the woman is **stronger** than the disease

A guidance journal for young women with breast cancer

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Updated, 2011
A diagnosis of breast cancer has now become part of your life. Yet, your cancer diagnosis is only one piece of your life. A medical diagnosis does not define who you are as a person. As young women, we define ourselves considering multiple characteristics, qualities and roles. This journal provides information about what you may experience in the months and years to come. This information was offered from young women, their families and friends, who together are living with breast cancer. They shared their experiences, insights and recommendations to offer you guidance and support as you begin your journey. Their experiences, stories and insight are highlighted in blue text. This journal is formatted to allow you an opportunity to explore multiple areas of your life before, during and after your cancer treatment. Read this journal to learn how other young women have proven they are stronger than any disease. Use this journal to record your own thoughts, fears, challenges, and blessings of living beyond breast cancer. May you find personal growth in your experience as you journey beyond breast cancer.

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life beyond breast cancer
A diagnosis of breast cancer has now become part of your life. Yet, your cancer diagnosis is only one piece of your life.
This journal was created by young women with breast cancer and their families. They opened their hearts and minds, and had the courage to reach out to young women in need. This journal is only possible because of them.

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Survivors speaking out
Letters of support written by young women with breast cancer and their families.
Surround yourself with positive, supportive, encouraging people. And, take time to...be gentle with yourself! You are a very special person!
DEAR SURVIVOR,
I am writing to you because I know that you feel alone and scared. I felt the same way in 1998 when I was diagnosed with breast cancer just shortly before Christmas. But here is the gift...you are not alone. There are women (young women) who have come before you and who will take your hand and help you find your way along this journey.

Let me prepare you for some things...

• Treatment is not fun – but necessary – you don’t have to enjoy yourself – but find an “up-side”. Mine was a boob job, a tummy tuck, new hairstyle (much easier to manage I might add) and a tan (radiation?). My attitude made all that was happening easier to accept.

• Everyone will deal differently with your cancer – but you stay focused on what you need. You are the most important component in this battle.

• You will be mad and sad and scared – and sometimes at the same time.

• Your life has changed – embrace it, cherish it – you only get one life.

• Laugh. A lot. Read funny books, watch funny movies. And when you feel down – go ahead and feel it – and when it passes – thank God, and laugh.

• Think of yourself as a survivor – not 5 years from now – but from today... you are surviving being told you have a potentially life-threatening disease – you are surviving the surgery – you are surviving the drugs that attack the cells that started this – you are surviving when your hair falls out – you are surviving while receiving the radiation treatments – you are a survivor! Your body may take a beating – but it is your very soul, the spirit of you that survives from the very beginning.

Know this: I wish you Godspeed on this journey – don’t look back, the path is in front of you.

FONDLY, PAM

DEAR FRIEND,
I know you have just been given the news that you have breast cancer. It is a shock. You feel like you’ve been kicked in the stomach. You can’t hear, you can’t see, you just want to wake up from this awful dream.

I know, I’ve been there, done that! I have found the best thing to do is to keep breathing! Gather your support team and try to take one day at a time!

Deal with it anyway you can! Sometimes you feel you can’t deal with it. That’s okay. I think we all go through that. Don’t be afraid to seek out help. It can really be of great help to have someone outside the family that you can talk to.

Your odds are pretty good that you will survive for quite a long time! Just live for today and whatever happens, happens! Don’t sweat the small stuff. Keep a smile on your face and it will be over soon.

YOUR FRIEND, BEV
DEAR SURVIVOR,

Yes, you are a survivor because you have survived living with breast cancer since the day you learned of your diagnosis. You have a rough road ahead of you. Your life will be put on hold for a year while you undergo surgery, chemo, radiation, a bone marrow transplant, or whatever treatment options you need to survive.

You will be sad and scared. You will ask “why me?” We all have. You will lose your hair – but it will take a lot less time to get ready to go somewhere. And you won’t have to shave your legs for a while. You will have little energy, but then you’ll have an excuse to take a nap every day. You will get to take time off from work. You will find out who your true friends are and you will be surprised at the thoughtfulness of others. You will be stuck a million times. You will spend a lot of time waiting at appointments – find a good book.

I found the courage to deal with my diagnosis by turning to friends, family, and God. My faith kept me going and kept me strong. I never really felt like I was sick and didn’t dwell on it. I just wanted to find out what I needed to do to become cancer-free, do it, and get better. I gave up a year of my life doing things I was told I needed to do. I leaned on people and let them help me – I think it helped them as well.

It won’t be easy, but keep the faith. You are a survivor.

SUZANN

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WORKING WITH YOUR HEALTHCARE TEAM

Prior to the time of your breast cancer diagnosis you may have seen your gynecologist or primary care doctor once a year. Many of us spend more time with our children’s pediatricians than with our own doctors. Now you will be introduced and will be working with a variety of professionals. For some, your team will include a breast surgeon, plastic surgeon, medical oncologist and radiation oncologist. This list does not include the many nurses, psychologists, social workers, phlebotomists, cancer education specialists and religious leaders who may also be members of your team. You may decide to include on your team your partner, spouse, friends, family, children, and neighbors as well. The sheer number of people may seem overwhelming.

I was extremely uncomfortable with the process of finding a surgeon, oncologist, radiation oncologist, and plastic surgeon all at once. Your surgeon or oncologist can help you build your team. Know your relationship with your healthcare team is like other relationships. It will not always be perfect. Remember always: you are in charge. You make the decisions with guidance and support from your medical team, family and friends.

My mother’s physician dismissed her fears of cancer when she showed him the lump she found, because she was too young for it to be cancerous. Anyone who challenges a decision you’ve made: let them know it’s you who has cancer and when they get cancer they can make their own decisions.

All three of my physicians came back and said to me, “I’m sorry I told you that it looked like it was nothing. You are the first person I’ve ever said that to.” Maybe that wasn’t a good term to use – that it looks like nothing. Each member of your team will assume specific roles during different stages of your treatment and follow-up. They are there to help you take care of yourself. You will call on them as needed for different areas of your physical, emotional, and spiritual care. It is important to trust your team and feel comfortable with every member of your team.

If you don’t have a doctor who takes the time to examine you thoroughly, speak with you in an unhurried manner, and offer aid in further references, then ask around or get a referral for a different doctor. You need to feel confident and trusting of the person in whose hands you’ve entrusted your life. I felt that trust fortunately with all three of my doctors, so I was blessed.

Speak up for what you need rather than worry about the comfort of the healthcare provider. The doctor works for the patient, not vice versa. I think it is extremely important to feel comfortable with your team of healthcare professionals, I needed that personalized attention and that is exactly what I got, it made an extremely difficult situation a little less frightening.

You must feel comfortable with your doctors (all of them) because you will be with them for a long, emotional and sick time of your life. Ask any questions. You will need a support person at your appointments. If you don’t have a good relationship with your doctor, then switch. This is a partnership and you’ll be interacting with this person for a long time. You have to feel comfortable, not intimidated.

Having a support person with you at your appointments will allow you to absorb the information being discussed while your support person takes notes. You may also decide to bring a tape recorder to use to playback later. Bring a list of questions to each appointment because you may not be able to remember your questions when you are with your doctor. Ask your doctor to show you a drawing of how your cancer is located and how your cancer will be treated.

My mother was able to find a home health nurse to discuss how to empty your JP drains.

A diagnosis of breast cancer raises a number of questions. You may not even know what questions to ask. Your initial appointment may not always be the best time to address these questions depending on your state of mind and the physician’s schedule. Keep in mind your physicians want you to have all the information you need to make decisions. There are steps you can take to help with this dialogue.

