



York and Scarborough
Teaching Hospitals
NHS Foundation Trust

Information for patients undergoing BCG bladder treatments

Information for patients, relatives and carers

Department of Urology

① For more information, please contact the hospital
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For York Hospital:

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What is the evidence base for this information?

This publication includes advice from consensus panels, the British Association of Urological Surgeons, the Department of Health, and evidence-based sources. It is, therefore, a reflection of best urological practice in the UK. It is intended to supplement any advice you may already have been given by your GP or other healthcare professionals. Alternative treatments are outlined below and can be discussed in more detail with your urologist or specialist nurse.

What does the procedure involve?

Instillation of BCG into the bladder for aggressive or recurrent superficial cancer of the bladder.

What are the benefits of the procedure?

To treat bladder cancer, helping to discourage re-growth and/or changes to bladder cancer.

What are the alternatives to this procedure?

Repeated cystoscopy, radiotherapy, surgical removal of the bladder with urinary diversion or bladder reconstruction, systemic chemotherapy.

What should I expect before the procedure?

Your consultant urologist has referred you for treatment of your superficial bladder cancer. Superficial bladder cancer affects the inner surface of the bladder only but has the ability to recur frequently and progress to more aggressive disease with invasion of the muscular layers of the bladder wall.

The aim of the treatment is to stop or slow down recurrence by instilling a drug in liquid form into the bladder. This is called intravesical immunotherapy. The drug treatment recommended for you is BCG. BCG is a commonly-used vaccine against tuberculosis (TB) and contains a bacterium from the same family as the TB bacterium which has been altered (attenuated) to reduce the risk of infection whilst retaining the ability to produce the immune reaction needed for its beneficial effect. It has been shown that putting liquid containing BCG vaccine into the bladder is an effective treatment for superficial bladder cancer.

Like all powerful treatments, it comes with some possible side-effects listed in this leaflet and the risk of these should be considered against the benefits of the treatment.

There is some evidence that the BCG treatment may interact with some vaccines. Therefore, please discuss any recent, or proposed, vaccinations with your urology specialist nurse prior to commencing treatment.

The initial course is called the “Induction Course” and lasts for six weeks. One treatment is given each week for six consecutive weeks. Following completion of this, you will enter a program of treatment (called the “maintenance therapy”) that lasts up to three years. This will consist of a series of weekly treatments over a three week period at three, six, and 12 months, and then in some cases a further six-monthly treatments for up to three years in total. Bladder inspections (cystoscopies) will be performed between blocks of BCG treatment to assess the response, or effectiveness, of the treatment.

The main reasons for patients failing to complete the full course are side-effects (see below) and/or disease progression or recurrence.

You should limit your fluid input for six hours before each treatment and for two hours after the treatment being instilled.

On arrival in the clinic, you will be asked to pass urine, which will be tested to ensure that you do not have a urine infection. If you do, your treatment may need to be postponed while you are treated with antibiotics.

Your first treatment will take up to three hours and, depending on how well you tolerate the first treatment, future visits will take approximately 30 minutes.

Please be sure to inform your surgeon or specialist nurse in advance of your treatment if you have any of the following:

- an implanted foreign body (such as a stent, joint replacement, pacemaker, defibrillator, heart valve, blood vessel graft or neurosurgical shunt)
- a regular prescription for a blood thinning drug (such as warfarin, Clopidogrel (Plavix®), Apixaban, Ticagrelor, Aspirin, Rivaroxaban or Dabigatran)
- a previous or current MRSA infection
- a high risk of variant-CJD (if you have received a corneal transplant, a neurosurgical dural transplant or previous injections of human-derived growth hormone)
- Problems with your immune system. This could be due to an illness or medication that you are taking. Such as HIV, Leukaemia or medication such as steroids or chemotherapy
- have, or think you may have, TB (tuberculosis)
- are on any antibiotic treatment
- You have urine infection
- You are allergic to BCG
- If you have been told that you cannot tolerate, or digest, some sugars. As BCG contains a type of sugar called lactose.
- You are pregnant, breast-feeding, or trying to conceive a child

- Your treatment will not be able to go ahead if you are passing blood that you can see in your urine. Therefore, if this happens, please ensure you tell the nurses prior to your treatment
- Your treatment should not usually be given within two weeks of your cystoscopy or TURBT (procedure to look inside your bladder or remove the bladder tumour).

