

Delays in Diagnosis- an informal survey

After the revelation that women are diagnosed with invasive, later stage bladder cancer far more often than men [see 'Women and Bladder Cancer'], Karen asked the discussion list;

"I would like to know who among us feel that our bladder cancer diagnosis was delayed-- that is, our PCP or GP or GYN did not send us immediately to a urologist or even to a basic cytology, when we complained of blood in the urine."

The responses were:

Women

No delay: 2 out of 11 responders

Delay: 9 out of 11 responders

Men:

No delay: 5 out of 9 responders

Delay: 4 out of 9 responders

Responses from women

No Delay Gender: Female Age at dx: 48 Delay between first report and diagnosis: 3 days Stage 3 Cystectomy October 1998 No delay... I think this quick turn around was due in part to the fact that I gave up gynecologists 15 years ago in favor of a female internist. Internists look at the whole body as a synchronized machine, I've never, ever had a problem with her or her team. She works closely with my uro, so I feel well-cared for. As of today, insurance has not been an issue. Kathy L.

No Delay Female 55 at diagnosis Saw a "travelling" doctor over holidays in '98 for hematuria. (My regular doctor was on vacation.) Took a week to get in. By then, no hematuria. Culture turned out negative. Was told to come back again if more hematuria. Six months later, more hematuria--no infection. Saw regular doctor same day. Scheduled for IVP within a week. That was clear. Referred to Urologist. Had surgery within 3-4 weeks of second hematuria occurrence. Ta, I/III Second tumor 6 months later. Uro instilled something at time of second TURB--don't know what. He said it was similar to the antibiotic he always has me take before and after a TURB. Was to help with seeding. Been clear 18 months. No further treatment. Once my regular doctor was on the scene, I can't complain about my treatment or speed of said treatment. My insurance (HMO) has paid all the way. All of this took place in Denver, CO. I am one of the lucky ones. Take care, Gwen

Delay Female- age at diagnosis 46- delay of 12 months- Ta Grade

1. Delay was due to a medical decision. Anne, UK

Delay I had symptoms for six months, frank hematuria, tiredness and lower back discomfort starting xmas while home in Scotland visiting. Saw my PCP on return to the US and was diagnosed as having a UTI. I was treated with at least 5 different antibiotics with little or no success for over five months. I could not get a referral to a specialist from my PCP despite my asking from the third month on. I had an HMO as health insurance at the time. I was forty at diagnosis (last June) , superficial large tumor and several small ones removed at initial TURB. BCG therapy thereafter. Recurrence this month. Undergoing repeat TURB on Thursday. The delay was pure and simple bloody mindedness on the part of my PCP, a woman, who insisted that I only had a chronic UTI. (I am a nurse, I think this also influenced her thinking, i.e. "I'm the doctor " power thing). This was definately a financial decision on her part. Thank God I didnt have an advanced staging or I would have been dead by now thanks to her. Try explaining that one to my five year old son.... Joyce

Delay 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) I was eventually diagnosed with stage IV bladder cancer and had a radical cystectomy at age 32. Lea

Delay Not even all urologists are on the ball to check for bladder cancer when there has been a history of bleeding. The first urologist I was referred to told me "he didn't see anything in my urine that would alarm him and I was probably trying to pass a stone. Another 6 months passed and more blood with urinating. I went back to him he FINALLY did a cystoscope check and gave me the news very matter of fact "you have a tumor and it is bleeding, didn't your prior urologist Dr. so and so do a cysto on you." I told him I had never been to Dr. so and so or any other urologist. That is another problem in medical offices - insufficient record keeping and patient profile. Obviously I did not stick with him nor his office. Rosie

Delay I am a woman and was 63 at time of diagnosis. I must admit that any delay was due to my not seeking advice about symptoms immediately. I had intermittent cystitis symptoms from about July through December. Finally in December I got to my doctor, an internist, who found hematuria but said the culture was negative. She recommended a urologist that I went to in December. The urologist ordered a urine cytology and asked me to get a CT scan. The CT scan was normal but the urologist told me on Jan 12 that there were malignant cells in the urine. She then made a Jan 18 appt for me with Dr. Donat at Sloan Kettering. Dr. Donat did the TURBT on January 24. The biopsy showed CIS and T1 high grade. I started BCG on Feb 15 and finished on March 22. Dr. Donat did a cystoscopy 6 weeks

later on May 3 which she said looked good, but she didn't want to wait 3 months to look again. So she did another cysto 6 weeks later on June 14 and saw what appeared to be a new tumor in a different spot. I had a second TURBT on June 20. The biopsy showed another T1 tumor, high grade. I decided to have the radical cystectomy which has been scheduled for July 24. My insurance is a PPO which has been very cooperative. When I inquired about their coverage for the options I was given (conduit, Indiana pouch), they said I should choose whatever is most appropriate and best for me. Hope this is helpful. Best, Marti

Delay The delay in diagnosing my cancer was entirely my fault. But I still think my experience is relevant because many women tend to ignore important signals and are not aggressive enough in demanding help. I ignored the symptoms of urgency/frequency for four months.

