

## Cynthia's Corner

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WebCafe is pleased to share the very personal insights, wisdom and poetry of Cynthia Kinsella. To read Cynthia's survivor story, see [Tales from the Trenches](#), Cyndi

## Looking past the mirror

I remember being 29 and conversations stopping when my posse and I entered a dance club on more than one occasion. We were a blond, brunette, and a red head all intelligent, independent, living in Europe and at our prime. The stories I could tell...but being a lady...well you understand. As the years went by my view of myself as a woman became very much a part of who I am. One day I woke up and was 47 all of the sudden. I imagined if asked I would have told you that I was at my best. While faithful to my husband, I did so love knowing I could still make a young grocery bagger stammer with just a smile.

Then the C word entered my life. I remember walking out of the bathroom in the hotel there was a full length mirror staring at you. I really looked at myself for the first time in a long while. I think by not looking I did not have to deal with it. And I stopped and wondered who this person was. She was bald not only on her head but all over. She was bloated from the steroids and the ravages of all her treatments. She had a scar on her breast from the port and bruising all over, it didn't take much anymore. Tired eyes looked back at me from a pale face, once soft skin now dry and dull.

I cried that day and looking back I realize that hardest part of it was not knowing who I was anymore. My looks had become such a part of me that I was adrift. Through that experience I have had to come to terms with who I am today. Chemotherapy and radiation are close to a year behind me and I really looked at myself in a full length mirror the other day. And I saw myself...a woman that has faced so many challenges in her life and battles on, a good mother and loved wife, smart, resourceful, resilient, blessed and a survivor. My husband loves me for me, my smile and laugh and even my warped sense of humor. I was the person I had been all along only older, wiser and yes with higher mileage. But at a good place a confident place, I no longer look as I did before the C word, but I look like me and that is not a bad thing at all. Things with time had improved my straight thin hair came back thick and curly I call it my little bonus. And the other day I made a grocery bagger stammer with a smile, not bad at a high mileage 49 in my book.

The affects of cancer treatment can be devastating to a woman on so many levels, an intensely emotional burden at a time that little energy is left to deal with it. For some surgery can hit us at our most basic levels threatening our sexuality and body images. I am far from having all the answers. The answer to most is intently personal and only come with time. But I will share with you what helped me.

I talked about my fears and concerns. Don't bottle it up. If you have a significant other tell him how you feel. Don't be upset if he doesn't have all the words you need to hear he is going through a lot also. But a therapist or a girlfriend will do as the main idea is to face your fears.

I never left the house without dressing nicely and putting on makeup. Knowing you look as good as you can is good for you confidence.

The ACS Look good Feel good is a great idea. They can teach you techniques such as how to use make up to get a good look after you lose eyebrows or eyelashes. As well as how to keep up your skin during chemo.

I bought the best wig I could afford. Synthetics are cheaper and easier to care for and if you get a good one they look

very natural. Shop around if you can and buy it before you need it. Take someone that you trust their taste. You have to try many on it is like finding a price you have to kiss a few&hellip;&hellip;&hellip;

We all have wig storys they were not the end of the world and I now laugh at mine. If one slips or the such just put it back on and act like nothing happens. If you really fear it find some wig tape and try that we all learn the ends and outs of them with time.

Treat yourself well. Apply a good skin and face lotion at least twice a day.

If you can get out and about have a facial it is a good investment.

A manicure and pedicure goes a long way in the feel good department.

A bubble bath is good for the aches and pains and very relaxing.

And last but not least give yourself time. You may look different as the months pass but one day you will look in the mirror and see the new you. Many of the changes during treatment will rectify themselves once it is over.

April '06

Learning to fly upside down while enjoying the view

While going through cancer treatment I have come to use writing as a type of therapy. It grants me the chance to put what happens to me into an order that some how gives it meaning to me. It gives me license to be a drama queen to be totally irreverent if I please and to say things I could never say to the people I love because I would worry about upsetting them. Looking back on the last two years as crazy as it may sound I have come to recognize the fact that the cancer has been one of the most incredible chances I have ever had for personal growth. It has taught me how precious every day is, that passing up the chance to experience joy is a grave sin and that most of us never notice how blessed we really are because we are blinded by the petty occurrences of everyday life. Who would ever think that good could come from something so terrible? But then life does have a way of surprising us when we least expect it, doesn't it?

