

Women's Issues

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See also: Women and Bladder

Cancer for some alarming facts and figures{/niftybox}The following are excerpts from our discussion group.

Thoughts on being a hairless wonder

women and blood in the urine

Women, bladder cancer and 'The Change'

Thoughts on being a hairless wonder

I wrote Jane off list about losing my hair and how hard it was and the things I had experienced. At the time, I wrote her I guess I thought it was too personal to post. Interesting I will post thing about all kinds of body functions here but that was too personal. That tells me how much of a blow to me it was and I imagine to most woman. This is something we have never really talked a lot on the list about in the time I have been here. Therefore, I faced it and wrote down my thoughts to share with all of you. I can only write from a woman s perspective. Nevertheless, for you follicley challenged guys out there I tip my wig to you. To tell you the truth I think on some men bald is very sexy. But remember some of the difference for a woman is that if you see a bald guy you do not automatically think Cancer.

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 where 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 where 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 best friend 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 Start 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.

If you are having chemo and are told you may lose your hair be prepared, my advice is as follows

Synthetic wigs are easier to care for than human hair and cheaper but discuss it with your stylist or someone in the know.

Get the wig before your hair falls out

Take it to your stylist and let them cut it, They know you the best and will give you the best results.

If it is not just thinning get it cut off. It will grow in stronger and even if you do. Also picking it up piece by piece is depressing.

Except that it will upset you and let yourself, cry. It is natural to morn a lose.

Have an assortment of scarfs and hats for those times you do not want to deal with your wig.

Have some soft hats to wear at night, if it is winter you will find you get cold without your head covered.

Hold your head up and let your beauty shine; it may take a while but never feel ashamed for being a fighter.

Cyndi

August 2005

Women and blood in the urine

The Department of Urology and Oncology University of Miami published a paper after reviewing the current trends of invasive

bladder cancer. This particular statistic and statement in the article

surprised me at first. "Women were more likely to be diagnosed with muscle invasion primarily than men (85.2% and 50.7%, respectively)....." On second thought, though, I realized women are so accustomed to seeing blood from monthly menstruation that the alarm does not go off in our heads when we see blood in the urine like it does when men see blood in their urine. After my dx, I learned that a relative by marriage had been having blood in her urine for years. I asked if she had been to a urologist. She had not, She went, had invasive bladder cancer and had her bladder removed. We as woman just don't feel alarmed by seeing blood. More woman need to be aware

that blood in urine is a concern to be investigated by a UROLOGIST.

Rosie

You are so right. I thought nothing of seeing the blood-- thinking it was related to the change, tho I had not menstruated in several years. But my doctor also thought it was uterine initially-- even when I finally said that it was only when I peed. I think we wasted about 3-4 months between the two of us, before I got referred to a urologist. I know the outcome would not have been different in terms of losing the bladder, but it was a wakeup call about taking anything abnormal very seriously. Karen

Karen, I recognize your delay in time because your GP or GYN did not

recognize the need to send you to a urologist. I had the same situation and delayed 3 years with other treatments from them until finally I was referred to a urologist. Luckily my delay did not cost me my bladder nor was it invasive. I think we as woman should call all the doctors we visited and tell them to refer woman to a urologist if they say there is blood in their urine. Maybe in that way, we could help others in our position to get the correct assessment and treatment sooner.

This is an interesting topic. Roni and several others have mentioned to me over the past 5 months how women are continually misdiagnosed. For years I had reoccurring bladder infections and they would give me antibiotics and send me on my way. (Note: Blood was ALWAYS present when they did a urine culture) They assumed that because I am paralyzed from the waist/hips down that I would have a compromised bladder and therefore be open to more infections. Actually I remember years ago I had this one primary care doc that I repeatedly asked to refer me to see a uro. and they told me it was not necessary. I changed docs and then this one, after a year, couldn't figure out why I had repeated infections and she finally referred me to uro.

The interesting thing was when I finally went to go see this uro I casually mentioned BC and he smiled and and told me that I was a 'little young for that type of cancer' [age 32]. Still, he was committed to checking out everything and not 3 weeks later he diagnosed me with Stage III Grade III BC.

Thank goodness this uro didn't blow me off like my primary care docs. He knew something was wrong and he did test after test until he found out that was wrong. Lea

My GYN sent me immediately (after finding blood in my urine) to have a sonogram, and the Dr. there sent me to a urologist. Four weeks later I had my bladder removed Stage 3 invasive. I t has been almost a year and I am doing great. I should have gone to the Dr. long before I did, I thought it was pre-menopause. Who knows if things would have been different. I can't second guess myself..... I have too much to be thankful for. It is nice to know there are others who have and are going thru the same thing as I am! Thanks for your messages.