Ask your doctors, nurses or members of your team what questions you should be asking. If an explanation seems overwhelming or unclear, ask your doctors to go over the information again. Remember your physicians and other members of your healthcare team want you to be well informed.

From a nursing point of view, what words can I share with you? Just as your physicians have specific expertise, nurses also share in this specialization. If you have questions about your care or the physical effects of treatment, the nurse best able to assist you is the one working in that area of medical specialty. Give them as much detail as you can about your concerns. For example, call the surgery nurse to discuss how to empty your JP drains.

As a psychologist, what can I tell you about working with your healthcare team? Your support team can be as broad or as narrow as you need it to be. If you need more people to support you (as examples, counselors, chaplains, or social workers) let your physicians and nurses know. They can help to get you connected with these additional resources. Working with your team will be an important process in your care and treatment. Consider what you bring to the team and what expertise you require from your team. You will have an opportunity to develop a working partnership during one of the most important times in your life. Do not be afraid or intimidated to be an active member of this partnership.

Asking your doctor questions about your diagnosis and treatment is an important step in your recovery. It will also help you to make informed decisions about your healthcare.

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What are the most important factors in your relationship with your healthcare team?

What can you do to feel more comfortable sharing information with your doctors?

What can you do to feel more comfortable in speaking honestly with your doctors?

Are you able to talk with them about problems in your medical care?
How do you best prepare to work with your healthcare team?

choosing your treatment

Ideas for identifying your medical decision-making approach and finding the most appropriate treatment for you.
stay positive
This may not be the easiest thing on my list but it is the most important. Banish negative thoughts pronto!

The top ten list that kept me sane and hopeful while undergoing treatment for my breast cancer:

10. Get in touch with nature because I feel it’s positive, nurturing, and energizing. You may do that by gardening, taking long walks with people you love or by yourself. Listen to birds or go to the Botanical Garden. And if you are too tired just sit and smell the roses!

9. Line up your silliest friends and relatives and go shopping for turbans, wigs, baseball caps and hats. You’ll all be so busy being silly you won’t have time to feel self-conscious about the reason you are shopping.

8. Have the same silly friends and relatives come over and make cancer whammy shirts. Our whammy shirts were of an Indian medicine woman that we painted on sweatshirts. We made one for everyone in the group and wore them everywhere.

7. Start exercising as soon as possible. This just means GET MOVING. When you are too sick to get out of bed, you can still do stretches and isometrics. The nurses laughed at me in the hospital when I would drag myself and my IV bottle up and down the hallways. When I got out of the hospital I set a goal to walk one mile a day. Within a month I was able to cross country ski with my husband. Just keep moving!!

6. Eat healthy: My brother sent me a juice machine and I made carrot juice with it. I eat lots of vegetables, fruit, yogurt and lean meat. I try to drink 8 glasses of water a day.

5. Visualization: When I was going through radiation I would visualize the cancer cells were being eaten up and pretend the noises the radiation machine made came from the cancer-gobbling creature making yummy sounds as he gobbled up my cancer cells.

4. Listening to music. I had a small stereo in my hospital room that I played 24-7. I loved it and so did the nurses.

3. Read uplifting books about cancer and cancer survivors. Bernie Segal wrote some great ones.

2. Stay positive. This may not be the easiest thing on my list but it is the most important. Banish negative thoughts pronto!

1. Say yes to mind-altering drugs! Don’t try to tough it out. Take everything they offer you. It all helps.

Good luck on your journey.

LOVE, MEGAN

UPDATE ON MEGAN
Megan was diagnosed at 34 with an aggressive breast cancer. After surgery, chemo, radiation therapy and bone marrow transplant, Megan is doing very well at 47 years of age!
Making medical decisions is never easy. Before your cancer diagnosis, you may have made choices that did not require a great deal of consideration. Now you are being asked to make what seems like hundreds of decisions in a short period of time during an emotionally devastating period of your life for a disease that may threaten your life. The terminology alone seems like a foreign language, and the information is not always communicated in a way that is understandable. You may question where to even begin to make the medical decisions you need to make to treat your cancer.

Meeting everyone (surgeon, plastic surgeon, oncologist, nurses, etc.) was great. The only problem was overwhelming! I had was that so many things were running through my mind that day and there was so much information and important decisions to be made – I was overwhelmed!

After reading all of the information on breast cancer and the corresponding treatment, I felt ignorant instead of a sense of relief at having this new “knowledge.”

Numerous national organizations exist to provide cancer treatment information you may use in your medical decision making. Be aware not all information available on the Internet is reliable or based on scientific studies. Ask your healthcare team about the best breast cancer Internet sites. Below are organizations which provide breast cancer treatment information and serve as a national advocate for women and families with breast cancer.

National Cancer Institute 
www.cancer.gov  800-4-CANCER

American Cancer Society 
www.cancer.org  800-ACS-2345

Young Survival Coalition 
www.youngsurvival.org  877-YSC-1011

Gathering information about breast cancer which is specific to you will help you to better participate in the decision-making process. Use the following page to record information specific to your cancer diagnosis and health history. Your healthcare team will use this same information to make treatment and care recommendations. Understanding what pieces of information are used to make your treatment recommendations may allow you to make decisions which are best for you. Keep this information for your files to aid in your future health care.

CHOOSING YOUR TREATMENT

Educating yourself about breast cancer in general and your specific breast tumor will be the first step to choosing your treatment. By educating yourself you may be able to make more informed medical decisions and will choose what is best for you at this point in your life.

Gather information from wherever you can, but discuss it openly and honestly with your healthcare professionals. Take what others say with a “grain of salt;” each breast cancer case is unique. Your doctor knows your case best and is the best person to give you information relevant to your health.

Read all you can about your diagnosis so you can communicate with them. My feeling is knowledge is power. Educate yourself so you can be an active participant.

Get involved in your care—really involved. Make them aware of what works and doesn’t work for you.

MY BREAST CANCER INFORMATION

- Breast cancer found in single breast or both breasts:
- Single breast
- Both breasts

Number and location of tumor(s): _____________________________

Type of breast cancer:
- Ductal carcinoma in-situ (DCIS)
- Invasive ductal carcinoma
- Invasive lobular carcinoma
- Medullary carcinoma
- Tubular carcinoma
- Mucinous carcinoma
- Inflammatory carcinoma

Type of surgical treatment:
- Type of reconstruction (if any):

Tumor(s) size:
- Sentinel lymph node biopsy:
  - Positive (number with cancer)
  - Negative
- Axillary lymph node biopsy:
  - Positive (number with cancer)
  - Negative
- Cancer stage:
  - Stage 0
  - Stage I
  - Stage II
  - Stage III
  - Stage IV
- Estrogen receptor status:
  - Positive
  - Negative
- Progesterone receptor status:
  - Positive
  - Negative
- HER2/NEU status:
  - Positive
  - Negative

Additional testing (if performed):
- MRI scan:
- Bone scan:
- PET scan:
- CT scan:
- Genetic testing: (which genes and how tested)

MY HEALTH HISTORY

- Height: ____________________________
- Weight: ___________________________
- Current Bra Size: __________________
- History of breast biopsies:
- Previous history of any type of cancer:
- Family history of any type of cancer:
- History of medical illnesses:
- Prior surgical procedures:
- History of atypia or lobular carcinoma in-situ:
  - Yes
  - No
  (If yes, when diagnosed)
- History of fibrocystic breast disease:
  - Yes
  - No
- Prior chest radiation treatment:
  - Yes
  - No
- Current smoker:
  - Yes
  - No
- Current Medications:

■侵襲性乳頭癌
■無浸潤性小管癌
■炎症性乳癌
Some Questions for Your Healthcare Team

Your healthcare team will make care recommendations based primarily on the characteristics of the cancer. Yet, your medical decision-making will consider many other factors. Your personal approach to healthcare, your personal experience with illness, and your self-image are only a few factors to consider. Since your healthcare team may not know you personally, they will not be able to advise you on all of these non-medical, personal issues. Consider the following questions as you make your decisions about your immediate and long term care and treatment.

