

"I Couldn't Stand the Thought of Losing My Hair"

Edited by Kathleen Avegno Bonie, Ph.D. and Kirsten York Harrell, Psy.D.

The Story Begins with One Woman

Life is a challenge. Each of us must walk along the path of life facing challenges -sometimes one challenge after another- working hard to maintain our balance so that we do not fall under the burden. Living with cancer includes many intense challenges. In particular, the treatment for cancer and the significant side effects can be very difficult emotionally, physically, and spiritually.

I have worked with many women with cancer since 1992 when I became the psychologist for the PALS for Life Breast Cancer Support Group at Franciscan Medical Center in Dayton, Ohio. PALS, which stands for "positive attitude, love, and support" has been truly a wonderful experience for the hundreds of women who have joined the group over the years. One of these women, Marianne, is a determined survivor of breast cancer and provided the inspiration for this booklet. She is a beautiful woman with a kind and generous heart.

Marianne's cancer treatment team recommended an aggressive approach to fight her cancer because of her youth, 33 years of age, and her type of cancer, ductal carcinoma with eight positive lymph nodes. Marianne accepted high dose chemotherapy and stem cell transplant as weapons in her battle to beat this disease and see her daughters, ages 6 and 4, grow to maturity.

Anyone familiar with this treatment knows the physical, emotional, and spiritual toll it can take on a human being. Marianne's struggle was not unique; she endured all of the common side effects, including fatigue, nausea, hair loss, anxiety and depression, to name just a few. Despite a difficult battle, those of us on her treatment team knew she would triumph, and that is exactly what she did! At the annual PALS Fund-raiser Walk on a most beautiful autumn day, Marianne's surgeon and I were striding along sharing our thoughts about the enormous amount of courage it takes for some women to devote almost a year of their lives to the treatment of cancer. We marveled at Marianne's determination and stamina and we expressed our mutual hope that she would be able to turn the corner emotionally and come through the ordeal soon. We both agreed that once her hair started to grow back she would strongly regain her feeling of health and her sense of self and that, indeed, would be a positive turning point for her. We then began to note how many other women we have seen go through a wide range of emotional experiences related to hair loss, a common treatment side effect. We concurred that so many health care providers don't realize the major effect hair loss can have on women emotionally and that this sensitive issue needs to be addressed in a delicate manner. This conversation with Marianne's surgeon stayed with me.

I couldn't stop thinking about how much I'd love for professionals to know what women go through emotionally when facing hair loss and what things they could say that would be helpful to the women, in addition to what they should avoid saying. I knew, however, that in order for my message to have real impact, it had to come from the women themselves and not just from me. I appealed first to the PALS women to write their personal experiences with hair loss. Then, I published an invitation to readers of Coping magazine, a national publication for cancer education, to share their stories with me.

I was delighted to receive 84 letters from remarkable women all over the country. These letters, usually several handwritten pages of personal disclosure, offered a glimpse of their pain, their strength, their humor and their wisdom to share with other women facing the same journey. These are women of courage, hope, trust, and compassion. Their willingness to re-experience their pain and anguish once again as they wrote their stories is remarkable. Many recalled these painful memories with the desire that other women may be able to face their own unique challenge feeling less alone, less frightened, and perhaps more open to accepting the special gift that the experience of cancer may hold for them.

My colleague, Kirsten York Harrell, Psy.D., and I then began to sift through the poignant stories and select the quotes we believed most adequately portrayed the meaning of the hair loss experience for these women. In this booklet, we share with you the stories and the words of these incredible women who struggled to meet the challenge of hair loss as a side effect of treatment for cancer. We have organized the booklet into categories based upon the content of the women's letters. It may be helpful to read the booklet all the way through or you can just read those sections that appeal to you. We also encourage you to share this booklet with your family and your health care professionals so they too may gain a better understanding of what it is like for women battling cancer to lose their hair.

I HAD NEVER THOUGHT ABOUT BEING BALD

Most women never have to think about losing their hair. We tend to assume we will always have our hair. Furthermore, our society places great emphasis on hairstyles, especially for women. In fact, many women pride themselves on their hair as being a significant part of their identity. Then, when faced with the diagnosis of cancer which can be terrifying in itself, a woman somehow has to cope with the devastating reality of losing her hair as well. This can be very frightening, even overwhelming for some women. As you read the thoughts and feelings of other women who have had to face a diagnosis of cancer followed by the loss of their hair, know that there are millions of others who have traveled this difficult road before you. You are not alone.

"Hair? Something I have always taken for granted, grumbled about, fussed over, but because I'm female, I had never thought about being bald." -Eleanor, VA

"Hair loss! Losing my hair was almost worse than hearing that I had cancer." -Mary, NY

"Losing my hair was far worse than losing my breasts because I felt I looked like I was dying when in reality I was trying so hard to stay alive." -Jewel, IA

In fact, for some women the thought of losing their hair is so terrifying that they consider forgoing treatment.

"I volunteer on a cancer hotline...and over the past 5 plus years have had maybe 10 women who have truly considered omitting any therapy that would cause them to lose their hair. Unbelievable but true!" -Louise, KS

"I found I shut the word cancer out. I was angry, devastated and scared. I said, 'I will not take any chemo!! I can't lose my hair!' -Donna, AZ

We believe that women can find strength and comfort by connecting with other women who have experienced hair loss from cancer treatment.

"Hair loss is a loss of identity, self-esteem, and an emotional roller coaster, not just something that 'will grow back.' Only someone who has had to face cancer and hair loss understands the impact emotionally of having to be reminded daily not only do you have cancer, you're branded, and the whole world will know too!" -Debbie, LA

MANY WOMEN... MANY REACTIONS

In general, women's reactions to hair loss vary greatly from finding the process appealing to feeling devastated. Although each woman's circumstance and reaction is unique, we wanted to give you an idea of some of the general patterns. This may help you feel connected with others as you face hair loss, thereby decreasing the sense of loss and emotional trauma.

For some women the hair loss was not difficult because they were more concerned with other details of their fight against cancer.

