

# Maintenance BCG for non-muscle invasive bladder cancer

**This leaflet explains more about the use of maintenance Bacillus Calmette–Guérin (BCG) as further treatment for your non-muscle invasive bladder cancer. If you have any questions or concerns, please speak to a doctor or nurse caring for you.**

## Why do I need maintenance BCG?

You have been diagnosed with non-muscle invasive bladder cancer, which is the most common type of bladder cancer. You have already had an operation to remove the tumour(s) from your bladder, plus a course of BCG (six week course), or a combination of BCG and electro-motive drug administration (EMDA) Mitomycin-C (MMC) (nine week course).

Your doctor has recommended that you have a further course of maintenance BCG following your recent check cystoscopy, to help reduce the chance of the bladder cancer coming back. Research has shown that maintenance BCG treatment can reduce the risk of tumours growing back in the bladder.

## When do I have maintenance BCG?

Maintenance BCG treatment will be started within one month following your check cystoscopy (after your first course of treatment). This is usually given as a course of three BCG treatments (one treatment a week for three weeks), repeated every six months, for up to three years.

Patients who are unable to tolerate the three dose maintenance BCG may be given a reduced course (if they have intense irritable symptoms or if they experienced extreme symptoms with the previous course).

## What do I have to do before each treatment?

Before each treatment, you will be asked to pass urine to empty your bladder. You should try not to drink very much for three or four hours before you come to the hospital for your treatment – particularly if you tend to pass urine frequently. Restricting the amount you drink will mean that you produce less urine. This will prevent the BCG from being diluted while it is in your bladder and maximise its effectiveness. You will also be more likely to be able to hold onto the drug in your bladder for the full treatment time if you have not had much to drink beforehand.

It is also advisable to avoid tea, coffee and alcohol the evening before and morning of your treatment. Tea and coffee contain caffeine, which can irritate the bladder and increase frequency of urinating. Alcohol will dehydrate you, which may make any symptoms from treatment worse.

When you come in for your appointment, you will be asked to give a urine sample before your treatment. This is because you cannot be given the treatment if you have a urinary tract infection (UTI) or blood visible in your urine. You will need to have the UTI treated, or wait until the bleeding has stopped, before your treatment can be re-started.

## What happens at each treatment?

A lubricated catheter (thin tube) is inserted into your urethra (the tube linked to the bladder that allows urine to exit the body). A local anaesthetic gel may be used to temporarily numb the area and to reduce any discomfort. Any remaining urine is drained away from your bladder and 50mls of BCG solution is passed through the catheter and into your bladder.

This catheter is then either removed from your bladder or left in place until the treatment is finished. To keep the drug in contact with your bladder, you will be asked not to pass urine for two hours. You do not need to lie down for the two hours – you can walk, sit or stand.

**Ideally, you should try not to drink anything for at least the first hour of treatment so as not to dilute the drug, and to help prevent the urge to pass urine before the treatment time is complete.**

## What do I do after each treatment?

After the two hours, the BCG will be removed via the catheter if this is still in place, or you will be asked to pass urine as normal into a toilet. Men will be asked to sit down to avoid the drug splashing onto the skin. The first time you pass urine after having the BCG, you will need to put 50ml of household bleach into the toilet and leave it to stand for 15 minutes before flushing. This neutralises the drug.

It is important to avoid getting the BCG in contact with your skin. Therefore please wash your hands and genitalia (reproductive organs) with soap and water immediately after passing the BCG into the toilet. If the BCG does come into contact with your skin it may cause a slight rash if not washed off. If you wash it off immediately with warm, soapy water, it will not harm your skin.

## Contra-indications

You should not receive maintenance BCG treatment if you:

- have an impaired immune response or on immunosuppressant medicines (reduced ability to fight infection)
- have HIV
- have a current UTI
- have visible blood in your urine
- have active tuberculosis (TB) (before you receive BCG treatment, your doctor may do a skin reaction test, to see if you have TB. This is called a Tuberculin Test. If you have had BCG treatment before, this may give you a positive result in this test.)
- have unexplained fever
- are pregnant or breast feeding.

## What are the alternatives?

If you are unable to receive maintenance BCG treatment due to irritable symptoms and side effects, you will continue to have regular cystoscopies to check your bladder.

## What are the side effects?

Most patients do not experience any major problems with maintenance BCG treatment, but it may irritate your bladder. After each treatment you may notice that you:

- have discomfort on passing urine
- need to pass urine more frequently, or
- have blood in your urine.

These problems should get better within a few days. **If your symptoms do not improve after two to three days, contact your nurse specialist for advice** (contact details can be found at the end of this leaflet), as you may need treatment for this.