Humor as a tool to healing

I could tell you so many things about the terror, pain, humiliating procedures and sheer tedium or having cancer but that would only be half the story. When I was diagnosed with Bladder cancer I remember the terror. The day after my biopsy I went to my computer and looked up Invasive Bladder Cancer and this is what I read &ldquo;The standard treatment is a type of surgery called radical cystectomy, which removes the bladder, together with nearby lymph nodes and adjacent

pelvic organs. In men, this procedure includes removal of the prostate gland and seminal vesicles. In women, it includes removal of the uterus, fallopian tubes, ovaries and part of the vagina. I couldn't breathe to scream. When my personal physician called with my pathology result we both cried. When my Urologist said "you do know that you may die no matter what we do" I to this day am still searching for the appropriate answer to that one.

At forty seven I learned I was more worried about how I would die than when. Would it be with dignity, could I handle the pain? If pressed I could tell you the nitty gritty of twenty trips to the infusion unit and forty to the radiation. I could tell you the side effects and what that does to a body. I could tell you about being in surgery seven times in a year. And I could tell you what it is like to try to retain your dignity when you are a thing on a slab in a teaching hospital, with your most private parts probed and seen by the world. Yes I could tell you many things but they would not be changed by the telling.

The other half of the story is this. I have sat taking chemotherapy with a woman who knew she would not see this Christmas with her children, and laughed until we cried about silly things. I have seen bald headed children laughing and playing as if the world was right toting their IV poles around the infusion unit. I have read things in chat rooms and list servers from other survivors that would hold no humor for others but make me smile because I know where they come from. I have found humor in things I would have been appalled at a year and a half ago. I have made jokes about glowing in the dark, being bald, bodily functions and a few things better left unmentioned. And in that humor I have found hope. The human spirit is stronger than the cancer. I really have no choice about what happens to me in the future. But I do have a choice how I handle it. Do I sit around and cry the rest of my life about what a rotten hand I have been given? Or do I find joy and laughter given the opportunity? I would think the answer would be obvious, what a waste to cry when you can laugh. And I think that is the most important part of the story.

## Miracles

Once there was a grumpy ungrateful man. He was never happy&hellip;&hellip;&hellip;..if it was sunny he complained that rain was needed. He never saw the beauty of the night sky because he was too busy cursing the darkness. He didn't have friends because they would take up too much of his time. He got rid of his dog because he ate too much food. His family was just too much trouble and always needed something.

One day this man became ill, and the doctors told him he had cancer and needed treatment. He complained that the nurses hurt him. He yelled at the Oncologists because the treatment made him ill. He became angry with his cancer support group because he didn't like what was said all the time. So the man gave up and he sent them all away.

When the man died he found himself in a white room with a young man holding a clip board. "Hello" said the young man "I am with the Miracle Output Committee. We felt that we needed to talk to you, as you have sent back every miracle we have sent you and we wondered why?" "Miracles? I was sent no miracles" yelled the grumpy ungrateful man. "All I was sent was problems." Immediately the young man said "Oh no you are very mistaken" he started sorting through his paperwork. "Here is the list of what we sent you and it is a very long one indeed." Reading on he said. "An intelligent strong mind as well as sight, touch and smell, glorious sunsets, the love of others, the beauty of a spring morning and the joys of nature" and the list went on and on. "And when you got cancer we sent you more miracles" "When I got cancer all I got was trouble and pain, I saw no miracles, I am here aren't I?" complained the grumpy ungrateful man. The young man looked at him with great pity and said "The cancer we did not send it just was. The miracle we sent you when you got cancer was one of our most wonderful miracles of all, the love of your fellow man." The young man was shaking his head sadly for he knew the grumpy ungrateful man could not see. "We sent family and friend to comfort and care for you. We sent you other cancer survivors that were willing to share your sorrows and joys. We sent advocacy groups working to make life brighter for all cancer survivors. We sent intelligent, talented people so filled with love for their fellow man that they dedicated their lives to them. Researchers to find a cure, nurses filled with compassion, Oncologists, Surgeons, and Radiologists with staffs to work tirelessly to help you. And through them all we sent you the greatest miracle of all&hellip;&hellip;&hellip;hope"

## Taming the Beast

The memory of reading my prognosis and normal treatment path the first time will always be with me. I was finally alone the pathology was back and I had what I needed to do some real research. I sat at the computer and typed in Invasive Bladder Cancer into the search engine. I picked the Harvard Medical web director as my first stop. As I read I felt a scream trying to come out but there was no air I couldn't breathe. It was August of 2004 and at 47 I looked into the face of the Beast known as cancer and knew true terror for the first time in my life. After that came a time of numbness and shock I was just living from moment to moment. But always with me was a feeling of dread of expecting the worst. The weeks and days after were filled with finding specialist, tests, planning and decisions. Doing things that had always seemed to be in the future. Living wills, health care proxies, my will and last wishes were taken care of.

