Bladder Cancer
Symptom Awareness

Action
Bladder Cancer UK

Women and Bladder Cancer

This information leaflet is aimed at raising awareness of the signs and symptoms of bladder cancer in women, and includes direct quotes from women about their own experiences of diagnosis.

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Bladder Cancer Symptoms

This information leaflet is aimed at raising awareness of the signs and symptoms of bladder cancer in women, and includes direct quotes from women about their experience of diagnosis.

Bladder cancer can often be diagnosed late in women. The earlier the diagnosis the better - both for the longer term outcomes for the patient and for effectiveness of any treatment undertaken. There are several factors which can influence this late diagnosis. Below we list the most common symptoms of bladder cancer, and highlight some things which women should be particularly aware of.

Symptoms in women can be trickier to notice, or assumed to be something else. If you have any of the issues listed here you should get checked out by your GP.

The most common symptoms of bladder cancer are:

- Blood in the urine (even just once). It's usually bright red, but sometimes rusty (cola-coloured) or dark brown.
- You may also see blood clots or threads of blood.
- If there's only a small amount of blood in your urine, it may not be obvious, but there are urine tests which your GP can use to check.
- These symptoms might look like those of a urine infection, but tests by your GP may not actually find any infection. If no infection is found, this needs further testing.
- See your GP at the first sign of blood in your urine. Even if it happens once or goes away for a while – don't wait.

Other symptoms may include:

- Pain or discomfort during or after passing urine when no infection has been found during urine tests.
- This may feel like an irritation.
- Feeling the persistent, or recurrent need to pass urine more often or more urgently.
- Pain or aches in lower back or stomach. Only some people will experience these.
- Symptoms can occur alone or in combination with other symptoms.

If you have ongoing symptoms, or recurring UTIs where symptoms persist despite antibiotics, it is important to monitor your symptoms and track them (make a note) as it could help GPs to identify who may need further investigations or a referral to a urologist.

It is important that bladder cancer is diagnosed early. Your treatment will depend on the type of bladder cancer that you have, where your cancer is, and how quickly it is growing.

You should always keep an eye open for any changes when you urinate.

Your period can mask blood in your urine so your doctor may ask for a sample when you are not having a period.

If you are no longer having periods, you should always tell your doctor about any bleeding you notice.

If your GP diagnoses a urinary infection after you have seen blood in your urine, make sure you ask if the urine test confirmed an infection or not – if not, ask whether you need further tests to rule out bladder cancer.

If you see blood in your urine, and your GP does NOT refer you for further tests, ask them to explain why.

It's OK to ask for a second opinion.

If you are referred, especially if you're over 45, ask your GP about fast track referral.

Although bladder cancer is less common in people under 45, you must still act.

If you have urinary tract infections that keep coming back, are hard to get rid of and last a long time this may be a sign of bladder cancer.

Ask your GP if you need further tests. If you're worried about bladder cancer or your symptoms, and you can't get an early appointment, stress your concerns to your surgery.

Bladder Cancer Symptoms cont,.

If it makes you more comfortable, ask to see a female GP.

If friends or family notice you aren't well, or are concerned about your health or symptoms, listen to their concerns and see your GP.

You can always bring someone along to your appointment for support.

Write down your symptoms and concerns before your appointment.

If you have a family history of bladder or kidney cancer, tell your GP.

Let your GP know if the following risk factors apply: smoking (or second hand smoke), chemical exposure (e.g. working environment) or previous radiotherapy treatment.

If your symptoms don't improve within 3 weeks, or if you're still worried, go back to your GP. Do this even if your tests were negative or you see no further blood in your urine.

Bladder Cancer

UTIs – urinary tract infections

The reason we are highlighting UTIs is because some UTI symptoms can be similar to the symptoms of bladder cancer, which can lead to a delay in diagnosis. Symptoms such as blood in the urine, pain or discomfort, or a frequent need to urinate which can be symptoms of a UTI, can also be symptoms of bladder cancer. UTIs are more common in women than in men.

Whilst most women who get urinary tract infections will not have bladder cancer, and their infection can be successfully treated with a course of antibiotics, blood in the urine should never be ignored and should be investigated.

Your period can mask blood in your urine so your doctor may ask for a sample when you are not having a period.

Do not assume this is happening just because you are getting older, or you are of menopause age, and it's 'one of those things'.

Recurrent urinary infections

If you are repeatedly getting symptoms of a urinary infection (especially blood in the urine), they keep coming back, or infections that are hard to get rid of and last a long time, this needs further investigation.