It was only when I experienced pain after urinating that I stopped by my GP's office (without appointment on my lunch hour) and saw the nurse. I thought I had a UTI. When I looked at the sample in the little clear jar I realized for the first time that it looked rusty colored. I still did not know that rusty urine was an indication of blood. I was not at all alarmed until she called the doctor to take a look. He asked a few questions and put me on a one week antibiotic with a strong admonition to report back next week.

There was no improvement with the antibiotic and the following week when I saw him he personally called the urology department of the local medical clinic. They couldn't see me for a month. So he turned to me and said, "If you were my wife, I would not want you to wait that long. Do you mind if I call someone else?" He got me an appointment the following week with a wonderful urologist who wasted no time in doing a cysto three days later. He in turn referred me to a urologic oncologist who saw me that same week.

Things moved quickly for me once I had the good sense to see a doctor. Too many women blame frequency and urgency on age and the inevitable pull of gravity on our bladders that cause stress incontinence, frequency/urgency. Also, as stated by others, women are accustomed to seeing blood and don't get alarmed. Sometimes, as in my case, we can be our own worst enemies!
Carole A./Georgia

Delay Gender: female Age at diagnosis: 29

Bleeding: 6-12 months before dx Stage: 2-3cm papillary, no invasion, small unifocal CIS at base. Treatment: no cystectomy required, on maintenance BCG, no recurs in 16 months IMO, delay mostly due to age, negative cytology on several urine tests, usually had an infection and slight improvement of condition while on antibiotics, delay had no relation to insurance
Melissa

Delay 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. I had a radical cystectomy on the 23rd of January, 2001, and have had no chemo. LaNette

Delay I was 52 when started having the hematuria. I thought it was uterine though I had not menstruated regularly in at least five years. I noticed it was only when I peed, and thought it was interesting that I did not need to wear a napkin since there was nothing in my underwear, it was only when I peed. It was so unalarming that I did not advance my usual GYN appointment and had the bleeding on and off for at least 4 months. I reported it to my GYN who ordered me in for an endometrial biopsy, which showed nothing. When I kept spotting/bleeding, she put me on a course of antibiotics thinking it might be a kidney infection. I finished that and reported that I was still bleeding, and reported again that it was only when I peed, she sent me to the urologist who discovered the tumor by scoping me. I had said throughout that the bleeding was only when I peed. My delay and her belief that it was uterine cost me about 6 months. By that time I was stage 4 with node mets, lost my bladder, and had 6 months of chemo.

What really saved my life was that my internist had given me prescriptions strength painkillers and then I REALLY started bleeding and putting out huge clots which occasionally occluded my urine flow. My GYN finally believed me-- and I finally realized that this was SERIOUS. Karen

Responses from men

No Delay As for myself.. I knew the second day I went to the hospital after I had passed blood in my urine. I went to the emergency room (Tripler Army Medical Center Hawaii).. and was quickly carded off to the urology dept. I was admitted for that evening and saw a uro the same nite. The next morning I was in pre-op and a TURB was done. I was shown the pic of the site and I quote " yep looks like it to me.. its called CIS and we will know more tomorrow "... then he said we got it early and its treatable with a good prognosis... but no less.. it scared the shit out of me.....

i often hear of crappy Dr's in the military...well I'm living proof that thats

a bunch of crap...from combat wounds to heart surgery to now "BC"...they did an excellent job.. " one day and no hesitation to the dx..as my doc said "lets nip in the ass now and move forward" Joseph

No Delay My husband had no delay at all from his PCP nor urologist.

Sharron Wife of Jerry, diag 3/00 TCC Renal Pelvis and CIS bladder.

No Delay I was diagnosed early, but if you are really surveying you should get both sides of the coin. Blood in urine detected by GP in 1985 Sent to Urologist. Cysto found anomalies. Looked in every six months. CIS detected in Jan. '89 Bladder Removed (at Mayo Clinic) in Oct. '95 Mine was a positive experience all the way starting in upstate NY with first check up through today in Rochester, MN. Wayland, 68

No Delay Maybe we need to give credit too where credit is due. Microscopic blood cells were discovered in my husband's urine by his endocrinologist and he was immediately scheduled for an ultrasound. Within a week he was seen by a urologist and a month later had a TURBT. Result: Grade 1 superficial papillary transitional cell carcinoma. Medical care doesn't get much better than that. Erika

Delay Rollie had blood in his urine over two years before being referred to a Urologist. It was not financial, it was simply incompetence. "It's nothing. It's gone now. No infection."

