

# Just for Me

*Focusing on your unique experiences as a woman newly diagnosed with breast cancer*



NEWS FOR THE NEWLY DIAGNOSED

## Hair Loss: What to Expect and How to Get Through It

By Mary Alice Hartsock

If your treatment could cause you to lose your hair, you may wonder how you'll respond.

Emotions related to hair loss vary. Like women of many cultures and backgrounds, you may find that hair loss affects the way you view your body and femininity.

"Women tend to define their attractiveness by their hair," says **Linda Abrams, PhD**, a psychologist with the Council for Relationships who had breast cancer 15 years ago. The key to coping is to figure out how you can feel more in control of the process, she says.

### What to Expect

Chemotherapy kills all rapidly dividing cells, including cancer cells. Unfortunately, what makes chemotherapy so effective also harms the rapidly dividing cells in skin called hair follicles, which are responsible for hair growth. You may lose hair in the shower or notice clumps on your pillow, comb or brush. Your eyebrows, eyelashes, pubic hair and the hair on your arms, underarms and legs also may fall out.

Hair loss does not cause physical pain, but just before your hair falls out, you could experience scalp tenderness or discomfort. The process may be quick or gradual. Whether and when it happens depends on your treatments. Most people lose their hair during chemotherapy, but some experience hair thinning or changes, and some do not lose their hair at all.

Chemotherapies commonly associated with hair loss include doxorubicin (brand name: Adriamycin) and paclitaxel (brand name: Taxol). Radiation treatment causes hair loss to the treated area, and tamoxifen may cause hair thinning. Ask your doctor what to expect.

### Your Emotions

How you react to hair loss depends on your personality and life situation. You may find that hair loss reminds you of the temporary loss of your good health; you might hate losing control over your appearance, or you could simply love having hair!

"You are so used to having hair, and it's the unknown that's scary," says **Penelope Johnsen-Sincaglia**, 37, recalling her treatment at age 32. "I was scared I would look ugly or sickly and people would feel bad for me."

"I just didn't feel whole," explains **Gloria Dorsey**, 60, of Baton Rouge, Louisiana. "I felt less than a woman. Seeing myself without the hair, it was almost as if it documented the fact that I had cancer. I knew I had surgery and chemotherapy, but the loss of my hair just sealed it. It was really there."

### Taking Control

Shaving your head before your hair falls out is one way to feel in control and make the experience less traumatic, says Dr. Abrams.

Penelope dreaded losing her hair, but she used the experience to "try on" different hairstyles. The night she shaved her head, her husband cut her hair to different lengths to find her favorite.

"Finally when we got it to about an inch long, I said, 'Let's just shave it.' I looked in the mirror, and I felt ugly. But then my bulldog came up to me and gave me the biggest hug and kiss. It made me feel so much better."

"I was afraid to look in the mirror when my hairstylist shaved my head," says **Stephanie Parry**, 55, of Erie, Colorado.

"My husband was holding my hand, and when I lifted my head, he said, 'You are not going to believe who you look like.' That made me look in the mirror. I looked exactly like my 24-year-old Iraq vet son! I never, ever knew he looked like me. I can't explain it, but I think that helped me get through it."

Head shaving is not for everyone. Gloria chose not to shave her long, full hair because she wasn't sure it would fall out. "I thought I would be the exception," she says. When it did come out, she let it happen in its own time.

### Preparing for Baldness

Before losing your hair, find out your options for head coverings. "Many women choose wigs that look like their natural hairstyles to make the

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*Penelope Johnsen-Sincaglia got a hug from her dog Jax on the night she shaved her head.*



## Managing Anxiety

In our last issue of *Just for Me* and on Facebook, we asked readers to respond to the question: How do you manage anxiety? One Facebook fan wrote:

*I watched the series "Alias" on DVD. My daughter, who was 14 at the time, got into it as well. I got a lot out of watching the heroine fighting so valiantly against evil—maybe it was like me kick-boxing my cancer?*

*Also, I had two women whom I never met who were my "chemo-angels" [chemoangels.net]. They wrote me weekly, if not more often, to tell me about their lives and support me with kind words. I never wrote them even though I wanted to, but I got a lot from this showering of love through letters and small gifts.*

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Brighton, MA

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transition easier," Dr. Abrams says. If you find wigs uncomfortable, purchase caps and brightly covered scarves or go bald.

Stephanie purchased a wig that looked like her long, light hair. She also purchased a short-haired, dark wig "just for fun."

"My daughter and I instantly loved it, and I've worn it since I lost my hair," she says. "The gentleman that was helping me [in the wig store] said that this was going to be my 'chemo wig' because it was short and easy to maintain."