- What is my personal experience with illness? How have I made medical decisions in the past?
- Who do I turn to in my life to help me make decisions about my health? Do I need to talk with someone else to discuss my cancer treatment?
- Which family members or friends will help me during my treatment? How often are they available?
- How important is it to me to have breasts? Are my breasts essential in how I define myself?
- How do I feel about surgery in general? Would I worry less about recurrence if I had a mastectomy rather than a lumpectomy?
- How do I feel about taking medications? Do I prefer traditional therapies or alternative medical therapies?
- What are the goals of each type of treatment?
- How will my medical approach differ if my cancer has spread outside of my breast?
- What is my family history of cancer? Do this history influence my choices?

It may be difficult to sort through all of the medical and non-medical issues associated with your treatment choices. One approach is to take a stepwise approach to your medical decision-making. First, consider what is the best treatment for your specific breast tumor. Next, consider what is the best treatment choice for you as an individual woman. Are these choices the same or different? Talk with your healthcare team about your treatment decisions and any discrepancies that exist in the answers to these two questions. Remember the treatment that is best for you may not be another woman’s choice. It is your body, your health and your life.

The biggest fears were of the unknowns. I needed to know the facts so I could figure where I stood and how I was going to approach the upcoming months.

One of the most difficult aspects of treatment is not knowing what to expect during different phases of your treatment course.

Fear of the unknown

The biggest fears were of the unknowns. I needed to know the facts so I could figure where I stood and how I was going to approach the upcoming months.
Some of the physical aspects I faced during my first year and how I addressed them. I am thinking in order of time over the past months.

1. Pain from mastectomy. Vicodin, great stuff!

2. Drains (both of them). Try not to pull on the tubing from the drains because they were literally stitched in my side. Avoid infection.

3. Limited flexibility in my arm. Yoga, yoga, yoga. I use my arm as much as possible to stretch and reach for things.

4. Tissue expander –ouch! I had to get use to the expander to prepare for the implant.

5. Loss of all my hair. Very vain, but I hoped to God it grew back.

6. Expander leaked and deflated. This definitely solidifies in my mind I’m not getting an implant.


8. Inability to concentrate. Enjoy my good days and concede to the days on the couch and in the bed!


10. Hair growing back, don’t like it short. Vain! The hair grew back. Move on!

11. Effects of Tamoxifen. Either deal with it or get off of it and increase my chances for a recurrence.

Women who have a mastectomy, reconstructive surgery and possible removal of lymph nodes underneath the arm may experience changes in sensation, arm flexibility and strength.

It’s just not normal. I have expanders and it is just not normal. Like, this doesn’t feel right. I can roll over and it pops in and pops out, and I think, oh no. They need to tell you more.

I did everything I could to avoid lymphedema, except no one told me that when you get on a plane you should wear a sleeve and a glove. So I got on the plane. I landed on our vacation and I couldn’t use my arm the whole vacation. They don’t tell you everything about implants. I woke up one morning and the entire bed was soaking wet because the implant did not take. I didn’t know what to do. I woke up and looked at my dog and thought, oh what did you do?

I had no idea that every time I raised my left arm it was going to hurt. Three years and two months out and still every time I raise my arm I can feel that muscle pull and I know, it is like a daily reminder.

Not all women undergo chemotherapy, but for those who do, many experience symptoms of menopause, which may include hot flashes, vaginal dryness, and disruptions in short-term memory.

You can read about Tamoxifen anywhere but they don’t say you are going to experience hot flashes and things like that. It really does mess up your hormones.

Vitamin E helped with hot flashes from Tamoxifen. Astroglide helped with vaginal dryness.

We used to snuggle and he would hold me at night. Now it is like, you sleep under those covers and I’ll sleep under these covers so I can sling them off. He’s sleeping under this huge comforter and I’m so damn hot I can’t stand it.

Between what I believe were the effects of anesthesia combined with “chemobrain,” I had some considerable short-term memory deficits. Somewhere along the course of my treatment I bought a small spiral notebook that I kept in my purse to jot down anything I needed to remember.

For radiation therapy, the doctor will mark your skin to target the therapy to a specific area. Just as each woman responds differently to the sun or to heat, each woman will respond differently to radiation therapy.

The first day of radiation therapy they mark you up like a road map. I wasn’t ready for that. No one told me I was going to look like that.

I would go to work early, drive to radiation treatment, drive home and try not to focus on the burns and pain.

I was always surprised how tired I felt during the time I received radiation therapy. It took me much longer to regain my strength than I had anticipated.

A small percentage of women have more extreme responses to the surgical interventions, chemo or radiation therapies. While these responses are not as common, they certainly deserve to be treated to limit any discomfort.

I had anal fistulas [cuts in the anal passages]. And I’m still having trouble. It was the worst pain I ever felt in my life and it was awful.

One thing that really hit me hard was when I developed ulcerations in my mouth. Not only did I feel lousy, but I could not talk or eat comfortably. I wish someone had let me know what to do if a problem like that arose.

A diagnosis of breast cancer demands you walk a difficult path, but you need not make that journey by yourself. To speak with other young women about their experiences with breast cancer, contact the Young Women’s Breast Cancer Program at Washington University School of Medicine, 314-454-5076.
What approach did you take in making medical decisions before your cancer diagnosis?

What medical and non-medical factors play a role in choosing your treatment?

Can you rank them in order of importance to you?
caring for self
Approaches to caring for your physical, emotional, intellectual, spiritual, and sexual self, now and in the future.
Dear Young Woman,

I understand you have just joined the club where nobody wants to be a member. Breast cancer is a frightening thing to face, and even more so at a young age. You may spend some time railing against the unfairness of the disease, and even being angry with your body for its betrayal—that is an understandable response.

Eventually, though, please take some time to consider where the cancer can fit in your life, not just whether or not it will cause your death. Breast cancer is a disease that can be managed for a long time, and may soon be controlled or eliminated. Time is on your side. The real question is “how will you use it?”

Take this chance to evaluate the quality of your life and your relationships. Are you happy with where you are? What areas need changing? This is your opportunity to move in a new direction. Time to focus on the people and activities that are meaningful. Time to consider your faith in yourself and your higher power. Time to reach out to whomever or whatever makes you feel more complete.

You will struggle — that is certain — but the struggle can lead you to a place of great strength and insight. The question becomes not “how long?” but “how well?” will I live.

I wish you strength and hope on your journey. May the discoveries you make about your place in life lead to great fulfillment for you and those whose lives you touch for many years to come.

With Love, Ellen

how well will you live

You will struggle — that is certain — but the struggle can lead you to a place of great strength and insight. The question becomes not “how long?” but “how well?” will I live.
As young women, we are experiencing an exciting time of our life. We are building more meaningful relationships, beginning our families, and developing our careers. As we journey through this time, we begin to redefine who we are as individuals and what we value.

Being diagnosed with breast cancer may challenge the physical, intellectual, emotional, sexual and spiritual aspects of your definition of self. Changes in your identity and how you feel about yourself are to be expected. As in your life before breast cancer, and as your life will be after breast cancer, redefining yourself will be an on-going process. You will find both positive and negative experiences along the way. Preparing yourself for the possibility of change is the first step.

When we hear the words “breast cancer”, the possible physical changes that may happen to our body quickly come to mind.