Colleen

Because of the publicized statistic the medical profession does not seem to be alarmed when woman report blood in their urine. It is

particularly difficult to get a correct dx if you are a young woman under 40. I know many men who went right to the emergency room at the first urinated blood. I know many woman on this list were having blood in their urine up to seven years before having found the cause as bladder cancer. How can we get the word out to other woman not on this list to have a urologist check it out and to let them know there are a number of woman of all ages with bladder cancer. I read an article recently that the instances of bladder cancer will increase because of the aging population and baby boomers. That should help

in alerting others to get tests sooner. Rosie

I know that when I first had pink urine, my Internal Medicine doctor (my

PCP) did a culture. When I called to get the results, the receptionist/nurse on the phone only told me that there was "no growth in 24 hours", and when questioned she only repeated it. It was only the nurse in me that persisted and went to the urologist. If I had not persisted myself (and if I were not a nurse, I would not have known to do that), my TCC would have been missed because the hematuria cleared up. Because I did get myself to a urologist, two bladder tumors were found and removed later that month --- centimeters instead of

millimeters, but still superficial and not invasive. Kathy K.

My name is Georgette. I was 52 years old at dx, female. My GYN was

grossly mistaking my complains of blood in urine, saying that I'm spotting, going to menopause--"You are not going to die from what you have; Your PAP is negative, you should have a D&C because is covered by the insuranvce (Personal choice)" He delayed the whole process for about a year, did not send me to a Urologyst. I went on my own when I went in urinary retention. DX with bladder CA on Jan 2,2001. On Jan 25 2001 had surgery-radical cystectomy, total hysterectomy. I feel the GYN was not competitive,even though he was my GYN for 20 yrs. I had a great surgeon-DR.LEONARD GOMELLA at Thomas Jefferson Univ. In 5 mos.since surgery I didn't have even an

infection.

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it was pre-menopause. Who knows if things would have been different. I can't second guess myself..... I have too much to be thankful for. It is nice to know there are others who have and are going thru the same thing as I am! Thanks for your messages.

Colleen

I am a 48 year old woman and my cancer was determined to be Stage III, T2. I Went undiagnosed by my female general practitioner for just over 2 years because she was sure my so called "bladder infections" were related to menopause. As it turned out, she was not reading my lab reports (urine tests) and my cancer was detected due to a nurse practitioner who did read my file at my first visit with her, and who recognized my situation. I feel I owe my good prognosis to her for being both educated enough and concerned enough to immediately get me a referral to a urologist. Lucky for me my regular doctor was too busy to see me that fateful day in October 2000.

I had a radical cystectomy on the 23rd of January, 2001, and have had no chemo. There were no nodes involved. My surgery was complicated by a bowel obstruction and pancreatitis which kept me hospitalized for 18 days and on IV feeding for 24 days.

I have an Indiana pouch which functions quite well for me. I cath ever 5-6 hours and have had no real problems with leaking. I feel optimistic and fortunate to have found this web site.

LaNette

I was misdiagnosed for approximately three to four months also. I had four pelvic exams and all kinds of antibiotics until crying and screaming I went into the gyno's office yelling that I needed a referral to a urologist! Still, he wanted to do another pelvic and I said no way and walked out. I PAID for a uro to see me and was diagnosed at that time with a large tumor growing. Finally my insurance sent me to a urologist who in turn diagnosed me (again) and did the surgery. Wow....this is so unfair and so unbelievable. Blood in the urine should be a sign to do something MUCH more drastic.

SIGH. Jane

My husband keeps telling me I should switch GYNs since she first thought it was uterine/change related, even after several months when I kept saying I only saw the bleeding when I peed -- but I sat on the bleeding[so to

speak] for several months and waited until my usual appointment... so who knows. Maybe it would not have spread to the nodes???? You can make yourself crazy with the second guessing and the blaming. There are no answers and it gets pointless. we do need to makethe GYN community aware of this. Maybe I will write an open letter to their journal.

Karen

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Women, bladder cancer and The Change

I guess this is directed to those of us who still do, or used to have, ovaries. I was finally diagnosed at 53. At that point I had not menstruated for about 5 years, and was considered "perimenopausal." I was having a somewhat gentle change, no particular loss of functioning or moodiness [though I guess you should ask my husband] and occasional hot flashes, no night sweats though. I noticed some difficulty recalling names. I was an active working wife and mother.

Now I am post chemo and post cystectomy/hysterectomy and am in abrupt surgical menopause. I am also trying to tease out what is normal aging, what is the result of the physical aspects of the surgery (for example, it still is hard walking up stairs), what are the residual effects of the chemo [dropping small objects, making horrendous typos], and what are the results of the intensified surgical/chemo menopause. I had rejected hormone replacement before since I am in a high risk group for breast cancer, and I also felt I could deal with the occasional power surges. Now they are more frequent and I am developing what I understand is change-related insomnia or less deep sleep. The forgetfulness is more severe it seems, I can't recall.

