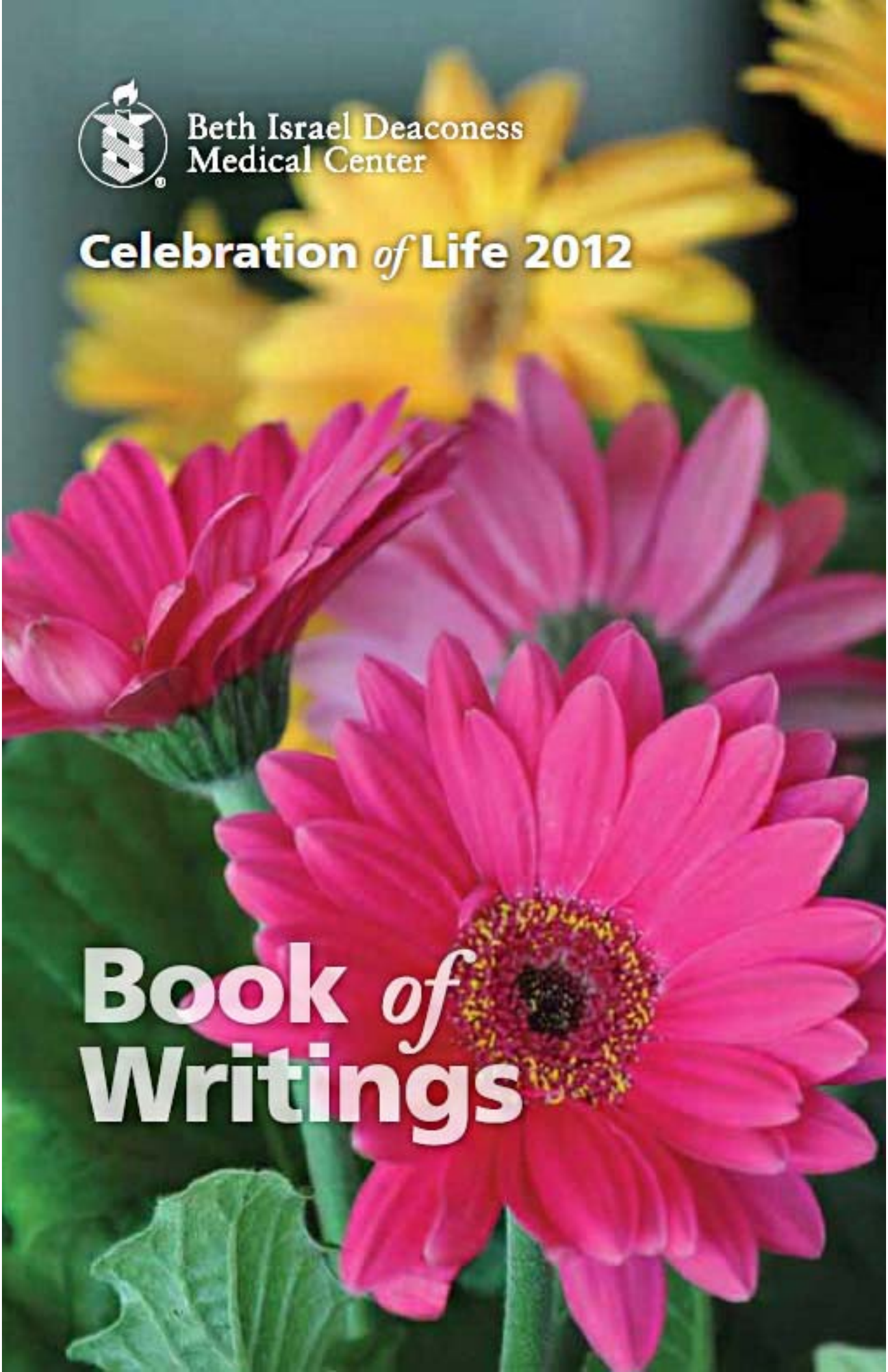
Beth Israel Deaconess Medical Center

Celebration *of* Life 2012



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Hester's Group
Introduction to the Next Pages

—Hester Hill Schnipper, LICSW

For more than twenty years, I have facilitated a weekly group for women with metastatic/advanced cancer. Without a doubt, this experience has been the most moving, instructive, inspirational, and marvelous part of my professional life. I hold dear the memory of those women who have died and treasure the relationships with those who are now part of our community. In every possible way, they have enriched my life.

The following essays were written by some of the women who are current members of the group. I am grateful for their honesty and willingness to share themselves and their experiences with us. If, after reading them, you think you would like to join us, please be in touch with me.

Jan Montgomery, who was part of this group some years ago, wrote this prayer that we use to close our meetings:

> *We are thankful to be with each other today, knowing that both our pain and our good news are truly shared by others. We ask that where there is heartache that we are given understanding and love. We especially hold . . . . in our hearts and wish her/them strength and comfort on difficult days. We pray for help to quiet our fears and raise our spirits and for strength to forgive others as well as ourselves. We are thankful for the love and support that we receive from each other and ask for both grace and grit to live each and every day.*

My Story

—Elizabeth Cobb

The cancer has spread to my brain. My worst fear. Tears silently rolled down my face as I listened to my doctor and struggled to understand what this meant. My doctor paused and then told me that I would require whole brain therapy (WBT). There were no other options as there were too many lesions to treat with the more targeted Cyberknife. She said the biggest problem with WBT is the potential decrease in cognitive abilities. More tears.

I realized this milestone was a game changer. I had taken my earlier treatments somewhat in stride by comparison. I was diagnosed with Stage III locally advanced cancer in 2007. My doctor gave me the "Cadillac" treatment which I took to be everything I could get. Double mastectomy, 6 months of chemo, 6 weeks of radiation to the chest at 30 minutes a day, Tamoxifen and one year of Herceptin. I was convinced I would be cured and worked full time in an intensive job through it all. For two years, I thought I had been cured, but the cancer came back in my liver, lungs and bones two year after treatment stopped.

I was taken aback by the metastasis, but I was told that many people live a very long time with new treatments and some still live 10-18 years. Statistically it is more like two years, but the statistics on length of life after metastasis are no longer predictive of the future given the new drugs coming on the market. So, in some ways I also took the metastasis in stride.

But this new progression in the brain was a game changer because chemo can't pass through the blood brain barrier. My first thought after absorbing the shock was that I needed to get busy tying up loose ends, and I needed a communications strategy for my loved ones. I spoke to my husband and we decided to have a "family meeting." I didn't want to communicate this on the phone and I wanted both daughters to be present (ages 21 and 23).

We assembled the day after the diagnosis and I told them the news about the brain mets and WBT. I said it was bad news, but treatable. I also told them that I now realized I will continue to get

calls and sometime in the future the call will be "there is nothing more we can do for you." I wanted them to know this fact and I wanted to find out how they would like me to communicate each event in this journey. I realize everyone is different and might not want to know the details each time. Both daughters agreed they wanted to know about each event. I told them that their father and I were working through all the legal work to make sure everything was spelled out.

I then asked a critical question. I didn't know how important it was until after I did it. It was "please tell me what fears you have now that you have heard this news." I was sure they were carrying some worries around that I could dispel. The result was unbelievable. In fact we were able to clear up many questions and make some key decisions about study, college, boyfriends, career planning, and other important life events. Being totally open and frank about my situation was extremely liberating. I had entered the conversation carrying a level of fear about death and left with an abundance of love that practically made the fear go away.

I shared my experience with my support group and several members were inspired to communicate more openly with their families and had a similar result.

The benefits of this communication approach continue to evolve. I now realize how important it has been to help us compartmentalize these intense feelings. We all know that nothing will be hidden but once shared, it freed us to enjoy our precious time together.

Whac-A-Mole

Whac-A-Mole is an arcade redemption game. A typical Whac-A-Mole machine consists of a large, waist-level cabinet with five holes in its top and a large, soft, black mallet. Each hole contains a single plastic mole and the machinery necessary to move it up and down. Once the game starts, the moles will begin to pop up from their holes at random. The object of the game is to force the individual moles back into their holes by hitting them directly on the head with the mallet, thereby adding to the player's score. The more quickly this is done the higher the final score will be. Wikipedia: *en.wikipedia.org/wiki/Whac-A-Mole*

Dealing with MBBC feels a lot like playing Whac-a-Mole. Especially with respect to side effects. When one chemo fails and you start another, a whole new set of side effects show up. By now, I think I have experienced most of the side effects listed in the boilerplate that seems to be included in each summary of a chemo drug. Not all at once, and not all with one drug. But overtime I have lost my hair 3 times, had the full range of GI issues, mouth sores, neuropathy, weight gain, neutropenia, rashes and fatigue. I find it best to treat one at a time and eventually the unique side-effects per regimen simmer down and I am able to cope. Knowing to watch for them like in the game makes them easier to deal with and eventually laugh about. Exercise helps and I know I've conquered the current batch when I am back to a regular exercise routine.

Side effects are bad, but life is much better.

Joining the Stage IV Support Group

—Amy Durfee West

A little over a year ago I began to notice some subtle changes in my left breast. There was a small, flaky lesion on the nipple. Then I began to have some discomfort near the underwire of my bra. I actually threw away one bra, thinking it was defective. Then I noticed it was larger than the right one. It sank in that this was not normal, and could mean I had cancer. That scared me, and I wrote about it in my journal, but it took me another month to pick up the phone and make an appointment.

By the time I got to the clinic I had decided the flakiness might be eczema. I get it on the palms of my hands, so I know what it looks like. In fact, the PA gave me a referral to a dermatologist, who agreed with me and gave me medicine that cleared it up in a few days. But she also said I should go in for a diagnostic mammogram, and I scheduled that for April 5. They found a "mass" in the left breast, one lymph node in my left armpit that the radiologist said was "a little too fat," and calcifications in the right breast. They scheduled me for biopsies two days later.

During the biopsy the radiologist (the same one who had done the ultrasound) was now calling the "mass" a "tumor," and told me I'd be getting surgery. I asked how big it was and she said "about one inch." I knew it had to be cancer. I was numb. It seemed unreal. I had to wait a week before I could go sit down across from my primary care doctor and hear the clinical words describing it. Even though I already "knew," I had been holding onto the thought that it might be something else. Maybe I would wake up and realize it was just a bad dream.

My doctor was very sympathetic. She told me she had been through it herself, and had had a bilateral mastectomy. You can't help it. Someone tells you that, and you glance down at her chest. She had breasts, or appeared to. She said, "You have a fight ahead of you" and gave me a card for the BU "behavioral health" department. She also gave me a pamphlet about taking a leave of absence from school.

That was April 19, 2011. I had my first meeting with the breast cancer "team" at my hospital a few days later. Getting a

diagnosis was surprisingly unhelpful. So was meeting the "team." There would be more tests to complete the "staging," then chemo, surgery, and maybe radiation. I got a book and a folder full of pamphlets. I was barely processing what I heard.

After a breast MRI, CT scan and bone scan I was called in again in early May, this time to meet just with the breast surgeon. She said the bone scan was clear, but there were a "couple" of spots on my liver and lungs. They'd need to biopsy the liver, and if that was benign or inconclusive then they'd biopsy my lungs. She tried to talk me out of taking a trip out of town that she had previously said I could take. The liver biopsy was scheduled for May 17, after I got back.

The radiologist who did the liver biopsy said the lesions had shrunk. He even asked me if I had begun treatment. He said the target was so small he wasn't sure he had gotten a good sample. That sounded like good news. Surely it couldn't be cancer if it was healing on its own.

A week later I called to get the results. My oncologist asked me if I could come in the next day to talk about it. I was in DC for my daughter's graduation from Georgetown, so no, I couldn't be there the next day, but I could be there in two days. I asked her to tell me what the test showed. She hesitated, then said there were cancer cells in my liver, but quickly added that the cancer would be "very manageable." Another shock. Stage IV. All I knew about Stage IV was from a drawing in the book the hospital had given me. It said breast cancer can spread anywhere, but especially to the bones, brain, liver and lungs. On the page is an outline of a woman with ugly black blobs in those areas. I met with the oncologist, and I started treatment two days after that.

