



With you, for you.

You're pregnant, and you

You will experience both differently than most women. You will make difficult decisions and work through tough emotions. But breast cancer during pregnancy is more common than you might think.



Every year, more than 1,000 women in the United States have breast cancer and are pregnant at the same time.

have breast cancer.

Still, you are likely to find that many people – family, friends and strangers, and also some healthcare providers – don't know much about what you're going through. They may recommend you end the pregnancy through an abortion because they think it will protect your health or they think the disease and its treatments will hurt the fetus. But research shows pregnant women with breast cancer can have certain cancer treatments safely, and give birth to healthy babies, without putting their own health at risk.

Living Beyond Breast Cancer created this guide to give you reliable information about your health and the health of your child, and to help you through diagnosis, treatment and beyond.

Women diagnosed with breast cancer during pregnancy helped us create this guide, and their photos appear throughout it. We hope their stories inspire you.

This guide focuses on breast cancer that is found or treated at the same time as a pregnancy. Breast cancer diagnosed while a woman is breastfeeding, or within a year after birth, is considered pregnancy-related breast cancer, but it is treated the same as breast cancer in a woman who isn't pregnant.

For more information, check out our Guide to Understanding Series, available at



- Breast changes caused by cancer can be confused with those caused by pregnancy
- Many women put off self-breast exams while they're pregnant
- Routine mammograms, which are performed without any symptoms being present, are not recommended during pregnancy

SECTION 1

This Pregnancy Will Be Different

Pregnancy can be one of the most exciting times in life. Breast cancer can shatter that happiness. Suddenly, you're worrying for two.

Know that pregnancy does not cause breast cancer. Nothing you did caused breast cancer. This is not your fault.

Learning of, and About, Breast Cancer **During Pregnancy**

Your breast cancer story may have started after you learned you were pregnant, with a lump found in your breast or under your arm, or with tests that showed a past breast cancer returned or spread. Or, you may have learned about the pregnancy soon after being diagnosed or starting treatment.

Some women, and some doctors, assume changes in the breasts are harmless and caused by pregnancy. They often are, but sometimes those changes are a sign of breast cancer.

Tests for Diagnosis

You may have a variety of tests leading up to your diagnosis, such as mammograms, ultrasounds or magnetic resonance imaging (MRI). Mammograms take an x-ray image of your breasts and involve a small amount of radiation. Ultrasounds and MRIs take pictures of the inside of your body. They don't use radiation. Ultrasounds can be used to look for cancer, but they are also used regularly in pregnant women to look at the **fetus**. ("Fetus" is a medical term that's used to describe a human baby from 8 weeks after conception until birth.) All three tests can be safe during pregnancy. But an MRI of the breasts may be difficult as pregnancy goes on, because it requires you to lie on your stomach.

A **biopsy**, a test that takes tissue from the area thought to have cancer, confirms a breast cancer diagnosis. Breast biopsy is safe during pregnancy. Tissue taken during the biopsy can be used to learn more about the cancer and how best to treat it.

Once you have been diagnosed, it's important to know if the cancer traveled to organs near your armpits called **lymph nodes**. You will need surgery, either **axillary lymph node dissection** (ALND), or **sentinel lymph**

- In theory, hormones involved with pregnancy can cause an already existing, undiagnosed breast cancer to grow more quickly. But most women diagnosed with breast cancer during pregnancy do not have tumors that grow because of the hormones estrogen or progesterone.
- Doctors and the women they treat sometimes hesitate to do tests during pregnancy. Lumps and other changes that suggest breast cancer are often watched longer in women who are pregnant than in women who are not pregnant.



In the past, pregnant women with cancer were usually told to have an abortion or delay their cancer treatment. Today, it is often safe to continue a pregnancy while on some kinds of treatment, without putting your health or the health of the fetus at risk.

Still, you may decide abortion is the right option for you and your family. Talk to your doctor about your options.

node biopsy (SLNB), to check. SLNB is the preferred procedure in women who aren't pregnant, because it leads to fewer side effects. But ALND is done more often during pregnancy, because research shows it does not pose great risks to the fetus no matter when it's done during the pregnancy.