My body image has definitely changed. How could it not? I no longer like to look at my breasts. When I do see a road map! I had a mastectomy and tram flap reconstruction. I then had the nipple put on and the other breast but it just doesn’t feel right.

Some women consider additional therapies to their traditional treatment such as acupuncture, massage or art therapy, meditation, yoga or tai chi.

The physical is harder now, only because while undergoing treatment I expected that once treatment was over I would return to the physical person I was before. But I have not – although I now accept that things are different. I was not prepared for the difference.

After my initial treatment and in anticipation of my hair falling out, I had it cut short. It was fun for it’s probably something that I would never have done on my own. My parents were out from Ohio to help me when my hair started to fall out. Since I seem to be an all or nothing kind of person I couldn’t see patches of my scalp and thin hair. It all had to go and I had my father shave it off. I liked being bald. It was incredibly freeing. I felt that my wearing a wig or hats I was trying to hide who I was and I wanted no part of that.

The few times I did wear a hat, I felt claustrophobic and not true to myself.

My body image is not a concern. I just want to be here for my kids. They need their mom!

After 28 years I still feel a sense of loss. I was nearly distraught upon seeing my chest for the first time in the shower in the hospital after surgery.

I told my surgeon I wanted to save my breasts, first and foremost. How naïve I was!

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It may be easier to put into words the physical effects of cancer. The feelings, which describe what it is like to have cancer, may be more difficult to express.

Initially, the physical pain was what I felt. The emotional pain, for me, still continues. If anyone had told me it was going to be this hard mentally and emotionally, I would not have believed them.

During treatment we are busy trying to make it to doctor appointments, chemo and radiation treatments, to maintain a job and to keep some normalcy in our daily activities. It is not unusual that we begin to address the emotional aspects of our breast cancer diagnoses after treatment has been completed.

Emotional aspects of living with breast cancer are extremely challenging for my wife and myself. During treatment, we had so much to think about, our focus was short term. Now as time passes, thoughts of children and recurrence have become more intense. I just hope she will be okay. She is a survivor.

I don’t have time for cancer.

Cancer sucks! The physical side effects are for the most part gone, but the emotional ones will probably last forever. I pray to stay healthy and not have a recurrence. But I look at myself like this: I am completely fine. I am back to normal about 80% of the time. Considering what I have been through, I am proud of myself for being that put together.

No matter what positive and negative changes you experience, it is important to find ways to care for yourself physically and emotionally. During your treatment, caring for your physical body will be paramount as the treatment can be physically demanding. Caring for our emotional self is essential as you learn what it means that breast cancer is in many ways a chronic disease. Your faith, your creativity, and some of your normal activities may be an important part of your healing.

We are very strong creatures and we adapt very well. So scream, rant, and rave. Throw things. Do whatever it takes to make you want to live. Exercise helped with fatigue. Even when I didn’t feel like walking, my buddy would push me to walk with her. If it were not for my faith, I don’t think I would have come through this experience well at all. My faith is what carried me and gave me strength.

Pursue an interest or take a class about something that you always wanted to know about or do.

The day I found out I had breast cancer I went to church. My pastor gave a sermon on “stand against your giant” (Samuel 1:7-4:30). God knew what I needed to hear. Find a balance between supporting your fear and pain with focusing on the opportunities that the cancer might open up in your life. I have a real need to release my anxieties and embrace life through self-expression. I have always loved to sing...but since the cancer I have begun writing songs usually related directly to the recovery process. Some of my more recent songs have been related to my efforts to stay away from negative energies.

The word “cancer” creates terror and disbelief, causes grief, sadness, anger and feelings of helplessness. But there is a word stronger than cancer, and that is God.

I have really gotten into sketching. I know from my work that taking the time to symbolize the vague and often frightening emotions that arise helps to contain and express them so they lose their hold on you.

My physical releases included walking, running, and yoga. I continued to work out with cancer and weight training. I was doing good for my body and it was a social place for me. I agree with those women who said their faith got them through, but I think God helps those who help themselves. To me, that means an active effort to support the healing effort through mind, body and spirit.
Before I was diagnosed with cancer I did not have a relationship with Jesus and now I have a wonderful one. It was a huge positive that came out of all of this.

Gardening was something I did instead of sitting in the house with an upset stomach feeling bad. Seeing the beauty of things growing in springtime and summer was therapeutic to my soul. I loved to get my hands dirty. Gardening helped time go by faster on days I didn't feel good, where time seemed to stand still.

As young women we may be active in our sexual relationships, looking forward to advancing these relationships for many years to come. The physical changes of treatment can influence our physical image and our sex life. Changes of treatment can influence the truth which doesn't seem to be a one.

My relationship with my husband changed because I didn't want to be touched in a sexual way. As soon as my treatments were over, he started acting as if everything was back to normal – but it wasn’t. Nobody said anything to me about changes in my sex life. I just wanted to feel like a woman again. I want to have that sexual desire. I feel like I'm wronged at a young age.

My husband wouldn’t touch my breast. It really bothered me at first. I felt like I wasn’t sexually appealing anymore. My breasts were no longer a part of my sexual experience. I just wanted to have overcome this but it still bothers me from time to time.

As you journey beyond breast cancer consider how you will renew your sexual relationship with your husband, boyfriend, or partner. Acknowledging your relationship is based on much more than physical closeness will help you to move forward in your sexual relationships.

My advice about romantic relationships is not to wait too long dwelling on what is different. Even though I don’t feel everything like before, my husband treats my implant just like my other natural breast.

When I am ready to have sex with someone I will tell them about my mastectomy and reconstruction. If they can’t handle it, I guess we just won’t have sex.

It was hard at first for me to take off my top or bra off in front of my husband, but now I am comfortable with it. Some things just take time to work through.

During the initial adjustment to the cancer diagnosis, many couples are emotionally overwhelmed. You need to gather information and deal with the fears and uncertainties that can temporarily disrupt your sexual relationship. For some, this disruption may continue during the treatment phase when physical and emotional changes are taking place. If this happens, it is important to keep in mind while these changes are challenging, most are temporary.

Communication about these issues will provide an opportunity to work toward increased trust and intimacy. As far as sexuality, I am feeling better about myself. I have had a very hard time feeling sexy around my husband. I am always covering my left breast. He has been very patient. I guess it just takes time.

It was a long time before my husband and I had sex. He was great about it. I felt pressure about having sex. I always wanted him to have his pleasure. So I always worried about him. We have found other ways to be with each other.

Maybe my breasts never really got me much in life. They didn’t really work to my advantage. I mean, it is one small piece and there is so much more and if you cannot see past that, that is not my problem.

When our group of young women with breast cancer was asked if they had changed since being diagnosed with breast cancer, the great majority responded yes and they all responded they had changed for the better. Even women who have an advanced stage of cancer, found positive experiences from their journey of living beyond breast cancer.

If anything can be said about my experience with breast cancer, I am a better person for having gone through this.

The most important relationship change is the one you have with yourself. If you don’t nurture and grow through this experience, you may have missed an opportunity.

When I am a better person than I was before breast cancer. I have such a clear picture now of what is important.

I am stronger now than ever as a person. A lot wiser I am sure. I try not to look back but ahead. I live in the moment more.

My list of the positive attributes of having cancer.

1. I found God.
2. I discovered my husband was even more wonderful than I ever imagined.
3. I have closer, more honest relationships.
4. I don’t worry about money as much.
5. I don’t worry about anything as much.

I believe the cancer diagnosis made us all stronger individuals. I know, for me at least, it gave me priorities. Life is potentially too short to spend it doing things or with people we don’t like.
How will you approach your sexual relationship after your diagnosis?