At your first appointment you will be asked to sign the consent form (reference FYCON100-3 Course of BCG) giving permission for your treatment to go ahead. This shows that you understand what is to be done and confirming that you wish to proceed. Make sure that you are given the opportunity to discuss any concerns and to ask any questions you may still have before signing the form. The form will be kept in your patient notes and you will also be offered a copy for your own records.

What happens during the procedure?

You will be taken to a cubicle and asked to remove the clothing from the lower part of your body and lie on a trolley bed with a towel over you for privacy.

Unfortunately, we usually cannot allow relatives or friends to come into the cubicle with you, and they will be asked to stay in the waiting room. If this is of concern to you then please discuss with the urology specialist nurses prior to treatment.

- we will clean your genital area with anti-septic solution and pass a fine plastic tube (called a catheter) into your bladder
- we will instil approximately half a cupful of the BCG preparation through the catheter
- we will remove the catheter from your bladder
- we ask that you try not to pass urine for the next two hours, to allow the medication to treat the whole bladder lining
- on your first visit, we normally keep you in the clinic until you have passed urine but, for any remaining treatments, you may be allowed to go home, with the medication in your bladder and pass urine after two hours when you are at home

If you have, or are told you will need, an indwelling catheter for the treatment then the procedure is altered, please see pages 24-25. If you have a septic tank at home then please notify us prior to your treatment.

What happens immediately after the procedure?

In general terms, you should expect to be told how the procedure went and you should:

- ask if what was planned to be done was achieved
- let the medical staff know if you are in any discomfort
- ask what you can and cannot do
- feel free to ask any questions or discuss any concerns with the ward staff and members of the surgical team
- ensure that you are clear about what has been done and what is the next move
- once the treatment has been completed, you will be able to go home

You should ensure you wash your hands and genitals well after you have passed urine for the next few days, and it is advisable to bring a wash bag into hospital when you attend for your treatment.

You must ensure that you pass urine at your own home and do not use public toilets on the way home, this is because the drug can be harmful. Urine passed within the first six hours after you have been treated should be disinfected by pouring a quantity of undiluted household bleach (equal to the amount of urine passed) into the toilet; this should then be left for 15 minutes before flushing the toilet.

For up to six hours after the treatment, men should urinate while sitting to minimise the risk of splashing urine which contains live bacteria.

You should drink plenty of fluids (two to three litres) for a few days after the treatment.

Regular paracetamol can help to reduce any aches, pains or flu-like symptoms.

Are there any risks or side-effects?

Most procedures have a potential for side-effects. Some of the side effects are of short-duration, or reversible, some are not. The impact of these side effects can vary a lot from patient to patient, you should ask your surgeon or nurse specialist about the risks and impact on you as an individual. Adverse effects can increase with the number of doses of BCG treatment received.

Frequent (greater than 1 in 10):

- urinary tract infection requiring antibiotic treatment and postponement of the next dose of BCG
- some bladder discomfort after treatment
- flu-like symptoms, such as tiredness and an elevated temperature (below 38.5°C), which can persist for two to three days
- frequency and urgency of urination which can persist for two to three days
- failure to complete the course of treatment due to bladder discomfort
- blood and debris in the urine
- Inflammatory reactions of the prostate gland
- Nausea

Common (between 1 in 10 and 1 in 100):

