Dear Friends,

We share our stories in this booklet to help women diagnosed with breast cancer. We are African-American women who are on a journey to live through breast cancer treatment and beyond. We share our feelings and ideas about what has helped us to cope and to live fulfilling lives.

We encourage you to connect with yourself, your family, your doctors, your nurses and social workers, to other survivors and to your own spirituality. The photos that you see throughout this booklet are pictures of us, our families and our friends.

We hope this booklet strengthens your journey of living beyond breast cancer. Please share this with your family, friends and other women who have been diagnosed with breast cancer.

—With love and hope to all of you,

From the many people who helped produce this booklet.
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This booklet is produced for you by Living Beyond Breast Cancer (LBBC), a nonprofit education and support organization. LBBC thanks all the people who contributed ideas and experiences and agreed to be photographed for the booklet. The images in this booklet are photographs of women affected by breast cancer who took part in group interviews and their loved ones, but they are not in any specific order. The text, quotes and subject matter in and around each photograph are not necessarily the words of the individual in the photograph.

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How will I live?

“I was shocked and scared when I heard I had breast cancer. Why me? Cancer is not in my family. I take care of myself. I eat right. I exercise. I was overwhelmed with questions about dying and worried about who would take care of my family. In time, things turned around. I asked, ‘Why not me?’ My feelings changed from ‘Will I die?’ to ‘How will I live?’

I got connected to myself, to supportive friends and family, to other survivors and to my healthcare team. And I got connected to my spirituality. I now see things in a different way. I get more pleasure from little things. I look at the sky, the moon, and everything else in a different way. I argue less and smile more. My fear has turned into faith. Life has a deeper meaning. I am not just surviving.

I am living beyond breast cancer.”

…from voices of women treated for breast cancer
We are survivors.

Survivors are people who have lived through a trauma or crisis.

Many of us dealing with breast cancer see ourselves as more than just survivors.

We are warriors against our cancer.

We have survived other things and will survive this.

We are strong-willed.

We will keep living.

We handle the tough times during our treatment.

We are strong.

We are connected to life.

We are living in a more meaningful way.

What does being a survivor mean to you?
Getting Connected: African-Americans Living Beyond Breast Cancer

First Reactions to Diagnosis

We all felt different things when we first heard the words “You have breast cancer.” Some of us felt overwhelmed. Some of us felt calm. Your feelings may change from day to day. Know that shock, denial, fear and worry are normal first reactions. Healing is a process. It is a journey. It takes time.

These are feelings that many of us had after hearing we had breast cancer:

**Shock and Denial**

“No one in my family has breast cancer. It can’t be true.”

“I was shocked. My mammogram was always negative.”

“I saw my mother go through it, and I didn’t want to deal with what was to come.”

**Fear**

“Will I survive?”

“Will my partner leave me?”

“Who will take care of my family if I’m sick?”

“Will it come back?”

**Money Worries**

“Will my health insurance cover my treatment?”

“What happens if I can’t afford the co-pays?”

“I don’t have health insurance. Will I still get good care and treatment?”

“Will I lose my job?”

**Accepting the Diagnosis**

“God knew I could handle this.”

“When I first heard I had breast cancer, I didn’t think ‘Why me?’ I thought ‘What next?’”

“Today I am not fine spiritually, mentally, emotionally. Maybe someday I will be.”

What were your first reactions?

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Reasons to Seek Medical Treatment

“If I take care of myself first, then I can take care of others.”

“The Scriptures tell us to take care of our bodies.”

“I want to be around for my grandchildren.”

“I have more things I want to do with my life.”

“I want to see my children grow up.”

“We owe it to ourselves and to our family to seek and stay connected to medical care.”
Surviving

Taking the Next Steps

In times of stress, it is easy to forget what helps us cope. We found that connecting with other people is an important part of moving forward.

Below are three steps to take toward healing yourself:

1. Understand Your Cancer.

Cancer is not a death sentence. Being told you have breast cancer is very serious, but it does not mean you will die from it. It is important to get the treatment you need and stay connected to medical care and support people.

Each person’s body, diagnosis and treatment are different. Find out what type of cancer you have and the best treatment for you. Your doctor and nurse can help you to understand your cancer. Even if the cancer has spread to other parts of your body, you may still live an active life.

2. Get Medical Treatment.

Go for help right away. Because each person is different, your treatment may be different from another woman’s treatment. Ask your doctor or nurse to write down all the treatments you could have. It’s your body, and you have a right to ask all the questions you need to understand everything about your cancer.

Self
You are a person with feelings and goals. You may want to spend some time alone or with others. Plan time to connect to yourself.

Friends and Family
Share your feelings with special people in your life. Tell them the best way they can help you. Connect with family and friends by having them take notes at your doctor appointments.