Then I did what I always do in situations like this. I started reading. One book said that people in support groups have better overall survival. I joined an online support group for people with my particular kind of breast cancer. I dug out the flyer about breast cancer support groups at Beth Israel Deaconess and called the number. Hester called me back, found out I'm Stage IV, and told me when that group meets.

My first visit to the group, not long after I was diagnosed, was pretty intense. Three people had just had medical emergencies. One had almost died, but her oncologist ordered some kind of Hail Mary Pass chemo combination and they beat the cancer

back. Another had been hospitalized with a dangerously low white blood cell count. I don't remember the other story, but it shocked me. Hester must have seen the look on my face. She asked how I was doing. I muttered something.

I hadn't really thought about the implications of this diagnosis. What does "incurable but manageable" mean? It means something different for each person. So much depends on tumor biology, on how one responds to each different treatment, and on other factors such as age and health status. Only about ten or fifteen percent of people with breast cancer are metastatic at diagnosis, but Hester told me about half the group members were. But there's no "Stage V." Stage IV is "late stage." It's the end of the line. It's what kills the vast majority of people with breast cancer. It's not the original tumor but the metastatic phase that is fatal. I had a lot to process all at once.

On reflection, I decided the group is perfect for me. I'm not one to hide my head in the sand. I figure you can't really make good decisions unless you have complete information. And I also realized that since all three women had lived to tell the tale (and to fight another day), the stories had happy endings. Thinking through the rest of it would take a lot longer. I imagine it'll be a lifelong process.

In the group we can be completely honest with each other. Also, believe it or not, we laugh a lot. There are smart, funny, beautiful, women in the group who are full of life and who I'm glad to know, although I wish we had met under different circumstances. We share information and teach each other. For example, I didn't know that the medications I was getting don't cross the blood/brain barrier, so I asked my doctor for an MRI to make sure I don't have brain metastases.

We can talk about anything, and we do. There are no taboo subjects. We are there for each other for the duration. Recently, one member discontinued treatment and entered hospice care. For awhile she kept coming to meetings. It was sad, of course, but it was also reassuring. She was the same as ever, only she was in the last part of her life. She has gone on ahead of us, but she's still one of us. In the room where we meet there are photographs of the group from earlier years. Only Hester and one 12 year survivor are people we know. Refusing to face that would not make it any less true.

By contrast, a member of my online support group posted this:

> *The week I was diagnosed with breast cancer, so too was a colleague of my husband's. We became fast friends. Her cancer was super aggressive, and within 5 months she was dead. She was a single mom, and left behind three teenaged kids with no plans in place. It was terrible and sitting in the ICU as she died was one of the hardest things I've ever done, especially given my extreme fears about my own mortality. After her death, I tried to process it in my breast cancer support group. I was shushed down, because others in the group found it too upsetting. They wanted to talk about knitting pink hats. It was ok to talk about lymphedema or side effects to chemo or types of reconstructive surgery or bone density. It was definitely NOT ok to talk about dying.*

Illness, disability and death are not pathological. Everyone gets sick. If you live long enough you'll probably have some kind of chronic pain or disability. And every single one of us will die. I'm in no hurry to check out, but I realize that, barring either a miracle or some other really bad luck, I will die of breast cancer. The more I say that the less weird or frightening it seems. Far from intimidating me or paralyzing me, the knowledge helps me make decisions about my life and how I will live it each day. I can honestly say I've had more moments of sheer unalloyed joy in the last year than in any prior year of my life. I can't do anything about the future. I never could, no matter what I unconsciously thought. But I can choose life in every moment of now.

I know this: my wholeness goes beyond my physical condition. My life is meaningful, good and full no matter how much more time I get to live. Healing in the sense of peace, acceptance, and ultimate security does not depend on my being disease-free. There is freedom in that. It is a strange freedom, but quite real. No one wants to die, but we all will. Apparently I have knocked the cancer back for now, but nevertheless cancer constantly rides around on my shoulder. I'm trying to make friends with it and find out what it has to teach me. Anything you put energy into opposing directly can end up owning you. It can deprive you of the joy of living without laying a finger on you. Rehearsing all the possible outcomes or recollecting past trauma can be a kind of living death. This illness, and this group, have taught me that no matter what happens, I can always choose life.

Dying

I read that Hester's response to a support group member who was talking about her "imminent demise" from breast cancer was, " No one drops dead from cancer." True, but almost all the people who do die from breast cancer die at Stage IV. There is no "Stage V."

They don't talk much about "prognosis" for us. Nobody really knows how it will be for any given person. In our group we have a member who's been living with the disease for over 13 years. She still has cancer, but it's stable on the treatment that she gets. A few people, maybe 2%, experience "permanent remission." They go on to live a normal lifespan, and die of something else. But most of us will die from this, and the median survival is somewhere around three years.

I belong to an online support group for people who have my type of breast cancer. Recently a member posted this:

> *Well ladies, I am officially quitting treatment. Had a long discussion with family and we all agree, that it is my choice to live a life feeling as good as I can for as long as I can, instead of chasing a dream and worrying ALL THE TIME. I know my fate and I am moving forward finally.*
>
> *I feel like a huge weight has been lifted from my shoulders. No more worry and wonder. Freedom from doctors and tests and pain and more worry.*
>
> *I hope everyone knows this is a personal choice and the right one for me. I am not saying it is the right one for anyone else, so please do not think I am proposing others pursue this course . . .*

She was first diagnosed in 2007, and progressed to Stage IV in 2010. She beat back the cancer twice, but recently had a recurrence in her lungs.

The response was mixed. Some people said they support her decision, and offered prayers, gratitude and love. But several challenged it, telling her she must be depressed, urging her to try something else, urging her to hang on until the next two miracle drugs become available. Here's what I posted (edited slightly):

> *Thank you for your generosity in creating a space for this conversation to take place. You didn't have to do that. I think it's a huge service to our community that you took the risk.I*

support you in your quest for healing and wholeness. I know you are the only one who can say what that means for you.

Healing is not necessarily a matter of bodily "health." One of the affirmations I listen to says something like, "More and more, I realize that I can heal myself and live, or I can heal myself and die. My physical condition is not a factor in my wholeness." When I first heard that, it was jarring. Then I sank into it and realized that my goal in life is not to avoid dying (which is, of course, impossible) but to live as fully and fiercely as possible, with as much joy and passion and peace (all three) as I can attain. From your post, it appears that's true for you too.

I hope this community can accept and affirm the rights of each person to decide her/his own course of treatment, and to decide when to stop fighting. I hope we're able to be supportive and loving in the ways we are being asked to do that, whether or not that would be "right" for us. It would be so sad to feel rejected for reaching out in this very personal way. I can't help but think that some of the push-back that you're getting is sadness for you, but that some is projection of personal fears. We will all take that journey someday. There's something to be said for knowing it's coming. There's a lot to be said for having time to say goodbye, for having loving conversations with everyone who matters, and for deciding to live with as much joy and passion as possible. If we didn't have to confront death would we even value our lives?

In Hester's group I know that as each of us decides we've had enough, that decision will be truly respected. On the other hand, since we meet in person week after week I also would be confident that if they thought I was giving up too soon due to depression they would be qualified to say that, and I would be inclined to take their advice. In this group I know I will be loved and supported no matter what happens to me and no matter what I decide to do about it. I know I will be heard and accepted no matter what. That is a priceless treasure.

For Anne Lamott & All My Other Teachers

She says there are only two prayers:
"Thank you, thank you, thank you"
And "help me, help me, help me."
The psalmist says help comes from God,
But God works through people.

When I close my eyes and summon them
I see the God-bearers in my life
And feel their love,
God's love
  enveloping me,
    enlivening me,
      sustaining me,
        sustaining the world.

They have names and faces and stories of their own
But for me they're also the face, voice, hands of God.
The grandmother who always had time for me,
  who always made me feel capable and worthy.
The babies I conceived and birthed and suckled
    whose warm little bodies once curled against me,
      trusting me completely.
The little girl with the broken, battered spirit
        who didn't trust me at all
          sent by the God with whom all things really are possible.
The lover who showed up at such an inconvenient time
            and showed me
              how to be fully present,
                how to love with nothing held back,
                  and then how to let go but never stop loving.
Loving, letting go.
Cherishing, learning, being present.
Treasuring, remembering, reminding.
Opening my hands, my arms, my heart;
Surrendering control
Then learning there's no need for it.

Help? It's already here
I already know what I need to know.
"It's alright, it's alright, it's alright"
is God's answer to prayer.

Thank You, Hester

—Pam Johnson

I needed to say thank you to Hester Hill Schnipper for the solace she has provided us in the Phase 4 support group at B/I. While being compassionate, she consistently supports us with what we need more—knowledge, tact, perceptiveness. She has made a place for us, now in a difficult phase of life, to vent, kvetch, exchange fashion tips ("no hair? no problem"). There have been tears but also laughter and we need to thank Hester for this.

Awakening from the Nightmare

—Amy F. Judd

Many people have the recurring nightmare of finding themselves in a college classroom about to take a test on material they've never studied. When I have this dream, I experience heightened anxiety and insecurity and am incredulous that I have landed in a situation so utterly unprepared.

Such became my reality when I was diagnosed with metastatic breast cancer two and a half years ago while in my early fifties. I had no significant risk factors, had been screened for breast cancer annually, and regularly performed self-exams. My mammogram from just one month earlier was deemed "normal", and at my annual physical a month before that, my primary care physician declared I was in excellent health. Several times before I had escaped a scary diagnosis when it was determined that a suspicious mass in my breast was benign. But the one I discovered in a lymph node under my arm one July morning was not, and somehow I became a Stage IV cancer patient seemingly overnight. Suddenly I was thrust into the most anxiety-producing situation of my life, without a clue about how I got there, if I would survive, or how I would cope. That was a true nightmare.

Some cancer patients refer to their diagnosis as a gift, as it has helped them re-prioritize and appreciate life more fully. I think it's a stretch to characterize cancer as a gift—who would ever want to subject herself, her family and friends to the associated distress and sadness? However, I fully recognize and appreciate that the period since my diagnosis has been one of tremendous personal growth and intensive learning.

My learning curve in "doing" cancer was steep. I urgently needed to understand the language and clinical procedures, as well as the management of side effects and strategies for stress reduction. I also needed to figure out how to communicate with family, friends and colleagues about my illness. While crash courses and patient education materials on most of these topics are readily available, much of my acquired knowledge was gained over time through personal experience and from information and

reflections shared within my support group. I began attending a group for metastatic breast cancer patients more than a year after my diagnosis. Had I realized how helpful and inspiring this group would be, I'd have joined sooner.

Early in my cancer journey I felt too overwhelmed to research my disease and available treatment options. I accepted my oncologist's treatment plan without question as my initial focus was on getting treatment underway immediately. Terrified to learn the prognosis and survival data, I avoided those topics. My older son's courageous effort to inform himself about my disease led him to some scary, depressing statistics. I wish I had forewarned him that the mortality rates reported on the Internet were not current, as those earlier patients did not have access to the highly effective medications now available. I began to refer to myself as a "cohort of one" whose treatment response and longer-term outcome could not be predicted by earlier studies involving groups of patients whose treatment regimens differed from mine.

While attending a patient symposium on metastatic cancer three months after my diagnosis, I learned that my disease was not curable and that I probably should have been on a different treatment regimen. Having received two conflicting physician opinions about my treatment course, I was compelled to seek a third. It was then that I realized that I needed to be proactive about accessing relevant information, and, to some extent, managing my care. I was relieved that accessing information and physician opinions was fairly easy, perhaps in part because I have professional experience and personal connections within the health care field. I learned that it was not unreasonable to question the medical advice I was receiving. Eventually I began to feel empowered and reassured by my active role in the treatment planning process, though researching and processing information often feels overwhelming. How I wish that scientific evidence could pave a clearer path to the most effective treatment.