What three specific activities help you to take care of your body during treatment?

How do you plan to continue these activities after treatment?
How do you express your feelings about living with breast cancer?

Involving family

Ideas for involving your family in your care and returning to routine family activities.
it could never happen to us
We both found out how much hope there was at the end of this tunnel that we thought was so narrow.

DEAR FAMILY MEMBER,
I know you love your family member with cancer, but right now she needs to love herself – sometimes the things she says may seem strange and scary, but this is a strange and scary time for her. She wants to live, but feels as if she has no say about the outcome of this battle. Ask her how she is, but resist the urge to say “it will be okay”. That hurts because no part of this is or will be okay. Allow her to grieve and laugh and to do both openly.

I suspect that this will be hardest on you. Although physically she is being challenged, you are on the sidelines, a helpless observer. I am sorry – but know that when she doubts herself she will look to you for the reminder that she is a fighter.

Allow her the room to grow – some things forever change and other things will go back to the way they were before the breast cancer. For those things that change forever – go with it – you have her with you – and change is good.

BEST WISHES, A SURVIVOR

FROM A MALE’S PERSPECTIVE: WHAT CAN I SAY TO YOU AS A WOMAN?
My wife and I in the beginning were terrified. It was something we never thought could happen to us. As days followed and we both got more information we became sponges. We gathered everything we could from doctors. As we went through this process, decisions became easier to make.
For both of us. As this developed, we both found out how much hope there was at the end of this tunnel that we thought was so narrow.

Remember one thing. I did not go through this – my wife did. She kept a great attitude and positive outlook. She’s still here. I love her.

MIKE
IN Volving family

We each define “family” with our own individual definitions. Maybe you have a traditional definition and spend a lot of your time with your children, parents and siblings. Perhaps your definition is less traditional, with your family being comprised of your partner and close friends. Maybe for you, family means your church family.

No matter what your definition, family involvement can be supportive and nourishing. Other times, family interactions are just plain stressful.

You are the person experiencing the physical and emotional effects of cancer. Yet, your family is also experiencing change. As you experience these changes together, expect there will be both positive and negative interactions. These interactions existed before your diagnosis. They will continue after your diagnosis.

The transition to who I am now was upsetting to everyone around me and my family most of all. Gone was the person they knew, replaced by this new being, a sometimes scared, often sarcastic, always open person. I think the cancer was hardest on my family.

My sister and I grew closer than ever before. We shared our hopes and dreams, our disappointments, music, books and especially our faith in God.

The day of my wife’s diagnosis was the worst day of my life.

My sister’s and my relationship changed after her breast cancer diagnosis. My sister was a very sarcastic, always open person, who didn’t express her emotions. After her diagnosis, we became closer, we talked more frequently and she began to open up to me more. We spent more time together. Our relationship changed in a positive way.

After my diagnosis my relationship with my husband changed. We became closer and he made me feel safe! I felt like I was on a roller coaster and couldn’t get off. My husband was my rock! He was there to listen to me to wipe my tears and just hold me. Now our relationship is a little different. I don’t feel like I can talk to him like I could when I was first diagnosed. He thinks I shouldn’t be thinking about breast cancer anymore. I should move on and never think of it again. I try to tell him that’s not how I work. I have to talk to him (for me) but then he doesn’t want to hear about it anymore.

My relationship with my husband has gotten even stronger through this experience. Looking back now I don’t think I asked him how he was doing enough. The focus was always on me. He was a rock – there for me at every appointment and on the Internet at night – he would bring a list of questions to each doctor. He appeared so genuinely happy to be there for me. We visualized the tumor shrinking and the birth of the baby and me having hair again and laughed a lot.

I was so scared for my wife. She is truly the most wonderful person I have ever met and it doesn’t seem fair that this happened to her. That is probably the worst part for me, guilt. I still feel so guilty that she has to go through all of this.

Your treatment may also impact you and your family in financial terms as well. You may have to take time off from work or hire someone to help with your daily chores. These financial changes can put additional stress on your relationships with your family members. Sometimes looking to finances is a way of trying to find a sense of security in the midst of crisis. Just remember the most important job is to focus on healing.

Due to the fact I was going to take family Medical Leave Act time at work, I would take a financial hit. I would only be paid at 60% of my salary and would not be allowed to take any vacation time until I had used up my FMLA time.

It reached a point to where I had to go through radiation everyday. I did not have anybody, so I eventually had to find somebody to watch my children. I was forced to look for a nanny to live there and help out, but it was going to be a financial commitment.

As a single woman, my financial security is even more important to me and an ever present segment of my life that causes a great amount of anxiety since my breast cancer diagnosis.

We serve many roles in our family. We are financial providers, caregivers, mothers, sisters, and friends. The physical challenges of treatment may force you to change how you manage these daily responsibilities. Consider what responsibilities your family members may assume. Allowing your loved ones to assist with some of your routine responsibilities is not only helpful to you, but also allows your family the opportunity to contribute to your care and well being.

I come from a large family, four brothers and three sisters. My sisters, parents, and mother-in-law from New Jersey all came to help with the kids, cooking, cleaning, laundry and car pools. They basically took over my responsibilities and allowed me to rest.

My husband went with me every chemotherapy treatment. I think he was scared. He always gave nausea medicine to me, encouraged me to eat when I didn’t feel like eating and did not encourage me by telling me, I’ll get through this. I would go to him and lay my head on his shoulders and say nothing, but it would always make me feel better. He would also call the nurse when I needed different nausea medicine. I knew he did the best he could.

The lowest point was after my surgery because I think I was unable to do my normal routine and appeared sick to our kids. We tried to keep our routines as much to normal as possible and talked and prayed a lot. No matter how yucky I felt I always sat at the dinner table with them.

Words of advice for a spouse from a husband of a woman with breast cancer.

1. Showring support and strength are paramount.
2. Be a good listener.
3. Hugs are a good thing.
4. Prayers never hurt.
5. Reading and researching the type of cancer and treatment help you understand what that person is going through.
6. Be a part of the decisions that need to be made.
7. Let your employer know of your situation. It will be necessary to miss work on occasion.
8. Good nutrition is part of the recovery. Talk to the doctor.

9. Emotional changes occur often. Understanding is the key.
10. Quality time takes on a whole new meaning.
11. After surgery and release from the hospital, make sure to get phone numbers should you have questions once you get home.
12. Physical therapy will be part of the recovery. Assistance and encouragement from you is part of it.
13. Never feel ashamed should you need some time to yourself. Close friends and family can fill in.

During this time in our lives, we may be planning on having children, may be pregnant at the time of our diagnosis or may have young children. Hoping to have children or mothering young children when we are diagnosed makes our experience different than older women with cancer.

I remember how strange it felt to be in the surgery’s waiting room with an infant in his carrier. I was by far the youngest woman there.
The physical effects of chemotherapy may alter our plans for having children in the future. It's funny how I'm only 31 when it comes to cancer and already 31 when it comes to having children. I was pregnant when I was diagnosed. We focused on the baby and how the baby would be fine. The kids both focused on their new brother–we found out the gender so we could call him by name throughout the pregnancy and treatments. When I was first diagnosed the issue of my periods stopping during chemo and the possibility of them not returning was brought up. So besides being stressed about the cancer issue, I did a little bit of research on egg freezing but ultimately decided against it. I didn't think about it too much… but it just added to the list of decisions I had to make. I ultimately decided that my survival and removing cancer was the number one priority and everything else would just have to wait.