Spirituality
Get in touch with your spiritual feelings through God, nature or prayer. Make time to connect to your spirituality.

Other Survivors
It may be easier to talk to women who have lived through breast cancer than close friends and family. Many women are happy to share their experiences. Make plans to connect with them.

If you do not know any survivors, ask your doctor, nurse or social worker for the name of a woman or support group. We also invite you to call LBBC’s Survivors’ Helpline at (888) 753-LBBC (5222).

Your Healthcare Team
Your team includes doctors, nurses, pharmacists, medical assistants and social workers as well as clinic and hospital staff. The more they connect to you as a person, the better they can help you.
Managing Information

When we first heard that we had breast cancer, many of us felt like we were on an emotional roller-coaster. We were overwhelmed—not just by thoughts of death, but by so many decisions!

Too much information can make you feel anxious. It can be hard to hear and remember what your doctors are telling you.

You can control how much information you get. Let your doctor or nurse know how much or how little you want to hear. Some of us found information on the Internet. After we read it, we asked our healthcare team to explain it to us in their own words.

Get all the information and advice you need to make the decisions that are best for you. Get the information in writing when you can, because you may not remember it. Take your time.

See page 47 for a list of groups that have information.

“You might need to make a decision as to who you’re going to listen to. There’s so much information out there and so many people trying to tell you what to do.”
Find out if your beliefs about breast cancer are keeping you from getting care or choosing the best treatment. Your family may have beliefs about breast cancer that may affect your decisions. Talk with them about their beliefs. Invite them to learn with you about what is true about breast cancer.

Remember
Beliefs that are not true can affect the way you think about breast cancer and may stop you from getting treatment. Talk to your doctor or nurse if something is stopping you from getting the care you need.

What are some beliefs you may have about breast cancer?
Some Common Beliefs

To the right are some examples of beliefs we had that are not true. You will also see things we learned that are true.

When they cut you and open you up to the air, the cancer will spread.

What is true: Air cannot make cancer spread. If the cancer has spread, it happened before the surgery.

Cancer is catching; you can get it from someone else.

What is true: You cannot catch cancer from someone else. If people stay away from you because they believe you will give them cancer, tell them they are not in danger.

If a mammogram finds cancer, it’s too late.

What is true: A mammogram can find cancer before you or your doctor can feel a lump. The sooner you find cancer, the more treatment choices you have.

The treatment is worse than the cancer itself.

What is true: If you do not treat cancer, it can spread to other parts of your body. Treatment is hard, but it does end. Your doctor can give you tips and medicine to make treatment less hard.

Everyone who gets treatment has bad side effects.

What is true: Some people have side effects, but some do not. Everyone’s body responds differently to treatment. Ask your doctor for tips to prevent or stop side effects.
Making Decisions

Getting the Best Care

Finding the right doctor is one of your first and most important decisions. Although many of us knew what we wanted, we realized that it might not be possible to find a doctor with all the qualities we needed and wanted.

Questions we asked when choosing our doctor and treatment:

Is this doctor someone…

• I trust and respect?
• Who will give me honest answers?
• Who will let me express my feelings and help me with them?
• Who is willing to explain things more than once?
• Who makes me feel safe and comfortable?

Before you select a treatment, ask your doctor…

• What medical tests will I need before starting treatment? Why do I need these tests?
• Do I have a choice of treatments? What are they?
• Will one treatment work better than the others?
• Is there a clinical trial or research study I can participate in?
• How much time can I take to make a decision?
• How can I get health insurance, if I don’t have it?
• How will I pay for the treatment?

About the treatment…

• How many treatments will I need and over how long a period of time?
• How long will each treatment take?
• How will the treatment be given?
• Can I work and get around during treatment?
• What side effects might I have from treatment? Can I stop them from happening?

Remember

It’s your health. You have the right to a second opinion. If you are not comfortable for any reason with the care you are getting, you may want to consult another doctor. Your care is your choice. You are in charge of you.
Our checklist for getting the best care

Expect to go for regular visits with your cancer doctors. Use this checklist to help you get the best care.

Before your appointments...

☐ Write down your questions, symptoms and worries. Bring the list with you.

☐ Ask one doctor to take charge of your care and to talk to the other doctors on your healthcare team. This gives you one person you can always go to when you have questions.

☐ Take paper and pencil or a computer so you can take notes. You can also ask your doctor if you can record the visit.

☐ Take someone with you who will help you. They can help take notes and listen to what the doctor says.

☐ Ask your doctor to refer you to another doctor if you want a second opinion. You have the right to get a second opinion.

At your appointments...

☐ Take notes or record the visit so you can remember what the doctor said.

☐ Ask for copies of your test results.

☐ Tell your doctors or nurses about your fears and concerns so that they can help you.

☐ Make another appointment before leaving. Write it down. Do not rely on your memory.

