what survivors most want or need from a visit or what specific concerns they have. Hopefully, doctors will ask specific questions or ask about concerns and create a supportive environment. However, even if not asked, it is important that survivors speak up. Let the doctor know about specific questions or concerns. Before leaving the visit, check with one of the members of the team about how to get in touch about any questions that come up after a visit.

### Visible Ink™

#### A One-on-One Writing Program for MSK patients

Interested patients will work individually with the guidance, encouragement, and support of a professional writer on a topic and project of their choice. This program is FREE. All levels and writing interests welcome.

For more information or to arrange a writing session, please contact Judith Kelman at 212-535-3985 or [kelmanj@mskcc.org](mailto:kelmanj@mskcc.org).

#### Patient and Caregiver Volunteer Program

The Patient and Caregiver Volunteer Program connects current patients and caregivers to volunteers who have experienced a similar diagnosis or circumstance related to cancer. If you are a former patient or caregiver of someone who has completed treatment, please consider becoming a Patient or Caregiver Volunteer.

For more information, contact Wendy Bonilla at 212-639-5007 or [patient2patient@mskcc.org](mailto:patient2patient@mskcc.org).



## A Dragon Changed My Life

By Susan Shaw

I tried to keep in shape during treatment because I realized how important it was —is — to try to keep myself as strong as possible.



Susan Shaw is an award-winning artist and writer. Her artwork is in public collections around the world. She discovered she had cervical cancer in 2013 and had the whole trifecta of surgery, radiation, and chemotherapy at Memorial Sloan Kettering. Now recovered, she joined the Empire Dragon Boat Team three years ago and is in the best shape of her life.

I tried to keep in shape during treatment because I realized how important it was —is — to try to keep myself as strong as possible. Every day after radiation I would make myself walk to the gym and take a water aerobics class. It was wonderful to feel the cool water week after week as the radiation burn built up. Very weak after treatment, I worked with a personal trainer to build up strength. I looked around for more sports to try.

At one of the survivorship celebrations, I discovered that MSK has a dragon boat team that practices on the water in Flushing Bay. A dragon boat holds 22 people: 20 paddlers, a drummer (to keep us all in sync), and a helmsperson. We don't just practice. During the summer we race in events up and down the Northeast corridor. On Wednesday evenings and Saturday mornings, the team goes out on the water for training. We practice hard, paddling all around Flushing Bay. It's quite a workout; you have to push with your legs; you bend and twist, extending your arms; you use your core and back muscles to pull the paddle to make the boat glide. Flushing Bay deserves its name because it is the recipient of what is called CSO, combined sewage overflow. But it's water.

Dragon boat racing is a sport that started in China but spread worldwide via Canada, where doctors recognized how the act of paddling could help breast cancer survivors regain their strength. Breast cancer survivors have their own women's division to race in,

and this year the Empire Dragon Boat Team started a mixed gender, mixed survivors of cancer boat. We have six paddlers so far (I am one of them) and can accommodate 16 more to become New York City's first ever ACS (all cancer survivors) racing boat.

The evening practices are my favorite. We paddle until the sun goes down. We bought a new boat that is solid red, the red shade of vintage cars they used to call candy-apple red. One evening I noticed how the reflected light colored the paddlers' hands. It was a transcendent moment. I thought the red hands represented the blood of a beating heart. When we are paddling together in sync, we are pumping that life blood through the team, and the dragon's beating heart is keeping body and spirit alive.

If you are interested in learning more about the Empire Dragon Boat Team, please contact Donna Wilson at [empiredragonsinfo@gmail.com](mailto:empiredragonsinfo@gmail.com).

## Resource Review:

# Mind-Body Therapies and the Meditation Station

By Christina Seluzicki, MBE

Many people having treatment for cancer are focused on the next step in their care, whether that's a therapy session or a doctor's appointment. After treatment is complete, they often find that their body and mind may have changed as a result of the cancer. It is here, in survivorship, that men and women may face an altered identity and confront their own mortality. They may also struggle with fatigue, sleep disturbance, anxiety, pain, and brain fog. These symptoms can significantly affect their quality of life. Stress can make it worse.

Mind-body therapies include meditation, yoga, Tai Chi, and Qigong. This group of healing practices improve the mind's connections with the body. They bring about feelings of relaxation and improve overall health and well-being.

**They bring about feelings of relaxation and improve overall health and well-being.**

Cancer survivors may find that these therapies help them control their symptoms. To support people in their new phase of survivorship, MSK's Integrative Medicine Service has assembled a collection of mindfulness practices.

These are available on a computer, tablet, or smartphone on the new Meditation Station at [www.mskcc.org/meditation](http://www.mskcc.org/meditation). The selections are suitable for absolute beginners and experienced meditators alike. People can choose from a wide range of practices regardless of their location, physical condition, or previous experience. Options include mindful movement, breathing exercises, music therapy, and visualization practices.

People often wonder what it means to meditate. It is actually a very simple practice in which we learn to befriend our inner life and all aspects of ourselves. You can do this by concentrating on the breath, a sound, a phrase, movement, art, or nature. Many people who meditate for the first time expect an experience that is blissful and relaxing.