You may have been given antibiotics, but if the symptoms have returned, this could be a sign that something else is going on. Persistent or recurrent urinary symptoms should always be properly tested to rule out underlying issues.

If you have been prone to infections in the past, it might be assumed that you have yet another UTI rather than being tested further for any other underlying cause, such as potential cancer.

When your urine has been tested for a UTI, it is important that you ask your GP to confirm whether or not an infection has in fact been found and if you need further tests. If no infection is confirmed and you have had blood in your urine, this needs to be investigated.

Women patients often tell us that their symptoms were assumed to be a UTI which led to a delay in their diagnosis – you can read about the experiences of women diagnosed with bladder cancer at the end of this leaflet.

Menopause – starting, during, or after the menopause

When you are going through the menopause you may have various symptoms, you may also have these symptoms leading up to or after the menopause.

You may start to have irregular periods, they may stop and then you might have some breakthrough bleeding a bit later on. You may have other symptoms. These changes may mask any symptoms of bladder cancer.

Don't always assume that any blood you see in your urine might relate to starting, or having the menopause, or the after-effects of the menopause.

If you are no longer having regular periods, you should always tell your doctor about any bleeding you see.

Gynaecological Issues

The symptoms of bladder cancer can sometimes be mistaken for other, or existing, gynaecological conditions so always ask your doctor about any ongoing bleeding or discomfort.

Even if you have had previous surgery for a gynaecological issue – don't assume any bleeding you may notice relates to this.

Risk Factors

Smoking is a known risk factor in causing cancer and if you do smoke it would perhaps be wise to consider giving up, and you can seek help to do so. There is some evidence that female smokers are more at risk than male smokers, although smoking is bad for anyone. Smoking is relevant in bladder cancer as impurities and chemicals in tobacco will pass into the bloodstream and then into the bladder to be stored until you pass urine.

Workplace issues such as exposure to chemicals or dyes have been shown to be a risk factor in bladder cancer. If your job involves using chemicals, make sure you use proper protective gloves or clothing, or ensure your employer provides you with these and reviews the safety of any chemicals being used.

Previous radiotherapy – if you have had radiotherapy in the past.

Women's experience of diagnosis of bladder cancer – these are all direct quotes from female bladder cancer patients who have helped us compile this leaflet

KEY

NMIBC – Non muscle invasive bladder cancer: cancer confined with bladder walls, however high risk NMIBC has risk of becoming MIBC.

MIBC – muscle invasive bladder cancer: cancer has penetrated the bladder walls.

Cystoscopy – examination of inside the bladder using a micro camera.

TURBT – Transurethral Resection of Bladder Tumour: procedure to resect (remove) a growth inside the bladder. This is both the diagnostic procedure for bladder cancer, and also the first part of the treatment.

BCG – Immunotherapy treatment administered by instillation direct into the bladder.

We have collected some comments from women about their symptoms before their diagnosis with bladder cancer

Nikki was diagnosed with grade 3 muscle invasive bladder cancer, when she was 50 years old. She has had courses of chemotherapy and her bladder removed.

November 2016: I had a really bad water/kidney infection that floored me for a week. Then in March 2017 I noticed blood in my urine. Luckily I had a sample jar which I took with me to the doctors and was asked if I wanted a cystoscopy to have a look inside my bladder, which I did. The image showed a dark red angry tumour in my bladder which I now know was muscle invasive bladder cancer.

My only thing to say is please, please do visit your GP if you notice blood in your wee, it could just save your life - it did mine!

Diane was diagnosed with grade 2 non-muscle invasive bladder cancer in 2014, when she was 59. The cancer came back again in 2015 and again in 2016. Diane has been treated with surgery and chemotherapy.

January 2014: I had a massive bleed when passing urine. I went straight to my GP's surgery taking a sample with me. This was sent for testing and I had an ultrasound 2 weeks later and in **March 2014** I had my first operation and chemotherapy.

It was found that I had a cancerous tumour in my bladder about the size of a golf ball which, when you consider the bladder is about the size of a large pear, was quite something. I have no idea why it bled, but I am very pleased it did as the surgeon estimated I had had this since 2012, with absolutely no symptoms.