- BCGosis (generalised and potentially serious infection with the BCG bacteria requiring treatment in hospital with antibiotics) see page 16
- anaemia
- Inflammation of the lungs with pneumonitis or granuloma
- Inflammation of the liver
- Reiter's syndrome (arthritis with inflammation of the skin, eyes and the urinary tract)
- abdominal pain, vomiting and diarrhoea, reduced appetite
- muscle and joint pain
- Skin rashes
- elevated temperature (above 38.5°C)
- urinary incontinence
- cardiovascular event (affecting your heart or blood vessels)
- stricture (narrowing) of the urethra (water pipe) following repeated use of a catheter
- reduction in bladder capacity
- inflammation of the testes or epididymis (tubes around the testicles)
- low blood pressure

Uncommon (between 1 in 100 and 1 in 1000):

- changes in blood results including blood clotting
- Reduction in white cell count and platelets in your blood
- persistent or severe bladder pain after treatment, sometimes requiring removal of the bladder
- difficulty passing urine
- elevated levels of white cells in the urine
- constipation
- sore or inflamed mouth or lips
- blocked ureter (pipe between kidneys and bladder)
- ulcers

Rare (between 1 in 1000 in 1 in 10,000):

- cough
- vascular infection such as infected dilatation of a blood vessel (infected aneurysm)
- kidney abscess

Very rare (less than 1 in 10,000):

- BCG infection of implants and surrounding tissue such as aortic graft infection, defibrillator infection or hip or knee joint replacements
- enlarged lymph nodes
- difficulty breathing, bronchitis or shortness of breath
- vascular fistula
- inflammation of the peritoneum (lining of the abdomen)
- infection of bone and bone marrow (osteomyelitis)
- psoas abscess (abscess of a muscle in lower back and pelvis)

- infection of the head of the penis
- swelling of arms and legs
- back pain
- acute kidney failure
- chest pain
- dizziness
- increased sleepiness
- headache
- changes in sensation and nerve conduction
- confusion
- reduction in growth of hair
- conjunctivitis
- vertigo
- acid reflux
- increased flatulence
- increase sweating
- inflammation affecting the genital area
- formation of granulomas (nodules within an organ)
- lupus vulgaris (tuberculosis of the skin)
- Allergic reaction. Symptoms of which may include: itching; a rash; swelling to the face, eyes, lips or tongue; difficulty breathing.

Frequency unknown:

- renal abscesses
- erythema nodostrum (red, tender lumps under the skin)
- lung disease which can cause scarring on your lungs
- Genital disorders/pain including pain on sexual intercourse
- Renal failure and inflammation of the kidneys
- Reduction or absence of sperm production
- Severe immune reaction with enlarged liver, spleen, fever, enlarged lymph nodes, jaundice and a rash (haemophagocytic syndrome)
- Spinal abscess

Hospital-acquired infection

- colonisation with MRSA (0.9% - 1 in 110)
- clostridium difficile bowel infection (0.2% - 1 in 500)
- MRSA bloodstream infection (0.08% - 1 in 1250)

The rates for hospital-acquired infection may be greater in high-risk patients e.g. with long-term drainage tubes, after removal of the bladder for cancer, after previous infections, after prolonged hospitalisation or after multiple admissions.

What else should I look out for?

If you have any of the following side effects, you must seek immediate medical attention:

- a high temperature (fever) that lasts for more than 12 hours
- chest pain or shortness of breath
- cough or bronchitis
- swelling of lymph nodes
- signs of an allergic reaction such as rash; itching; swelling of lips, eyes, or tongue; difficulty breathing and/or nausea, vomiting or abdominal pain
- are unable to pass urine

A generalised infection with the BCG bacteria (sometimes called BCGosis):

The most serious side effect from BCG is developing a generalised infection with the BCG bacteria. **Tell your doctor immediately if you experience any of the following symptoms.** They may appear at any time and can sometimes be delayed, developing weeks, months, or even years after your last dose.

Not everyone who develops this will have the same symptoms as it can affect different parts of your body.

- A high temperature above 39.5°C, or over 38°C for days/weeks.
- Night sweats.
- Unintentional weight loss
- Feeling increasingly poorly

- Symptoms specific to certain areas of the body including:
 - Breathing difficulties or a cough
 - Liver problems – change in blood results relating to the liver or pressure in the right upper abdomen
 - Pain and redness of the eye, vision changes or blurred vision
 - Infection of an implant, graft, or prosthesis such as a vascular graft or joint replacement.
 - New or worsening pain to a part of the body

A severe infection can lead to sepsis which can be life-threatening.