To help prevent these problems, it is a good idea to increase your fluid intake after each treatment for a couple of days (aim for two litres a day). This will help to flush any remaining drug from your bladder. You may want to reduce the amount you drink after 7pm or 8pm so you don't disturb your sleep.

You should contact the nurse specialist, ward or doctor immediately if you develop any of the following:

- a temperature (more than 38.5°C or 101°F) and chills or flu-like symptoms
- sweating
- chest pain or tightness
- sore throat
- swelling of lymph glands
- problems with passing water or having a large amount of blood in your urine
- joint pain
- a cough
- a skin rash
- exhaustion
- nausea/vomiting.

**These symptoms could indicate that you have an allergic reaction or that some of the BCG has got into your system, giving you TB symptoms. These symptoms are rare but if they do occur, you will need treatment. Please do not wait until your next visit to tell your nurse specialist.**

If you notice that your urine is smelly or cloudy you should contact your GP as this may indicate a urine infection. You will need to give a urine sample and you may possibly need antibiotics. This is unlikely to be due to the drugs, but can happen after catheterisation. **Please tell your nurse specialist of any side effects you have** at the time of your next visit or by telephone.

To prevent irritation for yourself or your partner, it is best not to have sexual intercourse for at least 24 hours after receiving BCG treatment. Please use a condom throughout each maintenance BCG treatment course and for one week after.

Further details of the possible side effects of this treatment can be found in the manufacturer's patient information leaflet – please ask if you would like a copy. If you would like further information or have any concerns about side-effects, please speak to your nurse or contact the pharmacy medicines helpline (contact details are at the end of this leaflet).

## Finding out the success of your treatment

You will have regular flexible cystoscopies in-between your maintenance courses of BCG, to find out how successful the treatment has been.

Two weeks before each check flexible cystoscopy you will need to **drop off a urine sample at the urology centre at Guy's Hospital**. This enables us to process your urine so the results are ready when you come back for the check flexible cystoscopy. This urine sample enables us to look at the cells to see if they are all normal or whether there are some tumour cells present. You will be sent an appointment for the check in the post, or your nurse will confirm this date on your last treatment visit.

## Useful sources of information

### Macmillan Cancer Support (all numbers freephone)

**t:** 0808 808 2020 (information on living with cancer)

**t:** 0808 800 1234 (information on types of cancer and treatments)

**t:** 0808 801 0304 (benefits enquiry line)

**w:** [www.macmillan.org.uk](http://www.macmillan.org.uk)

**Cancer Research UK** has a patient information website, with information on all types of cancer and treatment options.

**w:** [www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

## Contact us

If you want any further information or any help, do not hesitate to contact the Urology Department for advice. Call **020 7188 7636** to speak to one of the nurses below (Monday to Friday, 9am to 5pm).

- Sue Amery, Bladder Cancer Clinical Nurse Specialist
- Kathryn Chatterton, Bladder Cancer Clinical Nurse Specialist

Alternatively ring **020 7188 7188** and ask the operator to bleep: 2840 or 1227  
Outside of normal working hours, please call Aston Key Ward on **020 7188 8860** or Florence Ward on **020 7188 8818**.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit [www.guysandstthomas.nhs.uk/leaflets](http://www.guysandstthomas.nhs.uk/leaflets)



**Dimbleby Cancer Care** provides cancer support services for Guy's and St Thomas'. We have a drop-in information area staffed by specialist nurses and offer complementary therapies, psychological support and benefits advice for patients and carers.

Dimbleby Cancer Care is located in the Welcome Village of the Cancer Centre at Guy's **t:** 020 7188 5918 **e:** [DimblebyCancerCare@gstt.nhs.uk](mailto:DimblebyCancerCare@gstt.nhs.uk)

## Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the clinical nurse specialist or other member of staff caring for you or call our helpline.

**t:** 020 7188 8748 9am to 5pm, Monday to Friday

## Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

**t:** 020 7188 8801 (PALS)      **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

**t:** 020 7188 3514 (complaints)      **e:** [complaints2@gstt.nhs.uk](mailto:complaints2@gstt.nhs.uk)

## Language and Accessible Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch:

**t:** 020 7188 8815      **e:** [languagesupport@gstt.nhs.uk](mailto:languagesupport@gstt.nhs.uk)

## NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

**t:** 111

## NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

**w:** [www.nhs.uk](http://www.nhs.uk)

## Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, and to become a member:

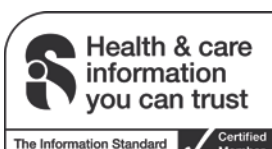
**t:** 0800 731 0319      **e:** [members@gstt.nhs.uk](mailto:members@gstt.nhs.uk)      **w:** [www.guysandstthomas.nhs.uk/membership](http://www.guysandstthomas.nhs.uk/membership)

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