Remember

You are the most important person. Your feelings count the most. Take care of your needs first. Do not worry about hurting the doctor’s feelings. If you are not happy with your care, try to improve the situation. If you are still not happy, consider changing to another doctor.
Clinical Trials

Some of us took part in clinical trials. Clinical trials are research studies where people get treatment for cancer and also help doctors find new, improved treatments for the future. Ask your doctor if a clinical trial is a choice for you. Also ask about the benefits and risks of the treatment given in the clinical trial.

We learned from talking to our healthcare team that all people who join a clinical trial are told what will happen in the study and receive the best care possible. You can choose to leave the clinical trial at any time and still get the care you need.

If you are thinking about being in a clinical trial, it is important to ask about it before you start treatment. Once you start treatment, you may not be able to join the trial.

“I asked my doctor about clinical trials. And I was, through the grace of God, able to join one.”

For more information about clinical trials:

- National Cancer Institute, Cancer Information Service (800) 422-6237
- The American Cancer Society, Clinical Trial Matching Service (800) 303-5691
- LBBC’s Guide to Understanding Breast Cancer Treatment Research Studies
Making Decisions

Understanding Treatment Choices

Each person’s breast cancer is different, and there are different treatments for each kind of breast cancer. Two basic treatments are local/regional therapy and systemic therapy. You and your doctors will discuss the type of breast cancer you have and your health history to decide the best treatment for you.

Local/Regional Therapy

Local/Regional therapy focuses on the breast area and nearby lymph nodes located under the arm. There are two types of local/regional therapy:

1. Surgery

There are two types of surgery to remove a tumor in your breast:

- A lumpectomy (lump-ek-toe-me) removes the cancer and some healthy tissue around the cancer. It is almost always followed with radiation therapy to treat the rest of the breast.

- A mastectomy (mas-stek-toe-me) is the removal of the cancer, the whole breast and one or more lymph nodes under the arm.

Ask your doctor what kind of surgery you should have.

The doctor may also take out and test some lymph nodes (glands) under your arm. These surgeries are called sentinel lymph node biopsy and axillary lymph node dissection.

In a sentinel lymph node biopsy, the surgeon looks for the first lymph nodes under the arm. The surgeon removes the lymph nodes to check them for cancer. If several cancer cells are found in the sentinel nodes, an axillary lymph node dissection will be done. In this surgery, the doctor removes most of the lymph nodes likely to be involved from the armpit to look for cancer cells.

2. Radiation Therapy

Radiation therapy is another kind of local treatment. It uses high-energy x-rays to kill cancer cells. After surgery, radiation may be used to kill cancer that may still be in the breast.

Some of our feelings about surgery:

“I feared I would lose my relationship. I wondered what my partner would think about my choice.”

“My breasts are my savior. I’m trying to adjust to losing them. I use my breasts for many things, even to keep my hands warm in the winter!”

“My breast was useless to me and it was diseased, so I told them to take it.”
Systemic Therapy

Systemic therapy uses medicines to kill or slow the growth of cancer cells throughout the body. Some of these medicines may be given intravenously (in-tra-vene-us-ly), which means through a needle into a vein. Others may be given as a shot into a muscle, or a pill by mouth.

Ask the medical team how the medicines will be given to you.

Your doctor may still recommend systemic therapy, even if tests show no cancer in other areas of your body. It can kill cancer cells that are too small to detect. It can also be used to keep the cancer from coming back. Cancer that comes back is called recurrence.
There are three types of systemic therapy:

1. **Chemotherapy**
Chemotherapy (kimo-ther-a-pee) uses medicines to destroy cancer cells. It works on cells that grow and divide quickly, such as cancer cells. These medicines are taken either by mouth, or put directly into a vein.

2. **Hormonal Therapy**
Hormonal therapy works against cancers that feed on the hormones estrogen and progesterone. Hormonal therapy lowers the chance that the cancer might come back. It also helps prevent a new breast cancer from forming.

There are different kinds of hormonal therapy. If you still get your period, you may be given a medicine called tamoxifen. It stops estrogen from reaching the cancer cells. Women who no longer get a period may take tamoxifen or other medicines called aromatase inhibitors. They are used to lower the amount of estrogen your body makes.

Hormonal therapy is given as a pill that you take every day for about five years. It is very important to take it every day to allow the medicine to work well. Some of us had side effects from these medicines. Talk to your healthcare team about ways to manage the side effects.

3. **Targeted (biological) Therapy**
Targeted (biological) therapy is medicine that attaches to certain proteins on and in cancer cells. These medicines stop the cancer cells from growing. Some cancers have too much of a protein called HER2. Herceptin (trastuzumab) is a targeted therapy that attaches to HER2 on the outside of the cell to stop the cancer cells from growing.

There are many medicines being studied for breast cancer. Ask your doctor about the most current ones.
“I show my new breast to people all the time. People need to see the positive side of things.”