Just as we may be facing the first serious illness in our lives, our children are also experiencing change. In the process of sharing this portion of your life with your children, be honest with yourself about your fears, concerns and prayers for them. These feelings are natural. The thought of my children being motherless and that they wouldn't even remember me was devastating. That was what was most upsetting to me. There is absolutely no comparison to being diagnosed as a young mother versus a mature woman whose children are adults. Being honest with your children will be essential. Children are bright, inquisitive people who often know more than we realize. How have you shared troubling news with your kids in the past? Anticipating how each child processes information may help guide you in speaking with your children.

My younger one was eight and he was pretty upset. I was trying to put [the cancer] in the most positive ways. He was more worried about me being away in the hospital than anything. All the positives I could put in there and I wasn't even sure myself. Our first instinct was to keep as much as we could from our children who were 5 and 3 and I was pregnant. We quickly found that our 5-year-old would piece it all together from listening to me on the phone, seeing grandma cry, etc. So we told them what I had and that to get better, mommy would have to feel sick. Our 12-year-old son was rather mature but the effect was to make him even more mature, introspective and self-sufficient. It is important to listen to your children's questions and answer them directly, but to keep the focus on the expectation of a positive outcome. Older children and teens may have trouble expressing their concerns directly. They may not express their feelings immediately, but months or years later. Ask your children how they are and try to have other caring adults available to support them.

I continued to help in my daughter's classroom. While the kids were curious as to why I was bald, no one was afraid and it created an open forum for discussion with both students and teachers. This may be the child's first brush with mortality, and the fears and unanswered questions will be overwhelming. They may not be able to verbalize their concerns, but that doesn't mean that they don't exist. They will manifest themselves in alternative ways if the words, or opportunities for them, are not forthcoming. My relationship with my youngest daughter who was 3 at the time of my diagnosis was changed for the better and not so better! After my surgery she just wanted to be close to me. She wanted me to pick her up and let her lay her head on my chest. I couldn't do that. I couldn't stand to have anything touch my chest and to this day I still don't like it. I couldn't pick her up. I really wasn't able to take care of her! The good part was she was very interested in what was going on with me. She always wanted to see my new breast. I would show her and then she would want to touch it. I always let her.

I've always dealt openly and honestly with my children. We don't hide things from each other, especially if it will have such an impact on our lives. Our 12-year-old son was rather mature but the effect was to make him even more mature, introspective and self-sufficient. How have you shared troubling news with your kids in the past? Anticipating how each child processes information may help guide you in speaking with your children.

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The following pages are provided so you may express your feelings about your family.

What family roles do you wish to continue during your treatment?

How does your family describe your family life since your diagnosis?

Consider three primary roles you play in your family. What roles or parts of roles do you wish to continue during your treatment? What may be best to give up during your treatment?

It has been six months since your family learned of your diagnosis. Your family sits down to talk about family life during the last few months. What do you think they will say?
What will your children say about your relationship with them one year from now?

including friends

Thoughts for including your friends in your care and discovering what you value in your relationships.
friends are important

Your friends will continue to be essential in your life as you learn to live with and beyond breast cancer.

DEAR SISTER,
I pray for you a dichotomy:
- accepting of a situation, yet fighting with every fiber of your being,
- surrounded by friends and family, yet time of peaceful solitude,
- wholeness of soul, when your body may not be whole.

BLESSINGS TO YOU. MAUREEN
INCLUDING FRIENDS

Our friends are important people in our lives. We get together to go to a movie or have fun at the ball game. Our children play together as we sit and recall the day’s events. We talk about our dreams for the future with our friends, knowing they will be with us along the journey. During times of stress, we lean on one another for care and support. Your friends will continue to be essential in your life.

It felt so good to be able to cry with them and get their hugs. My husband was in shock and stoic trying to control his own emotions, so the outpouring of affection and support from friends was so important to me. Remember, true friends love and care for you. They want to help you care for yourself. The choice will be given to you to be open to their support. I am grateful for the help, but at the same time I didn’t want to feel that I could be easily replaced. I had to change my attitude and let others serve me.

In regards to family and friends helping me, it was extremely difficult to be the recipient of good will instead of the bearer. You don’t want people to think you can’t do things. I didn’t want people to pity me. As people slowly took over many of my normal responsibilities I was so grateful and learned to accept their kindness without shame.

Our friends try as best they are able, but sometimes you may need to provide direction about how they can be supportive. Just as your cancer diagnosis may be your first serious illness, it may also be the first experience of a significant medical condition for your friends. They may need guidance on how best to be supportive to you. If you need to hear words of comfort or a show of concern, you will probably have to convey your need for it.

I am originally from Chicago and so all of my really good friends are all up in that area. When it happened to me, of course a lot of people called and sent letters, but some people I saw years later said they didn’t know what to do. “I didn’t know if I should call you, write a letter, what I should say.” They didn’t know what to do, so they didn’t.

Don’t be afraid or ashamed to ask your friends and family for their assistance. In accepting their support, you will be giving them the opportunity to reach out. Both you and your friends may grow from the experience.

My sister came over and decorated my Christmas tree. My husband tried to do it. I never told him she came over and fixed it. He said the tree looked great.

When people ask me now what they should do, I’ll tell them to write a letter, send a prayer card.

I was on disability for a while. I had a group of co-workers who donated vacation time. I emailed my calendar to family and friends telling them when I needed rides to chemo and radiation treatments. They signed up for drive times.

My friends brought me meals, they brought me groceries, they called me, and they brought me cards. I have one friend who could come at least once a week and bring me Christian music to listen to and books to read. I had one friend who would go to my doctor’s visits with me, go to my radiation treatments.

We moved three weeks following my surgery. I couldn’t help them move, but I could direct them. Somebody went in and cleaned the house before we moved in. Somebody came in and did my yard work. I had a great support system.

It was very nice that people weren’t afraid to come over. If there was hockey game on, people came over. If I was sleeping that was fine. If I was up, that was fine. If I was bald they didn’t care. It was nice.

My sister brought catalogs because I was in bed from surgery. She went shopping for me.

My friend went with me to every single chemotherapy. She would sit there and hold my hand and we would talk about how I was going to go and get a short leather mini-skirt when my hair fell out and put a tattoo on my head.

During times of stress, we lean on our friends and family for their assistance. It may help you to be cognizant that changes will occur in your relationships. Staying positive and focused will be most important for you.

I had one close girlfriend who wasn’t around quite as much during my treatments. But her mother died of breast cancer and she had a hard time seeing me sick. We have regained our closeness since then.

Being around positive people, family, friends, co-workers and acquaintances makes all the difference in the world. Some acquaintances backed off especially during the time while I was in treatment. I think that they were intimidated and didn’t know what to say and were not close enough to check it out.
As the end of my treatment was drawing near I could hear in their voices and see in their eyes they were worn out. As a result, one particular friend, whom I’ve known for 10 years, and I pulled apart. The fact I had to let work into my personal life after my diagnosis was painfully difficult. Perhaps some women were comfortable asking for time off and sharing their timeline of surgeries. I was not pleased with the fact I had to share I would be out of work for four weeks due to a mastectomy. I was not comfortable calling in sick because the chemo effects were making me vomit in the car during my commute! No one I cared about stayed away from me. I am immensely grateful for that.

Some people will remove themselves from the situation. The woman with cancer should know this is not her problem. She cannot be worried about these kinds of people at this point in their life. You will be excited to realize that there will be people who you never realized cared out there supporting you. You may find the qualities you look for in a friend have changed since you first learned you had cancer. This change is natural and is part of the positive growth that can occur during this time in your life. Be open to this growth.