If I had to give one piece of advice it would be that if you have any worries about your bladder or wee get it checked out, don't just put it down to a urinary infection. Do not put it off, do not make excuses, do not say 'I'll go next week', do not think 'I don't want to bother the doctor', or 'I can't get the time off work'. The cemeteries are full of indispensable people and whatever you do, do not die of embarrassment! I am so pleased that I got checked early and would urge everyone to do the same.

Caroline was diagnosed with high risk bladder cancer, when she was 51, after noticing small amounts of blood in her urine. She had her bladder removed.

I first noticed ... two tiny spots of blood, the size of a pin head, on the paper. I'd had an operation to remove the lining of my womb two years before, so I just thought it might be related to that and didn't think anything more of it. A couple of weeks later I went to the toilet and noticed blood on the paper again, along with a streak of blood in my urine.

I went to see my doctor straight away and gave a urine sample so that it could be tested for blood, but it came back clear. I was also given a physical examination, but my doctor told me the symptoms were probably related to my operation and I was asked to monitor my symptoms for three months to see if they formed a pattern.

Just two days later, I noticed blood again, so I went back and saw another doctor. A second urine sample came back clear, I was asked to monitor my symptoms for a month. Over the next four weeks I noticed very small amounts of blood on two occasions but when I returned to my doctors, a third urine sample again showed no sign of blood.

In the meantime, I was referred to a gynaecologist for an ultrasound, it was then that an abnormal growth on the lining of my bladder was discovered. I do think that if I hadn't been persistent with my worries I may have been diagnosed at a much later stage and the cancer could have been more difficult to treat.

As a woman, you get used to bleeding. I hadn't had any pain and I didn't lose weight. Everything else was normal. So many women, particularly my age, would have done nothing. They would have taken the doctor's advice and left it three months to see if there was a pattern. That's what you want to be told so you believe it. I want to tell women not to accept symptoms as gynaecological. The chances are that it won't be cancer, but if you can catch it early, it can be treated more easily. Cancer is scary, but the thought of getting it is probably more scary than dealing with it.

Debbie was diagnosed with G2 bladder cancer in 2012, and subsequently Carcinoma in Situ (CIS). She has had BCG treatment.

I had had many visits to my GP over the years for UTIs and was given antibiotics as usual. At New Year 2012 I noticed blood in my urine and went back to the GP again, asking to be referred as I was not happy with being given yet more antibiotics. I had an ultrasound scan and was told there was a' fuzzy area' that needed more investigation. I drove home feeling slightly worried, but thinking 'Hey - cancer won't happen to me!' When I walked in the door the phone was ringing and it was my GP surgery to say they had had a call from the hospital. I was amazed at this speed but also more worried now as it must be serious for such haste!

Bobbi was diagnosed August 2022, with T1 Non muscle invasive bladder cancer, aged 42. First noticed symptoms early 2022, treated for UTIs and also checked for early menopause. She has had BCG treatment and a recurrence.

Symptoms first experienced and what happened next:

Early 2022: Experiencing what thought to be UTIs

February 2022: Started with UTI's, had quite a few courses of antibiotics from February 2022 to July 2022. Had 3 different antibiotics (Nitrofuratoin, Amoxocillin and Co-Trimoxazole) and none seemed to help. I kept having to take in samples and then was given antibiotics.

July 2022: one of the GP messaged to say I'd had a lot of courses of antibiotics, so needed a review. I went in and by then I had visible blood in my urine (cola coloured). My GP sent me for an ultrasound which showed something in my bladder. I was fast tracked - had a call with consultant who said needed a camera.

End August 2022: Had cystoscopy end of August - found tumour.

01 September 2022: First TURBT. Diagnosis – Bladder cancer T1 3-4cm tumour at age 42.

At the GP: I spoke to at least 3 different GP's and none seemed to register that the antibiotics weren't working and that it was an issue. I felt if I'd not kept taking samples that nothing would have been done. The GP I did see said that due to my age (42 at the time) that it wasn't normal protocol to investigate further.

Mistaken for anything else: At the time I was being checked for Early menopause - common symptom is UTI's so I think it was thought to be that. To be honest, I thought it was that. Had bloods in August 2022 which showed post menopause.

April 2023: Recurrence - Ta 0.5cm

Treatment: TURBT (no Chemo given), BCG - 15 doses initially advised, but due to recurrence of Ta 0.5cm in April 2023, I was given 18 treatments which finished in November 24.

Kate was diagnosed with Non Muscle Invasive Bladder Cancer, when she was 65. She first spotted blood in her urine in July 2024, she had several courses of antibiotics before diagnosis.