“I decided to adjust to what my body looked like once I lost my breast. Then, if wearing a prosthesis is too hard, I can always get reconstruction later. I don’t want to take on too much.”

Remember
Rebuilding your breast is your choice. Ask your surgeon about reconstruction and the kind that may be best for you. It is common to get a second opinion before having any surgery. Also, talk to other women who have had breast reconstruction. They can tell you how the surgery was for them.

Making Decisions

Deciding About Breast Reconstruction

If you have a mastectomy, you can ask your doctor about surgery called breast reconstruction (re-con-struk-shun). During this surgery, the doctor builds a new breast after removing the one that had cancer. This surgery can make a breast look similar to how it looked before cancer.

You do not have to decide about reconstruction right away. Often it can be done at the same time as your mastectomy, or you can wait until treatment is over. You can even have your breast rebuilt many years later.

There are different kinds of breast reconstruction. Some of us had breast implants, and some of us had our breast rebuilt using tissue from other parts of our body. We learned that we still need to get tests and still need to check our breasts for any changes, even after reconstruction.

Knowing your choices about breast reconstruction before surgery can help you prepare for a mastectomy.

Some of us did not want more surgery. We chose to wear a prosthesis (pro-sthe-sis). A prosthesis is a kind of breast pad or form that is worn with a mastectomy bra to hold it in place. The prosthesis has a weight inside to help with balance and support for the neck and back. Check with your insurance to see if it will pay for a prosthesis or mastectomy bras. It is important to feel comfortable when wearing your prosthesis.

The decision to rebuild your breast is very personal. It is up to you to decide.
“I didn’t want any more surgery. I was afraid of what they would put in my body.”

“When I had my reconstruction, they used my own body fat from my belly and gave me a tummy-tuck. I got a new breast, a new figure, and a new attitude!”
Making Decisions

Dealing with Side Effects

Each of us responded differently to treatment. Some of us had serious side effects, while others had few or no side effects. We learned that many side effects can be prevented, and most can be treated. It is important to talk to your doctor and nurse about how you feel so they can help you to manage your symptoms.

How your treatments affect you depends on many things, such as:

• The type of treatment and how much you receive.
• The timing of treatments. If more than one treatment is given at the same time, such as chemotherapy and radiation, you may have more side effects.
• The stress in your life.
• The other demands on your body, what you eat, and your general health.

Some common side effects of breast cancer treatment include:

- hair loss
- fatigue
- weight gain
- weight loss
- nausea
- diarrhea
- constipation
- dry skin and nails
- mouth sores
- darkening skin and nails

Many of us felt tired a lot of the time. We struggled with low blood counts, which made us more likely to catch a cold or virus. We had to wait for our blood counts to return to normal before we started our next treatment.

Other side effects are problems with memory, or what some of us call “chemobrain.” Menopause symptoms, such as hot flashes and vaginal dryness or discharge, can also happen.

Some of us felt tingling in our hands, which the doctor called neuropathy (nur-op-o-thi). Some of us had joint or muscle aches and tightness. Others had swelling of the arm called lymphedema (lim-fa-dima). Ask your doctor about your risk of having these side effects and if there are ways to prevent them.
Remember, many of these side effects can be treated. LBBC has booklets about these and other side effects like insomnia (trouble sleeping), fatigue, bone health, and lymphedema.

Talk to your doctor or nurse about what kind of exercise is best during treatment. Exercise can help reduce some of your side effects, such as weight gain and fatigue. It can also help you feel better overall during treatment.

Having cancer does not mean you have to suffer. Be sure to call your doctor or nurse if your side effects are bad, even if you are between appointments. Side effects should not keep you from taking care of yourself and feeling as good as you can feel.

**Our tips for dealing with side effects**

- Eat small, healthy meals often and drink plenty of fluids.
- Eat what makes you feel best, and relax during meals.
- Add fiber to your diet to help with constipation.
- Meditate, pray or do deep breathing exercises.
- Use sunscreen, and wear a wide brimmed hat, long sleeves and pants when outdoors. If you are having chemo, the sun can burn your skin easily.
- Wash with mild soap and use creams for dry skin.
- Take short naps to help your energy level.
- If your doctor gives you medicine, take it as directed.
Hair Loss

Of all the side effects we had from treatment, hair loss was the hardest for many of us. While some of us did not lose any hair, many of us did. Hair is part of what makes us feel like women. Ask your doctor if your treatment could make you lose your hair.

Losing your hair can be very emotional. It is normal to feel sad about it. Remember, your hair will grow back in time. The texture of your hair may change after treatment. Your nurse, doctor, or social worker may have tips to help you deal with losing your hair.