As of mid-2016, the American Society of Clinical Oncology recommends against SLNB in pregnant women. Research shows a dye often used in the procedure carries a risk of a severe allergic reaction in the mother, which could indirectly affect the fetus. Some dyes less commonly used for SLNB can hurt a fetus if injected into nearby fluid. It is unknown if they could affect the fetus when injected into the woman's tumor. It's possible, though, to do SLNB with a radioactive material instead of the dye.

Studies show this small amount of radiation does not travel throughout the body and

Your team should give you treatment that is close to what a woman who isn't pregnant gets, making changes only to protect the fetus.

doctors believe the dose is small enough to keep the fetus safe from harm.

Talk to your surgeon about which surgery is best for you.

It's also important to know if breast cancer has spread to other parts of the body, called metastatic, or stage IV, disease. But knowing may not affect your treatment during pregnancy. Unless you have symptoms, many doctors will suggest you wait to test for metastatic breast cancer until after you give birth. Putting off tests may make you feel anxious. Talking to your doctor may help you feel more confident you are making the best decisions for both you and your baby.

What Happens Now?

With so much going on, your head is probably spinning. Give yourself time to take in what you've learned about breast cancer and pregnancy so far, and to think about your needs moving forward. A great first step is finding healthcare providers who can help you through both breast cancer and pregnancy.

Your team should give you treatment that is close to what a woman who isn't pregnant gets, making changes only to protect the fetus.





Questions to ask providers as you build your cancer care team:

- Have you treated anyone who had breast cancer during pregnancy?
- What treatments would I get if I were not pregnant? How will my treatment plan change?
- I am [fill in the blank] weeks pregnant. How will that affect my treatment?

JENNIFER was diagnosed with triple-negative breast cancer at 8 weeks pregnant. Her small-town obstetrician and surgeon recommended abortion. "They basically told me it was me or the baby," she says. On top of that, Jennifer had to tell her 7-year-old son what was happening.

"Emotionally, it was crazy," Jennifer says. "Having to tell him that I had cancer and that I was pregnant was harder than being told it myself. It's so hard to put in words."

But Jennifer started reading about similar women who had healthy children. She found a surgeon and an oncologist in a bigger city and had a mastectomy. In her second trimester, she began chemotherapy.



Her new doctor "had absolute confidence that the baby and I would make it through, so I trusted her," she says.

At 37.5 weeks, Jennifer gave birth via C-section. She named her healthy baby girl Charlie.

 Has the recommended chemotherapy been given to other pregnant women?
 How did it affect them and their babies?

• Will I need to give birth early? If so, why? Can it be avoided?

 What are the risks to my and my baby's health if I put off treatments until after I give birth?





Myths About Breast Cancer During Pregnancy



Women with breast cancer who are pregnant do worse than those who are not pregnant.



When factors like stage and tumor size are the same, pregnant and non-pregnant women have the same chance of survival.



Pregnant women can't get chemotherapy.



Pregnant women can get certain chemotherapy medicines after the first trimester and until the 35th week without great risk to themselves or the fetus.



Breast cancer will spread to the fetus.



It's rare for breast cancer cells to reach the placenta. Even if they do, they are very unlikely to reach the fetus.



Pregnant women who have chemotherapy will give birth to bald babies.



Most women who get chemotherapy during pregnancy give birth to babies with hair.



Pregnant women with breast cancer always have premature babies with low birth weights.



When no other serious conditions, like kidney disease, are present, unplanned early birth and poor fetal growth are not higher in women with breast cancer than in women without. Research shows most babies born at a low birth weight were delivered early so the woman could start or re-start cancer treatment.



Treatment Safety

Surgery

Almost all people with breast cancer, including those who are pregnant, have surgery. Breast surgery, either lumpectomy or mastectomy, does not pose great risk to the fetus, no matter when in pregnancy it is done. But after 20 weeks of pregnancy, lying flat on your back is unhealthy for you and for the fetus, because it puts pressure on the main vein that sends blood in your lower body back to your heart. If necessary, a wedge will be placed under one of your hips before surgery to get you into a safer position.

