

LOSS & GRIEF UNCOVERED

What it meant to lose my hair after chemotherapy

By Doris Zagdanski

I couldn't think of what to do so I sent this text to my family: *'My hair has started to fall out. I'm at work in a meeting, so I can't even cry.'*

In November 2012, I was diagnosed with breast cancer. Two weeks later, I'd had a lumpectomy which removed two tumours, dozens of pathology tests and a recommendation by my surgeon that I would need radiation therapy to target any stray cancer cells. I thanked my lucky stars that I'd gotten off so lightly.

But at my post operative check up, the diagnosis had changed. The tumours were much larger than anticipated. I needed to begin a treatment of chemotherapy and radiation.

I was shocked with this news – How could this be happening to me – I'm so fit and well and look a picture of good health – on the outside.

Next I was off to the oncologist – he would be my chemotherapy doctor. A very personable man, he explained I would need to go back to hospital to have a 'portacath' inserted in my chest which would deliver the chemo to my body. I'd be having a third generation chemotherapy known as FEC, followed by something called Taxotere. In plain English, it meant 18 weeks of chemotherapy, a short rest, then 6 weeks of radiation followed by 5 years of hormone therapy. One by one he explained the side effects – tiredness, nausea, vomiting, skin changes, risk of infection, constipation and hair loss. I'd already read up on chemotherapy and radiation and everything I read said the good news is that hair loss was only a possible side effect and didn't necessarily happen to all chemo patients.

So when it came to question time the first question I asked was, 'what percentage of patients actually lose their hair?'. Gently, but very assertively, the oncologist explained that there were many things he could not guarantee about my health but he knew one thing for sure - all patients taking this particular type of chemo will lose their hair – I would lose not just the hair on my head but eyebrows, eyelashes, all body hair.

I know I left his office in shock, too shocked to even cry. And so began one of the biggest challenges for me in having cancer – I think I was okay about the cancer but I know I wasn't okay about losing my hair.

So what did hair loss mean to me?

- Loss of my identity - I am a professional career woman, not a bald cancer patient
- Loss of my appearance – I have always been fastidious about my grooming.
- Loss of my familiar face - no eyebrows and eyelashes meant no 'face' – I would look blank.
- Loss of privacy – once you go out with a turban on your head it screams 'I've got cancer, I've got no hair'.
- Loss of control – there was nothing I could do about this.

Once the treatment started there were new losses because of what chemo was now doing to my body and my lifestyle:

- Loss of energy
- Loss of job role – I've had to modify my work schedule
- Loss of taste and appetite
- Loss of daily routine – working, morning walks, housework all needed to change
- Loss of memory – nicknamed 'chemo brain'

- Loss of simple pleasures – my morning skinny flat white coffee, my after work glass of wine
- Loss of surety and security

There is a principle about loss – *losses rarely exist alone* and we need to understand that the principle loss in our lives usually triggers many more associated losses.

So why tell this story? It's a story of loss and grief. But in our society, we often reserve the word 'grief' for people coping with the death of a loved one. In reality though, if we look around us, people every day, everywhere, are coping with grief – grief over the loss of someone or something significant in their lives that has been taken from them. Losses like:

- Separation/divorce
- Loss of job/income
- Loss of good health
- Relationship/friendship breakdown
- Loss of home and possessions through natural disasters
- Infertility, disability, loss of body part or function
- Loss of hopes, plans, dreams
- Ageing – loss of mobility, independence, senses, choices ... it's a long list.

The grief that results from loss is real, painful and legitimate. Shock, despair, anger, frustration, fear, guilt, loneliness, sadness, resentment, preoccupied thoughts, issues with sleeping, eating and general wellness ... again the list is endless.

Another loss that many people experience is their disappointment or dismay at what friends say to them. They'll find that some people don't know what to say, so stay away. Others think they have to say something cheery to brighten you up. Others don't know how to mention what's happened and talk about everything else except the issue at hand. And then there are those who want to say something philosophical to help you look on the bright side.

Here are some of my hair loss no-no's that I've had to hear:

- "When your hair grows back it'll be much thicker than before."
- "It'll probably come back all curly."
- "It could have been worse; you could have lost your breast."
- "Think of all the money you'll save on shampoo and the hairdresser."
- "You can get fabulous wigs these days."
- "You've got a great head for baldness."

None of these comments made me feel better. Whilst I understand the motivation behind them, you can't whitewash someone's grief with a snappy answer. I know my hair will grow back. I know I'm fortunate not to have had a mastectomy. I know I won't have the expense of regular visits to the hairdresser. But the reality is, I'd give anything not to have been put in this position in the first place. I don't want curly hair. I don't want a nice wig. I just want my old hair and my old life back. That's the honest truth.

What I would have preferred to hear was something like this:

- "Gosh, it's going to be really hard to get used to having no hair."
- "I can see you're upset at the thought of losing your hair."
- "It looks like you've got a big challenge ahead of you."
- "No hair, what a bummer!"

However, having said all of this, all is not lost according to my view of the world. And this is the secret of coping with your cancer – you can't be forced to take on the view of well-wishers, you need to make decisions yourself as to what attitude you will take, how you will deal with the challenges, how you will think all this through.

Here are 3 significant decisions I made.

- Headwear – I decided on turbans to cover my head rather than a wig. I have a collection of colours and styles to match every outfit in my wardrobe. I decided that if I have to wear something on my head it would be as stylish as possible. I call it doing 'chemo chic.'
- Therapy – when you're grieving you get no prizes for toughing it out on your own. I sought the help of a specialist therapist attached to the clinic where I have my treatment. I needed someone outside of my family, friends and colleagues to talk to. I have learnt the art of relaxation and meditation as an important new way of behaving and learning to 'be still' with my situation.
- New mantras - I knew my thoughts could either assist me or debilitate me. So I created new words that would guide my thinking when things were getting tough – Calm and Gracious. Open and Appreciative. Every day I remind myself that negativity and anger will not help to repair my body and that I need to be open to new ideas and new people who can help me. Every day I look for something or someone to appreciate – I smile more at strangers, I talk to dog walkers, I thank the council workers who are up at dawn to clean the beach where I walk.

I have another new mantra which came by email from a dear colleague in Christchurch, New Zealand who signed off his get well message with the words '*Kia Kaha*'. I didn't know what they meant but thanks to Google I learned that these words originate from a Maori phrase meaning 'stay strong'. When the 2011 earthquake hit Christchurch, '*Kia Kaha*' became an iconic message used by the Maori and Pakeha (European) people alike to give solace and comfort to the people of the city. These words just resonated with me. They didn't say 'be brave' or 'don't cry', they just said you have the strength to get through this. I wanted to be counted amongst those people who know how to survive adversity and decided then and there that chemo could take my hair but it would never take my spirit. *Kia Kaha*!



Christmas Day 2012, after



January 2013, with my hairdresser, no more locks



February 2013, doing 'chemo chic'

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