As far as relationship changes go, all I can say is expect them. Some people you may have thought would really be there for you may disappoint you—others you may not have even known before may step up unexpectedly. I have a number of new friends since my cancer, several of whom are cancer survivors themselves. I try not to tell new friends about the situation. I do not like to be judged. I am hesitant to share with people, new people, I had BC. I survived. I am ok. Bad things happened before BC and I am sure more bad things will happen throughout the remainder of my life. This, BC, was just a chapter in the book of life. I’m not really into little social friendships, I want to be a true friend and want true friends. I have few of those. By the same token, if there was somebody out there who was a true friend but negative, they are out. All negative energy is gone. Consider the qualities you value in your friendships. Do you reflect these same values and characteristics? Take this chance to focus, really concentrate, on the friendships which you value and find most positive.

In the future you may find the qualities you look for in a friend have changed since you first learned you had cancer.
What could your friend do to help you while you receive treatment?

How would you describe the relationships you have with your friends?

Do you consider some of these relationships to be close?
What qualities do you now consider in a friend, one year after the completion of your treatment? Are these qualities different than before you were diagnosed with cancer?

planning for the future
Motivation to help you plan for the future, both now and in the months to come.
While sitting in church the Sunday after I had surgery, my son was asked to sing a solo. The words to the song were very simple and powerful. The words are, and I say them to you without a shadow of doubt in my mind:

You Can Make It
You can make it
You can make it

This trial that you’re going through
God’s gonna show you what to do
I don’t care what’s going on
God won’t let it last too long
You can make it

it’s ok to think ahead

No matter what your approach to planning for the future, being diagnosed with cancer may alter not only how you plan, but also your specific plans for the future.
Planning for the Future

From the time we are children, we think about or make plans for the future. What will I do when I grow up? Will I get married? Will I have children? It is only natural to consider what the future may hold. Some of us take events as they unfold in our lives. For others, we plan every step, every detail along the way.

No matter what your approach to planning for the future, being diagnosed with cancer may alter your fears of dying of cancer may be heightened during your treatment. Life keeps moving on. You can either focus on trying to have many more years, or look forward to it. Waiting for the other shoe to drop, as the saying goes, is really no way to live. Now we have our land and will be building soon.

Fears of dying of cancer may influence our plans for the future. A day did not go by without me thinking, would I live? Perhaps someday I will fall into this category [women who die from breast cancer]. One does not know, I am not fatalistic, rather realistic. Everyone is called away, at some point. I only hope from this point forward to the time I am called away, I will have sewn the quilt of life with the most textured, colorful, varied pieces of fabric stitched together with love of friends and family. As best as you are able, don’t let your fears hinder you from continuing to consider and plan for your future. Planning makes you feel optimistic, gives you goals, and keeps you hopeful.

I think it’s just natural that I get that funny twinge whenever the future gets brought up. But the more time passes since my diagnosis, the more I feel less odd about the future. In planning for the future, I take a position of realistic optimism. Get your ducks in a row then embrace life with both hands. Do things that make you feel strong and complete. Don’t waste time on trivial social niceties. Sing, dance, take walks, spend time with people you love, breathe fresh air, look at beautiful things. Use your cancer experience as a reason to celebrate life.

The fear of a recurrence may appear after treatment has been completed. We begin to question whether the treatment eliminated all of the cancer cells. These concerns may be heightened during your follow-up visits with your doctors. My main concern is what will happen in the future. I am scared to death of recurrence. Please God, don’t let it happen. I can’t say I really worry about dying from BC. I am confident in the care provided by my medical team. I fear, instead, a cancer recurrence.

Actually, you need to think about your future so you can feel some “normalcy”. At first, I didn’t think about my future because I wasn’t sure I have a future (at least beyond 3 years). That was quite depressing. We had been planning on buying land and building a home and were really getting more serious in our search when I was diagnosed. Not only did we quit looking, we cancelled vacation plans that year because we lost some income due to my being off work. So, not only do you feel you life is “topsy turvy” but the feeling of what might come after keeps you from looking past treatment. In retrospect, I wish we could have kept the vacation plans that were very much needed when treatment ended, but I also wish my husband and I had planned some alone “down time”. Instead, we just plunged ahead with a little R&R to help us rebound from the emotional strain this whole event caused. Looking to the future is exactly what one needs for all of your health. Many women think of their breast cancer experience as an opportunity to make changes in their life; a focus on the importance of relationships, improving self-care, and avoiding stress will enhance your appreciation of every new day.

The way you approach planning for the future may change as you reassess multiple areas of your life. How could your approach not be different? Don’t be afraid to allow yourself the opportunity to explore these changes.

I used to be a saver but now I’m not. I’m not a fool – I don’t go throwing money out. We would rather spend our money enjoying ourselves now than investing a ton in an uncertain future. Having said that, I’m going to sound like one big contradiction when I say that we still contribute to a 401k, but I guess it’s all about balance.

Our focus on trying to have many of life’s materialistic items is no longer in the forefront. We both are trying to work less and spend more time together.

I started doing more traveling. Trying to get places I have never been before. Worrying that I won’t make it, my husband and I started investing in a retirement fund for him in case he has to live on one income.
JOURNAL
The following pages are provided so you may consider how you will plan for the future.

What were your plans prior to being diagnosed with breast cancer?

What short term goals have you made as you undergo treatment?
Now that you have completed treatment, have you addressed the emotional aspects of your diagnosis?

Facing the possibility cancer may shorten your life

Life may be shortened, but not conquered by breast cancer.
October 13, 2009 marked the first National Metastatic Breast Cancer Awareness Day. In the U.S., approximately 6% of newly diagnosed women will present with metastatic breast cancer or breast cancer that has spread to distant parts of the body at time of diagnosis. Many other women will develop metastatic disease some time after their initial diagnosis. During a pink October, this day to recognize the unique needs of women with metastatic disease calls attention to the issues these women face.

Women who have been told they have metastatic disease must decide what this news means to them as individuals. Think about metastatic cancer as a chronic illness. There are many examples of chronic illness – diabetes, asthma, hypertension – the unifying characteristic is that they are not curable. These diseases can be deadly and require active management and medical oversight. Metastatic cancer fits the chronic disease model quite well. It will mean chronic medical treatment, regular medical follow-up, and vigilance on the part of the woman with the diagnosis.

When chronic diseases become deadly, they rarely do so quickly. There is usually forewarning – scans indicating progression, changes in the treatment regimen, and conversations with the medical team about ineffectiveness of treatment. Although it may be hard to avoid thinking about death, it’s worth trying to do so as this kind of worry makes it hard to focus on living. If treatments start to fail, there will be time for women to focus on end of life concerns then, when it is relevant and more useful.

So, what does it mean to “live your life”? The answer depends somewhat on what life was like before the diagnosis of metastatic cancer. Think over what was going on before and choose which of these activities you want to continue. What is most important? Maybe a metastatic diagnosis will give the incentive to follow through on some of those delayed wishes.

It is very easy for cancer to take over your life, particularly in the face of metastatic disease and chronic treatment. It’s important to maintain a life beyond cancer. Be sure to continue to participate in pleasurable activities and make fun a priority.

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Making choices

You have the choice to continue to enjoy your life, the right to make decisions, and the opportunity to contribute to the lives of those you love.
Facing the Possibility Cancer May Shorten Your Life

Medical advances have led to improved treatments for breast cancer and have lowered the risk of dying from this terrible disease. Yet, when we hear the words breast cancer, our immediate thought is that we will die. Don’t misunderstand I had a lot of moments where I was fighting. But I also had a great feeling that I was definitely going to die. This part of not knowing whether or not your dance ticket has been punched for the whole dance or only the first half was the most difficult part.

Not all women will survive despite the best efforts of treatment. This section is written specifically for women with metastatic breast cancer (stage IV) or whose disease has progressed.