I wonder what others are experiencing in this regard. What has it been like for those younger women on the list who were not already in the change when diagnosed? I was told that the first round of chemo kills the ovaries, so I have been low or without estrogen for about 18 months now. I know that post menopausal women need to be vigilant about bone loss and heart disease. Since this is a coed list, I don't think BC is at all estrogen related, but are we endangering ourselves in some other ways if we do replacement? Is anyone else having problems in this area? What are you doing about it? Karen

The instant menopause was harder on me than the cystectomy. I wasn't in pre-menopause, all my parts were running like clockwork. 4 days post-surgery, my Internist came to my room to talk with me about hormone replacements...indicated that we wouldn't start until I returned to work. In my head I was thinking how hard can this be, my Mom sailed through it. HA. I returned to work and the hot flashes began a non-stop invasion of my sweat glands, relentlessly squeezing every ounce of fluids in my body. The night sweats were so bad, I slept with 4 pillows so I could toss a drenched one and cling to the next. Insomnia found a home with me, I slept for 2-4 hours, but it was restless. I couldn't construct a complete sentence without a pause in

my speech, focusing was a problem. Now I was never one to jump on the ginkgo bandwagon, but I am an avid reader so I crammed all my free time with reading hoping to get the sparkplugs to fire a few more times. That helped my concentration and focus...however, my big breakthrough came with the estrogen replacement. No more night sweats, very few hotflashes and my sleep pattern is much improved. I still search the crevasses of my brain for words every now and again. As much as I hate it, I keep my sentences simple and if I can't find that wonderful 6 syllable word that used to roll off my tongue, I take whatever word the neurons have teed up for me. I am happy with the estrogen replacement and my internist monitors me regularly, mammograms, blood pressue, etc., I visit her every three months and report any body drama I may experience, so far none. Internist and I talk freely about the pros and cons of replacement and I'm comfortable that we/she are monitoring "ME" closely. As an aside, she supports some alternative medicines as enhancements to mainstream treatment...and we did try natural products, but I did not respond.

Going up and down the stairs...oh, man that has been the source of much pain for me since the surgery. The left side of my body (groin and knee) have gone on strike and I have compensated with the right side. I've had x-rays, scans, etc., visited the ortho, my knees are in great shape. I am being treated by a rheumatologist for fibromyalgia and he sent me to physical therapy, it has helped. It's very frustrating to not be able to bound up and down the stairs or have a little difficulty maneuvering in and out of some cars--I have a litany of movements that exacerbate the knee/groin pain. Did I miss anything here? Best Kathy L

I have absolutely the same situation, high risk for breast cancer, but my new GYN said that comparing the benefits of hormone replacement with the risks, he would recommend Estrogen. I am taking it for a month now, it feels great, I am less moody, and it helped my bladder too because I am not as tense and nervous as I was before. Georgette

Bladder cancer and THE CHANGE - now there's a combination! With an abrupt menopause, hot flashes (sweats for many), mood swings and vaginal dryness are dramatic and common. HRT does indeed ease the symptoms, but it is not recommended women at high risk for breast cancer or anyone with blood clotting disorders. Fortunately, there are blood tests for a few blood clotting disorders. They include: Factor V Leiden (FVL) Mutation, Activated Protein C Resistance (APC) aPTT-Based, Activated Protein C Resistance (APC) PT-Based, Anticardiolipin Antibodies (IgG, IgM, IgA), Lupus Anticoagulant Panel, Protein C Functional Assay, Protein S Functional Assay, Prothrombin (G20210A) Gene Mutation, Thrombosis Panel, and Methylenetetrahydrofolate Reductase (MTHFR) Mutation. One of my 2 sisters, one of my 2 daughters and I have Factor V Leiden.

My son has not been tested. FVL is a hereditary mutation, passed by one or both parents. If passed by one parent (heterzygous), as ours is, each of my children has a 50-50 chance of having FVL. If passed by both parents (homozygous) - all offspring will have FVL. The risk of venous thrombosis is much greater with homozygous FVL from both parents. Factors that may

trigger thrombosis in people with FVL include: smoking, pregnancy, obesity, oral contraceptives, Estrogen and hormones, and immobility. People have heterozygous FVL and never know it and never have a problem. It takes one of the triggers to cause a thrombosis. Although I really liked the effects of estrogen, I stopped taking it because of my FVL. Thankfully the hot flashes have moderated and KY jelly or estrogen cream help vaginal dryness.
Best, Roni

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