"I really wasn't that concerned about losing my hair at first. I had too much on my mind - primarily my children, to think about it." -Rollande, CT

"At first, that was not such a big concern to me. My concerns were trying to believe that I had cancer and to find out as much as I could regarding this disease as quickly as possible."
-Denise, DE

"To me, the absolute worst is the initial diagnosis - 'it's cancer, it's invasive.' After that, everything is a step in the adventure of recovery." -Marilyn, MD

For others being bald was not an unpleasant experience, it was just a part of treatment, an opportunity, and symbolic of their fight.

"I looked at being bald as part of my treatment; and if treatment was to cure me then how could I complain." -Anonymous, IA

"In fact, the idea of being bald appealed to me. I felt like this would be my socially acceptable opportunity to sport this look." -Wren, OK

"I was completely bald with the 4th cycle and I did not scream in the mirror as planned. For the first time, I saw in me a typical black woman like never before. I felt good about myself and my baldness." -Vernette, NY

"I think it almost became a badge of honor to be bald and I was kind of proud that I was holding up pretty well." -Joan, CT

There were some who reacted more strongly and felt a significant emotional response to their hair loss.

"I wasn't excited about the way I looked with a bald head and never let anyone see me without the wig or turbans - even my husband." -Jonelle, GA

"I cried a lot about it and mourned the loss of my hair long before it actually fell out."
-Joanna, OR

"I knew it would grow back, but losing one's hair for the first time is always traumatic."
-Sandy, MN

"Despite my positive and cavalier attitude, I cried." -Melodie, OH

"Then I lost my hair. For the first time, I felt depressed. For the first time, I cried."
-Marriwood, GA

"To me it is the one outward sign that distinguishes you as a cancer victim." -Margy, Idaho

"No matter how many cute hats, wigs or turbans you wear, when you look in the mirror at night, it's a depressing reminder of one's mortality." -Kathryne, IL

"The treatments were pain free, the shock of my baldness was painful! I felt like my whole body was nude - not just my head. I was embarrassed to have my husband and family see my bare skull, and responded in anger when they said 'It's OK, we understand.' My response was a counter attack i.e. 'that's easy to say when you all have hair!'" -Joann, OH

... and yet there were others who were devastated by the hair loss. It seemed to be one of the most traumatic aspects of treatment for these women.

"The humiliation of being bald and the emotional devastation it caused in my life, was as bad or worse than the physical damage the chemo inflicted." -Joanna, OR

"(Frankly, in many ways I feel that the loss of my hair was only slightly surpassed by the loss of my breast.)" -Kathy, IL

"... the grief cannot be imagined. It is just as traumatic as losing a limb, i.e., the loss of a part of yourself." -Kathryne, IL

"I felt worse losing my hair than losing my breast. I took it a lot harder." -Sandra, WI

Some women wrote about how difficult it was to prepare for the emotional impact of hair loss...

"Nothing prepared me for the devastation of losing my hair. On a scale of one to ten, for me it ranked at the top-right along side of cancer. As I heard someone else say, you can hide cancer, but you cannot hide hair loss. Hair loss is associated with cancer. I knew it would happen. What I was not prepared for was it happening." -Pat, OH

"On day 21 when I got up and still had hair, I thought, well they were wrong! On day 22 I jumped in the shower and this started what was the longest nightmlare I have ever encountered. So many people had tried to prepare me for losing my hair. But nothing prepared me for the feeling of being so ugly and hopeless when I got out of the shower on the 22nd day after my first treatment." -Bonnie, TN

"I tried hard to prepare myself for this, but it was especially difficult because only a month before I had lost both my breasts and already felt like a 'freak.' Damaged, and defective, now this was going to be one more physical sign of cancer, that everyone else would notice." - Debbie, LA

"Nothing I had ever read or talked about had prepared me for the moment. Not only did I feel sick, now I looked sick and since my hair was my best feature, I felt very ugly, embarrassed, naked, and alone."

-Dale, AL

...and others were surprised by their own reaction to the loss of hair.

"I really thought I was prepared for this to happen, and was even handling it pretty well. So my hair would fall out - they had caught the cancer early, I was going to do everything I could to fight this thing, and if that meant losing my hair, OK! It would grow back!! The important thing was being around to be a pain in the butt to my two teenagers (16 & 13), right?... Boy, was I wrong!! When it started coming out just a few strands at a time, I thought, gee, this isn't so hard... I was in the shower when great handfuls of hair came out at once. I was surprised by my reaction. I stood there and sobbed." -Roberta, IN

"I was in a word, DEVASTATED... I cried every day and night of that 3 weeks, surprised at how much it affected me." -Kathryne, IL

"For the past twenty-one months I have felt my nakedness. Nakedness, not only of a body bereft of so many parts but nakedness of heart and - maybe even soul... My bald head was separate and totally detached from my body. It screamed out and begged for the thickness and curl that once crowned my head..." -Sheila, MD

"I have to admit I was surprised, even though you know it will happen and you are prepared, there is a tiny spot occupying your mind that says maybe not me." -Margaret, NJ

A loss of self-esteem was another repercussion of hair loss. Some women really suffered a blow to their body image.

"It was grotesque to see parts of myself fall away and I wondered who was living inside this scarred shell of what was once me. I felt old and ugly and had difficulty looking at the bald-headed, skinny, cut to pieces person that stared back at me from my bathroom mirror."
-Sheila, MD

"I have gone through a bad case of the 'uglies.' I was so repulsed by what I saw in the mirror and assumed everyone else was too. I thought no man would ever look at me again." -Joanna, OR

"I absolutely hated being bald. I felt like an alien when my eyelashes and eyebrows fell out."
-Pamela, IL

"It was horrible. I felt like a freak. I had no hair, eyebrows, or eyelashes, even my pubic hair fell out. I was not ready for this at all." -Mary, KS

"Sometimes I just felt like punching my fist through the mirror in hopes I would see my old self again, with hair. It is bad enough that I have cancer and don't feel like my energetic self, but to not look like me is even harder. I found myself feeling embarrassed for my husband, especially if he introduced me to someone new. Oh how I wanted them to see the real me and not some drawn out looking bald person. On the days that I felt bad my hair loss took a toll on me, and I wanted to hide inside the house where I felt safe. On the good days I really did not care what anybody thought." -Denise, DE