If a generalised infection from the BCG bacteria is proven then treatment will involve the use of antibiotics that are usually used to treat tuberculosis, and it may be necessary to be on them for a prolonged period of time. Other treatment may also be required depending on the area of the body involved, for example, surgery to treat an abscess or if a joint requires replacement.

What should I expect when I get home?

By the time of your discharge from hospital, you should:

- be given advice about your recovery at home
- know when to resume normal activities such as work, exercise, driving, housework and sexual intimacy
- have been given a contact number if you have any concerns once you return home
- ask when your follow-up will be and who will arrange this (the hospital or your GP)
- we will send a copy of your treatment details to your GP

If you think you have a urine infection (i.e. pain on passing urine, frequency or foul-smelling urine) or if you develop a high temperature or backache, it is important to contact your GP and get treatment with antibiotics.

Are there any other important points?

Because this treatment is put directly into the bladder and not into the blood stream, you will not experience the side-effects often associated with other cancer drug treatments.

There is currently a worldwide shortage of the intravesical BCG treatment. You may be offered a brand of the treatment that is unlicensed in the UK but is given in other countries. If this is the case, we will discuss this with you prior to commencing this treatment.

If you are a smoker, you should be aware that smoking seems to encourage recurrence of bladder cancer. We strongly advise patients with bladder cancer to stop smoking.

For advice on stopping, you can:

- contact your GP,
- access your local NHS Smoking Help Online
- ring the free NHS Smoking Helpline on **0800 169 0169**, or
- contact your nurse specialist for advice

Driving after your treatment

It is your responsibility to ensure that you are fit to drive following your treatment. You do not normally need to notify the DVLA unless you have a medical condition that will last for longer than three months after your treatment and may affect your ability to drive. You should, however, check with your insurance company before returning to driving. Your doctors will be happy to provide you with advice on request.

Is there any research being carried out in this area?

Before your operation, your surgeon or specialist nurse will inform you about any relevant research studies taking place.

All surgical procedures, even those not currently the subject of active research, are subjected to rigorous clinical audit so that we can analyse our results and compare them with those of other surgeons. In this way, we can learn how to improve our techniques and our results; this means that our patients will get the best treatment available.

Frequently asked questions

Can I continue to work while receiving treatment?

You should take the remainder of the day off work after each treatment. This is because of the precautions needed for disposing of your urine. If you feel well enough, you may return to work the next day. However, if you experience any of the side effects mentioned earlier, please take things easy and rest.

Can I drink alcohol during my course of treatment?

It is not known whether drinking alcohol has any effect on BCG. However, it is recommended that you drink only one bottle of beer or one glass of wine a day whilst having treatment.

Can I have sex during my course of treatment?

Yes, however, you are advised not to have sexual intercourse for at least 24 hours after each treatment as this can cause some discomfort. For the duration of the treatment course and for one week after the course, you should use a condom during intercourse. This is to avoid infecting your partner with BCG. You should ensure that your genital area has been thoroughly washed to remove any traces of BCG.

Women should use an effective contraception for the whole duration of their treatment to avoid pregnancy.

Can I have BCG if I am pregnant or breastfeeding my baby?

No. BCG is not recommended if you are pregnant or breastfeeding.

Can BCG affect my fertility?

There is the possibility that BCG can affect the production of sperm. Please discuss with your medical team if you are concerned.

Can I have BCG if I am in contact with, or live with, someone who has a reduced immune system?

Yes, however, BCG bacteria can be harmful to those who have a weakened immune system. Please ensure you comply with the hygiene guidance including washing your hands well, sitting down to pass urine, and pouring bleach down the toilet prior to flushing.

What will happen if I have a urine infection?