Among the many resources and tools available to cancer patients and their families are those associated with stress reduction. Support groups and workshops, scores of invaluable websites and self-help books, meditation, massage, and spiritual learning have equipped me to ease my physical pain and anxiety about my future. My ability to manage stress effectively is tested at regular intervals as I undergo scans to monitor disease progression.

Fortunately, I am no longer sitting in this real world classroom totally unprepared.

Fundamental to my ability to alleviate inherent distress is a focus on the present, as well as the letting go of concerns about insignificant matters and issues over which I have no control. The petty stuff was pretty easy to train myself to dismiss, but the long-standing issues took somewhat longer to release. Gradually I noted over time the relative ease with which I could simply let go of unhelpful baggage and annoyances. Rarely do I become rattled by a last-minute schedule change or a lost earring these days. Further, my clear recognition that I am doing relatively well right now strengthens my ability and resolve to live my life, essentially, as I had prior to my diagnosis. I continue to cherish time with my sons, husband and closest friends, and have a rewarding professional life. I travel and socialize, assist my elderly parents, and try to make time to nurture myself. I am engaged with life.

Without doubt, my quality of life and physical comfort have been tremendously enhanced by those closest to me. I gain strength from those surrounding me, even some whom I'd previously considered casual friends. Some of the most terrifying moments during my cancer experience were very precious times for me and my family and best friends. These intimacies have helped to transform my nightmare into a bearable and unexpectedly profound chapter of my life.

Recognizing and coming to terms with one's mortality inevitably is part of the cancer experience, particularly for those with Stage IV disease. It's easier to remain in denial about the certainty of eventual death when one is well. Often I feel as if my life has been fast-forwarded three decades. Grieving, both for the loss of my health and well-being, as well as for a long future I won't likely experience, is painful. Learning to let my tears flow without judgment has enabled me to move through brief periods of overwhelming sadness. But beyond the grieving I am gaining wisdom, clarity and acceptance. I am resigned to facing hard moments of vulnerability. In my personal experience of facing cancer, my quest to achieve inner peace and wholeness has become a priority—a process of nurturing myself and focusing on my relationships with loved ones.

How deeply grateful I am for all that I have been given and can access to support my healing and survival. Tragically that is not

the case for those who live in impoverished countries. For a cancer victim there the nightmare never abates. I feel compelled to find ways to contribute both professionally and personally to the alleviation of pain and suffering of those without access to treatment, palliation and social support in resource-poor regions around the world. This is no small challenge, but as we witnessed during the AIDS epidemic in Africa in the 1990's, there is much that can and must be done. Helping to address this disparity is one of my major goals for this lifetime.

My exploration of spiritual teachings suggests to me the possibility that some aspect of my life force will remain in this universe after my body leaves it. The following passage from *Tuesdays with Morrie* by Mitch Albom comforts me:

> *"As long as we can love each other, and remember the feeling of love we had, we can die without ever really going away. All the love you created is still there. All the memories are still there. You live on—in the hearts of everyone you have touched and nurtured while you were here. Death ends a life, not a relationship."*

A diagnosis of Stage IV cancer did constitute a nightmare for me, one from which I continue to awaken. It is an ongoing process to be sure. I wish for everyone who is afflicted all I have received and pursued: stellar medical and supportive care; useful information; resources for managing stress and pain; ongoing love and caring attention from family and friends; and, an extraordinary experience of rich personal growth and clarity.

Waiting Area

—Marylin Kass

It takes me a moment to place her. You know how it is when you see a face you recognize, but you're not sure from where. Then it hits me: Joanne, from my Monday group. I haven't seen Joanne outside of Hester's office; she always wears her green plaid scarf turned round like a turban. Today she sports a cap, a fitted cap. The plaid scarf dangles out of her purse, a thin book on top. I try to make out the title, but between the text size and the distance, it's too much effort to read. I don't have effort to spare and certainly not for someone else's Amazon indulgence.

Joanne hasn't noticed me yet, so I use the brief reprise from social obligation to indulge in the colors and textures she has adorned herself in, starting with the soft blue cap on her head. Fuzzy fibers halo the crown—mohair or angora? Fibers that, anywhere else, would smell fresh like baby powder. But nothing smells fresh here, Shapiro 9 Oncology Waiting Area # 1. The deep breaths we take for stethoscopes and exams fill our lungs with a mixture of rubbing alcohol and anxiety. Smells of life are elsewhere, on another floor, another building, another story all together.

Shapiro 9 has two large waiting areas and two large treatment areas, a warren of offices, exam rooms, rooms with "caution" signs on the doors or "authorized personnel only," and a modest gift shop near the bank of elevators that sells wigs and hats and jewelry just in case your chemotherapy requires a booster of retail therapy. Tucked in a far corner of the sprawling Oncology Hematology floor is Hester's office. The plaques on Hester's wall are testament to her accomplishments, the books she's authored scattered on side tables. But nothing inside or outside her office signals the depths of Hester's gifts as a healer. She isn't a doctor, though she's married to one. She can't cure cancer, nor does she know what might. But, she does make it easier to deal with, and that is very important to me and to all the other women she counsels.

On Tuesdays Hester holds court for "women newly

diagnosed." I spent many Tuesdays in her office with similarly afflicted woman until a couple of years ago when I graduated to Monday's group.

Monday's group is reserved for the pale castaways, "women living with advanced disease." Hester is a master of compassion and, in her Dojo, we can prepare ourselves for battle: the scans, the next treatment, the loss of desire, the loss of hair, the loss of other members of the group.

Loss has been a common theme except where my weight is concerned. I might be able to forget I have cancer, but not the ten pounds I gained in treatment. I despise scales, especially hospital scales. I walk past them as quickly as possible on my way to the Monday group.

If you can answer "yes" to living with advanced disease, or metastatic disease, or stage IV cancer you are welcome to join. No need to knock, no initiation fee, just drop by between 11:30 and 1p. The size of our group varies, attendance is never taken, and no one is tardy. We arrive in dribs and drabs for a round robin of sharing, each of us taking a turn discussing the highs and lows of life on loan. We let rip whatever comes to mind; mundane or morose, everything is fair game. We are a secret society of seriously ill sisters.

Paula's hair is tousled just enough to look real. And, after a decade on Taxol, her smile has not diminished, her skin signals rigorous exercise. These are my beacons of hope; the women living for decades. Statistics are irrelevant; we've already beaten the odds. But the abyss is close by: Laura stopped being coherent shortly after brain metastases captured what was left of her grey matter. The following week she was in hospice, a week later she passed.

There is no group today. I am on the 9th floor waiting for blood tests and infusions. Joanne must be doing the same. I finally speak up; tell her that I like her fuzzy cap. We chat and smile like two people anywhere. She complains that she is cold and pulls the plaid scarf from her purse. The paperback that sat on top, falls to the floor. I pick it up, see the title now, and say nothing, quickly handing the book back to her. "Becoming Friends with Death." Maybe she'll bring it up at next Monday's group. For now, I don't want to touch the book, or the topic.

"Marilyn Kass" Someone calls my name. I cringe. Time for vital signs. I hate those scales.

The Ecclesiastes

—Peggy Soo

The Ecclesiastes passage is all about the cycle of each person's life as well as the cycle of the seasons and the orbit of the earth. A new life brings joy and celebration; as a person goes through life, sadness is bound to come. As sadness lessens, laughter can return. Emotions follow each other in a constant ebb and flow. A person's life is a series of cycles, and that person's life is another cycle in the context of other people's lives. My parents gave birth to me; I gave birth to my children, who will have their own children. No life is immune from sorrow and joy.

The Chinese principles of Taoism reflect this view. All qualities of life flow along a continuum between opposite poles. The seasons come and go; winter gives way to summer, which flees all too quickly, and winter comes again. Weeping can be followed by laughter, which can be followed by weeping. Sadness brings mourning, but over time, it may turn to dancing.

A cancer diagnosis comes at a certain time in a person's life, perhaps after that person has experienced both joy and sorrow. I celebrated my wedding, the births of two children, experienced challenges with school, work and whether or not I was measuring up to my own high standards. Then came the shock of my diagnosis. But hope and action must follow shock and grief. Beginning treatment gave me hope; when results began to look promising, I danced (and, twelve years later, I'm still dancing). There have also been challenges and scares along the way, and eventually I will die most likely of my disease or of something related to it. I know my life cannot be an 'everlasting banquet'; I must try to face whatever comes. When triumphs and challenges come are different for each person, as each person's journey is different in quality and duration.

But I know I am part of life's cycle. I was born, I will rejoice, but I will also mourn and I will die. My two sons will continue with their lives, perhaps pausing a moment to mark my passing, and will experience the same cycles, each within the context of his own life.

Here's the Ecclesiastes original from the Bible, *Ecclesiastes III* (King James Version):

3:1 To everything there is a season, and a time to every purpose under the heaven:
3:2 A time to be born, and a time to die; a time to plant, and a time to pluck up that which is planted;
3:3 A time to kill, and a time to heal; a time to break down, and a time to build up;
3:4 A time to weep, and a time to laugh; a time to mourn, and a time to dance;
3:5 A time to cast away stones, and a time to gather stones together; a time to embrace, and a time to refrain from embracing;
3:6 A time to get, and a time to lose; a time to keep, and a time to cast away;
3:7 A time to rend, and a time to sew; a time to keep silence, and a time to speak;
3:8 A time to love, and a time to hate; a time of war, and a time of peace.

Tom's of Maine

—Trisha Andron

Throughout Radiation treatment, my skin is likely to get sunburned and sensitive, and it is recommended that I use all natural, fragrance free lotions during this time. So like a good patient, I purchased some all natural, Tom's of Maine. I was amenable to the switch, having heard that the aluminum in other deodorants is linked to Alzheimer's, and decided that all natural deodorant was a smart choice all around.

Let me just tell you, Tom's makes a bad situation worse. I have never been so smelly in my life as after a day of sweating and wearing Tom's deodorant. You're better off wearing nothing at all, I guarantee the smell of your own sweat and salt is far better left alone. Lee tested the theory on the same day, and I can attest to the fact that he, too, smelled to high heaven.

After two weeks of Radiation, I have yet to feel serious side affects (making me question the real necessity for Tom's deodorant). Every day after work, I drive to the Cancer center in Framingham, change out of my shirt and into a johnny, and await treatment with the rest of the patients. When they call my name, I am escorted down a long hallway with several odd turns in it, and walk through two heavy doors, each 6" thick. The technicians ask me to remove my johnny, put my arms up in stirrups, and whatever you do . . . DON'T MOVE. This leads me to wonder if I should sneeze, would radiation go to the wrong part of my body? Can I intercept a beam with an uncontrolled cough? It's more likely that they would only have to readjust me, lining up my tattoos and marking me with a sharpie to be sure they are radiating the right spot. However, the idea of sending a Radiation wave pinging across the room in the opposite direction is enough to keep me as still as a stone. Of course, the second they tell you don't move . . . everything begins to itch.

For all I know, the technicians play video games when they leave the room. After getting me lined up, they tell me they'll be RIGHT BACK, and make a beeline for the door. The two 6" thick doors close heavily behind them, sealing me up by myself with my

radiation treatment. Once they leave, nothing happens . . . that I can see. I hear some machines buzzing around me, but I can't turn my head to see where it's coming from. And I can't see the medicine going into my body, the way I did with chemo, leaving me to wonder if there really is any treatment happening. Here's the weird part—Radiation treatment can kill cancer, but it can also cause cancer . . . hence the thick doors, twisted hallways and Roadrunner routine from the technicians. All told, it leaves me with an uneasy feeling, as I watch the technicians retreat from the chamber to set up their next game of Space Invaders.

The Incredibly Shrinking Personal Space

Grace—no personal space! One of the things I love about Grace is her lack of personal space. I can get up in her face and cover her with kisses, and it doesn't bother her. When she was a year old, we would do the "baby mind meld", and she would press her forehead to mine. The child has not yet developed a need for personal space, and I love it.