"The pillow and bed were covered in hair, I jumped out of the bed and ran to the bathroom mirror. My heart was in my throat, and the tears made it hard to focus on the reflection in the mirror. I was trembling so hard I grabbed the sink to keep myself standing. I stared at a person I didn't even recognize, a person who was 98% bald. A sight I could barely look at; what would everybody else think. Bald is far from beautiful, it's ugly." -Debbie, LA

"I wore something to bed and NEVER left the bathroom without a hair covering. Also, I NEVER looked at myself bald. When taking a shower I covered the mirror with a towel, so there would be no accidental sightings. I knew that it would be depressing to me and I didn't need any help with negatives." -Anne, OH

And finally, here are a few other interesting comments that offered rather unique perspectives to the experience of losing one's hair as a result of chemotherapy.

"Yes, I did allow myself to be photographed. Why not? It's a part of my life, and my journey, I wanted to document it. I have a series of pictures showing the hair loss and regrowth process. I still get them out and look at them and have used them to help others prepare for their journey and lessen their fears." -Ginny, VA

"By the time of the third treatment I was beginning to accept, I was going to be in that percentage that would not lose their hair. Darn!! I felt disappointment and even cheated. Here I was undergoing this really stressful life experience and putting toxic drugs in my body and generally feeling awful, with no outward sign at all. " -Wren, OK

I SPENT MOST OF THE TIME HIDING

Because of the compromised self-esteem and body image, some women reacted by isolating themselves and withdrawing from others.

"I spent most of my time hiding in my apartment turning down invitations from friends and relatives since I hated the way I looked in the few available scarves I had." -Kathryne, IL

"I did avoid places where I knew people would know me. I stayed away from 2 funerals because I couldn't stand their look of pity. I knew I looked like death." -Patricia, TN

"I was bald, uncomfortable, depressed, and wouldn't go out of the house." -Anonymous, MI

I BEGAN TO FEEL LIKE LESS OF A WOMAN

The loss of hair combined with loss of breast(s) caused some women to experience a loss of their own femininity.

"...I just cried and cried and kept trying to get all the hair off of me. I felt like all my dignity and the rest of my womanhood was going away with my hair." -Kathalene, OH

"Mentally I began to feel less of a woman because I was losing my hair." -Sarah, AZ

"Having no hair was a daily struggle. Not only did I lose the hair on my head, I lost my eyelashes, eyebrows, and pubic hair, and my breast, everything I associated womanhood with." -Debbie, LA

IS THERE ANY WAY TO PREPARE FOR HAIR LOSS?

There were women who found that cutting their hair short or shaving it off before the actual loss was helpful in managing the physical discomfort, shock, lack of control, and messiness of hair loss.

"In order to exercise some control over the hair loss, I decided that 'if' was out of the question but 'when' was well within my power. I made my appointment with my hairdresser and told her that we would have some fun in the process. I first had a radical mohawk haircut and then some more bizarre looks before the final tuft fell to the floor." -Sandy, OH

"I decided right away to have my long hair cut short. I knew it would be easier to watch short strand fall out than long ones. I was right. It really helped." -Joanna, OR

"...took some really sharp scissors and cut it all off as close to my head as I could safely cut. I asked my husband to bring the Dust Buster in and dust bust me off... get all those little tiny hairs still clinging to my scalp. We had a good laugh at the time... as we have had in the telling since. After the laughter I/we had a really big, good cry." -Louise, KS

"...cut off what was left of my hair to a short crew cut. It was the best, most liberating thing that I did. I felt like I finally had some level of control whereby I didn't have to watch all my previously shoulder length hair go down the drain." -Susan, MA

"I sat in the chair and watched as she cut all my hair from my head. I FELT RELIEF! And I felt a little sad. I looked in the mirror at the familiar face with the unfamiliar hair cut. My hair was different but I was still the same person on the inside." -Marianne, PA

...one woman shared a creative and unique idea about what to do with the hair that she cut off.

"She came to my house and put my long, blonde hair into a braid and then cut it off. I then used clear nail polish and painted the thick end to keep all of the ends of the hair intact. I had intended to use velcro to create a cap with my own hair coming out of the back." -Kathy, IL

Yet, others felt that cutting their hair before the loss was not helpful and in fact was more difficult.

"I chose not to cut my hair as then I would not only have the shock of losing my hair but also the shock of a very short hair cut." -Judy, CA

"I have to honestly say that cutting off all those years of growth were more difficult than going bald." -Mary, NY

WHAT WILL IT FEEL LIKE WHEN I LOSE MY HAIR?

As the women started to experience the actual hair loss, many women talked about the issue of the messiness and inconvenience of hair falling out everywhere.

"Hair began to shed all over my sheets and pillowcases, it was as though I was sleeping in hair. Very strange." -Margaret, NJ

"Three weeks to the day after I began my first round of chemotherapy, my hair began to fall out. Pieces of me were all over my house. Little bits of hair were everywhere. On the bathroom floor. In the sink. On my pillow. In the kitchen. The shower drain was covered. Tiny wisps of what was left shot out from the back and the sides of my head and what remained was thin and dead." - Sheila, MD

As their hair began to loosen and fall out, some women felt tingling or noticed that their scalp was more sensitive.

"During this period, my scalp was extremely sensitive and I had to learn how to be gentle with myself and new methods of washing my hair and touching my head." -Sarah, AZ

"When my hair was ready to fall out my scalp started to tingle and itch." -Mary, NY

For some women, the hair loss experience was actually painful.

"When my hair started to loosen, there were times when my scalp, especially at the top front and sides, actually hurt. Sometimes it would itch like crazy and it became very, very sensitive. AND when I sneezed, did it ever hurt then!" -Ruth, PA

"When I rode bikes with my kids - the breeze hurt my hair. It really hurt when my hair came out." -Jewel, IA

"Also, there is pain involved in the hair loss. My scalp became very sensitive during the heaviest loss period. My eyelids hurt as I lost my lashes and eyebrows. Legs, underarms, pubic areas - all were sensitive during that period because you do loose hair everywhere on your body." -Melodie, OH

IT'S GONNA HAPPEN... BUT WHEN?