I'm a 65 year old mum and grandmother. My symptoms started with pink pee last July and I went back to the docs so many times for more antibiotics because they didn't know what to do with me. I went on holiday in October and started bleeding again. It was bad. It looked like red wine. When I came home I called the surgery and fortunately got a new doctor who fast tracked me to the hospital.

Christine was diagnosed with G3 NMIBC in 2024, she was 61 years old. First noticed symptoms in 2023, she had a radical cystectomy.

August 2023: I first went to my GP. Burning and sore when urinating. Nurse tested and there was blood in urine so was told I had a UTI and given a course of antibiotics.

November: same symptoms but visible blood in urine, saw nurse practitioner. Told her my older sister has had bladder cancer and cystectomy. Still said UTI and given different antibiotics.

December: still had symptoms, more antibiotics told to see GP after Xmas if symptoms persist.

Early 2024: Saw GP who gave me antibiotics and a blood test and was told to return the following week.

When I returned she tested my urine, still had blood showing and GP said that she would refer for ultra sound and cystoscopy. Hospital called the next day and I had both tests 2 days later.. which identified the tumours .. three I believe and also CIS.

Following week I had a TURBT, and 2 weeks later I had another TURBT the result was aggressive bladder cancer … NMIBC G3pT1 plus CIS.

I discussed treatments with 2 consultants who advised radical cystectomy due to the cancer being high grade and aggressive. I was 61 years old.

All my treatment was undertaken through the NHS. I can't thank them enough. However, since my surgery I have to inform GP's about my cystectomy and bladder cancer, as several that I have seen have very little knowledge of cystectomy in females and the implications after.

Michelle was diagnosed November 2024 with MIBC G3 pT3b. She noticed first symptoms in July 2024. Had cystectomy in December 2024

Beginning of July 2024: I saw blood in my urine, the nurse wasn't concerned as no infection was shown.

Beginning of August: more blood in urine and GP referred me for an ultrasound, apparently this got rejected.

Beginning of September: getting blood clots and GP referred me on the 2WW.

From July until the end of September: blood in the urine became more frequent with blood clots getting bigger, no other symptoms, no weight loss. During this time I felt I wasn't being taken seriously, and did my own research and knew that I should be seen urgently, I felt that the longer it was left the worse the outcome.

End of September: I had a Cystoscopy, which found a tumour, and a CT scan.

End of October: I had a TURBT.

15th November: meeting with surgeon – was told I had MIBC G3 pT3b N0 R0and kidney had died, and definitely need surgery (Radical Cystectomy), and given lots of information. Decided to go ahead with the GUSTO trial (they decided 'straight to surgery'), had blood tests, MRI, PET scans and Iron infusion.

Early December: Surgery RC, Hysterectomy and kidney removed

Early February: 4 rounds of chemotherapy.

I was relieved when they said straight to surgery, as the thought of the tumour growing inside me was scary. Recovery was hard and chemo was hard too but all I wanted was to get on with my life. I thought I was going to die soon but now I am living life with a stoma and trying to adapt and adjust to live a long healthy happy life.

Karen was diagnosed with NMIBC G3 pT1 and pTa and CIS bladder cancer, aged 60. Diagnosis to cystectomy took 3 months.

During the pandemic, and just after my 60th birthday, I noticed a few spots of blood in my underwear. Shortly afterwards I had a bath and the water turned red.

It was a time when GPs were under great pressure but, having googled this symptom, I (very fortunately) decided to report it in an 'e consult'. I expected just to receive a reassuring message but was told to take a urine sample to the surgery. When he received the results, the GP phoned and asked me to come for an in-person appointment straight away. He felt my abdomen and said he couldn't feel anything abnormal but was referring me to Urology as a precaution.

I soon got an appointment at the hospital for a cystoscopy. At this I was told there were cancers in my bladder and I was shown them on the screen.

Things moved pretty rapidly after that. After an initial TURBT, treatment options appeared to be immunotherapy or early cystectomy. But after a second TURBT a month later, it was clear that a radical cystectomy offered by far the best chance of removing the cancers. The diagnosis was Multifocal G3 pT1 and pTa and CIS bladder. I had the major operation a month later. Diagnosis to cystectomy took 3 months. I have now enjoyed almost 5 years cancer free since the treatment.

Susan was diagnosed with MIBC squamous cell carcinoma in January 2024. First saw symptoms in November 2023, aged 65. Sent to A&E in December.