Finally on a crisp fall day I stood in front of the Cox Cancer Center in Boston ready to go in and it all hit me. This was the day I would begin radiation and chemotherapy. I couldn't move there was no going back and I couldn't go forward. As I stood there I hear a child's laughter. And a little bald head rushed past me closely followed by Dad. Decker out with his back pack he ran in and pressed the button for the pediatric infusion unit. And the numbness wore off in a flash. I made it to the bathroom stall as the tears came. I to this day do not know if I cried for me or the little bald headed boy. And the words of my father rang in my head. We truly have control of nothing in life but our attitude towards what happens to us. How could I be a coward when this little one could laugh and he hadn't even begun to live? I walked out of the bathroom knowing I have had a full life and that everyday that was before me was a gift.

One day as I sat in radiation waiting my turn I was talking to a friend I had made. Dave always made me laugh and feel better just by being there. He was my age, good looking, successful, humorous, articulate and intelligent. His sister was with him this day and when he went in for his treatment we talked. I found out he was there for palliative care that they had gotten to his cancer too late and he had maybe a few months. I walked out that day grateful that I had a chance that life was not yet finite for me. Once again I heard my father's words. We truly have control of nothing in life but our attitude towards what happens to us.

As I was being set up for chemotherapy one day I could hear a lot of laughter coming from behind the curtain from the bed beside mine. And a voice called out "how are you doing I am Judy". I answered and before long was part of the party. Judy was the ringleader and her daughters were helping her out. When her daughters went to lunch Judy and I talked. Judy asked me how long I had been without hair and I told her and she proceeded to give me advice about handling it when it came back in. She told me not to dye it too soon as she did and it had turned purple from the chemo drugs still in her system. I asked her what she had done. She smiled and said "I went out and bought a purple purse of course". Judy was end stage and knew it. I walked out that day knowing that to waste one hour of life on regrets and fear was a sin not to be committed. Once again my father's words echoed in my head. We truly have control of nothing in life but our attitude towards what happens to us.

If the little one or Judy or Dave can face life without finding it hopeless no one ever should. I am sure Dave and Judy who are no longer with us would laugh and tell us that they would willingly live with a small thing such as uncertainty, and be happy for just one more sunset. What we face is not hopelessness but uncertainty. I choose not to let the Beast live my life for me. I choose to live life as the gift it is, with as much joy and laughter as I can. Because I know that my father's words are very true. We can not control what happens to us in life but we can control how we react to it.

## Thoughts on being a hairless wonder

Cancer takes away so many things. You're feeling of invincibility. Your faith in the future, life as you know it has changed forever. On the other hand, it brings out the fighter in most of us. You deal with things most people never have to think of. When you are told you may die, you do not crawl away and hide, you face it square on. You tell them ok give me my best shot. You walk in and tell strangers here I am, irradiate me and give me poison. You even learn to see the humor in it. I remember the day I lost my hair as being almost as traumatic as the day I was diagnosed. So why was losing my hair enough to bring me to my knees after all that I had been through? A very complicated question, was it just

ego? No, I do not think so, not for me at least.

I had finished my first course of chemo it was low grade to help the radiation do its work. I was told it may or may not fall out this time. I was past the time I thought it would happen and was no longer looking for it. My husband was on travel and I had gotten up and was showering. As I washed my hair, I felt something on my hands. When I squinted through the shampoo bubbles I saw they were covered in hair. As the tears started, I quickly rinsed as the shower drain was clogging. By the time I looked in the mirror the towel and floor were covered also. I looked like a mangy dog and for the first time I saw cancer. I had talked about cancer and studied it but now I saw it. I felt ashamed I did not want anyone to see me. For the first time I wanted to just crawl away and hide. By the time I sat and cried with my hair stylist as she shaved the rest off there was little left but a few tufts.