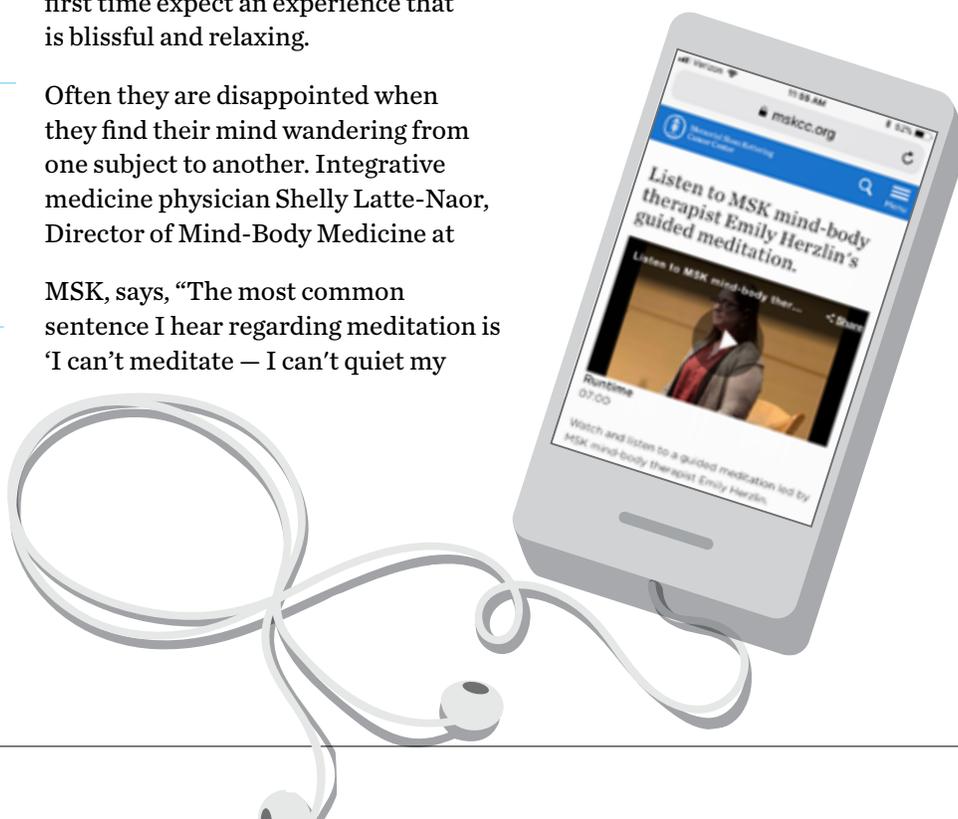
Often they are disappointed when they find their mind wandering from one subject to another. Integrative medicine physician Shelly Latte-Naor, Director of Mind-Body Medicine at

MSK, says, "The most common sentence I hear regarding meditation is 'I can't meditate — I can't quiet my

mind.' It is completely normal for meditation to sometimes be quite challenging, and having guidance can help with the learning process. We are here to support you along the way."

The Integrative Medicine Service offers a variety of therapies, classes, and workshops. We are here to help patients and survivors manage symptoms associated with cancer and its treatments. Our service can help improve your physical and psychological well-being.

Call 646-888-0800 to learn more. To schedule an appointment with an integrative medicine doctor, call 646-888-0845.



# Survivorship Insights

“The best thing I’ve learned as a survivor is patience.”

— David

“The best thing a fellow survivor told me was you can feel whatever you want without judgment. If you want to cry, cry; if you are angry, be angry; and if you want to laugh, laugh loud!”

— Valerie

“The best thing a fellow survivor told me was that we will never again take for granted every morning that we wake up in good health.”

— Alexandra

“The best thing I’ve learned as a survivor is the need to cultivate a broad view about life. Survivorship should inspire us to not take life’s irritations so seriously.”

— Anonymous

“The best thing a fellow survivor told me was you are not alone. For many years, I operated in a vacuum and never spoke to other Hodgkin’s survivors. Once I met a fellow survivor who was highly educated about survivorship, a whole new world opened up to me. I found my people and have enjoyed their camaraderie and support ever since.”

— Anonymous

“The best thing a fellow survivor told me was that I inspired her after she saw a performance of my poem in the 2015 *Visible Ink* anthology. She admired my courage and is now a published member. Every year when we meet, she always gives me a big hug and thanks.”

— Ann

“The best thing I’ve learned as a survivor is that at the toughest times things seem impossible, but I had to push myself mentally and physically so I would be able to get well and eventually leave the hospital and go on with my life as a student and a kid.”

— Klaus

“The best thing I’ve learned as a survivor is that life is always precious and nothing should ever be taken for granted.”

— Anonymous

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## Memorial Sloan Kettering Blood Donor Program

Help MSK patients by donating blood or platelets to the MSK Blood Donor Program. Both general and directed donations are welcome. Please call for hours and more information.

**MSK Blood Donor Room**  
Schwartz Building Lobby  
1250 First Avenue  
212-639-7648 or 212-639-8177

Interested  
in sharing  
your story?

Please visit  
[www.mskcc.org/bridges](http://www.mskcc.org/bridges)



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