Penelope's wig looked like her normal hair, but she felt uncomfortable wearing it.



*Since her treatment, Gloria Dorsey worries less about her appearance.*

"I had every kind and color of scarf you could think of. I also learned to do my makeup a little differently."

If you go bald, wear sunscreen or protection outdoors, and wear a hat or wrap in cold weather.

Penelope eventually embraced baldness. "It was positive for me because it made

me see that I was beautiful, and that it wasn't my hair that made me who I was," she says.

### Coping

While Penelope quickly accepted her new appearance, it is common to feel very upset. For Gloria, losing her hair was almost as devastating as being diagnosed with cancer. She was so self-conscious that she withdrew from family and friends who wanted to support her.

"Often the negative thoughts we have are associated with words like 'never' and 'always,'" says Dr. Abrams. "You may think you will never feel attractive again. But if your doctor says your hair will come back, know that and focus on how you can feel the best you can about yourself in the meantime."

She suggests listing the things you like about your mind, body, spirit, activities and relationships. Ask a friend to help, and refer to the list for support.

### Partners and Children

Hair loss impacts everyone around you because it's a visible reminder you are coping with cancer, says Dr. Abrams.

"I didn't know how my husband would react," remembers Penelope. "Would he still be attracted to me? Would he leave me? I talked to him about these things, and he said that he loved me and we would deal with it together."

If your partner is having a hard time coping, it doesn't mean he or she isn't supportive, says Dr. Abrams. Talking to a professional can help your partner cope.

If you have children or grandchildren, base your conversations on their ages and maturity levels, she says. Be open

and honest about hair loss, and let them know they can ask questions. Pick up cues about whether helping you shop for a head covering will help the young people in your life cope.

Stephanie told her grandchildren, ages seven and three, that she would lose her hair and wear a wig while it was growing back. They were eager to help select the wig. "After my head was shaved, I went over and visited them, and I let them feel my shaved head," she says.

Getting your hair shaped when it begins to grow back could give it more style as it grows in.



### Moving Forward

Your hair could come back during your chemotherapy or within the months following treatment. Most women have about an inch of hair a month after the last chemotherapy treatment. When your hair grows back, it could be a different color or texture than before, and it may slowly adjust back to what it was before your treatment. Getting it shaped early on could give it more style as it grows in.

You may find that you see your hair in a different light after cancer treatment.

"I wear my hair in a bun now," says Gloria. "I have realized that it isn't about my appearance. It's just living life to the fullest and doing everything I can with each minute. We are not our hair," she says.

LBBC

# Finding Support in Unexpected Places

By Venita Lewis, for LBBC

**O**n March 31, 2009, I was diagnosed with stage IIA, triple-negative breast cancer. This type of breast cancer is often more aggressive than other types of breast cancer and does not respond to treatments such as hormonal therapy. I was glad to hear that chemotherapy is a good treatment for this type of cancer, but I was still very scared about going through it.

I am a 41-year-old, divorced single mother of a 14-year-old boy. We live alone in Culver City, California. I was born and raised in Chicago, Illinois, and I moved to California in July 2006 for work. My entire family and support system are in another state, and before my treatment, I had little to no support here in California.

To get the encouragement I need, I seek the support of strangers in various breast cancer support groups. I try to develop new friendships and keep the company of positive people to help me feel better and get through this difficult period in my life. New friends are a great source of support when my family can't be with me in the same city.

My handsome son, who is the light of my life, is a very strong support for me during this time. I can recall one statement he made to me while attending one of my chemotherapy treatments. He said, "Mom, we can get through this. We have each other, and besides, you are my strong and beautiful mom." I will never forget such a beautiful statement. It was then that I knew this cancer too shall pass.

When I am feeling sad and alone because I don't have anyone to drive me to and from chemotherapy treatments, I remember my son's statement. I also tune in to my spirituality so I can

keep focusing on my wellness. My focus has shifted from feeling isolated to being at total peace and living a simple, beautiful life. I have to be positive for my kid and me.

To help myself focus on getting treated for this disease, I look for other ways to take my mind off of my illness and the absence of my family. I bargain shop (because that soothes me), and I ask my friends to connect me with people they know who are going through the same thing that I am going through. I stay busy with volunteer work, and I am improving my mood through positive



*Venita's son Adrian inspires her to move forward.*

self-talk. I'm also reading a lot of books to keep my mind sharp. I take yoga classes for relaxation, and I recently began a regimen of cooking healthy foods. I make sure I have time to go out with friends for positive, uplifting events.