Our tips for hair loss

- Cut your hair before your treatments. You will get used to seeing yourself with short hair and feel like you lose less.
- Sleep with a cloth night cap or scarf to stay warm at night and collect your shedding hair.
- Try on wigs before you lose your hair, or try a hat or other head wrap.
- Wearing a bald head is OK too.
- Talk to your nurse and close friends about ways to feel more attractive during treatment.
- When your hair grows back, talk with your healthcare team about what hair products are safe to use.

“I tried wearing a wig but I just didn’t look natural. My husband told me he liked my bald look.”

“Losing my hair was not as bad as the way it came out. When I washed it, it clumped up into a ball and fell out. I was shocked and devastated.”

“When my hair came back it was baby fine. It did what it wanted to do.”

“No one told me I would lose my hair all over, including down there [pubic hair].”
Making Decisions

Understanding Emotions

Taking Care of Yourself
Your feelings may change a lot. It is common to feel a sense of loss. Cry when you need to. Sometimes we tried to be strong by being silent. Being strong so that you don’t burden your family is a natural reaction. You may want to protect your family by not sharing your feelings with them. Try not to let your worries or a busy life get in the way of caring for yourself. It is not always easy to accept help, but getting help is a sign of strength.

You can get through this.

When You Need Extra Help
Healing takes time. It’s OK to feel sad for yourself, as long as it doesn’t last too long or keep you from getting treatment. If it does, you may need to ask for help.

- Ask your doctor, social worker, nurse or support person for names of counselors; or talk to your religious leader or clergy.
- It’s important for you to do what makes you feel the most comfortable.

“I’ve been dealing with my cancer in stages. My first reaction was fear. As I went through it, my faith got greater, and I came out with hope.”

“I was the key part of my family. I had to be strong for them, so I never really faced what I was going through.”

“I think the hardest part is that my life is not like it was. I had to readjust. You’ve got to rearrange things.”

“I believe that this happened to me because the Lord was telling me I needed to slow down. Breast cancer is not a dead end. It’s a speed bump. You’re going to get over it.”
Seek Positive People and Help

When we are stressed, it helps us to be with positive and supportive people. Family, friends, breast cancer support groups, and your spiritual community may offer the kind of help and comfort you need. Your healthcare team, including your social worker, can also be a resource for you.

Sometimes people do not know how to be sensitive or understanding. They may be afraid for you or in a bad mood. You do not have to share with people who are negative and unsupportive. You can decide who you want to talk to and go to for support.

Things to think about:

- **Family and friends.** Tell them how you feel and what you need. Don’t be shy about explaining things they might not know.

- **Your family may feel like they have to “fix” the cancer.** They may feel frustrated that they can’t. Let them know that fixing it is not their job, but being there for you is.

- **Let your support persons know that it is OK to have their own life.** Sometimes you may need a break from each other.
“Sometimes I feel like nobody understands. But then when I talk to other people who are in my shoes, it makes a difference.”

“It’s really good to have support, because you find out what’s happening. I can deal with situations a lot easier, because I know I’m not going through it alone.”

“If I can be of assistance to somebody else who has gone through what I’ve gone through, who is newly diagnosed with cancer and doesn’t know what to do, I’m there for you.”

Messages to Family and Friends

You can use the messages in this letter to express how you feel to your family and friends.
Dear Family and Friends,

I want to live beyond breast cancer and need your help to do it. Each of you is important to me. The kind of help I need may change from time to time. I do not always know how I am going to feel. Please know that it is sometimes hard for me to ask for help.

Here are some ways you can help me:

• Pray for me.

• Help in the way you feel most comfortable. Give me hugs, cook for me and make me laugh. Sit with me, or take me to my treatments.

• Please don’t keep things from me, but try to be sensitive in how you say them.

• Understand that I am changing because of this experience.

• Different smells may make me sick. Before you start cooking or painting the house, ask me if I think the smell will bother me.

• Please offer your help without an attitude. And I’ll try to accept it without one.

• Sometimes I want company, but please understand when I want to be alone.

• Be there with me, even if you don’t know what to say.

Your help means a lot to me.

Thank you.
Getting Support

You and Support Groups

A support group is a group of people who meet and talk about thoughts and feelings. There usually is a group leader. In many support groups, a special bond develops among members. Groups help you realize you are not alone.

Here are ways groups have helped us:

- We get connected to other women.
- We get lots of hugs.
- We hear positive stories.
- We pick up tips on ways to cope.
- We can speak freely without worrying about hurting someone’s feelings.
- We gain the strength to go on.

What if I don’t like support groups?

Not everyone likes to share with groups of people. You don’t have to join a group to get support. Sometimes faith can be a source of support. You can take a few minutes each day to connect to a special friend or neighbor who supports you. All you need is one person you trust.

There are other ways to feel connected and supported. Check the ones below that you want to try.