General anesthesia, medicine given to numb your body during surgery, is not thought to be unsafe for the fetus. But if you wish, your doctor may use **local anesthesia**, which numbs a smaller area. If you are at least 24 weeks pregnant, your doctors may monitor fetal heartbeat during surgery to check that everything is OK. Remember, this is to make sure nothing goes wrong, not because something *is* wrong. Taking pain medicine after surgery for a short time as needed is also safe during pregnancy.

If you are 20–24 weeks pregnant at the time of surgery and getting cancer treatment in a center that does not have its own labor and delivery unit, you may be asked to have your surgery somewhere that does. This ensures the proper equipment and doctors are there to monitor fetal health before, during and after surgery.

People with cancer often get a **port**, sometimes called a mediport or a port-a-cath. It's a small device that gives doctors easier access to your veins. The port is placed under the skin, usually in the upper chest area, and requires minor surgery that is considered safe during pregnancy. Your surgeon may place it during your lumpectomy or mastectomy. After you finish treatment, the port can be removed.

Radiation Therapy

Radiation therapy, also called irradiation or radiotherapy, uses high-energy x-rays to destroy breast cancer cells and shrink tumors. Radiation is almost always given after a lumpectomy, and sometimes after mastectomy. But radiation therapy is rarely given during pregnancy, because it could hurt the fetus.



Your doctor may recommend mastectomy without radiation instead of lumpectomy with radiation, especially if you've been diagnosed during the first trimester. It's also possible to have a lumpectomy during pregnancy and have radiation therapy after the child is born. Delaying radiation until after delivery is not thought to cause health problems for the mother.

Chemotherapy

Chemotherapy is used to kill fast-growing breast cancer cells throughout the body. The idea of having this powerful treatment while pregnant can be scary. You may fear you're poisoning your baby. But research shows the **placenta**, the organ that connects your body to the fetus and nourishes it during the pregnancy, can provide protection from the harmful side effects of many chemotherapy medicines.

Chemotherapy is not given during the first trimester because the baby's organs are just starting to grow. Chemotherapy may be given to shrink the tumor before surgery, called **neoadjuvant treatment**. It can also be given after surgery, called **adjuvant treatment**. After the first trimester, certain kinds of adjuvant and neoadjuvant treatment are safe in pregnant women. It is safe

for pregnant women to receive the same dose of chemotherapy women who aren't pregnant would receive.

Chemotherapy is not given after the 35th week or within 3 weeks of a planned early delivery. It can lower your white blood cell and blood platelet counts too close to the time of delivery, increasing the risk of infection and bleeding.

If you are diagnosed in your third trimester, you may begin chemotherapy treatment before giving birth. You may also be able to wait until after giving birth. Talk to your doctor about the pros and cons of waiting to start treatment.



00000

Cancer and Pregnancy Registry

Elyce Cardonick, MD, a reviewer on this guide and an expert on cancer during pregnancy, collects information about it through the **Cancer and Preg**nancy Registry, With permission, she uses this information to learn more about the treatments pregnant women receive and the outcomes for their children, whose health she follows for years after birth. She is available to talk to women and their doctors.

For more information, visit cancerandpregnancy.com or call (877) 635-4499 (toll free) or (856) 342-2491

Targeted Therapies

Targeted therapies are medicines that can recognize a specific feature of a cancer cell, attach to that cell and destroy it. These are not used during pregnancy because they can hurt the fetus. Targeted therapies include **trastuzumab** (Herceptin) for **HER2-positive breast cancer**. After you give birth, you can safely begin targeted therapy.

Hormonal Therapies

Hormonal therapies, such as tamoxifen and aromatase inhibitors, are used to treat hormone receptor-positive breast cancer. These are not used during pregnancy because they can hurt the fetus. After you give birth, you can safely begin hormonal therapy.

Clinical Trials

Because few women are diagnosed with breast cancer during pregnancy, clinical trials studying it are small and not very common. But taking part in a clinical trial can help women diagnosed with breast cancer during pregnancy in the future. Ask your providers about ongoing research you could take part in, and visit ClinicalTrials.gov.