Breast cancer may spread, or metastasize, outside of the breast to other areas of the body. Common sites where it may spread include the lungs, liver, and bones. A woman’s life may be shortened when breast cancer spreads.

Improvements in treatment have helped women with metastatic breast cancer to live longer. The question becomes how will you take advantage of this time in your life? How will you continue to fully live your life? Consider the following approaches.

- **Make short and long term goals.** For many women, cancer may be managed for months or years even when it has spread. Don't let the fear that you may die tomorrow prevent you from living today. Consider what achievable steps you can take to make progress toward these goals. I would have never quit my job if I had known I was going to continue my life for so long.

- **Continue to take good care of your physical health.** Exercising on a regular basis and eating healthy foods will help you to maintain your energy level, to feel healthy, and to lift your spirits. Talk with your doctor about any exercises you should avoid. Perhaps inviting friends or family to join you will help you make your daily routine a social outlet as well.

When I was diagnosed three and a half years ago at the age of 49 with metastatic breast cancer, I felt pretty overwhelmed and alone. My husband and I had just bought a house and were trying to have our first child. Instead of a baby, I was blessed with a very rude tumor that pretty much came out of nowhere and literally grew daily before my eyes until I was able to have surgery to remove it. It turned out to be a highly aggressive breast cancer and had already spread to both lungs. Since then, I have had numerous chemotherapy protocols, radiation, two experimental clinical trials involving immunotherapy, high-dose chemo, a stem cell transplant, and most recently, radiofrequency ablation for lung metastasis. It has been a long road, but I’m still kicking and doing well.

Experiencing breast cancer at a young age may seem isolating. Having incurable cancer may seem even more so. I feel a deep amount of sadness for the women’s voices we won’t hear from in this project. As cancer progresses you have choices to make about your treatment and how to spend your time. The right to receive help in managing your symptoms, and the opportunity to contribute to the lives of those you love. How will you choose to continue to live, really live, during this time in your life? Consider the following suggestions.

**Strive for an open and honest communication with your doctors about this period of time.** Determining how much time you have left is not an exact science, and limited lines of communication may make it easier for you to make medical decisions during this phase of your care.

**Write down your short-term goals.** Work with your healthcare team, family, friends, or spiritual leader to identify practical steps to move forward in these final stages of life. Laying out your end of life plan may help to lessen your anxiety.

For many women, cancer may be the most difficult aspect of this time in your life. Every time I looked into my kids’ eyes I wondered if they would remember me or if I would get to see them graduate. I’m sure there were times that my adolescent growing pains were exacerbated by my fear of losing my mother, trying to find some distance so it wouldn’t hurt so much, and anger over her leaving.

I made sure everything was in place for my children. I want them to know that another woman will not love them adequately—I so love them wholly now, while at the same time, attempting to have them able to stand alone without me there. This is undeniably the most painful part.

Talking openly with your children may help to lessen their fears of the unknown. They may cherish this time with you, as they remember your love for them. You may wish to speak with your pediatrician or a child psychologist regarding the best age-appropriate approach to sharing your cancer diagnosis with your children. It is important the entire family shares this openness. Mixed messages will only confuse your children.

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I don’t hide anything from my kids. Death is not to be feared. It is part of the circle of life, although it is very sad for those left behind. When my friend was dying, the kids came to visit her with me. My husband was not comfortable with this, but it opened up the discussion and let them face their own fears.

Some women wish to give permanent written or visual remembrances to their children and family. Your children may not be old enough to appreciate these now, but in future years may cherish these lasting memories. Here are a few suggestions.

- **Write letters to them now and for the future.** Visualize them at older ages and what you would like to share with them. Identify a family member or friend whom you want to give these to your children when appropriate. Your children will not only have your words of comfort and love, but simply reading your handwriting will be special.

- **Make a scrapbook.** Scrapbooks contain pictures and other memorabilia of the entire family. Maybe times we share with one another. Your children and family can look back on these with happiness and laughter.

- **Video tape yourself and your family.** You may choose to tell your story or just document simple activities of your daily life, such as cooking a meal or face your own fears. A video allows your children to cherish your voice and watch your mementos. They may find similarities in themselves as they grow older.
Encouragement to record the story of your own life beyond breast cancer.

Consider also how you wish to live your life, especially when death is near. Making decisions early in the end of life period will help you to maintain as much control as possible. Consider the following questions as you plan this time in your life.

What are your preferences for medical care at the end of your life? Have you expressed these preferences to your family and your care team?

An advance health directive is a written document that states your wishes regarding your medical care when you are unable to communicate this information directly. This document provides a formal means to express your preferences.

Who will make medical decisions for you if you are unable to do so?

A durable power of attorney is a legal document which gives permission to an individual you choose, the power to make health care decisions for you if you become unable to speak for yourself.

Have you spoken with your care team about a referral to a hospice program? Hospice care is focused on relieving the symptoms of a person who has exhausted or decided against further treatments focused on cure. Healthcare professionals, social workers, and clergy work as a team to provide hospice care.

Have you spoken with your partner or spouse about your children’s future?

Working with a lawyer to create a will and trust empowers you to protect the interests of your children and other loved ones.

Where do you prefer your death to occur? At home? In a hospital? In a care facility?

We don’t always get to make this choice. Talking openly with your family about your wishes helps them to understand your desires and to accommodate them when possible.

Have you made your own funeral arrangements?

For some women, making these arrangements in advance helps to ensure their wishes are carried out and removes the decision making burden from their family.

Believe in your heart, mind, and spirit that cancer will never lessen who you are, the contribution you make, or the value you offer. You will live in the hearts and minds of those who love you.

There is a future – we don’t know what it exactly is, but it is a legacy that we get to participate in no matter how the final outcome shapes itself.

my story

Encouragement to record the story of your own life beyond breast cancer.
DEAR YOUNG WOMAN:

If you are feeling frightened, you are not alone. If you are like many young women diagnosed with breast cancer, you have suddenly gone from being a healthy person to a cancer patient. I was barely 35 when I was diagnosed with inflammatory breast cancer, a particularly aggressive form of breast cancer. I had 3 young children and was at the peak of my career when my life seemed to come to a halt. Faced with the uncertainty of the future, the fear of treatment, surgery, and trying to deal with the day-to-day stuff in life is so overwhelming.

I completed treatment 9 months ago and my life is so good. Yes, you will lose your hair, your appearance may change from surgery, and you will be tired and emotional from the effects of chemotherapy. But while you are going through this, remember there will be an end in sight. Use whatever support you have—family, friends or God. Take care of yourself, rest and exercise when you can, and never give up hope.

Now that I am finished with treatment, my hair has grown back, I’ve lost the weight I gained from chemo and I feel like my old self again. But yet I am a changed person. I can look in my children’s eyes and thank God that I am alive. I have a great life and it is well worth the fight. Know that you can do this and live.

KAREN
This journal is filled with the shared experiences of young women with breast cancer. Yet, there is something missing: your story. We wish to hear your voice, the story you have to tell. You may choose to write your story. You may choose to draw or paint your story.

Perhaps you will choose to share your story during the months you receive your treatment. Maybe you will offer your story ten years following your diagnosis. No matter when you choose to share your story, it is exciting to know it will always be an ongoing work in progress.

This will be a story filled with challenges, losses, celebrations, and blessings. Your diagnosis will not be the focus, as you are the main character in a story filled with many people and woven with simple and defining moments, lasting several acts long. For some of us, our cancer will threaten our life or may end it early. Yet, our diagnosis does not define who we are, for we are stronger than any disease.

Be proud of your story. You have so much to tell.

It is the aggregate of those individual days that have left an indelible mark upon me.

MY STORY

yes, i have breast cancer, but there is much more to me than that.