The timing of hair loss after chemotherapy depends upon the type of drugs received. For some, the hair loss came within 2-3 weeks of the first treatment, while for others it took months.

"Three weeks to the day after I began my first round of chemotherapy, my hair began to fall out. Pieces of me were all over my house. Little bits of hair were everywhere. On the bathroom floor. In the sink. On my pillow. In the kitchen. The shower drain was covered." -Sheila, MD

"I began to lose my hair exactly two weeks after my first chemotherapy treatment."
-Mariwood, GA

"Still, I was a good two months into chemo before the hair loss really hit me. My doctors were amazed that my hair hung in there as long as it did." -Melodie, OH

"My actual hair loss began within 2 weeks." -Sarah, AZ

EACH TIME I LOST MY HAIR WAS VERY EMOTIONAL

Those women who unfortunately experienced hair loss more than once described their reactions.

"I've been through hair loss 3 times in the course of my treatment with different reactions each time. The first time I thought I was fully prepared. I knew I'd lose my hair, my doctor said it would happen 3 weeks after my 1st treatment and I had a wig bought, styled and at home ready and waiting. Still, I was devastated. Analyzing this later, I think I know what contributed to this. First, although I thought I was prepared no one told me how quick it would be from first signs of hair loss to total baldness. It was a matter of 2 or 3 days. Second, this was the second assault on my femininity. First the loss of my breast and then the loss of my hair. Third, it made me fully face the seriousness of my illness. My second and third times of hair loss were much easier. Although I wore wigs with my first hair loss I did not the next 2 times. -Ruth, NJ

"I have not found an easy way to lose my hair. Each time was very emotional. The good news is that the hair grows back beautifully." -Mary, NY

WIGS... A BLESSING OR A CURSE?

Wigs...a blessing or a curse? The reactions to wigs varied quite a bit. The wigs were either greatly appreciated as a fun opportunity, a self-esteem booster, and a kind of protection...

"Try to have fun with it. Try on blonde, brunette, and red-headed wigs. Short hair, long hair, curly, straight. It's the chance of a lifetime." -Ellen, FL

"I immediately bought two wigs... I do not have much money, but the wigs were important to me - for one thing the head gets very cool to cold without covering. To my surprise scarves and hats were often less comfortable." -Nancy, CA

"I chose to wear the wig throughout my treatment. I didn't want people to see me as sick or feel sorry for me. I didn't want to see myself as sick. In some ways it was a mask, a kind of protection." -Daphne, CA

"I highly recommend that if a woman wants to, that she find a reputable wig shop and get fitted with a wig that will help her feel more like herself. It is well worth the money to buy a wig that looks and feels good." -Joanna, OR

...or the wigs were viewed as uncomfortable, humiliating, and fake.

"The wig really was not me. It still was fake and so I felt fake. I finally said to myself, stop trying to please everybody else and wear what you feel comfortable in." -Denise, DE

"I remember going to try on wigs as one of the most humiliating experiences of my life."
-Rollande, CT

For those women who choose to purchase a wig during this time, here are some helpful tips from other women...

"...a hair-loss clinic, and the folks there showed me how to claim my wig as a 'hair prosthesis.' My insurance paid for it!" -Melodie, OH "My good friend... accompanied me on this wig shopping trip and that made the event much more pleasant and less stressful. Bringing along a support person is definitely a plus." -Marilyn, MD

WHAT ARE MY OPTIONS?

For those women who are not comfortable with wigs (or just like to take a break from their wig), there are many other options such as scarves, hats, and turbans. Many women were grateful for these options.

"I wore the wig the rest of the day and that's the only time I ever wore it. From that day on, for a number of months, I lived in one of my four different turbans. I ate, went out, slept, and all but showered in those turbans." -Kathy, IL

"It took only once to figure out, the wig was not for me. So the kids and I went to a local store and they picked out the most beautiful, colorful bandanas they could find." -Margy, ID

"I wore the wig a couple of times but felt I was trying to hide myself and my condition from the world. I chose instead to wear the hats and hold my head up high." -Judy, CA

...some even thought that matching the head coverings with their outfits was fun.

"The scarves were fun to find and plan coordination with my casual clothes." -Laura, TX "I bought several hats and turbans to match my outfits." -Jenny, CO

AU NATUREL

Still other women disliked any of the optional head coverings and preferred to go au naturel.

"I had lovely wigs, but I preferred to go bare. It was more fashionable." -Vernette, NY

"The bandannas felt funny on my head and the wig was just to wear to work. I was so glad when I could just take both off in the privacy of my own home." -April, PA

"I even shaved my head with a razor to make it slick and bought large earrings." -Jenny, CO

A SUPPORT SYSTEM CAN MAKE A DIFFERENCE

The support from friends and family played a significant role in helping women get through the difficult times associated with hair loss.

"Later, in mid august, my eyebrows and eyelashes fell out and that was the toughest time for me. At this period I felt so ugly and low that I asked my husband for extra hugs." -Joan, CT

"...I thought losing my hair would be devastating, but it wasn't. My caring family, friends, and support group made all the difference." -Sue, CA

"Support of family and friends and a strong faith kept me going through those months of treatment." -Ginny, VA

THERE'S EVEN A TIME AND PLACE FOR HUMOR

Humor also helped many women through the hair loss experience. Humor was a very important coping skill that provided great relief from the gravity of the cancer diagnosis, treatment, and side effects.