I left the shop in my new wig and it felt like something alien was on my head. My girlfriend bless her did not just say it will grow back dear, as most people would in the future. She understood and said coffee hell you need a stiff drink. By the way, I promised to never tell anyone we got tipsy before noon, so keep that to your self-ok? I remember the first time my husband saw me without my wig. Would he still find me attractive? He held me as I cried and laughingly told me he had always had a secret fantasy. He had had it ever since he had seen the Star Trek movie with the bald alien. In addition, in his book it made him a lucky man. He could have a blond a brunette or a red head and his wife would not care. The darling man, he made me laugh through my tears.

In the months, since I have gone through a lot, the wig is now affectionately called the Rat at my house. After systemic chemo I have lost my eyelashes and eyebrows also. My hair has come in and fallen out again. My oldest calls the short time it was coming in my dike phase; by the way, he is out of the will. I have found that when two women see each other without hair a bond is immediately formed. Just as children are drawn together so are we in the sisterhood.

I think the most important lesson I learned was when I went back to exercising after chemo. I had put it off because I knew I could not do it in a wig, much to hot. So I got my nerve up and walked in whipped off the wig threw my keys into it and went to work. It is an all woman group and to say some stopped dead would be an understatement. Then in the days to come something miraculous happened. One by one, they came up and started talking about their experiences and those of family and friends.

I rarely wear the Rat I mean wig anymore except to work. By saying here I am I have nothing to be ashamed of with a smile on my face I have allowed others to face the beast, and see hope. I now know that even if I am bloated by steroids and bald as a cue ball I am still me. So why is a woman losing her hair during chemo so traumatic? You have to face the question, who am I without my looks. The inconvenience of it all and the discomfort of hot flashes in a wig can be a factor. I imagine any woman that has been through it could add her own to the list. However, I think ultimately the biggest reason is it makes you face the beast in the mirror every day.

So you endure.....

I once ran into a lady in chemo, who was just wonderful. She knew she was end stage ovarian cancer and had been fighting ten years. She had seen it all and I had the pleasure of spending six hours with a fascinating lady. Of the twenty times I sat in chemo the day with her stand out the clearest in my mind. One of the things I asked her was what systemic chemo was like. I had that part ahead of me I had just started. "Well" she said "it's like this... when you think they are going to kill you they stop" She smiled "When you start feeling good again they start again. That is the idea of it she said. They give you as much as you can take and keep breathing, hoping to kill the cancer. It is a lot like going to war, and I guess that is an apt description, a war is waged in your body. And the good guys fight until they have taken enough casualties and then the general pulls them all back to regroup and fight another day.

And I asked her "How do you stand it?" And again she smiled saying "if you are here you have already made the decision to fight the monster so you endure... it is as simple as that. You will do what you have to survive." And she was very right you put your chin up as high as you can get it and go straight forward. Keep in mind that as high as your chin may get that day is the top of the toilet or the mattress. You

persevere&hellip;&hellip;.knowing that beating the beast is the reason you did this.

Now we will all do this in our own way. Some of us will whine, even if we never have before. And yes going in and saying fill me up with toxins does have a way of dampening your usual stellar sense of humor at times. Some of us get testy. Some of us get depressed. Sometimes we all cried. Grown men know to be stoic may become child like. Woman thought of as being emotional may become stoic. No two people handle it the same. But handle it we do, no ones way right or wrong. But the only thing that will make it any easier is keeping the end in sight and that is winning the war...so you endure.

Why All the Fuss

Over the time I have read many things about how to get well and stay that way. Some where common sense others where way out there. It put me in mind of what my father once said. When I asked him how his doctors appointment went he answered that by the time the doctor told him everything he needed to give up to get well he couldn't remember why he wanted to live. I wrote this for all of us that have ever felt that way. Before you ask no I am not a member of AA and no I don't have Lloyd's number. But if you want a list of my real bad habits just send a self addressed envelope and a large check and I will send them out to you right away.

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My doctor took away my will to live on

As he told me what I had to give up I thought of Dr. Kevorkian

So I gave up meat a vegetarian and a vegan I became.

I threw out the coffee, chocolate and caffeine now green tea is just the thing, even though its not the same.

Sugar, fats, nitrates, preservatives, enhancers, fillers, thickeners, and empty calories are a thing in my past. The folks at Whole Food know me by my first name not my last.