- Speak to another woman with breast cancer on a regular basis. There is nothing like hearing, “I really know how you feel.”
- Call a hotline such as LBBC’s Survivors’ Helpline at (888) 753-LBBC (5222).
- Talk to your treatment team, your nurse, or your social worker.
- Help someone else who has breast cancer.

Remember

Talking and sharing helps us feel understood and less alone.
Being Young With Breast Cancer

Some of us were under 45 years old when we were diagnosed. We had trouble finding support groups for women our age. We felt different than older women. We had some unique concerns about:

- If we needed different treatment than older women.
- If treatment would keep us from having babies.
- How to date or meet a new person.
- How to talk to young children.
- If treatment would keep us from working.

You can contact LBBC to help you connect to someone your age.

“What I’ve been really yearning for is something for young women of color. I want to talk to other women that have fears like, ‘Am I going to be able to have children?'”
When Active Treatment Ends

When we “graduated” from active treatment, many of us had mixed feelings.

We were happy and sad at the same time. We cried with relief.

Some of us missed the close contact and support of our treatment team.

Others couldn’t wait to stop treatment.

We wondered, “Now what?”

We worried about the breast cancer coming back.

Even a simple headache could seem like a brain tumor! Now we know that this worry gets less over time.

We used follow-up visits to get questions answered and to stay connected to the doctors and nurses who helped take care of us. We used support groups and LBBC’s programs to stay connected.
Follow-up Care

Regular follow-up care can help you stay healthy.

When you finish your treatment, find out when and who you need to see for follow-up care. These visits are very important. We found that by working with our doctors, we could manage any long-term side effects we had.

After treatment is over, it’s a good idea to:

• Ask your doctor what symptoms to be aware of, and how long to wait before calling them about your concerns.
• Find out who is on your follow-up healthcare team.
• Write down when you should schedule follow-up visits.
• Keep a record of all your cancer treatments in a safe place.

Remember

It is OK to feel nervous at check-ups. It’s common to worry about the breast cancer coming back. Going to the doctor’s office can bring back unhappy memories of treatment. This gets better with time.
What symptoms should I watch for?

Who will be on my follow-up healthcare team?

How often should I check in with my healthcare team?
A word of caution:
It is dangerous to get pregnant during your treatment. Talk to your doctor before starting treatment about safe birth control methods.

Our tips to improve your relationship.
- Listen to your body and mind.
- Share your thoughts and feelings with your partner.
- Be clear about what you want or are ready for.
- You and your partner can still enjoy closeness in sexual ways.
- You can be together by just touching, holding and kissing.
- Let your partner know where you want to be touched, and where you don’t want to be touched.

Intimacy is a way we express our feelings of tenderness, understanding, warmth, and affection. How we feel about ourselves and the way we look can affect intimacy. At first, weight change, hair loss, tiredness and breast surgery can make you feel less attractive. Letting yourself feel close to your partner may be the first step to expressing your sexuality.
“If I meet anyone, they need to accept me as I am.”

“All my life I’d been told that my femininity was connected to my having breasts. The spirit of God allowed me to have the mastectomy, and I still feel feminine.”

“We women who live alone don’t have a lot of things at home to help after surgery. We need to know about programs that can help us.”

Living Single

Although some women prefer to be single, many want to be part of a relationship. Some of us who did not have partners had concerns about how breast cancer would affect our future relationships.

The first step is to feel comfortable with yourself and the breast cancer. Breast cancer does not have to define who you are. It does not need to keep you from meeting someone.
I was 12 when my mother died from cancer. I was left out of her situation and felt cheated. Now that I have breast cancer, I don’t hide it from my children.”

You and Your Children

Each child reacts differently to their mom having breast cancer. The reactions depend upon their age, their personality, family life and so many other things. Their reactions may make you cry, laugh, or even get angry.

Understanding Our Children’s Reactions

Our children need to be able to express themselves. They might not ask questions but may express their feelings in other ways. Sometimes we need the help of a good counselor, teacher, or spiritual leader to help us and our children understand each other. This is true whether our children are very young or grown up.
Remember
There are books, videos and other resources to help you share information about breast cancer with your children. Ask a librarian or call LBBC’s Survivors’ Helpline at (888) 753-LBBC (5222) to get information about these resources.

“ My college-age son was ashamed. He said, ‘I don’t want to talk about it, see any scars, hear how you feel.’ I guess he couldn’t deal with his fear of losing me.”

“ My grown daughter said, ‘I feel helpless. All I can do is pray and trust the Lord.’”

Our tips to stay connected to your children.

- Ask them about their feelings. Listen to their response.
- Control your own response. Think before you respond.
- Share with your children. Answer their questions honestly.
- Let your children know that they won’t be punished for what they say or feel.
- Talk about things other than cancer. Remember, cancer is only one part of your life.
- Laugh and have fun in your home.
- Spend time alone with your children each day, even if it is only a few minutes. A few minutes can go a long way.
- Encourage your children to go on with their dreams.
“My 7-year-old son asked, ‘Mommy, are you going to die?’”