"I guess one of the most important things I did during my state of baldness was to laugh at myself. I wouldn't have wanted anyone else to laugh at me, but laughing at myself in the privacy of my home was a good thing..." -Ruth, PA

"One of my wigs caused an itchy rash on my scalp. After trying various creams to no avail, someone suggested using a handkerchief. Not being handy with sewing I would just place a small white handkerchief on my head and cover with the wig. It seemed to be working quite well until one day someone who had no idea I was wearing a wig said to me, 'I don't understand but there is a piece of white material sticking out from under your hair on your forehead' - How embarrassing!" -Ruth, NJ

"Another good thing was when I could joke about it and tell my kids that if they didn't do good on their report cards I would go to school and write on my bald head, 'Ian and Derek's Mom' and walk through the school." -Kathalene, OH

"In my doctor's office is a poster that says 'I'm having a NO hair day!'" -Ellen, FL

"My 16-year-old daughter was in the living room while we shaved my head and made it look like a 'Mohawk.' I danced around the kitchen laughing at myself..." -Mary, NY

"I sang with the choir at an outdoor sunrise service I watched the wind take bits of my hair away. At first I was shocked, then I started to chuckle. But I thought, why not laugh - it's just hair, and I'm still alive!" -Ginny, VA

"We had a wonderful evening. It ended with my taking off the wig so [my daughter] could see me with a naked head. We laughed so hard we were in tears. It was a very special moment of love, joy and pain." -Daphne, CA

"It provided humor! While hanging Christmas lights on the trees out front the wig snagged on branches. Was I hanging wigs or lights?" -Daphne, CA "Oh, well, hair today, gone tomorrow!" -Daphne, CA

"As saying goes... 'it's always something.' That became my motto and humor got me through most days." -Sarah, AZ

"My family, friends, and I make jokes about my bald head and really find that having a sense of humor makes things so much easier." -Rollande, CT

"My wig took on a personality of her own; I named her Myrna. Occasionally, Myrna would have a 'bad hair day,' but certainly less frequently than my own hair! I didn't mind putting her on every day. Incorporating humor into the situation helped alleviate the trauma of losing my hair." -Susan, MA

NOW I'M USED TO IT AND I THINK I'M KINDA CUTE!

Despite the difficulties, including the emotional and physical pain, many women experienced a remarkable shift in their attitudes about hair loss. They found themselves moving toward acceptance, recognizing that the hair loss was only a temporary blow in the battle against cancer.

"One night I got up to go to the bathroom in the middle of the night. I saw my reflection in the mirror. I gasped. I remember thinking I was the ugliest person in the whole world. I just about scared myself. I had those times in the beginning once in a while. Now, I'm used to it and think I'm kind of cute!" -Rollande, CT

"As the days following surgery gradually went by, I began to realize that losing my hair was only a small price to pay considering the lethal effects of my aggressive tumor if untreated. I told myself that it was better to lose my hair through treatment if this is what's going to get me better, than to die sooner with a full head of beautiful hair." -Vernette, NY

"I hated my bald head and wore a turban to sleep. In the morning, I'd close my eyes while I took off the turban and donned the wig. I did this so it wouldn't ruin my day. As the weeks went on I began to accept it and felt that it wouldn't last forever." -Donna, AZ

"Yes, hair loss is difficult and upsetting. But it is a small and temporary price to pay for a chance to regain your health." -Ruth, NJ

"Through all of this I learned that we are such vain creatures. It amazed me that I felt my hair was more important than my life!" -Mary M., NY

"Being alive and surviving the cancer outweighs the baldness." -Mary R., NY

"But I'm a survivor. My hair loss was a temporary thing." -Jhynelda, TX

"I knew my hair had to go if I wanted to live." -Clara, OH

"Once I accepted the loss of my hair, something strange happened. My bald head became a symbol of my survival and badge of courage." -Pat, OH

I AM NOT MY HAIR!

Once they accepted the hair loss, something amazing happened... the women gained incredible insight about themselves. Remember the devastated self-esteem? Well, with some time and healing, many women began to recognize that the loss of hair really did not alter their core self. They came to realize that they were strong, powerful, and beautiful women despite their baldness.

"The most important thing I learned through this experience is that my body is not me. This shell can be altered by chemotherapy, radiation and surgery, but what's really me doesn't change. If my cancer returns and I have to do it all again - I'd do it in a heartbeat, it's just hair - and I want to live." -Ginny, VA

"I found out that 'I am not my hair!' That was a revelation. In the months ahead the gradual nakedness - a body without hair - became a gift. I could see that the chemotherapy was working. The nakedness revealed my vulnerability. Seeing and feeling that vulnerability opened doors for personal growth beyond imagination." -Daphne, CA

"I have learned so much through my hair loss. I now know that people like me for me and not because I'm pretty. What a wonderful freedom has come with that lesson... I'm so grateful for the hair loss. Isn't that strange?" -Becky, OH

"I know everyone around me loves me with or without hair for who and what I am. And I... love myself too, which is the most important part of surviving cancer, chemo, and hair loss. So... hair loss is nothing. Survival is what it is all about. Believing in yourself, and your God, and loving both! Hair loss doesn't change who or what you are, never has, never will." -Teri, WI

"During my initial hair loss period when I let no one see me I found a picture of myself when I was 7 mos. Old. I looked exactly the same. It was the most wonderful experience for me. My head was slightly misshaped and my ears stuck out which I never knew, but I looked the same as I had at 7 mos. It was great to know I was still me." -Bonnie, FL

WISDOM GLEANED FROM A DIFFICULT EXPERIENCE

In addition to the powerful lessons regarding sense of self, many women had other wonderful realizations. The wisdom these women gleaned from the difficult experiences associated with cancer treatment is truly inspirational.