Like Grace, I find that New Yorkers have less personal space than the average American. Once, while I was living in Greenpoint, Brooklyn, I got on the subway only to notice I was standing next to a man with no pants. Everyone else was at the other end of the car. Unblinking, I joined the rest of the passengers at the opposite end of the packed car. In New York, space is limited, and is always being infringed upon. While I value my personal space, I don't think I'm overly sensitive to it, having lived in New York. I like getting up in my daughter's face after all, and I've always been free to give big bear hugs. That is, until now.

I never realized how much my breasts factored into personal space. Now that I don't have them, I find myself hunching my

shoulders more than I used to, wearing scarves around my chest, and crossing my arms a lot. Some of that is insecurity; some of it is a basic need for body heat—those mammaries kept me warm! But most of all, I find that my personal space has shrunk. I'm no longer a fan of the bear hug – the looser the embrace, the happier I am. I've lost my physical boundary, and have yet to find my new comfort zone.

Looking back, I realize that my personal space began to deteriorate as soon as I was diagnosed. While many people ask how you are, or how you're feeling, what they really want to do is tell you how your cancer makes them feel. Because knowing how others feel about your cancer is what's keeping you up at night. It's understandable . . . not knowing how to react, or what to say, people will say whatever comes to mind—a sort of verbal diarrhea. But like the man on the subway, the act of over-sharing can chip away at your personal space.

I'm friends with an older woman, who is what I would call a Unique Individual. She's an artist, at times highly entertaining, and oftentimes quirky. We were discussing my double mastectomy, when she asked me if I was sure I wanted to get new breasts. "They get so saggy when you're older" she told me. Now, I began developing when I was in 4th grade, and have always been well endowed. I know saggy, and said as much. "Besides," I said, "they will be insured for life—I can always get a replacement set!" My friend went on to tell me what her breasts meant to her, and offered to send me a photo of hers, so I could fully understand what they look like later in life. With a good dose of my usual sarcasm, I replied "You'd do that for me?"

Low and behold—she *would* do that for me, because the next morning her husband emailed me a naked photo of his wife. I let out a yelp, and promptly deleted the message, but not before the image was seared on my memory. I couldn't help but wonder what had possessed my friend to share so openly with me, and after a few weeks of awkwardly avoiding her calls, I finally asked her as much. She thought that sharing her perspective would help me, and had taken my response of "You'd do that for me?" as a green light. Even though we had shared each of our perspectives on cancer and breasts throughout the conversation, my friend thought that my seeing her naked would help me to further clarify how I felt. About *my* breasts.

As I reflect on the past six months, I can laugh at situations like this. Now that I'm not 100% focused on my physical health, I have the opportunity to examine things that have happened, and think about how I feel about my cancer experience. That's a good and bad thing, and can be overwhelming. I do know that my personal space has changed, and that somehow, I've changed as well.

Why

—Patricia Bateson, RN

I am often asked why I am an oncology nurse
And the answer is quite simple
I see courage, strength and faith wrapped gently
around hope and love
I hear inspirational stories that can instantly
bring a smile or a tear to my face
I get to touch, hug, support and nurture
I am able to make a difference in their lives as they do in mine
For my patients and I are all connected to something
much greater in this universe
We all share similar but different stories
We are all walking the "walk" together, one day at a time
My heart is filled with such gratitude in the work that I do
I get "IT" and I get my patients
For I too am a cancer survivor.

Requiem

—Glenn Bubley

It hits me as soon as I drive into work. There in your parking space is a car I don't recognize. I walk up the stairs into medical center hallways crowded with people walking past, but I don't see anyone with your face. Like always I am here in the early morning, long before clinic starts, but your office door is now locked. There is no one inside finishing progress notes, and so no one to barge in on, to talk to about the Celtics, sheer pins for snow blowers, the decline in health care, check engine lights and any of the other numerous topics that we covered while I sat in a chair in front of your desk and drank lukewarm coffee before the onslaught of the day. I still talk to you, on elevators, in my car alone, outside an exam room feeling tired and used up before going in to deliver yet more bad news. You tell me to keep going. There are gemstones in the commonplace, renewal in a single human touch. Sometimes through the mystery of relationship; we are lifted up, transformed in ways we can't know.

These mornings I rise slowly, my back hurts and my knees are sore. But I still leave home before dawn, wearing a clean shirt and a starched white coat. Your burden is still here, your mission ongoing as long as there are the least, the last and the lost among us. God gives us only as much time as he wills, but we alone have the power to lose ourselves in the journey. Although the future has never seemed so uncertain and I have lost a counselor, today's troubles are sufficient for today. Tomorrow, you would say, can worry about itself. Besides, you showed me there can be rebirth in an evening at home after a day being poured out and spent. Take time and joy in your family for who they are, not for what you think you want them to be. These days together are fleeting. I am thankful I still hear your voice in the quiet moments before rising and just before I pass into sleep. By the example of the life you led, you left us with a great gift. And that's why I hope that by running my race I might, in small ways, pass on a portion of it to those left you left here.

Normalcy

—Wendy Chapin Ford

Sometimes, the qualities that we desire most are those that are most elusive. My husband Bruce, a.k.a. BG, loved to take care of his family. When we received the news that he had cancer, he immediately determined that we should strive for normalcy. It was his desire for normalcy, as elusive as it seemed to us at that time, that set his family down a path of carrying on, doing well, and enjoying life. It served us well through his illness and beyond, and I am sure will continue to do so.

Every patient is unique, and no two families are alike. What this slim little volume offers is a collection of decisions, thoughts, and actions that worked for our family when my husband was diagnosed with cancer. If it helps just one other family, it will have been worth going back to our trial with this disease.

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Speak of your loved one, and often.
Strive for smooth sailing.
Fear not the memories; you will smile again.
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Take care of things early.
You never know what you might be saving.

It was an unlikely start to our trouble, originating years before with an early health scare.

Soon after our first child, Westy, was born, we tried to buy life insurance and were declined. Bruce's enzyme levels were the height of a person who drank a quart of vodka a day. Yet he had never been a heavy drinker. It was merely the way he was built: a simple case of bad luck.

The diagnosis was primary sclerosing cholangitis (PSC), an incurable, but manageable liver condition. We chose not to dwell on the possibility that in a small percentage of patients, the disease would lead to cancer. Ironically, this scare may have gained us years. Had the illness gone undetected—and thus untreated—we might have lost BG much earlier. Strong, active, athletic, he did so very well on the medication for so many years, and then our luck ran out.

The last normal year for us was 2006. We were a typical family of four, and fortunate—happy and healthy, athletic and fun. People would say that we did more in one week on vacation than most do in a month, and BG set the pace. He loved to be outdoors, bike-riding, sailing or skiing, passions that his children carry on to this day. A larger-than-life figure, his joie de vivre was infectious. People young and old loved to be near him. His wit and humor, in fact, his entire approach to life was luminous and magnetic.

I never thought that thirty years could pass so quickly.

It was Christmastime that year when his color began to change. His eyes and skin began to show a slight yellow tinge, and his urine darkened. In January 2007, BG's doctors scheduled him for the first of several endoscopic procedures (ERCP) to relieve the blockage of his bile duct. The procedures sometimes took hold, enabling BG to get back to his regular life. At other times, a low-level infection with its attendant, disabling fever would result, laying him low for several days.

That was our first period of uncertainty. We never knew how successful the procedures would be. The setbacks were subtly devastating, as neither of us wanted to give voice to the outcome that we dreaded each time he experienced a complication. As it turned out, those setbacks were harbingers of things to come, despite the biopsies done during the procedures that initially came back negative.

Pay attention.

In June of 2007, BG was due for yet another procedure. At that point, he had been doing well. His latest ERCP had taken hold, and there were no complications. Rather than risk compromising our precious family summer in Maine, we consulted with the doctors, who said that it would be fine to push the procedure to the end of summer. If it ain't broke, we all agreed, let's not fix it —just yet.

As it turned out, that summer was one of the most glorious our family ever had. As usual, we were at our favorite place in Maine, and the weather was perfect. The four of us, like a family of ducks, were out on the water every day. Westy was a beloved sailing instructor at the local race camp where Lindsay was doing so well; BG steamed around the harbor, sailing his beloved Force 5, never quite leaving behind the little boy in himself; and I enjoyed it all from the vantage of a simple rowboat, skittering around the water like a mother duck.

One afternoon toward late summer, BG and I were heading to the dock at once. I landed first. After tying up my boat, I began to walk up the ramp, the evening's dinner plans doubtless on my mind. But for some inexplicable reason, halfway up the ramp, I was compelled to stop and look back, and just in time to see BG

execute a perfect, stop-on-a-dime landing under full sail, right to the dock. It was gorgeous. He was so skillful and vibrant. I was so proud of him and glad that he was enjoying himself so much, especially after all the uncertainties of our year. It was a glorious moment that left me beaming.

It was also the last time I would ever see him sail.

That unforgettable scene of my strong, good, handsome husband flying toward the dock, completely in control—as usual—is a treasure, locked in my mind's eye forever. That would come to be the image that would supplant other images to follow, thank God, and the one that *he* would certainly want me to carry. My turning around at that moment on the ramp was a gift of presence and remembrance.

That September, our whole family felt good about returning home after such a successful summer. Lindsay was in seventh grade, Westy, a junior in high school. BG had his ERCP in mid-September. On October 1st, the call came from the brilliant and compassionate Dr. Michael Curry, BG's primary specialist, and head of the liver center at BIDMC. He had the results of the biopsy, always done in conjunction with an ERCP. Up to then, they had been normal.

This time was different. I quickly sensed that something was wrong. Bruce took the phone and spun around a bit, pacing as he listened. He caught my eye and gave me a "thumbs down" gesture and in that moment, my world stopped. Everything fell away. I could see, but everything was gray. I felt numb, I couldn't think. Dr. Curry's news was ominous. There was a tumor on Bruce's bile duct. He was in the unlucky small percentage of PSC patients whose condition had devolved to cancer.

Trust your instincts, even in a split second.

The call came late in the day. Fortunately, Westy and Lindsay were upstairs and out of ear-shot. Bruce and I had been preparing to go to the home of friends for a dinner party. We changed course. We still went out, so as not to raise questions with the kids, but to our favorite restaurant, instead. I called our friends to explain that we couldn't come to dinner, after all. I can't remember what I told them, but I didn't have to explain. They knew what we had been

going through, and they also knew that something was wrong.

That was the first of the myriad decisions that we would make throughout this awful journey. Some were made in a split second; others required more time; others, we chose not to make at all, or to put off for a time. It always felt as though we were flying by the seat of our pants. But this was a time to trust our instincts, and I want to believe that we made good decisions.

At Glenn's Galley, it seemed as though Julie, the hostess who had known us for years, understood that something was different for us that evening. She led us to the most private table in the restaurant, and that is where we began to plan our strategy. BG took the lead. This was his dreadful ballgame, after all, and all I wanted to do was back him up, however I could.

"I want normalcy."

That was BG's first directive, and I thought it was a pretty good idea, too. Right then and there, we were off on our awful adventure.

The theme of normalcy turned out to be brilliant, successful, even exquisite, in its terrible way. Simple and straightforward, it informed every decision we made and every single thing we did in the weeks and months to follow. At each step of the way, it helped us manage this monstrous illness that was barreling down on us.

Always, our top priority was Westy and Lindsay.

The first decision we made was actually *not* to speak to the children—until we had a plan. We wanted to be sure that whatever information we gave Westy and Lindsay would be as accurate as possible. That meant keeping a secret until we met with the doctors. Initially, we would meet with Dr. Curry, who would provide us a more thorough explanation of next steps and options.

Talk to the doctors, even if it seems out of line.

Prior to our meetings with the doctors, my secret mission began. In addition to the decisions that BG and I would make together, I had to navigate another course: to do as much as possible to ensure Bruce's comfort—mental and physical. This often meant calling BI ahead of our appointments to speak with the doctors privately. I had to prepare them for dealing with Bruce—without Bruce knowing.