SECTION 2

Monitoring the Health of Mother and Child

Your healthcare providers will keep a close eye on you and your baby. Your cancer doctors and pregnancy doctors will each want to see you for check-ups, treatments and tests. All this time spent in doctors' offices may be stressful, but your doctors want the same things as you — for both you and your baby to be healthy.

Tests You May Have

Ultrasounds

You'll likely have more ultrasounds than a woman with a low-risk pregnancy. Your doctor may suggest monthly ultrasounds starting at 28 weeks, to measure fetal growth. Before each chemotherapy session your healthcare providers may listen to the baby's heart rate and ask you how much he or she is moving. They may also perform an ultrasound to get a baseline understanding of fetal health and development. One upside is that you'll get to see your baby more often than most pregnant women do.





Non-Stress Tests

During a **non-stress test**, or NST, special belts are attached to your belly to measure the heart rate and movements of the fetus. This test confirms the fetus is getting enough blood and oxygen. Talk to your healthcare providers about when to start these weekly tests. If you ever feel that the baby is moving or kicking less than before, tell your obstetrician right away.

Treatment Side Effects Versus Pregnancy Symptoms

Issues that can be both symptoms of pregnancy and side effects of cancer treatment include:

- Fatigue. It's normal to feel tired while being treated for cancer, especially during pregnancy. You should rest as much as possible. If fatigue is related to anemia, or low red blood cell counts, it can help to eat more iron-rich foods or take iron supplements.
- Nausea. This could be caused by morning sickness, chemotherapy or both. Ondansetron (Zofran) is often prescribed for pregnancy-related nausea, whether the woman has cancer or not. Aprepitant (Emend) is used to treat chemotherapy-

related nausea, and is considered safe for pregnant women. Nausea can affect your appetite, so try to increase your calories between treatments to maintain a healthy weight gain. Your doctors can put you in touch with a nutritionist, who can help you achieve your pregnancy weight gain goals.

But feelings that are associated with cancer and its treatments, not pregnancy, include:

- Bone pain. This could mean breast cancer has spread to the bones, so you should tell your doctors about it right away. You may be mistaking back pain or sore joints for bone pain, but it's still important to tell your doctor.
- Low white blood cell counts. This is a possible chemotherapy side effect you're not likely to feel, but it may show up on tests and can make infections more likely. You may be able to take medicines such as filgrastim (Neupogen) or **pegfilgrastim** (Neulasta). Women with cancer who aren't pregnant of-

Your doctors can put you in touch with a nutritionist, who can help you achieve your pregnancy weight gain goals.





ten get these medicines to prev-ent infection, whether they are likely to have low white blood cell counts or not. In pregnant women, doctors may wait to give medicine until tests show low white blood cell counts. Then it may be given before each chemotherapy treatment. If you have any signs of infection, including fever, chills, rash or sore throat, tell your doctor right away.

One chemotherapy symptom unique to pregnant women is **contractions**, the tightening of muscles in your belly that happens before and during birth.

- Pregnant women often feel contractions during or right after chemotherapy. This is more likely to happen if you aren't drinking enough water.
- If you feel contractions after chemotherapy, tell your providers. Sometimes, the treatment is as simple as helping you stay hydrated. But sometimes contractions are associated with early labor, so it's important to tell your doctor.
- If you experience five or more contractions in an hour, and drinking water doesn't help, call your obstetrician right away.

SECTION 3

Your Emotions

Both pregnancy and breast cancer can be stressful. When combined, that stress can feel unbearable. No matter when in pregnancy it happens, a breast cancer diagnosis is likely to bring out strong emotions.

Enjoy the happy moments of your pregnancy. You may lose your hair or feel you don't look your best. But try not to hide from life, or from cameras. Later, you may wish you stopped to enjoy your pregnancy more and that you had documented that enjoyment.

You may feel isolated from or resentful of cancer-free pregnant women and women with breast cancer who aren't pregnant. If being around these people causes stress, it's OK to limit your time with them.

Reading about women like you who gave birth to healthy children may make you feel less alone and more hopeful. But you may also find stories or statistics online that discourage you. Know when to step away from the computer.