"Losing my hair, the most feared side effect of my cancer treatment, turned out to be a gift. A special vulnerability was awakened with my baldness and I was reminded of our bodies amazing healing powers." -Daphne, CA

"Though we learn many things as we travel through life, living with cancer, ultimately becomes our greatest teacher. Cancer has opened many new doors for me. I have learned that the 'maybes' and 'what ifs' of life are in themselves malignant and so I have discarded them and given up second guessing. Cancer has taught me to accept what is in the moment and to know what is truly important. I have learned how to say no and to avoid what is unpleasant and I have found that there is extraordinary meaning to even the simplest act. Cancer has made memories more vivid and precious. I have learned to appreciate every moment of the day and have discovered that to wake up each morning is a miracle and a cause to celebrate. I am a stronger and wiser woman and have become acquainted with an inner peace that I had never known before and with peace, I believe will come healing. There is life after cancer." -Sheila, MD

"The most important thing I learned from hair loss - and, indeed, from the experience of having cancer - is to accept the situation... Each day of life is a beautiful blessing and focusing on the more important things helps, like one's faith in god, the love of friends and family, the beauty of creation, etc." -Joan, CT

"I often have to remind myself that the situation (hair loss) is only temporary. Being open and honest and able to joke about it was good, too. But being realistic is important - there will be days when you will feel frustrated, unattractive, envious of every full head of hair you see, and frantic for you hair to grow back. I'll never take hair for granted again." -Joan, CT

"That made me think about how I had never seen how much I loved other people and how much they loved me until I had no hair. In a way losing my hair was like pulling off a mask. I can see what is really important now, to love and be loved." -Dale, AL

"The most important thing I learned and want to share with others: THIS TOO SHALL PASS. It's just another one of life's experiences or journeys. It was a humbling experience, but humbling experiences can be good for your faith journey. Losing your hair and a breast still leaves a person whole enough to be valuable to God, her family and others." -Anne, OH

BEING BALD HAS ITS ADVANTAGES...

Yes... believe it or not, there were some women who were even able to identify benefits or gifts from the hair loss and baldness.

"This hair loss isn't bad at all, it made me rediscover myself and I like myself." -Marlene, MO

"Being bald has its advantages. Getting ready for work in the morning is simplified, shampoo lasts a long time and you can't have a bad hair day!" -Ginny, VA

"It takes a LOT less time to shower and get ready to go someplace; you can save a bundle on shampoo and conditioner; no hair cuts, perms, or color appointments to take time away from your busy schedule or to be paid for; and (this is the BEST!!), you don't have to shave your legs for months!!" -Roberta, IN

"Being bald had an advantage too. I saved money on haircuts, perms, shampoo, etc. and could be showered and ready to go out the door in record time." -Debra, MD

"Chemo gave me a chance to have short hair which I probably wouldn't have done myself."
-Anonymous, IA

I LIKE MY NEW HAIR

After all the shock, trauma, and acceptance, finally there is new growth. Most of the women found the new hair to be different from their hair prior to treatment, and they enjoyed the new look.

"After chemotherapy, my hair came back thicker and with a different texture and color. I loved it." -Mariwood, GA

"It's thicker, curlier and the same color as before. What a wonderful indication of our bodies amazing power to heal itself!" -Daphne, CA

"I like my new hair. It's hair I never knew I had before. It's curly, soft, and silky like a baby."
-Vernette, NY

THE MOST HELPFUL REACTIONS FROM PEOPLE WERE...

The reactions and comments from others play a significant role in how the women themselves handle their hair loss. We asked the women to write about reactions from others that were helpful. In general they indicated that supportive, reassuring comments from loved ones really helped boost their damaged self-esteem.

"My mom said I was still her beautiful daughter. My husband, son, brothers, sisters, cousins, friends had all positive things to say including that my head was nice and round shaped." -
Marlene, MO

"It has been helpful to have people compliment me on my wig, or tell me I look nice in my hats."
-Joan, CT

"My husband was so great about my hair loss. My husband has always made me feel loved and accepted, hair or no hair - one breast or two." -Ginny, VA

"My hairdresser was extremely helpful and reassuring when it came time to buy a wig. She and I looked through the wig catalog and she helped me with the style that would look best on me. She reassured me that my hair would come back and that she had several customers who had lost their hair two or three times and it always came back (and sometimes even curlier and a different color)." -Sandy, MN

"I've joined a cancer support group where people have helped and encouraged me, and I can help and encourage others." -Melodie, OH

"The most helpful reactions from people were honest and sincere reactions." -Candice, IL

"I received a lot of hugs and 'my, you look good's.' As my confidence soared life began to look brighter and happier for me." -Sarah, AZ

"Family and friends reacted well to my baldness and even when I try to keep it covered to avoid the expression of shock from them, I was discouraged to do so. In fact, my head attracted kisses and caresses from my siblings instead." -Vernette, NY

"... my husband, had his head shaved too! It was a great sign of support for me and I really did appreciate it." -Jenny, CO

"It really helped when people told me how great I looked, when I was bald, wearing hats, etc. or beginning to get my hair back." -Jenny, CO

"I was sitting on the bed crying. She sat down beside me, and put her arms around me I laid my head on her shoulder I sobbed uncontrollably, Becky ran her hand over my head, and started to cry. I knew at that moment this was the one person who understood how difficult this was for me, and the one person who I would always find comfort in. When she touched my head, she said without words, I love you, I care, and I'm not afraid, hair or no hair we are in this together. And during the course of the treatment she taught me what true friendship was. The good, the bad, and the ugly." -Debbie, LA

"...my brother-in-law hugged me and said, 'Teri, hair or no hair, wig or no wig, you're still a beautiful person.' And that... is what really, truly matters! (I cried)." -Teri, WI

"My husband was my greatest source of encouragement. He told me everyday how pretty I was to him and how much he loved me and that he wasn't in love with my hair which gave me enough confidence to keep going." -Dale, AL

"The most helpful reaction came from my husband. He looked at my nervous, embarrassed, awkward self and said, 'I think you look sexy!' His reaction truly was the one which mattered to me most. I no longer felt embarrassed or awkward - we laughed together." -Mimi, CA

"My husband constantly tells me I look beautiful and my children say I look just fine, cute, younger... They have made it quite easy to be a bald person at home!" -Marilyn, MD

THERE WERE HURTFUL REACTIONS TOO

We also asked the women to write about the comments and reactions that were painful. It is important for friends, family, and health care professionals to realize that their comments can be unintentionally hurtful. They need to be as sensitive as they possibly can during this difficult time. Sometimes it is not even the words, but the actions of loved ones that can be upsetting.