This was no small feat with physicians like Dr. Curry, in

great demand with work in clinic at BI, research, and teaching at Harvard Medical School. Fortunately, his understanding assistant was able to get me through. It was imperative that I talk to him ahead of that first meeting, especially.

"Dr. Curry," I remember saying, "forgive me for directing your meeting with Bruce. But there is something you need to know about my husband, as we move through this process. He doesn't want to know anything he doesn't *need* to know. This includes staging levels, percentages, or survival rates of patients with cholangiocarcinoma. It's fine to answer his questions. But please don't give him more information than he needs to know about his own, particular case.

"Some patients probably want to know everything they possibly can," I explained further. "But for Bruce's frame of mind, his mental health, this is how we have to work it."

We met with Dr. Curry and his resident fellow, and although he followed my wishes to a T, I was on edge the entire meeting, so afraid that something might slip out inadvertently. But Dr. Curry offered his information as precisely as I had requested, with minimum thoroughness and maximum compassion.

One of the options Dr. Curry discussed with us was surgery. We quickly scheduled a meeting with Dr. Mark Callery, BI's chief of general surgery whose specialty just happened to be the Whipple Procedure, which was precisely what BG required. If that didn't work, the next option would be a liver transplant.

We met with Dr. Callery soon after, on a beautiful day in early October. We arrived at his office at BI and hardly had to wait to be ushered in. He greeted us, introduced his team, and explained the daunting procedure. Put simply, it involved resecting —or removing—the tumor and surrounding area in the morning, then putting things back together in the afternoon. To BG and me, Dr. Callery represented the epitome of knowledge and capability.

Toward the end of the meeting, Dr. Callery described a most positive scenario—no guarantees, of course—just one of several he laid out for us. As he spoke about the potential outcome of this particularly sunny possibility, I actually found myself swooning. "Who knows," I heard Dr. Callery say, "but in three months, you may find yourselves right back to your normal lives, and all of this will be a memory..."

"Dear God," I thought, doubtless half-praying. To hear this

brilliant doctor speak in such optimistic terms was almost more than I could bear. I began to feel as though I might faint right out of my chair, as I allowed myself to imagine a time that this C-monster that had barged into our life might one day soon be history.

At the end of our meeting, we were still concerned, but certainly more hopeful than before. We had both been mightily impressed by Dr. Callery. Knowing that this accomplished doctor, the *chief,* whose specialty was just what BG needed—and that *he* would be performing the surgery—was a tremendous morale booster. I was walking on air as we left.

BG's pre-surgical CT scan was scheduled for October 11th, one week before the surgery. But in the time between the diagnosis in late September and October 11th, as the CT scan would reveal, the tumor had spread to the pancreatic head and to encompass the two major blood lines to the liver. This aggressive growth eliminated the surgical option, as well as radiation.

Our only remaining course was chemotherapy.

Talk to the kids, thoroughly and truthfully, but at the right time.

Once we knew the plan, it was time to talk to Westy and Lindsay—and BG wanted *me* to do the talking. As anyone who knew BG would have realized, that in itself was a poignant departure from the norm. Bruce Ford had *never* been at a loss for words.

Without a doubt, the talks that I had with the children about what was happening with their father during that time were probably the most difficult things I shall ever do. But they had to know what was happening, and they had to trust that we were being straightforward with them. I also knew that I had to stay calm, for them and for BG: *normalcy*. I don't know how I managed. I am just grateful that I had—or found—whatever inner mettle I needed. I suppose we find it when we need it.

We never intended to keep anything from Westy and Lindsay. We just had to be sure that whatever we did tell them was accurate. We wanted to avoid confusion or raising false hopes, which is why we waited until we were as certain as possible about next steps.

We called the kids into the kitchen, and I sat with them at the table while Bruce stood behind me. I didn't look at him—I don't think I could have looked at him. I think he was pacing. I had no speech planned, I was expecting a conversation. But BG had told me just moments before, "I want you to do the talking."

As Westy and Lindsay sat down, I couldn't help but feel that I was handing down a sentence of sorts. It was dreadful, but it had to be done. As would be the case in so many instances to follow, there was simply no alternative.

Sometimes, we just have to walk the plank.

"West, Lindsay, you know that Daddy and I saw the doctors in Boston today," I began, "and there is a tumor. There's a cancer. But Beth Israel is one of the greatest hospitals in the world, and we have the best doctors imaginable. We couldn't possibly be in better hands.

"The thing about cancer," I somehow continued, "is that it is always different. No two cancers are alike, and every case is different, and that's all we can know now. We're just going to do the best we can. We're in one of the best hospitals in the world, and Daddy is getting the best possible care.

"And," I added, "everyone is very smart and very nice."

There were no tears, just understanding and thoughtful acceptance. It was an evening of grace—awful grace—but grace, nonetheless. The kids were stoic from the beginning.

Appreciate the people around you, even if you don't know them. You may make some wonderful friend.

We arrived at Beth Israel's Shapiro Center on a day in early November for BG's first session of chemotherapy. One arrives at Shapiro-9, the hematology/oncology floor, with some trepidation. After checking in, we sat down and waited for Bruce to be called for his treatment. Soon after we arrived, an especially dear fellow named Sam approached us with a little trolley of breakfast treats and juice. He introduced himself, remarking that he had never seen us, and asked if we were new.

"Will this be your regular day?" (for chemo), he asked.

"Well," we surmised, "probably. We're to come every two weeks, so this must be the day."

"That's good, because there's a different group of volunteers

each day," he declared, "and we're the nicest!"

Soon enough, we understood what Sam meant. Over the course of the day, we met the other volunteers, and one by one, they endeared themselves to us, as well. Former chemo patients all, they simply moved around the clinic, dispensing treats, lunch, and dessert, along with their own special brand of comfort and encouragement.

It was inspiring to have such a group of warm and welcoming survivors befriending a new crop of cancer patients as they faced the great unknown. These people became so dear to us that I think we actually found ourselves, at some level, looking forward to BG's bi-weekly chemo sessions.

Then there was Annie. Ann Brady was Bruce's primary chemo nurse, and she was one in a million. Whoever could have guessed that a chemo clinic could be so cheery and optimistic, but with Annie in charge, that's exactly what it was. Kind, competent, and understanding, Ann Brady was the archetype of the ideal oncology nurse.

My first question to Annie was about pain, if BG would have it and what I could do about it. She immediately shook her head. "No," she stated, in no uncertain terms. "He does not have to be in pain."

Hearing those words from her was like a weight lifted from my heart.

Finally, we had the great fortune to have Dr. Rebecca Miksad as BG's oncologist. It was she who explained to us how the chemotherapy would progress, and who oversaw his care at the clinic. Bruce had chemo every other week, and we met with Dr. Miksad once a month. Every two months, BG had a CT scan to assess progress, with a week's wait to learn results. Dr. Miksad was equal parts intelligence and compassion. She stayed with us every step of the way at Beth Israel, even when she was no longer in charge of his care. I am so grateful that she was with us. I can't imagine having gone through it with anyone else.

Find ways to enjoy your days.
They are all that any of us actually have.

BG's first CT scan was scheduled for December 26th: *Merry Christmas.* Fortunately, during what would have been a dreadful

time waiting for results, we were well distracted by friends who invited us to Maine over the holidays. It helped so much to get out of our routine and into a completely different environment. Once back home, we were thrilled to learn the results of the first scan. To quote Dr. Miksad: "The cancer was stopped dead in its tracks!"

We could hardly believe it. At the same time, though, it seemed that it *should* go that way for Bruce. I think we both began to wonder if that was the way things would play out and BG, once cured, would ultimately go off the chemo. Or, perhaps the chemo would shrink the tumor back so that it could be surgically removed. After all, things had always gone our way. However, at the same time, I think we also learned to put the brakes on, so as not to tempt the gods. We were encouraged, but cautiously so.

Then, somehow, we were able to return to a semblance of normalcy that we so desperately wanted. Bruce, "a bull" of a man, in the words of our nephew Alex, took the chemo well. Though his energy was a bit diminished, he was able to continue teaching and enjoying life. At the beginning of March two months later, the next CT scan also revealed that there was no further growth, and a couple of other markers were down. We began to see even more light at the end of the tunnel.

But by the third scan in early May, our luck changed. As soon as I walked into Dr. Miksad's office, I knew that she had bad news before she even said a word. She had taken care to place two chairs by her desk side by side, touching. In an instant, I knew what it meant. She knew that BG and I would also want to be as close as possible when we heard the news she had for us.

"The cancer has outsmarted us, it has jumped to the lungs," the young doctor calmly explained. "But, we can try a different type of chemo."

We briefly returned to the clinic to schedule an appointment for the new therapy. As we walked back from Dr. Miksad's office, BG told me not to say anything to our new friends. "They'll find out soon enough," he said. But then I ran into Sam. I didn't dare break down, and I had to respect BG's wishes.

"Everything has changed, Sam," was all I could say. "We're not staying today."

(A Primer for Dealing with Cancer—available as a free download under a Creative Commons license. To read Normalcy, go to www.togetbackhome.com)

Glove

—*Carol Dine*

I lost a black fleece glove,
soft, sturdy
under the back seat
on the sidewalk
on the classroom floor
better to have one glove . . .
I put its mate
in my lingerie drawer
beside the black satin
pear-shape
a woman sold to me,
saying
sorry.

The Mighty Tree

—Linda Floyd

Should I begin at the end? In the end, I was alright. I was ok. I really was. But the beginning, the beginning, it changed my life forever. It was like a ball rolling downhill that seemed to pick up momentum with each rotation. It was a strange, stressful, confusing world I found myself in.

It began with a mammogram which I wasn't worried about until they walked me down this l o n g hall to the ultra sound room to get a better look at this spot. This spot wasn't on my last mammogram. I had early stage breast cancer.

Here's the middle part of the story, the scary part. I had my lumpectomy. Three weeks later I was in the emergency room and needed surgery because an ovarian cyst burst. I had ovarian cancer. The ovarian cancer was an early stage also. I had hot flashes that drove me crazy. I had two surgeries, had chemo and I had radiation. I had two primary cancers.

I was in shock about the turn of events and knew I was going to die. Thankfully, I was assured I wasn't going to . . . The "Big C" wasn't gonna get me.

I walked my dog in a place where a mighty tree stood. I noticed how this tree swayed to and fro with each passing breeze. The roots were strong and deeply planted in the soil. The branches were flexible yet tough. The leaves floated off the tree and gently swirled and spun in the air until they found the right spot to land in. The tree was by the bay on the sunny side of the island. I imagined myself as the tree. I could sway back and forth to every breeze that entered my life, my air. In the end, I knew I was stronger like my friend the mighty tree.

Believe Me

—Casey Malanga

You tried to tell me.
Everyone tried to tell me.
I nodded my head and smiled,
but deep down, I just didn't believe you.
I tried, but it was still too new, too fresh.

It gets better with time, you said.
I nodded my head and smiled,
but deep down,
we both knew,
I didn't really believe you.
At least not then.

My skin was dry and cracked.
My head was bald.
And the tears poured out
as if someone had turned the faucet on
full blast.

It takes time, everyone continued to tell me.
Really, the only thing that helps is time.
Chemo ended and I waited.
Radiation finished and I waited some more.
July 6th came and went.
Was it easier?
Well, maybe just a little.

I still cried, but with each
passing week I seemed
to cry a little less.
Life was still hard, but I could manage.
I started to tell myself that
maybe it was
just a little easier.
At night I would often think,
It's not as bad as it was a month ago.
Progress? Maybe just a little bit.

Now I look back,
more than a year later.
I'm healing.
Slowly, steadily,
all in good time.

I didn't believe you then.
I wanted to, but it seemed
Impossible and improbable.
But I do believe you now.
Time helps.
Time heals.
Believe me.

Ovarian Cancer vs. The Love Mafia

—Joe Mansfield

My wife Diane's ovarian cancer diagnosis came out of the blue. Our family had been innocently going along through our life. Back then, we certainly appreciated our many life blessing and believed most things in our life together were predictable. Since then, with the help and inspiration of "The Love Mafia", our love for each other has gone to a much deeper level.