If you experience depression during or after your pregnancy, don't be embarrassed. Talk to your doctors. They can refer you to a therapist and talk to you about the safety of antidepressant medicines while pregnant or breastfeeding. For more information about depression after childbirth, visit postpartumprogress.org.



Ask your providers if they know of in-person or online support groups of women who had cancer while pregnant.

Create a Support System

If you are partnered, your significant other will likely experience many of the same fears and worries as you do. Let family and friends know how they can help, whether you need someone to talk to, someone to go grocery shopping or someone to watch your other children.

It's also OK to distance yourself from people who question the choices you've made or make you feel anxious about your child's future.

Your religious community or nonprofit organizations can also support you. To be matched with a woman who has also experienced breast cancer during pregnancy, contact LBBC's **Breast Cancer Helpline** at (888) 753-LBBC (5222). Hope for Two...The Pregnant with Cancer Network can also connect you to a trained volunteer who was diagnosed with breast cancer, or any type of cancer, during pregnancy, and who has delivered her child. Call (800) 743-4471 or visit hopefortwo.org.



You may find support groups helpful. Ask your providers if they know of in-person or online support groups of women who had cancer while pregnant.

De-Stress

Try to set aside time to relax, enjoy yourself and set your worries aside. With guidance from your healthcare team, choose calming activities like massage, yoga and meditation.

Share Your Experience

It may feel good to share your experience with others. You could write a blog or join an online community of other women who have had cancer during pregnancy. You may also want to reach out to your community or your local media to educate them about cancer during pregnancy.

LEARN MORE

For more information, read our *Guide to Understanding Your Emotions*, available on
LBBC.ORG.

My Story

KRISTIN found a lump in her breast when she was 17 weeks pregnant. Soon after, she was diagnosed with

hormone receptor-positive breast cancer. Two doctors told her to pick between herself and the baby, but she found information that showed she didn't have to choose. She put a healthcare team together. She had a mastectomy at 20 weeks and four rounds of chemotherapy while she was pregnant.

Many people were shocked that Kristin could have chemotherapy. Kristin's response: "When this is all done, the baby is going to be fine and so am I."



At 36 weeks, she gave birth via a planned C-section to a healthy baby girl. After a few weeks, she began another type of chemotherapy.



Kristin wasn't able to breastfeed, but she found women who produced extra breast milk and wanted to donate it. She had the milk tested for safety through a local milk bank.

Even though it might be tempting, Kristin encourages pregnant women with breast cancer not to rush to deliver.

"You want to take time to appreciate that you're growing something and you're fighting something at the same time," she says. "It's hard, and may seem impossible at times, but try to find time to enjoy your pregnancy. Do the normal things pregnant women do. You're not going to get that time back."

Research suggests children born to women with cancer develop similarly to children born to women without cancer.

SECTION 4

Beyond Birth

You may worry about how your child will grow and develop. But when therapies are chosen carefully, breast cancer and its treatments do not appear to affect a baby's development after birth.

Research suggests children born to women with cancer develop similarly to children born to women without cancer. Your child may have lower than average birth weight from a planned early delivery, but sudden early birth and poor fetal growth are not more common in pregnant women with cancer than in pregnant women without cancer.

Your Treatment After Delivery

Once you have your baby, you may have tests and treatment that weren't recommended while you were pregnant, such as:

- Certain tests for metastatic breast cancer
- Radiation therapy
- Targeted therapy
- Hormonal therapy
- Some types of chemotherapy



My Story

KATHLEEN, 29, was diagnosed with metastatic inflammatory, hormone receptor-positive breast cancer when she was 32 weeks pregnant. Like many women, Kathleen dismissed symptoms for a few months, thinking the changes in her breast were normal during pregnancy. She had one chemotherapy treatment while

a healthy baby boy at 37.5 weeks.

Since she needed to start chemotherapy again soon after the birth, doctors recommended against breastfeeding.

But her obstetrician gave her information about donor breast milk.

pregnant and then, via a natural birth, had





"I would love for more people to know about donor breast milk," Kathleen says.