How do your children feel about you having breast cancer?
“The fear of death is so powerful. But living is greater. Just open up to living, finally living!”

Living beyond breast cancer is a journey. It means different things to different women. Some of us wonder, “Who will I be when this is over?” To some it means letting go of negative feelings. For others, it means letting God take care of things. It also may mean living in the present and taking “me” time.

Sometimes we get stuck living in the past. Sometimes we fear the future. When we live in the present, we take each day as it comes. We accept what is good and what is not so good. We count our blessings. We find meaning in what has happened to us.
Some of Our Stories

We are African-Americans living beyond breast cancer.

**Stephanie J.**
Diagnosed July 2008 at age 34

“What keeps me going is my faith in God, family and friends. After going through breast cancer, I just appreciate life so much more. I don’t take anything for granted!”

**Kathy**
Diagnosed December 2007 at age 50

“Through prayer and faith, my son and family, close friends and my godchildren, I made it through the storm. I feel blessed and highly favored that I can continue my pleasing lifestyle and continue traveling to see the best of God’s world.”

**Karen**
Diagnosed March 2009 at age 45

“Having breast cancer has opened my eyes to a whole new way of thinking. God provided me with all the family, friends, prayers and support that are crucial to going through chemo, radiation and beyond!”

**Stephanie L.**
Diagnosed April 2009 at age 45

“I choose to keep a positive attitude about life, stay connected spiritually and continue to share my story with as many people as I can. I believe it is my purpose to use my experience to empower other women through their journey with breast cancer so they too can be victorious.”

**La Tanya**
Diagnosed May 2010 at age 42

“Loving life, taking it one day at a time.”
Valerie  
Diagnosed April 2010 at age 44,  
Living with metastatic breast cancer  
“I put myself first instead of everyone else, which is something I never did before I was diagnosed with breast cancer. I am living and enjoying my life.”

Mary  
Diagnosed December 2009 at age 50  
“I got my strength by having a very supportive husband, loving Creator and good family.”

Rana  
Diagnosed April 2009 at age 41  
“I keep living life to its fullest and allowing myself to surrender at each and every moment. The most important lesson I learned as a result of this journey is to just be in the present.”

Tonya  
Diagnosed November 2009 at age 49  
“It may sound a little clichéd but living beyond breast cancer HAS changed my life. Work? Not as much. Because the moments I continue to share with my daughter are priceless. True, I’ve been in sorrow’s kitchen and licked all the pots, but I’m still cooking!”

Edna  
Diagnosed March 2008 at age 61  
“Living beyond breast cancer is seeing all the positive and beautiful things in life. What keeps me going? My husband of 45 years, our four daughters and our eight grandchildren, the breast cancer support groups and my faith in God.”

Sonara  
Diagnosed December 2007 at age 45  
“Counting the years of remission keeps me going. Three years and counting!”

Sharon  
Diagnosed March 2010 at age 30  
“I have decided to live life on purpose and enjoy every moment of it. Lemons are not so bad for me, because I have learned to make much lemonade of life! Smile today because you are blessed!”

Vernell  
Diagnosed April 2010 at age 49  
“Finding the lump in my breast was a real eye opener for me. My physical life has not changed much at all, but mentally and spiritually I am a new person. I’m grateful for everything today.”
Dawn
Diagnosed June 2008
at age 35
“I made this eventful journey part of my life. I will never forget how breast cancer has changed my life in terms of not taking life for granted.”

Pat
Diagnosed January 2009
at age 61
“I continue to go to breast cancer survivor programs and educating myself. I’m constantly in contact with my doctors about any pains. I have a fantastic support group, which has helped me survive.”

Betty
Diagnosed March 2010
at age 63
“God, family, love and hope. God had this in His plan. There was no need to worry. God knows where I am going with this.”

Latrece
Diagnosed May 2009
at age 38
“I have a wealth of spirit. I have to continue to be who I am beyond cancer. You are wealthy beyond just what you can see or how much money you have. I’m getting better by helping others.”

Virginia
Diagnosed June 2009
at age 50
“My family and my friends really support me. I have a 20-year-old daughter who has been by my side the whole way. When I hear her voice and see her eyes, that is what keeps me going.”

Terry
Diagnosed November
2009 at age 47,
Living with metastatic breast cancer
“Keeping faith in God through the short, little, sweet messages of my granddaughters for positive thinking and well-being.”

Nathalia
Diagnosed February 2010
at age 43
“I can’t change the fact that I had breast cancer but I keep going by being surrounded with good friends and family. I also make healthy choices—physically and emotionally.”