My brother also was having blood in his urine and is a heavy smoker. After Rollie's DX, he had to beg his PCP for the appropriate tests and to see a urologist. And the urologist had to be begged. One of the Dr.s said to him "about 80% of bleeding resolves itself. don't worry." My brother insisted and the appropriate series of tests were fine. Now they are telling him "See?? We told you so." sherry

Delay To Begin, I first noticed blood in the urine in April of 2000 but only when the light was on. So I chose to leave the light off for a few weeks

Went to my HMO beginning of May and emergency room doc. said it was probably UTI prescribed antibiotics, said not to worry and

that a culture would be done and if there were any problems my regular doc would call me. (antibiotics cleared up hematuria) Never

heard a word more about that and doc began treating me for high blood pressure and diabetes. A few months later I made another

appointment due to hematuria and (Thank God my regular doc was off.) second

doc said "We know the first episode was not UTI

because the culture test was negative for infection." Took second culture and more antibiotics but this doc. called me back in a

few days telling me he had scheduled a CT Scan. Fired my first doc and got another Primary Care Physician. New doc. called me with

the results of the CT scan and referred me to a Urologist who did the cystoscope exam and scheduled me ASAP for my first of two

TURBs.

In Summary: First delay in DX and treatment was my own denial and second delay was due to my 1st Primary Care Physician ignoring

the negative results of the urine culture. From 1st hematuria (May 3 or 4, 2000) to DX was end of August. or nearly four months.

Male - 62 at time of DX - 4 months delay (2 months I attribute to doc.)
- 21 tumours Stage & Grade II/III - 2 "All Clear" No New
Tumours - Poor medical decision on docs. part (we were not having a good patient/doc

relationship --- personality conflict or something and I would have changed docs eventually but I did not then know I had a serious possibly life threatening disease - now I would like to choke the man.) This doc. is no longer at my HMO.

Though very unhappy about that one doctor, I am very well satisfied with my nearly 40 year membership in Kaiser Permanente HMO.

Kaiser seems to be focused on education and prevention but they still have a tendency to push pills. I have great confidence in my

Urologist. Dr Paul Nguyen has saved my bladder and his goal was always to cure the cancer.

I hope all the above is of help and am very interested in the final survey results. Yours in Christ and in Good Health, Ed in California - You and all BC Cafe Warriors are in my prayers

Delay Slightly different twist. Urologist failed to suspect BC although there was spasmodic blood in the urine.

The blood showed up after a Radical Prostatectomy. It was discounted as being that "some stitches from the surgery were probably pulling". This continued for months after the surgery. I would categorize this as a faulty "medical decision".

It was purely by a coincidental small kidney stone, 18 months after the Prostatectomy, that a cytology was ordered and the BC discovered. Fortunately it has been treatable, so far, but the CIS has returned at least once. I now believe that ANY blood in the urine should be suspect. Best Regards, Paul San Diego, CA 71 years old

Delay Re: my husband, age at diagnosis, 51

1. Primary care physician didn't sent him to a urologist, even tho he had blood in his urine. Treated it with antibiotics, assuming it was an infection. When it didn't clear up after the antibiotics, dr. finally referred him to a urologist. This was the second try; the first guy didn't see any blood in the specimen, even tho my husband was seeing it.
2. Length of time between blood in urine and BC diagnosis: 4 months.
3. Tumor was stage IV, don't know grade. Invading bladder wall. Went straight to radical cystectomy, neobladder. (Followed by bone mets 6 months later).
4. Source of delay: medical decision. First dr. didn't believe him, and the second guy didn't believe him, but finally came around. His urologist said anyone who says he has blood in his urine, whether the dr. sees it on a slide or not, should be scoped. Nellie

Delay Ben, 45, 1976 - 2 bright red drops of blood after first AM urine. GP checked the urine in the office. All clear. Check again in 2 weeks. Again, clear. No further symptoms.

Approx 3 years later, gradual frequency & slower urination. GP suggested urologist. Cysto - papillary tumor size of peach pit. IVP, CTscan & TUR - stage A, grade II papillary tumor. Cystos every 3 months plus annual IVP, CT, TUR and random biopsies all clear for 2+ years. No BCG or chemo.

January, 1982, routine cysto - small sessile tumor.

March 1982, age 50, 4500 rads radiation followed by radical cystectomy w/ileal conduit in April, 1982. Bladder had multiple sites of CIS plus sessile tumor. GP said Ben did not fit the profile to even consider bladder

cancer - too young, non smoker, Mr. Clean & fit. Hello? Even in 1976, GP should have known to check with a urologist. But then, we should have as well. In 1982, uro should have sent Ben to one of the comprehensive cancer centers specializing in genitourinary cancers. Like most uros, he and his partners saw only a few cases of bladder cancer in their entire careers! Again, we should have investigated on our own. Could probably have avoided radiation altogether and the resulting scarring and problems. Talk about "too old smart." Roni