Diane's careful watchfulness played a big part in the early cancer detection. With a maternal history of two types of cancer, she had been requesting regular CA125 blood tests (CA125 is a predictive blood test for pelvic cancers). So within less than a week after a slightly elevated CA125 score, we went through a whirlwind of doctor appointments, an ultrasound and exploratory surgery was scheduled.

Diane's fate was to go into that surgery hoping for, at best, an unnecessary incision—or at worst, the removal of one or possibly two ovaries. Her fate that day, however, was to be the discovery of stage 2 ovarian cancer and a complete hysterectomy.

From that surgery, we were speedily sent to a female oncologist who explained what Diane was facing for odds and treatment. She and her staff took Diane under their wing and went after any possible remaining cancer cells with the fervor of a warrior. Diane's chemo infusion treatments began. As I struggled to meet the challenge of doing my best for Diane and our two sons, I was more overwhelmed than at any time in my life.

But, I was about to learn a very deep life lesson. It was a lesson of unexpected loving support. The vast majority of this support came from women: women I had never met. As a man, I was totally blown away by the amount, directness and steadiness of the love from these women. I have lovingly come to think of these outstanding women as "The Love Mafia".

They were of all ages, degrees of separation and proximities. The one thing that they shared in common was the willingness and ability to give a very direct and steady, unconditional love. First,

they seemed to "take over" the florist and gift basket -food delivery systems. Next, they commandeered the US Postal Service. From there they absorbed the telephone and e-mail systems.

The women in Diane's life: family, friends, neighbors and co-workers immediately placed a strong circle of love around her/us that never faltered. Way above polite "how are you"s, the Love Mafia showed up and nursed her through the messy part of her chemotherapy treatments, came, at times from great distances and stayed for days on end. This was a direct "hands on" love.

It was about a sister holding her hand, in a discrete back room at a hair salon, while she had her head shaved—to at least feel some control of the side effect realities of the chemo.

It was a neighbor setting up elaborate childcare arrangements for us during our hospital trips.

Endless, and I mean endless, gifts of cards, flowers and food. We'd return from a treatment and our home answering machine would be blinking like crazy with voice messages, mostly from women—often voices I didn't recognize—all essentially the same message of encouragement—all ending with the same exact phrase "I love you!"

Beyond our local Love Mafia, there was an endless shower of blessings. One day a box full of berets arrived from an old friend from California. A Mary Kay consultant arrived one day with Diane's sister from a neighboring state to give her help with her appearance. Due to the proximity of our 25th anniversary, Diane's rabbi agreed to perform an unofficial re-marriage ceremony at the temple for our small family—hupa and all.

I don't mean to imply that the men in my life didn't show up for me. One friend from my church men's group stood before the congregation and lit a candle of caring for Diane's speedy recovery. That night the men's group held a special, unscheduled, meeting to be of support to me. Even the minister that Sunday altered her sermon to share her experiences and to offer words of hope.

On two occasions relatives arrived and ordered me off of the property. They insisted that I take a break. On one of these breaks I went to the ocean. It was a sunny spring day. I parked and walked through the Plum Island dunes to a deserted beach. There had been quite a storm the day before. I was struck by the power, sound and enormity of large, post storm, pounding waves. I just collapsed into the sand and cried. I felt so small and vulnerable.

When I was able to dry my eyes and focus on the shoreline, I witnessed a small group of tiny shore birds. They were just plipping along – just doing what small shore birds do (I think they were sandpipers). My tears and sadness began to fade away. Despite the storms residual pounding waves, strong winds and dramatic sky, these little birds seemed safe, okay and just being about their little birdy business. A small voice inside told me that Diane and I, Josh and Alex were just like this small flock of birds. We were weathering the awful storm of cancer, and chances were, that we'd be back to our usual business - back plipping along the shoreline of our life together. That was 12 years ago. Today we are okay.

My Poetry

—Jean E. Marzilli

Survivor Ring

The ring encircling my finger is crafted from the finest gold
The diamond encased within this ring is 32 years old
Another diamond took its place many years ago
But the story of this ring really must be told
We waited seven years before the ring was bought
We didn't want to buy it and have it bought for naught
How proud my husband was to place it on my finger
We knew we would marry soon we didn't want to linger
Our marriage had it's up and down, yet we still persevered
Hallelujah! We beat the odds and made it to 32 years
The "Crying Ring" is no longer hidden in a box being cloaked
The diamond shines much brighter, it is now infused with
everyone's hope
It doesn't resemble the old ring in any shape or form
As my husband fights cancer, he too shall be reborn
Paula made this ring for us, a ring for a cause
We thank her for this gift, say a prayer and pause
This "Survivor Ring" she made with love while
shedding many tears
And will forever remain cherished through the coming years
It holds within its gold many years of sweat and pain
A constant reminder that our life has not been in vain
This ring embodies all the goodness in our life we've achieved
And that there will be a happy ending, this we strongly believe.

Is "Something in God's Hand"

"God's Hand" gave me something incredible today
It's an epiphany and happened in a mysterious way
I gazed lovingly at my husband and didn't know what to say
"God's Hand" hit me with lightening and said
I'll show you the way
Your husband is deadly sick; you cannot speak what you feel

Don't ever forget Gods love is all consuming, precious and real
I'll teach you how to express your fears, concern and love
And once you do, you'll feel free and fly like a dove
So as God poked, prodded and spoke into my ear
As deaf as I am, he felt so very near
This "Something" he gave me was poetry and prose
It sprang ever eternal and opened my heart like a beautiful,
budding rose
This "Something" some say is really a hidden gift
But I believe its Gods way of giving me a much needed lift
I was never very religious but I never once despaired
That God would come into my life and show me how much he cared
"God's Hand" has done "Something" I don't question why
I think it's for my husband so I pray that he won't die
As I sit here and write my poetry which helps relieve my stress?
I hope my husband reads these poems and
know in God's eyes he is truly blessed.

Jayope

There is an island and its name is "Jayope"
It was formed solely by little Jay's hope
Little Jay is the leader and welcomes children with open arms
He says, "Don't be scared, I'll teach you all this lands charms"
I'll show you how to have so much fun,
you'll forget all about your pain
Here you can drive your own car even be a conductor on a train
There is no bedtime here you can eat what and when you want
The demons in your dreams can no longer pick on you to haunt
The children frolic joyfully within this enchanting land
Every child within keeps its essence in their hand
You see this place is special, not everyone can come in
You must have faced cancer, fought it strong enough to win
Everything here is joyful; there is no worry or strife
The children living here will not settle for half a life
They pick dollypop flowers, then blow,
which send spoors floating in the breeze
The spoors create little rainbows they try to catch with childlike ease
If lucky enough to catch one, it rains chocolate pennies from the sky

And they behold with wonder as the one who catches a chocolate
penny can now fly
They frolic and swim in the crystal clear waters at
Dreamandy lake
Dreamandy is made from their dreams, favorite candy and cake
"Jayope" has no bullies; children from around the world come here
The children have comfort in knowing their family is
still very near
The children know they cannot remain for very long
Their family needs them back; back, where they belong
So when it's time to wake up they remember with great joy
The fun they had at "Jayope" and can't wait to play with their toys
All who dwell on this island called "Jayope"
Will live long and prosper their life no longer determined
by a microscope
They have one thing in common that creates a special bond
It is called hope and it helped them all move on.

Angry

He's being such a tyrant; he has a bone to pick
I am so very "Angry"; I want to beat him with a stick
I'm tethered to a ball and chain locked only by his will
I wish he'd learn to calm down, I wish he'd learn to chill
All is fine and right with him as long as I am near
To be at his beck and call and stay close enough to hear
He can get up and help himself whenever in the mood
In the morning he rises early and makes himself some food
He lets the dogs out so I can get some rest
But then he gets "Angry" at me, what is this a test?
I guess he thinks I'm selfish to want a little break
It seems all he wants to do is take and take and take
I know he doesn't feel well, I know he's very scared
But this is something that we both are forced to share
So though this poem sounds "Angry", it's just my sounding board
He really has been quite thoughtful and
justly deserves a major award
I'm aware that with his cancer he might once again take a dive
But he must know, with my love, he will definitely SURVIVE!

Haunted Reflection

I look in the mirror; I don't like what I see
Who is that haunted reflection; can it really be me?
I look old and tired; how much more can I give?
Only my soul so that my husband can live
The face shows the struggle and turmoil I'm living
I really wish the mirror was a little more forgiving
I don't see that I've worked hard all throughout my life
Always stood by him, tried to be a good wife
I don't see an aura of radiance for all the love that we've shared
I don't see happiness that he loves me and really does care
What shows is new wrinkles; definitely not laugh lines
Is this not what they should be as we've shared many good times?
Deep in the mirror I see my soul has been laid bare
Yet I keep looking; what possesses me to continue to stare?
I keep staring intently and hope someday to find
A small piece of Jeannie not tangled vines
I will acquiesce to each day as it comes
I will try each day not to be glum
For life is a journey and what are a few more wrinkles
Well worth the price to see Jay's eyes once again shine
with a twinkle
I know one day I will look in the mirror and like what I see
It will happen when Jay is cancer free.

Solitary

I will one day walk alone without my husband by my side
I will one day walk alone and hold my head up with pride
I will one day walk alone pondering what went wrong
I will one day walk alone and know I must remain strong
I will one day walk alone sagaciously aware he wasn't iron-clad
I will one day walk alone; reflect on our life;
and feel profoundly sad
I will one day walk alone no longer able to hold
my husband's hand
I will one day walk alone and gaze lovingly at my wedding band
I will one day walk alone wondering if the tide will wash away
my pain

I will one day walk alone diligently striving to remain sane
I will one day walk alone because it's just a fact of life
I will one day walk alone no longer anyone's wife
I will one day walk alone outraged he is no longer here
I will one day walk alone and shed myriad, melancholy,
rainbow tears
I will one day no longer walk alone; my soul will leave
this sacred land
One that day we will walk together, rejoicing, holding God's
beatific hand.

Healing Branches

There sits a solitary willow tree; its branches fold and weep
The roots sink deep into the ground and then begin to creep
It will anchor itself against any raging flood or storm
Its branches strong; not deformed; just a little weather worn
It will provide a tranquil place where all can come and rest
To gaze upon the flowing stream and for a short moment feel no
distress
Its lovely draping branches will cradle you within their boughs
They will gently sweep across your forehead;
caress your weary brow
As the wind begins to blow it will carry your sorrow
down the stream
Have I made you feel better? Better enough for pleasant dreams?
Dream of the phenomenon you'll see and still believe
Do not dare not to dream and sit here just to grieve
Dream of all the wondrous sights your eyes have yet to see
It has been chosen for you; it is your life's decree
Daring to explore where you never have before
You are now ready to go out and do all this and more
My healing branches shall remain for at least fourscore
When you have done all these things,
return to this tranquil shore
Tell me that I have helped to enrich your life forever more.

Divine Pennies

I've been finding "Divine Pennies" since we began
our willful fight
Some are very shiny, some are not so bright
I wonder if they're from heaven and represent God's tears
Showing me he cries to alleviate my fears
Or could they be from loved ones gazing at us from above
Is it their way of showering us with their cherished love
As in God's children, no two will be the same
If I didn't pick them up it would be a crying shame
My eyes gaze with wonder at the "Diving Penny" lying tranquil
on the ground
It shouts, look at me, I'm waiting to be found
I see them as they lay, pick them up and hold them tight
And as I finally hold them, I pray that all will turn out right
We have a life long battle, of that we have no doubt
I hope "Divine Pennies" keep falling and never become a drought
I do not question why they're here or how they came about
I know they bring great joy to me; I find them and want to shout
I have saved all my "Divine Pennies" and look at them in awe
And as I look more closely, not a one has a single flaw
They will not be placed in a jar, hidden far from sight
I want all to share with me their alluring inner light
I know our life will be alright if "Divine Pennies" continue to fall
They cast an intriguing spell to keep me forever enthralled.