Sandra
Diagnosed May 2009
at age 58
“My faith in God, first and foremost. I also enjoy that I can share with others my experience. So many women are being diagnosed around me. It is rewarding to say ‘I went through it and look at me: I’m fine now.’”

Virginia
Diagnosed June 2009
at age 50
“My family and my friends really support me. I have a 20-year-old daughter who has been by my side the whole way. When I hear her voice and see her eyes, that is what keeps me going.”

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Resources

American Cancer Society
(800) 227-2345
cancer.org

Breastcancer.org
breastcancer.org

Black Women’s Health Initiative
(202) 548-4000
blackwomenshealth.org

CancerCare
(800) 813-4673
cancercare.org

Intercultural Cancer Council
(713) 798-4614
iccnetwork.org

Living Beyond Breast Cancer
(888) 753-LBBC (5222)
lbcc.org

National Breast Cancer Coalition
(800) 622-2838
breastcancerdeadline2020.org

National Cancer Institute
(800) 422-6237
cancer.gov

National Witness Project
(716) 845-1394
thenationalwitnessproject.org

Sisters Network
(866) 781-1808
sistersnetworkinc.org

Susan G. Komen for the Cure
(877) 465-6636
komen.org

Y-ME National Breast Cancer Organization
(800) 221-2141
y-me.org
Resources

Living Beyond Breast Cancer

This booklet was produced by Living Beyond Breast Cancer (LBBC), a non-profit education and support organization dedicated to empowering all women affected by breast cancer to live as long as possible with the best quality of life. LBBC programs and resources include:

Conferences and Teleconferences

LBBC's large-scale educational conferences and teleconferences feature experts who share the latest information about medical and quality-of-life concerns.

Survivors’ Helpline (888) 753-LBBC (5222)

Private, toll-free telephone service staffed by volunteer breast cancer survivors. Volunteers provide support and education to callers.

Publications

The Guide to Understanding series addresses the unique needs of women newly diagnosed, with early-stage breast cancer and women with metastatic breast cancer. Publications are distributed for free.

We Celebrate Tomorrow: Latinas Living Beyond Breast Cancer/Celebramos el Mañana: Latinas que Sobreviven el Cáncer del Seno is similar to Getting Connected. This booklet promotes informed decision-making and provides support and encouragement to Latinas as they go through treatment and begin living beyond breast cancer. This booklet is in English and Spanish.

Newsletters

Insight, LBBC’s quarterly newsletter, delivers medical information in clear language and explores emotional issues compassionately.

Website

LBBC.org offers the most current breast cancer information. Visit our library of transcripts and MP3 podcasts and learn about our upcoming programs.
Healthcare Provider Trainings
Small-scale workshops and trainings for healthcare providers are held nationally. LBBC strives to increase awareness and sensitivity of the complex needs that women experience during and after breast cancer treatment.

Outreach Programs
LBBC’s outreach programs give African-American and Latina women a safe place to learn and connect with other women.

Living Beyond Breast Cancer’s Getting Connected is designed for educational and informational purposes only, as a resource to individuals affected by breast cancer. The information provided is general in nature. For answers to specific healthcare questions or concerns, you should consult your healthcare provider, as treatment for different people varies with individual circumstances. The content is not intended in any way to be a substitute for professional counseling or medical advice.
Living Beyond Breast Cancer empowers all women affected by breast cancer to live as long as possible with the best quality of life.
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Thank you to the 44 women from Philadelphia, Chicago and Little Rock for participating in group interviews for this booklet and for sharing your insights. In addition, thank you to the 24 people who participated in group interviews in 1998 for the first edition of this resource.

We dedicate this edition of Getting Connected to Janet Cash, who passed away in 2010. Janet served on our advisory committee and assisted countless women through their journey with breast cancer.
Tell us what you think of this booklet.

You can tell us online at:
surveymonkey.com/s/GettingConnected
After we were diagnosed with breast cancer, we saw many different healthcare providers. These people may be part of your team. It is a good idea to write down their names and phone numbers in one place.

### Your Healthcare Team

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<th>Role</th>
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<td>Medical Oncologist</td>
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<td>Surgical Oncologist</td>
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<td>Radiation Oncologist</td>
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<td>Breast Reconstruction Surgeon</td>
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<td>Insurance Provider</td>
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This booklet will help you from the moment of diagnosis, through breast cancer treatment and beyond. African-American women affected by breast cancer discuss their reactions to diagnosis, how they made treatment decisions and where they found support.

With compassion and clarity, this booklet helps you take steps to get good health care, understand your breast cancer treatment options, get help from your family and friends and consider what to do after you finish treatment. This culturally sensitive booklet was written using the words of 68 African-American breast cancer survivors who shared their stories.

Living Beyond Breast Cancer is a national nonprofit organization whose mission is to empower all women affected by breast cancer to live as long as possible with the best quality of life.