"...some would not even look at me and that tore me up inside. It tore my heart out to think that I made people feel that uncomfortable." -Kathalene, OH "At times when I didn't feel closeness with my husband and he did not touch me, my insecurities would surface. I'd think he is turned off by my baldness." -Pat, OH

"My husband is incredibly loving and supportive... However, hair loss was a very emotional issue for him. He asked that I not allow him to see my head without a covering. I honored his request because I knew it was painful for him. I did not tell him at the time, but this felt like a personal rejection. I only removed my wig or turban in a closed bathroom and had a vague uneasy feeling as if I had done something wrong and needed to hide my indiscretion. I had to continually remind myself that it was the disease he was rejecting not me." -Kay, VA

"The most hurtful comment I received, was, 'you might as well not cry, you knew you would lose your hair.'" -Lancie, OH

"I had so many people tell me that I shouldn't even worry about my hair loss. Big mistake."
-Joanna, OR

"The first time I went there wearing a turban one of the teachers said 'oh wait, Ro, don't come in yet.' The next thing I heard was 'Quick kids everyone get in the other room.' They quickly got the other kids into the back room and then told me I could come in! It took all that I had not to cry. I don't know if they were trying to protect me from the stares of the kids or protect the kids from being scared of me. That was the worst experience with hair loss that I had. They made me feel like a freak and it really hurt." -Rollande, CT

"Anytime I'd mention being without hair, I'd get a lecture from Mom. I should get on my knees and thank God to be alive. I was thankful to be alive, but couldn't I have hair too?" -Eileen, PA

"One thing I found troublesome was although everyone knew I was wearing a wig, no one made any comment, either positive or negative. In my sensitive mind, I took silence as negative. I thought, it must look terribly unnatural and fake. I must look awful!" -Joanna, OR

INFORMATION FOR MEDICAL PROFESSIONALS

For medical professionals who work with women cancer patients, this section is important for you to read. Your attitude and words play an important part in this process. Some women have described what was helpful and hurtful from their medical team.

"The nurses were incredibly kind. One nurse said (when she came in and I had taken my wig off) 'but you really look nice without your hair.' She was so genuine that I relaxed a little after that about always 'needing' my wig. My surgeon was one of my favorite sources of comfort. He managed to encourage me, laugh with me, give me information - just by being a fine doctor."
-Jewel, IA

"The doctor overseeing the treatments explained the procedures, but he said very little about hair loss. 'You'll probably lose your hair,' he told me, 'because about 70 percent of patients do.' And that was that... he said each patient is different. We had no conversation about how I might feel when the time came." -Mariwood, GA

"One thing I admire about my oncologist is his total honesty and compassion." -Pamela, IL

"Years ago I used to be an oncology nurse and I used to tell people - don't worry your hair will grow back. Easy words to say but much more complex to deal with." -Rollande, CT

"I've had great compassion, understanding, care and communication from them. They've let me be a major part of all the decisions and treatments so far. Both my surgeon... and my oncologist... have not only asked how I have been doing, but how my husband and daughter are doing through all of this. That truly has touched my heart!" -Teri, WI

...some even offered advice for ways medical professionals can be more helpful and supportive to women who suffer hair loss from chemotherapy.

"I believe doctors can help their patients deal with the trauma of sudden hair loss by talking about it early on." -Mariwood, GA

"If there is one thing I could say to all Oncologists is: Listen and answer ALL questions honestly!"
-Pamela, IL

"This whole experience is hard on the survivors and their spouses. Maybe that's something the medical community needs to be more aware of -- how to 'treat' the emotional side of this whole diagnosis/treatment/recovery for the individual and their spouses/family." -Jenny, CO

SUGGESTIONS FOR FAMILY AND FRIENDS

For family and friends of a woman cancer patient... here are some tips so that you can lend the support that is so crucial during this difficult time in treatment.

"...I needed to hear the words 'You are beautiful with or without your hair and I love you if you never grow any.'" -Pat, OH

"We as patients know our hair will grow back. That is beside the point (although are you aware of how many years it will take for me to replace long hair?). What we are concerned about is how will we look in the meantime? Our hair gives us identity, makes us feel feminine and beautiful." -Joanna, OR

"If I could give any husbands advice it would be to hold your wife tight and tell her 'You are beautiful to me.'" -Patricia, TN

"Don't ever downplay to a patient how important or unimportant her hair loss is. Some women actually do not mind as much. They have other things they are more concerned about. If a patient is telling you how devastated she is or how ugly she feels, all she wants from you is a listening ear, a warm hug and when appropriate, throughout her treatment, remind her how beautiful she really is." -Joanna, OR

ADVICE TO WOMEN NEWLY DIAGNOSED

And now some specific advice to those of you who are newly diagnosed with cancer and are about to face hair loss from chemotherapy or radiation...

"...this is not the end of the world, although at times it feels like it. You are facing perhaps the toughest battle of your life. Don't forget to love, pamper and take care of yourself. Assert yourself. Let your needs (emotional and physical) be known. Surround yourself with those who love you. And remember, this battle can be won." -Joanna, OR

"I believe the most important things I have learned and want to share are: 1. LAUGH! It's amazing how a good sense of humor can get you through a horrible time... 2. HAIR LOSS IS TEMPORARY! I was truly surprised how quickly my eyebrows grew back (within 3 weeks of final chemo treatment). My eyelashes came back slowly and will probably never be as thick as before

(small price to pay!)... 3. GOOD RELATIONSHIP WITH ONCOLOGIST! My doctor is NEVER too busy to speak to me. He is extremely patient and will answer ALL my questions without ever making me feel rushed! 4. BUY LOTS OF CUTE HATS! Your wig will drive you crazy after a while. 5. Most important - TRY TO KEEP A POSITIVE ATTITUDE!" -Pamela, IL

"My best advise for other woman who will lose their hair is to take care of yourself first. Do whatever you have to do to have good health. There is life after cancer, and your hair will come back in time. Be strong and cry when you need to, tears really help." -Mary, KS

"Believe in your treatment and, remember, you hair loss is only a small price to pay."
-Vernette, NY

"My advice to anyone facing this type of treatment is to take one day at a time." -Carol, OH

PRACTICAL SUGGESTIONS

Also, some women offered important practical suggestions for women going through hair loss.