Rainbow Tears

I'm angry, I'm not happy, I'm not very glad
My husband has cancer, I'm very sad
I'm scared and confused, don't know what to do
In the color spectrum, paint me blue
I try hard to be there to remain very strong
And I pray each day that his life will last long
I cook, clean and take care of his needs
My soul cringes, I cry "Rainbow Tears" when he bleeds
We scream and we fight, it makes no sense
Why do we do this, let's not create a fence
I want our life back, all the fun that we had
Am I wrong to want this, am I very bad

Pyramids, gondolas, castles and more
The world's at our feet, so much to explore
The rainbow spectrum is varied and bright
We'll find the pot of gold and have a good life.

A Visual Narrative of Remission

—Roger Preston

Journal Entry

Remission seems to have many different levels both physically and psychologically. I believe that making connections with how the remission of my cancer was resolved will help me maintain the ability to avoid cancer later. To make the connection is to understand what the actual meaning of remission is. I am starting to realize that the remission time period is a new time that I have to consider reorganizing my life. That means that the present external reality has to be realized and that my art will remain a personal self-contained reality of both the former and recent experiences. As an artist the one connection that I will be able to continue to use as a proactive connection is the process of the mind, body and spirit healing with my art. I have a personal feeling that I cannot let my guard down, but can use the concept of the mind, body and spirit healing as a preventive medicine along with my doctor's care.

I am in remission but I am continuing the chemo treatment to ensure that the cancer cannot return. So the reality of cancer has not changed that much at the present time. The sleepless nights persist! My sanity is kept intact during the night with my conversation during my nite talks (talking to myself) and creating thumbnail drawings to assist me in being proactive visually with the cancer. The thumbnail drawings are the start of my self-contained reality.

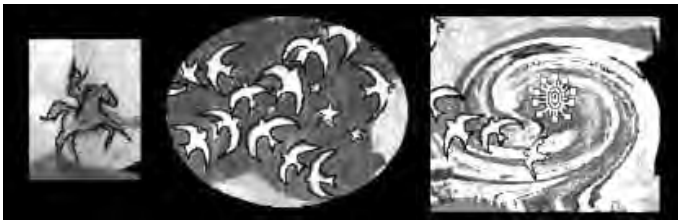
These thumbnail drawings are an example of what happens during my night talks: *Night takes us and keeps us awake. Where is the cancer? I hope that the cancer will disappear. It is going!* I drew the above idea then used it to visualize the disappearing process of the cancer (*It is going!*) in my mind's eye.

Regina, my wife, had cancer four years ago and had two major surgeries they took the cancer and she lost a kidney and the lower lobe of a lung. Regina was a wonderful example on how to handle personally a major illness such as cancer. Then when I was told that I had cancer, they also discovered that Regina's cancer had returned. So we have become two people experiencing cancer and at the same time and are each other's caregivers. So together we have made new connections and commitments to each other. People that care and love us have supported us. The new connections and commitments were parts of our marriage; marriage is like a work of art and is a work in progress and change. Remission is also a process and a change experience.

It has taken me some time to deal with and understand the remission of cancer. The computer art, *A Visual Narrative of Remission*, has many layers embedded into the work. The symbols that I have used seem to be probing me with haunting images of a personal remote viewing of a questioning imagination.

The knot placed over the broken heart has become the symbol of tying the connections of everything together.

Details of the original



The above symbols are personal to me. Both the horse and the flock of flying birds are symbols of freedom, and right now symbols of freedom from cancer. The abstract symbol on the above right is a cancer in the center of the energy of a chemo storm and the birds are flying out of the storm into the freedom of the remission of my cancer.

I am now realizing that the remission of my cancer is another and important phase of the cancer experience. I know that there is no evidence of cancer in my system. My doctor keeps telling me that my blood count is good. In fact, the last time he said that my blood was beautiful . . . So I will not worry that cancer might return. I have heard several older people comment about life, they said, "I will live till I die." I think that is a very healthy attitude about living a good life no matter what… It is exciting to see what serious researchers are finding about the brain and the different healing processes used with medicine and how they support and work together.

As I said in an earlier journal entry," When we make connections with what we see we can believe in the art."

My Personal Experience

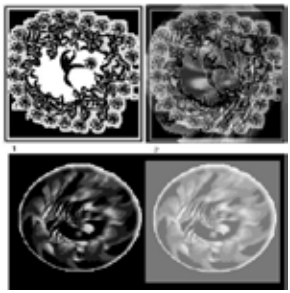
Finding My Creative Process of the Mind, Body and Spirit Healing. When Does Nothing Become Something?

Living with cancer has been to me both a learning, and at the same time a debilitating experience. It has been a time when I have lost friendships and also developed closer friendships with the people that care for me. In some ways I have lost my physical freedom because of my exhaustion. Much of the time became committed to the appointments for the doctors, and chemo treatments. When I lost my physical freedom I gained both an intellectual creative state of freedom of mind, and the willingness to test the imaginative creative process. Thumbnail drawings are marks on a surface that remain marks until the imagination finds a symbol in those markings. The thumbnail drawings are only the start of an idea of leading to something. My imagination and the creative process of the drawings allow me to accept changes in the experience of processing recognized or subconscious meanings in my art. The thumbnails at the beginning of this journal entry were created early in the cancer experience. For some reason there was something about the drawing that I questioned. In looking at it, I felt that the shapes overwhelmed the figure. Later, every time when the drawing was considered to be reworked, I was reminded of the feeling that I had when I was first told that it was cancer. It was over whelming. The drawing was saved in a file on the desktop because I might choose to rework it later.

In Chaim Potok's book," My Name is Asher Lev"; the epilogue contains a statement by Picasso, which says, "Art is a lie, which makes us realize the truth." I have been influenced by that statement because it has given me a creative freedom with the art that was produced for the proactive visual reactions to my cancer. Art deals with the truth of modern man and my art tell part truths. I say part truths because the whole truth in art is the combination of both the art of the artist in association with the intellect and the spirit of both the artist and the observer. My art is a circle of interaction in looking at my mirror image and the world that I am part of and to express what is observed and encountered.

As I said, I felt overwhelmed inside the shapes of the first thumbnail drawing and wanted to escape the confines of the shapes. (I felt trapped and felt that nothing could happen with the proactive intent in the drawing if I was trapped.) So the figures where added around the outside of the overwhelming shapes to see if that would change the intent of the work. The figures seemed to be running away from the confinement of the figure. That confinement seemed to become an unwanted symbol of cancer. There are times that I can not continue working on a particular idea, so everything was put on hold. At this time I am in remission, but this work has bothered me because I wanted the cancer to disappear. Realizing that the process of creating the intent of the healing process is to imagine what will occur. The actuality for healing to work I knew that I should change the intent of the computer drawing so that the symbols in the art would be successful in my minds eye. The reworked drawing has four symbols. The figure from the original thumbnail was saved and placed in the center of the circle of figures and the inside figure is kicking the symbol of the cancer to the outer edge of the drawing. The circle of figures is a symbol of the supporters who have cared for me. Medically, physically and emotionally. The figures were also created to keep the cancer that was kicked out of the circle from returning. The gray symbols are the cancers starting to disappear.

In remission I still wanted to create something else that indicated that the cancer would *neve*r return. I wanted my art to be about living and not dying, so decided to continue a visual search for healing.



The drawings on the left are samples of the metamorphous of transformations of the art to nothing. Number *one* seems like a celebration because the outside cancer cells look like flowers and I did not want to celebrate so I

pasted number one over a distortion of a drawing creating Number *two*. I wanted to destroy the cancer completely and forever, so I distorted number *two* to lose the drawings visually, and that has become number *three*. With my computer I copied, then continued to paste transparent number *three* and repeated it until nothing was inside the circle of number *four*. The repeated pasting of each transparent file was finally dissolved into nothing.

Nothing became *something* because nothing became a symbol of *no cancer*. The white circle became a white non-objective abstraction, and because both the process of creating the white circle and the white circle itself became parts of the symbol that no cancer is in my body. Both the white empty circle and the process of creating the circle are equally important for the symbol to work. In Feldman's book *Varieties of Visual Experience*, He writes, " . . . it seems that we are looking for a key that can make the excitement and confusion of modern life fit into a pattern. In addition to pleasure, we want reassurance." The empty white circle became my reassurance in how the Mind, Body and Sprit Healing can work along with my doctor's care. We all need reassurance during and after our cancer experience. Using a creative process in the arts, we can cultivate reassurance with our personal experiences and imagination.

Topic of Cancer: Riding the Waves of the B C

—Stafford, Meg

Keeping it Fresh

I certainly espouse the notion that it is always good to be trying new things, keeping the marital relationship from becoming stale or routine. With my 3rd treatment today, on our 20th anniversary, I was unexpectedly presented with a unique opportunity for my betrothed and me. The Neulasta arrived as

planned yesterday at Emerson, and they were keeping it chilled for me. I had thought that I would receive this as part of today's treatment, but no, it is to be administered between 24 and 48 hours after the treatment, meaning tomorrow. Ish.

The best place to inject is in the fatty part of the upper arm, which makes it difficult to self-administer. I volunteered Duke for this task, and the two nurses who were there just stared at me, with similar looks of something between skepticism and confusion on their faces.

Both said nothing for a moment.

"He'll be okay with it," I offered confidently.

"He's not here for us to explain to him how to do it," one of them said.

"Well, you teach me, and I'll teach him." More blank looks.

I didn't know what the hesitation was. Did they not believe me? Which part was the confounder?

"What about a neighbor?" one asked.

None of our immediate neighbors know what's going on. I could see this approach. "Hey, by the way, I'm having treatments for breast cancer, and what do you think about giving me a little shot in the arm? I'll show you my hats, and wig, and we can have tea!" If I thought I was getting odds looks from these nurses, I can only imagine what that would bring.

The nurses also offered that I could come back before 5:30 and any one of them would do it. But that would mean another trip back. And I was so sure that Duke would be up for the task.

They did agree, and showed me the already-loaded syringe. The only thing to make sure of is that the needle is actually in before pressing the medicine. Ejecting the medicine into the air would be considerably less effective, to say nothing of the expense. So we have that to look forward to tomorrow evening when I get home from seeing the 3 or 4 clients who were too tricky to reschedule. Our first new adventure in the 21st year. I count my lucky stars that I did not even hesitate to volunteer my buddy for this.

This morning, Kate asked me to fill a tiny bottle with conditioner to take with her to Becket, her 3-day school trip. She handed me the enormous bottle and the teeny one with a minute opening. I started filling the dense liquid into the tiny hole.

"Kate," I pointed out, "I'm going to have hair again by the

time I get this thing filled!"

"Hey, good one," Gale called from the other room.

"Have fun at Becket," I called as they were heading out to the car.

"Thanks. Have fun at chemotherapy!" Kate replied.

Yep, it's all becoming just that normal.

Chemo did go fine; my counts were just where they should be. I came home, ate lunch, and went for my second acupuncture treatment. I feel much less spacey than after the last 2 treatments, and I think more energetic, too. Eating was also key.

Hey, thanks for listening and boosting me through this odd territory.

A Shot in the Arm

As I expected, it was pretty much a non-event. We prepared the arm with the alcohol rub, Duke washed his hands, we made sure the syringe didn't have air in it, and he injected. Really not a big deal. I wouldn't exactly recommend it for an amorous evening, but it was not an evening killer either. Took about a minute and we were back to our respective businesses of getting the remote control helicopter to work (Duke's B'day present) and tending to e-mail (guess who).

I had a great day. So good, in fact, that I had a flash of concern that there was only a saline solution in the bag that dripped into me for an hour and a half. There was a handwritten sign that read Cytocin, but I feel so normal today that it makes me suspicious. I'm learning not to look gift horses in the mouth (you never know what they're storing in there).