She found two groups very useful — Eats on Feets and Human Milk for Human Babies. These groups allow women to post that they're in need of breast milk or they have extra breast milk to donate. Kathleen also had friends who donated milk to her. Kathleen wasn't interested in traditional, in-person support groups. But she found a support network online she says helps her feel connected to people who can relate to what she's gone through.

Kathleen extended her maternity leave by 6 weeks, but she is now back at work and raising her infant son, taking him with her to her weekly chemotherapy appointments. She says many people are surprised and impressed by what she's gone through and how she's managed to overcome it to continue to live her life.



It is important to start, or re-start, your treatment as soon as possible after you give birth. As long as you don't have an infection or too much bleeding after your delivery, you may be able to start chemotherapy within 7 days of a vaginal delivery, or within 2 weeks of a C-section. Ask your oncologist how soon to start or resume chemotherapy.

Risk of Recurrence

Little research has been done on the risk of recurrence for women who have early-stage breast cancer while pregnant. But studies suggest stage at diagnosis is the biggest factor in predicting risk of recurrence. The higher the stage at diagnosis, the higher the risk of recurrence, regardless of pregnancy.

Looking Forward

During your pregnancy and right after the birth, family and friends may be very vocal about wanting to help. Their concern may quiet down after a few months. But you may still want support. Let them know you still appreciate help.

You might be surprised to feel most emotional after you give birth, when you're able to look back on all you've been through.

Your healthcare providers may have talked to you about emotional support before you were ready to hear it. It's OK to go back to them when you're ready to talk to someone.

If you're up to it, consider helping others by letting your doctors, nonprofits and members of your community know that they can give your contact information to others dealing with cancer during pregnancy.

As long as you don't have an infection or too much bleeding after your delivery, you may be able to start chemotherapy within 7 days of a vaginal delivery, or within 2 weeks of a C-section.





Dee had a mastectomy and four rounds of chemotherapy during her pregnancy. She was induced a month early and gave birth to a healthy baby boy. After, she had another type of chemotherapy, and radiation. She is now on hormonal therapy.



Dee was given information early on about counselors and other emotional resources, but she didn't feel it was the right time to use them. Most treatment is now

behind her, but she's still working through tough emotions.

"You get into this zone of doing what you're told to do," she says. "Now that that's slowing down, I think that's when things will start hitting me, like 'what just happened this past year?'

"I have noticed that we got a ton of support in the first few months. But a lot of that has died down. I think this is the time, when things start to quiet down, that someone with cancer wants someone checking in with them and seeing how things are going."



Author Erin Rowlev

LBBC Staff

Nicole Katze, MA, editor Amy Grillo, reviewer Janine E. Guglielmino, MA, reviewer Arin Ahlum Hanson, MPH, CHES, reviewer

Special thanks to the following people and organizations for contributing their time and expertise

Elyce Cardonick, MD Shari Gelber, MD, PhD Elizabeth Ginsburg, MD Cara Kondaki, LCSW, ACSW, CBPN-IC, OSW-C Kutluk Oktay, MD, FACOG Hope for Two...The Pregnant with Cancer Network

And for sharing their personal stories, photos, or both

Dee Hinote, Tampa, Florida Roxanne Martinez, Fort Worth, Texas Simone Meade-Holt, Freeport, New York Kristin Nutter, Atlanta, Georgia

Lauren Smoke, Chicago, Illinois Jennifer Stewart, Cañon City, Colorado Kathleen Sutton, Federal Way, Washington Dawn Thurman, Bowie, Maryland

Creative Development

BECK Photography Masters Group Design GERBER+SCARPELLI PHOTOGRAPHY

This brochure 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 substitute for professional counseling or medical advice.

©2016 Living Beyond Breast Cancer, 1st Edition.

Fill out our online survey today for a chance to

win a \$25 gift card!

VISIT: surveymonkey.com/r/2016LBBC



Tell us what you think of Breast Cancer InFocus: Breast Cancer During Pregnancy.

Thank you

for helping Living Beyond Breast Cancer improve our programs and services.



With you, for you.

(855) 807-6386 LBBC.ORG

This brochure was supported by the Grant or Cooperative Agreement Number 1 U58 DP005403, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.