November 2023: My journey began, just after my 65th birthday when I began to feel generally unwell. This progressed to feeling some discomfort when I needed to pee and the urge became increasingly frequent. I was no stranger to the UTI and kept urine test strips at home. The result of my home test was positive for blood but not much else, although no blood was visible to the naked eye. My GP surgery informed me that test strips are no longer reliable when you reach 65 but after a phone conversation with a practice nurse I was prescribed a course of antibiotics. Five further courses of antibiotics followed and there was no improvement in my symptoms.

By early December the blood in my pee was pretty spectacular and everything felt wrong. My lab tested urine sample showed no evidence of infection. ➤

At this point I felt stuck in a never ending loop of antibiotics and I was feeling increasingly unwell. I requested a private referral to a urologist as this seemed to me to be the quickest way to get some help. Unfortunately the referral for a CT scan was delayed because Christmas was looming.

29 December: When the CT scan finally took place, I was sent directly to A&E. The scan showed a large tumour in my bladder blocking the tube draining urine from my right kidney to my bladder. My kidney was swollen and misshapen and I needed an emergency nephrostomy to relieve the pressure.

January 2024: Things started to move quickly from this point. A few days later I had an urgent TURBT to investigate the tumour in my bladder, which showed a muscle invasive bladder cancer. The histology results confirmed this to be a squamous cell carcinoma, a particularly aggressive form of bladder cancer for which the only treatment option is surgical: a radical cystectomy. This took place two weeks later.

So November to January was a roller coaster ride for me and my family. I look back now on those early symptoms and the length of time that it took to navigate my way through GP services in search of the help that I needed, and I reflect that the outcome could have been very different. Yes, my particular cancer is rare but it is known to be aggressive, and awareness of symptoms and risk factors within my GP practice was low.

Anne was diagnosed with MIBC G3pT2 TCC in June 2020. She has first had symptoms in August 2019. She had a cystectomy in December 2020.

August 2019: The first symptoms I noticed was, when after going to the toilet, I noticed a light pink colour on the toilet paper. There was no blood in the toilet at all and naïvely I thought it was just “one of those things”. I was also almost through the menopause and thought it possibly might be something to do with that.

Some weeks later, I experienced exactly the same symptoms but they were no worse. However, this time I did make an appointment with my GP.

At the appointment I did explain to my GP that the blood on the toilet paper was not like menstrual blood, and I felt sure it was possibly something to do with my water works. My GP did a quick urine test but it showed no blood in my urine whatsoever and because I was 57 at the time, I was referred to the gynaecology department for investigations. ➤

January 2020: Some months later I underwent a hysteroscopy procedure which proved inconclusive.

Precious months had been wasted going down the gynaecology route and I went back to my GP as I was still having intermittent symptoms which had now evolved to include an overwhelming ache/pressure/uncomfortable need to wee.

March 2020: Finally, I was due to have an ultrasound scan of my bladder but unfortunately this was postponed due to the outbreak of the Covid-19 pandemic.

May 2020: Two months later, I received a phone call from the hospital asking me to go in the following day for an ultrasound scan on my bladder which I did. The day after my ultrasound scan I was told a mass had been found on my bladder, most likely cancerous and I would need a TURBT. I was 58 years old.

My treatment was shared over three hospitals. I had one TURBT in June 2020 at Kettering General Hospital, which confirmed my diagnosis as Muscle Invasive Bladder Cancer G3pT2 TCC. I then underwent three cycles of intravenous chemotherapy (Gemcitabine and Cisplatin) from mid July 2020 until mid September 2020 at Northampton General Hospital.

December 2020: I underwent a Radical Cystectomy, full hysterectomy, part of my vagina removed along with 41 lymph nodes in Leicester General Hospital. My surgery lasted 6 hours and was carried out robotically. I now live with a Urostomy bag and stoma and life is very good.

Sandra: Diagnosed at 75, following 3 rounds of antibiotics:

I initially had a UTI with antibiotics this did not clear.

Another 2 rounds of antibiotics then seen by GP. He obviously felt something on exam and suggested I see a urologist. At this point I had evidence of bleeding.

Referred to Urologist whereby I had several scans and then diagnosis. Once the diagnosis was established and dates for surgery explained my tumour was growing and I could not sit down. This was extremely distressing and I’m not sure I was believed. Pain control at this stage minimal only advised Panadol.

I was a very fit active 75 year old. Once in the surgical care excellent support and treatment.

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