The two differences this time were the acupuncture treatments and the fact that I skipped the Ativan last night. Not sure which is making the bigger difference, but it doesn't matter. The triumvirate of nausea, fatigue and spaceyness were all at bay today (probably searching out that boat ride that should come on day 6). I know enough to know that this does not mean it will be like this every day, but I'm taking each day for what it is.

I started with an hour long walk with my friend Martha and Mr. Dog, and I'm happy to say that it was Mr. Dog who was panting on the way back. Downhill even.

And I put in a few hours at work. Four hours is a great way to go at work. All this does mean that my sloth imitation may need some work. I have the whole weekend to work on it, including tomorrow, so I better get out my book and start practicing draping myself on the sofa or reclining chair.

My practice suffered its first casualty today in relation to the Breasty Business. One client realized that she was reluctant to call because she felt that her concerns were so trivial compared to what I was dealing with (she didn't find out until earlier this month because of vacations, etc.).

We were able to talk about it today when she came in. She thanked me for all the work we had done together this past year, and told me that I was instrumental in getting her to listen to herself and do what's best for her. In this case, it meant going back to her previous therapist of many years. So perhaps it is just another example of doing what's best for her, or at least trying it out. It was important that she not be worrying about me or feeling like she needed to take care of me. Seeing me today made her realize that she didn't have to, that I'm really fine, but this will be an important issue for her to look at in any case.

Other reactions have included concern, elicited cards, flowers, a journal and some ginger, feelings of protection. It's been amazing to see what will come up. This was the first person for whom it was too difficult to stay in treatment, even treatment that had gone well.

Needles to say (that's a pun, not a typo), I'm wondering if the Decadron of this morning is making me chatty, but I'm signing off in any event.

The Right Stuff

Any concern that it was not the right stuff has been allayed. I have been working on my sloth thing this weekend, even taking a nap on Sunday, which proves that something other than my norm has been happening. Duke was relieved to know that the shot in the arm was not for naught, and that this stuff is working its way through my system to flush out the alien cells.

I'm glad that I pushed out my work start time to 10 o'clock this morning. Would have been a stretch to get in there

for 8. We'll see how the day goes. I'm understanding the appeal of coffee, too, which typically serves to wind me up into a large-scale (albeit bald) energizer bunny. Now it seems to bring me up to cruising speed. I have still been able to appreciate the spectacular days, even if I am not out there pedaling away the miles this week. Maybe on the weekend.

Fire up the Barbie

No, not the one in pink pumps, Silly. The one that brings back MEAT to the anemic. I started my day with coffee and a sausage (chicken apple), and had salad with Ana for lunch (I ate the bacon from both).

Then I found out at today's Ralph visit that my red blood count is low. If it gets much lower, they pile on Procrit or something else to give it a boost. And my red blood count had been holding steady after that first dip, until now. So whoever told me that eating meat doesn't matter is probably wrong, because when I was making a more concerted effort to eat it, my counts were up. At the very least, it can't hurt, so bring on the steaks!!!

My white blood cell count had spiked as a result of the Neulasta. Yea!! And the nurse said that if I were going to experience bone pain as a result, it would have already happened. And I didn't. So I'm going to give that particular side effect a miss. How cool is that?

I asked if the bump in white blood cell count would head off some of the other mouthy side effects. She said that they were just teeny tiny white blood cells, and probably wouldn't make a difference. And how long do they take to mature? I asked. "About 2 days," was the answer. So doesn't that support my theory that with the plethora of them now in attendance, some of them could possibly spend some time in my mouth making sure I don't need the rinse and spit?

Personally, I thought that a cold sore was trying to pop its way through yesterday, and I told it not to give me any lip, and so it hurried back where I couldn't feel it. Smart. Anyway, I've expended whatever energy was lurking, and it's time to get to my meeting.

(Meg Stafford's book, Topic of Cancer: Riding the Wavers of the B C, is available at local bookstores, Amazon and Barnes and Noble, or at her website: www.MegStafford.com)

My CyberKnife Journey

—Ellen Venturo

My journey started in March 2011 at the Beacon Resort in Lincoln, New Hampshire. My girlfriend and I went to celebrate St. Patrick's Day. On the third morning when we were getting ready to leave, I had difficulty in breathing. When I arrived home I called my primary doctor S. Liu who ordered an x-ray. The x-ray showed I had pneumonia and lung cancer. I then had an appointment with Dr. Sadrnorri, a pulmonary doctor. He ordered stress tests, MRI, CT scans, PET scans, etc. The doctor then told me that a lung operation would probably be fatal. So he told me about the CyberKnife treatment at Beth Israel in Boston.

Off I went to Boston with my daughter, Kirsten, for more tests. I had 5 CyberKnife treatments. I was very comfortable having the tests. They lasted for about 90 minutes. I relaxed with my Andre Rieu CD and before you know it the treatment was all over. On the last two treatments, my daughter from Maine came with me. We stayed in the Holiday Inn hotel in Brookline. We met people from all over the country who were being treated for all kinds of diseases. No one of them complained. On a free day my daughter and I went to the Franklin Park Zoo. Great day. July 29, 2011 was my last CyberKnife treatment. In January I went back to the hospital for a PET Scan and consultation. Dr. Stuart Berman said it looked pretty good. My next appointment is May 16, 2012.

I want to thank Dr. Stuart Berman and the CyberKnife team. All the doctors, nurses, and technicians. Everyone was so kind and helpful. I think they all of them are my earth angels.

Sincerely,
Ellen

Personal Genetics

—Suzanne Woodman

I arrived at the diagnostic mammogram area for my seven-year unilateral screening just a couple of weeks ago. Clear again! Yay!

I headed up to my oncologist's office for my annual visit. Physical exam clear. Yay!

And then this smart, savvy and compassionate doctor raised the issue of genetic testing once more. She always raises it gently, never pushes. This time she talked about a few more specifics. It was true that my breast cancer was very small and easily treatable. But I did have a mother who died at the age of fifty-three of colon cancer. I also knew that one of her brothers had contracted colon cancer, and I had a strong suspicion that her two other brothers also had the disease. These factors brought forth a more serious discussion of potential multi-cancer syndromes.

I expressed to her that I had concerns about genetic testing. It's not that I don't support the practice of research in the field of genetics, but I do have personal ethical issues about my own genetic testing. As always, this wonderful doctor, one I look forward to seeing every year, expressed support for any decision I made. She further assured me that a consultation with a genetic counselor would be an informational meeting only.

I left her office with the knowledge that I could no longer avoid the issue of genetic testing. I know what I would do if it were only about me. I wouldn't have it. I'm fifty-eight years old and, in reality, had waited for colon cancer most of my adult life—only to be blind-sided by breast cancer with none of the typical risk factors (though I know there is some connection between colon and breast cancer now). And, as trite and cliched as it sounds, breast cancer has transformed me in a wonderful way. My life is richer and more meaningful. I am, simply put, more alive.

But I have two daughters, so it's not just about me. One will turn 32 this year and one 27. They will certainly get their

mammograms starting at the age of forty, as my oncologist has recommended. And I'll encourage them to begin colon cancer screening at the same age.

But my genetic testing is not my decision to make. And here it comes again. Another opportunity for me to let go. Another chance to believe that my girls are the only people who really know what's best for them. Another chance to pass the baton of the future to them. I can't be making this decision for them. It's not fair. It's not right. It's not ethical.

So I've decided to tear a leaf from my oncologist's notebook. I'll offer my daughters the concerns and questions I have. I'll let them do their own research, if they wish. I'll ask them what they want me to do. And then, I'll do it. And I'll do it gladly and gratefully.

So, dear daughters, on an admittedly public forum, here are some questions I offer for your consideration:

What is the impact of the following on cancer rates in the United States?

> *Joy, friendship, pets, little warning flags on millions of American lawns, genetically modified seeds, love, diet, lifestyle, depression, sorrow, pesticides, pink slime, hormones in poultry and dairy products, cell phones, alcohol, fast food, irradiated food? And the list goes on . . .*

How will your genetic testing impact the future of:

Health insurance, selective conception, employment opportunities, life insurance?

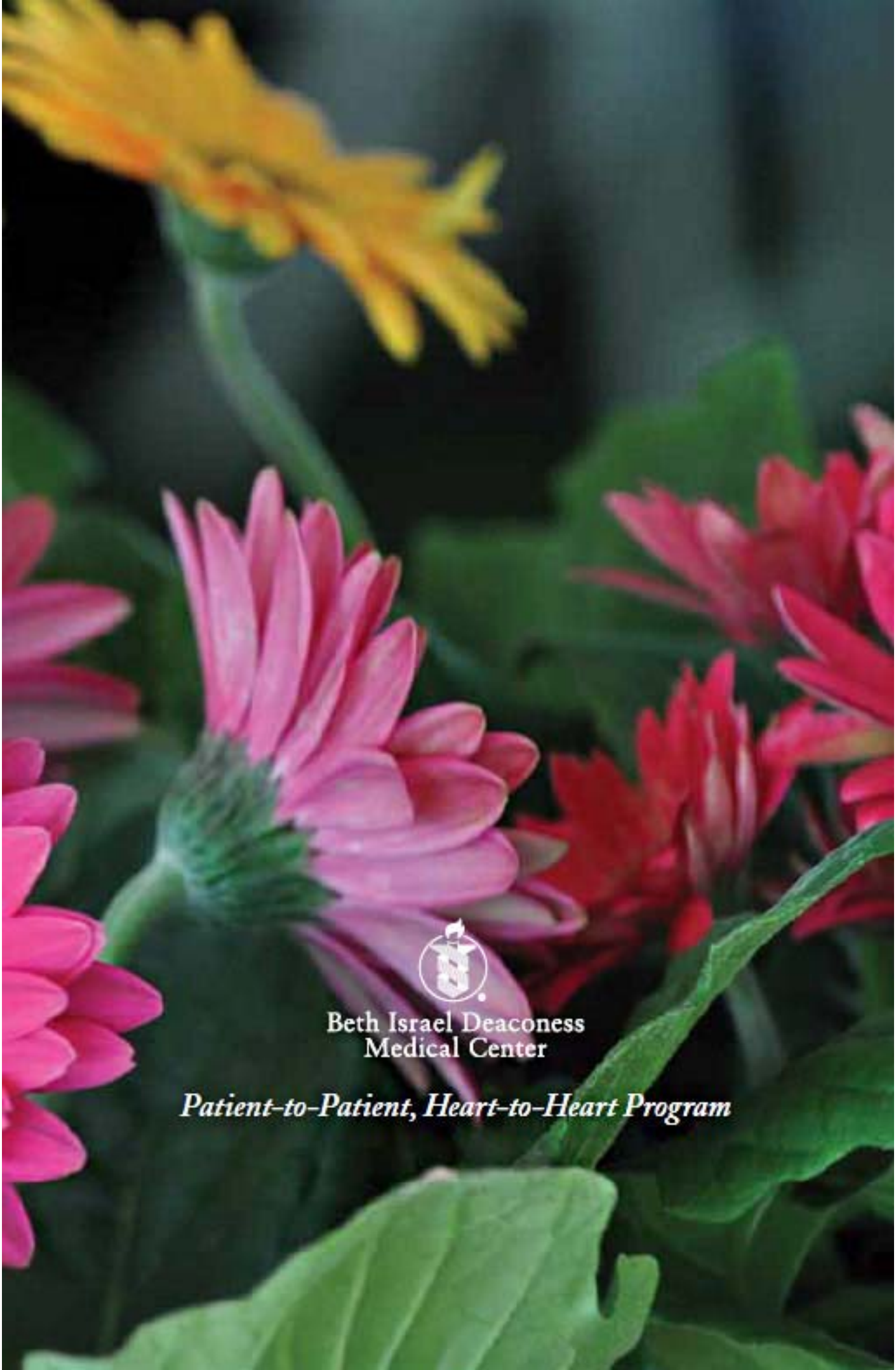
Why do some people *with* a genetic marker *not contract* the disease?

Why do some people *without* the genetic marker *contract* the disease?

Finally, I'll close with what I believe may be the most thought-provoking question of all:

What is the impact of our expectations on disease?

Thank You



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