"At night I would wear a stocking hat to bed to keep my head warm. That sure did the trick." -
Sandy, MN

"My head would get cold at night, so I bought a baby blanket and had the women who made some of my hats make me a night turban. This was great and I would recommend it for anyone who loses hair. It was soft and warm and helped me sleep." -Jenny, CO

"At the time, I struggled with the perplexing dilemma of whether to use soap or shampoo. It was easy to dismiss any type of conditioner. If soap was the designated choice, should it be deodorant soap, or facial soap, a moisturizing soap, or a bacteria-killing soap." -Ann, IL

"I was lucky enough to have purchased a longish nightie (with a hood). I lived in that thing at night all winter. Just pulled the hood up and slept very comfortably." -Louise, KS

A TRIBUTE TO LIFE

As you can see by the words of these women, dealing with total hair loss from cancer treatment is quite a challenge. But, with inner strength and healing even this challenge can be conquered with dignity.

It is our hope that by getting to know these women through their own words you are encouraged on your own journey. Recognizing the courage, the pain, and the wisdom of these women who walked before you on a similar path might provide a sense of comfort and support.

While some of them stumbled at times, all of them suggest that we must walk on and not let the unknown or the difficult times cause us to falter on our way. It is by coping with life's difficulties that we strengthen ourselves and gain greater confidence and self-assurance.

These 84 incredible women demonstrate that it is not what happens to us in life, but rather how we handle it that really matters. They speak of embracing life... life with all the unknowns and all the challenges. And all the while, continuing to care and to love.

ACKNOWLEDGEMENTS

We would like to express our deepest appreciation to the 84 courageous women who contributed to this booklet. Without their inspiring heartfelt words this booklet would not exist. We greatly admire their strength and their passion for life. We also extend our special thanks to Marianne for sharing her incredible journey that was the inspiration for this project.

- Ruth A. Burke -- York, PA
- Ruth Wolf -- Emerson, NJ
- Kathalene Howard -- Vandalia, OH
- Sandy Archer -- Dayton, OH
- Pat Barone -- Dayton, OH
- Ellen Currau -- Orlando, FL
- Debra Clark Grissom -- Franklin, TN
- Mary Marvin -- Lockport, NY
- Bonnie Butts -- Shelbyville, TN
- Marlene Leddick -- Kansas City, MO
- Ethel Austin -- Ft. Pierce, FL
- Sheila Sloane Dusseau -- N. Bethesda, MD
- MaryKay Maloney -- Matthews, NC
- Mary Ruoff -- Pennellville, NY
- Jhynelda Hahn -- Odessa, TX
- Clara M. Botson -- Killbuck, OH
- Nancy K. Chandler -- Wilmington, CA
- Laura A. Cross, MSN -- McAllen, TX
- Jewel Henderson -- Pella, IA
- Jonelle Jett -- Monroe, GA
- Kay Hale -- Clintwood, VA
- Joan Dunning Smith -- Ridgefield, CT
- Ginny Mason -- Grottoes, VA
- Mariwood Harden -- Peachtree City, GA
- Lancia Spragg -- Adena, OH
- Daphne Schaffer -- Sacramento, CA
- Wren Stratton -- Muskogee, OK
- Joanna Berg -- Gresham, OR
- Margaret Holland -- Lafayette, NJ
- Patricia Reagan -- Maryville, TN
- Pamela Sullivan -- Berwyn, IL
- Sherry Collins -- (910)
- Sandy Ludford -- Blaine, MN
- Mary J. Higgins -- Lawrence, KS
- Melodie Wineland -- Mansfield, OH
- Roberta Duncan -- Richmond, IN
- Candice Zito-Gilhooly -- Wauconda, IL
- Sarah Fox -- Chandler, AZ
- Sue D. Muller -- Sonoma, CA
- Robin M. Stevenson -- Baltimore, MD
- Rollande Barganier -- Newington, CT
- Denise Johnson -- Wilmington, DE
- Lois O'Harra Lund -- Phoenix, AZ
- Kathy Chaberlin -- Westchester, IL
- Vernetta James -- Brooklyn, NY
- Jenny M. Yeck -- Loveland, CO
- Eileen M. Morgan -- Palmerton, PA
- Louise Barnow -- Overland Park, KS
- Margy Kane -- Boise, ID
- Donna Jenkins -- Scottsdale, AZ
- Jane C. Moore -- Lebanon, NJ
- Pat Langenberg -- Marshalltown, IA
- Susan R. Thomson -- Brookline, MA
- Kathryn V. Suess -- Chicago, IL
- Ann Adrian -- Richmond, IL
- Anonymous -- IA
- Anonymous -- MI
- Debbe Legano -- Bossier City, LA
- Evangeline Miller -- Sheridan, KY (?) 82801
- Becky Hoak -- New Vienna, OH
- Ruth A. Burke -- York, PA
- Patricia McBroom Clayton -- Kittrell, NC
- Debra L. Getson -- Cresaptown, MD
- Teri E. Mageras -- New Berlin, WI
- Carol A. Patterson -- Sterling, OH
- Dale Cox -- Alabaster, AL
- Sandra Honey -- Kenosha, WI
- Mary Duzan -- Oakland, IL
- Bonnie Brooks, M.Ed., Sarasota, FL
- Betty R. Lach -- West Allis, WI
- Mimi Deeths -- Bakersfield, CA
- Marilyn Goldhammer -- Rockville, MD
- Sandra La Porte -- La Grange, IL
- Eleanor Laughlin -- Arlington, VA
- April Reitnauer -- Fleetwood, PA
- Eleanor Filewod -- Brockville, Ontario
- Joyce Shon -- Berkeley, CA
- Joann Callander -- Dayton, OH
- Judy Snijdewind -- Mission Viejo, CA
- Marianne J. Abromitis -- Selinsgrove, PA
- Debra A. Allen -- Brookfield, WI
- Anne T. Pickenpaugh -- Belle Valley, OH
- Estell L. Knight -- Jacksonville, FL
- Margaret P. Barnhart -- Green Valley, AZ