Since I am unable to go to work full time, I mentor young women to uplift their spirits and help them focus on the good in life. I have learned that support can come from many unexpected places. I have benefited so much from the help I have received during the course of my treatment. Life is good. **LBBC**

## 10 Good Ways to Find Breast Cancer Clinical Trials

1. Ask your healthcare provider about clinical trials when first discussing your breast cancer treatment options.
2. Request a second opinion from a doctor who conducts research studies.
3. Know your diagnosis, stage and treatment history and search [emergingmed.com](http://emergingmed.com) or call (877) 601-8601.
4. Check the National Cancer Institute database at [cancer.gov/clinicaltrials](http://cancer.gov/clinicaltrials) or call (800) 422-6237.
5. Search TrialCheck listings from the Coalition of Cancer Cooperative Groups at [cancertrialshelp.org](http://cancertrialshelp.org) or call (877) 227-8451.
6. [BreastCancerTrials.org](http://BreastCancerTrials.org) searches by medical details.
7. CenterWatch has trials sponsored by industry and government at [centerwatch.com/clinical-trials/listings](http://centerwatch.com/clinical-trials/listings).
8. Get help finding studies at [searchclinicaltrials.org](http://searchclinicaltrials.org) or call (877) 633-4376.
9. Contact breast cancer organizations, such as Living Beyond Breast Cancer, for guidance about finding clinical trials.
10. Talk with other women who participated in breast cancer treatment trials.

*Read more in LBBC's Guide to Understanding Breast Cancer Treatment Research Studies. Order your free copy at our "Marketplace" at [lbbc.org](http://lbbc.org) or call (610) 645-4567.*

When you are ready, we encourage you to call our Survivors' Helpline at (888) 753-LBBC (5222) for guidance, information and peer support. Our trained volunteers are here to listen and help you.

# Get the Facts: Triple-Negative Breast Cancer

**B**elow we share excerpts from our new brochure, *Understanding Triple-Negative Breast Cancer*, created in partnership with the **Triple Negative Breast Cancer Foundation**. The brochure covers triple-negative basics, risk factors, common treatments, research, emotions, post-treatment issues and lifestyle changes. Visit [lbcc.org](http://lbcc.org) to order your free copy.

## Three Myths About Triple-Negative Breast Cancer

**Myth:** Women with triple-negative breast cancer can have the same treatments as all other women with breast cancer.

**Fact:** Many people, and even some women who have had breast cancer, do not understand the differences between triple-negative breast cancer and breast cancers that are hormone receptor-positive or HER2 positive. Women you meet may have taken a hormonal treatment pill for five years to protect them from recurrence (a return of the cancer), or they may know someone who has. These women may not understand that this option does not exist for you. Having to explain the differences between triple-negative and other breast cancers can be frustrating, especially if you are just learning about this diagnosis yourself. On the other hand, you may actually be taking some of the same chemotherapies as women with other types of breast cancer.

**Myth:** Triple-negative breast cancer always is hard to treat.

**Fact:** Your doctor may tell you triple-negative breast cancer is harder to treat than other types of breast cancer. While many triple-negative cancers are aggressive, your doctor's prediction of how well your treatment will work depends on the tumor size and whether the cancer has traveled to the lymph nodes under your arm just as much as it does on the triple-negative status. There are some very effective treatments for triple-negative breast cancer. Your doctor will work with you to find the treatment that is right for you.

**Myth:** Only African-American women get triple-negative breast cancer.

**Fact:** Triple-negative breast cancer affects women of all races. Breast cancers in African-American women are more likely to be triple-negative than those in white women.

## Dealing with Myths

Many people do not understand triple-negative breast cancer, and having to explain it can feel overwhelming. It's likely you will spend a lot of time with women diagnosed with other types of breast cancer in doctor's offices, treatment facilities or at events. Your family and friends may have heard misleading information from the Internet or other people. These misunderstandings can happen with any breast cancer diagnosis.

Because triple-negative breast cancer can be aggressive, some people will be concerned about or feel sorry for you. They may believe falsely that you have advanced breast cancer or that triple-negative breast cancer always becomes metastatic.

Hearing negative comments is frustrating and distressing. After all, you are focused on staying strong and getting well! If people make comments like these, gently explain that chemotherapy is very effective for triple-negative breast cancer. If someone insists on saying negative things, be direct. Say, "Thank you for your concern, but you are not helping me right now."

Help your family and friends understand how to support you. They might not know what to do or how to talk with you about your diagnosis. Ask if they can help out with meals, take care of your kids or run errands. Remember, you have control over who you tell and how much detail you give. Consider giving more detail to people close to you and those who are very supportive and sharing less, or nothing, with others. Empower yourself by ignoring myths and focusing on your recovery. **LBBC**