Each week when you come for your treatment the nurse will test a sample of your urine. If it shows signs of an infection, you may not be able have your treatment that week. The nurse will arrange for you to have a course of antibiotics and will send a sample of your urine to the laboratory for testing.

You will return to hospital the following week for your treatment. The nurse will make you another appointment for you to replace for the one that you missed. This is to ensure that you receive the complete course of BCG.

Can I have my vaccines while I am having my bladder treatment?

It is possible that some vaccines may interact with BCG, therefore, please discuss any proposed, or recent, vaccinations with your surgeon or specialist nurse.

What happens when my course of treatments are finished?

Following your final treatment, you will receive an appointment for a bladder examination called a cystoscopy. This will be usually six to eight weeks after your last BCG treatment. The cystoscopy allows the consultant to monitor your bladder cancer.

Special instructions for patients with indwelling catheters

When you come for your treatment, the nurse will take a sample of urine from your catheter. If your urine is clear the drug will be placed into your bladder via your catheter. The catheter will then be clamped, or a small bung (called a spigot) placed in the catheter to prevent the drug from draining out.

You must stay with us for the full two hours each time you come for your treatment.

When the drug has been in your bladder for the required time the nurse will release the clamp or spigot. This is to allow the drug to drain into your catheter bag.

After a short while, when the nurse is sure that all the drug has drained from your bladder, they will remove your catheter bag and replace it with a new one. At home for the following six hours any urine from your catheter needs to be disinfected using the following instructions.

Wear the gloves, which we will have given you. Put two bleach tablets or a cup of undiluted bleach into the toilet. Empty your catheter contents into the toilet and leave it for 15 minutes before flushing.

You will need to apply a new catheter bag in the morning. Again, using gloves, the used bag should be placed in the yellow container that we will supply you with. If you are unsure about changing your catheter bag, we can arrange for a district nurse to do this for you.

We will give instructions for disposal of the yellow container before you leave on the day of your treatment.

Always wash your hands before and after handling your catheter.

Contact telephone numbers:

York Hospital:

Day Unit 01904 726010

Extended Stay Area 01904 721265

Jo Gales-Todd, Alyssa Frost,
Fiona Ayre, Samantha Bell or
Rebecca Marmion
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Scarborough/Bridlington Hospitals:

Carol Popplestone 01723 385246
MacMillan Cancer Nurse Specialist

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Kind acknowledgement to BNF (British National Formulary) and smPC (The Summary of Product Characteristics) for resources.

Tell us what you think of this leaflet

We hope that you found this leaflet helpful. If you would like to tell us what you think, please contact:

Mr J R Wilson, Consultant Urologist, Department of Urology, York Hospital, Wigginton Road, York, YO31 8HE or telephone 01904 725846.

Teaching, training and research

Our Trust is committed to teaching, training and research to support the development of health and healthcare in our community. Healthcare students may observe consultations for this purpose. You can opt out if you do not want students to observe. We may also ask you if you would like to be involved in our research.

Patient Advice and Liaison Service (PALS)

PALS offers impartial advice and assistance to patients, their relatives, friends and carers. We can listen to feedback (positive or negative), answer questions and help resolve any concerns about Trust services.

PALS can be contacted on 01904 726262, or email yhs-tr.PatientExperienceTeam@nhs.net

An answer phone is available out of hours.

Leaflets in alternative languages or formats

Please telephone or email if you require this information in a different language or format, for example Braille, large print or audio.

如果你要求本資 不同的 或 式提供 , 電
或發電

Jeżeli niniejsze informacje potrzebne są w innym języku lub formacie, należy zadzwonić lub wysłać wiadomość e-mail

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Telephone: 01904 725566

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|--|-------------------------------------|
| Owner | Mr J R Wilson, Consultant Urologist |
| Date first issued | July 2008 |
| Review Date | September 2026 |
| Version | 8 (issued October 2023) |
| Approved by | Urology MDT |
| Linked to consent form | FYCON100-3 Course of BCG v8 |
| Document Reference | PIL493 v8 |
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