My water is the purest sort gathered by vestal virgins at the mother source.

Even though I miss my drinking and smoking buddy Lloyd and his gang, the ones at AA are filling the void as much as they can.

I took up yoga and it is quite the thing, but my chiropractor thinks it may be too much of a good thing.

I doing my best to learn how to meditation and my Dolly Lama thinks I may one day levitate if I can learn not to hesitate.

I wrap up tight to avoid the sun but I am getting tired of signing autographs for Michel Jackson.

My consumption of garlic and onion has become so copious; my children now walk behind me because I am so odorous.

Imagine my disappointment when I got a hernia from heaving around bags of supplements. They are expensive but a second mortgage is a small price to pay if they do all they say.

Last night I woke with a start from a nightmare that almost made my heart stop. All around me at my funeral where my new friends from AA, they were all looking depressed and grey, and then with horror and dismay I heard one of them say you know it is too bad she went to all this fuss only to be run over by a bus.

Through the eyes of James

When faced with real adversity we can no longer hide behind the everyday wall most wear, made up of fake smiles, greed, jealousy, discontent and insincere if polite words. Because you have reached a place where the petty everyday things no longer matter and are not worth precious time. What status and honors others give, you know, is just fleeting and not worth the paper or stone they are written on. That true strength is not measured by a person's muscle, power or money but what lies in their actions, heart and mind. That true love is to have loved others above yourself, to put them before your own needs and comfort is to have shown the depth of that love. And that it is only the richness emotionally and spiritually of a life and not the length that can deem it a full one. You know that to have been truly blessed in this life is to have known enduring faith, and that the only lasting sin is to have missed one moment of joy or the chance to bring a smile. You know that the mark of a life well lived is not what we leave behind that can be touched but in the memories and the caring we give and are given. Your only wish would be to teach the world the worth of every day and every minute as the true gift they are. That the only true treasure to be taken from this earth worth having is to have known and given love; and that the only truly poor man is the one that never lived outside of his everyday wall

Three Years of Living

August sixth 2004...if I give into it I can recall the intense terror that day brought. The feelings of confusion, fear, anger, sorrow, regrets and guilt for doing this to my family paralyzed me. Only the knowledge that doing nothing was not an option moved me forward. Then the second opinion, and I knew I was in for the fight of my life and determination to slay this beast became my reason for being, and fight I have. Radiation, chemotherapy, endless test, scans and so many biopsies and tumor removals I lost track of the numbers. But no matter what we threw at it the cancer thrived and took root once again necessitating major life changing surgery. Then one day I realized that maybe just maybe we had won the battle. Only time will tell if it will attack again.

August sixth 2007... Today finds me thriving with the constant rechecks for recurrence a part of my life but no longer the center of it. When looking back I think of a conversation I had with an Ontological Social Worker, sitting in chemotherapy one day, as being a pivotal point in my life. I told her that I was having trouble imagining living life with such uncertainty in it. How do you go forward if you do not know if you are going to be here this time next year or not? And she answered me with a question "How would you live your life differently if you knew?" When it comes down to it none of us really do know what the future will bring. The only thing any of us know with any certainty is that we have today. Maybe I was given a gift in a way for I think most of us never realize how tenuous life really is. I am no more perfect than I was three years ago but I like to think I am wiser. I try very hard to make sure that the words that I would regret not speaking are spoken. I try never to be too busy to see the small joys and miracles of life, the fall day, a good cup of coffee, a new baby or sharing a joke with a friend. I no longer think of doing things someday I do them now. I



celebrate birthdays with abandon my age no longer something to morn but to celebrate. I try to forgive others and myself more quickly and love as I want to be loved. I try to think of unlimited possibilities instead of why something is impossible to accomplish. I no longer see sitting with my feet in a stream reading a book as a waste of time. And I try never to forget that tomorrow is a miraculous gift.

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Coming soon <http://www.bladdercancersupport.org/>

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T2 g4 CIS Aug.2004, Clinical Trial chemo. radiation bladder sparing

CIS Jan.2005

Ta g4 Sept.2005

Oct.2005 - Jan 2006 BCG

T1g4, CIS March 2006

Radical Cystectomy Indiana pouch May 2006

Just proving I have a true talent for getting things backwards

Cynthia's Tale from the Trench