

Bladder cancer

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About this information

NICE guidelines provide advice on the care and support that should be offered to people who use health and care services.

This information explains the advice about bladder cancer that is set out in NICE guideline NG2.

Does this information apply to me?

Yes, if you are an adult aged 18 or over with suspected or diagnosed bladder cancer.

It does not cover people with a type of cancer called sarcoma, cancer in the upper <u>urinary</u> <u>tract</u> but not in the bladder, or cancer that has spread to the bladder from another part of the body.

Bladder cancer

The bladder stores urine before it is passed out of the body. It is located in the front of the

pelvis. It is made up of 3 layers – an inner lining, a muscle wall and a thin layer in between called 'connective tissue'. Bladder cancer is a growth of abnormal tissue that starts in the lining and can spread to the muscle wall.

Bladder cancer is one of the 10 most common cancers in the UK. It is most often found in men aged over 60, but women and men younger than 60 can also get bladder cancer.

Your care team

A range of professionals who specialise in different areas of treatment or support may be involved in your care. These could include <u>urologists</u>, specialist nurses, <u>radiologists</u>, <u>pathologists</u> and your GP. Sometimes these professionals work together in a special type of team called a <u>multidisciplinary team</u>, or MDT for short.

Working with you and making decisions

Your care team should talk with you about bladder cancer. They should explain any tests, treatments or support you should be offered so that you can decide together what is best for you.Your family, partner or carer can be involved in helping to make decisions, but only if you agree. You can use the questions at the end of each section of this information to help you talk with your care team.

You may also like to read NICE's information for the public on <u>patient experience in adult</u> <u>NHS services</u>. This sets out what adults should be able to expect when they use the NHS. We also have more information on the NICE website about <u>using health and social care</u> <u>services</u>.

Questions to ask your care team

About bladder cancer

- Can you tell me more about bladder cancer?
- Can you recommend any websites or reading materials?
- Are there any cancer support organisations in my local area?

• Can you provide any information for my family, partner or carers?

About making decisions

- Will I be involved in making decisions?
- Is there someone in my care team who will help me to make decisions and choices?
- Can I have support with decision-making from my family, partner, carer or a close friend?

Some treatments or care described here may not be suitable for you. If you think that your treatment does not match this advice, talk to your care team.

Types of bladder cancer

Most bladder cancers don't grow deeper than the lining or connective tissue of the bladder. They're called 'non-muscle-invasive' bladder cancers. But sometimes a bladder cancer grows into the muscle wall of the bladder. This is called 'muscle-invasive' bladder cancer, and it can spread to other areas of the body. Bladder cancer that has spread to other parts of the body in this way is called 'locally advanced' or 'metastatic' bladder cancer.

Doctors also use the terms 'stage' and 'grade' to describe cancer. The stage describes how deeply a cancer has grown. The grade gives an idea of how fast the cancer cells are growing.

The support and treatment you should be offered depend on which type of bladder cancer you have. They are described in <u>treating non-muscle-invasive bladder cancer</u>, <u>treating</u> <u>muscle-invasive bladder cancer</u> and <u>treating locally advanced or metastatic bladder</u> <u>cance</u>r.

Questions to ask your care team

- What are the types of bladder cancer and why are they important?
- What does stage mean and why is it important?
- What does grade mean and why is it important?

Diagnosing bladder cancer

Looking inside your bladder

If you have been referred to a <u>urologis</u>t and they think you might have bladder cancer, they should offer you a procedure called a cystoscopy to look inside your bladder. A thin instrument called a cystoscope is inserted into your bladder through your <u>urethra</u>. The cystoscope has a light and a small camera that allows the inside of your bladder to be seen.

If anything looks abnormal inside your bladder, you should be offered an operation to do a procedure called a biopsy, in which samples of tissue from you bladder are removed for testing (see <u>taking tissue samples for testing</u>). If it is thought that you might have a bladder cancer that has spread to the muscle wall of your bladder, you may also be offered a <u>CT scan</u> or an <u>MRI scan</u> to give a more detailed picture.

Taking tissue samples for testing

You should be offered an operation called transurethral resection of bladder tumour (or TURBT for short) to take tissue samples from your bladder. During the operation the areas of tissue that look abnormal are removed so that they can be tested for cancer. Samples of tissue from the muscle wall of your bladder should also be taken. This is to check whether there is a cancer that has spread to the muscle.

You should be offered a dose of <u>chemotherapy</u> with a drug called mitomycin C, which is given to you at the end of your TURBT operation. If the abnormal tissue in your bladder is cancerous, the mitomycin C may help to stop bladder cancer coming back later.

Sometimes the tissue samples that are taken don't include tissue from the muscle wall. If this happens you may be offered another TURBT operation to take these samples, which should be done within 6 weeks of your first operation.

After your operation, if it's confirmed that you do have bladder cancer, you should be told whether or not the cancer has spread to the muscle wall of your bladder. You should be offered information, support and treatment as described in the next sections.

Questions to ask your care team

Looking inside your bladder (cystoscopy)

- How is a cystoscopy done?
- What is the difference between flexible and rigid cystoscopy?
- How long does it take?
- Will it be painful? Will I have an anaesthetic?

Taking tissue samples for testing

- What happens during a TURBT (transurethral resection of bladder tumour) operation?
- Why is it important to have the muscle wall checked?
- When and where can I have the operation?
- Do I need to do anything to prepare for it?
- How long will I need to stay in hospital?
- How long will it take to recover?
- Will this operation tell you whether I have bladder cancer?
- When will I get the results? How will you let me know?
- What might happen if I decide not to have the operation?

- Will I need another operation or more treatment after this?
- If it's confirmed that I have bladder cancer, will the mitomycin C I was given during the operation prevent bladder cancer from coming back again?

Scans

- Where will my scans be done? Do I need to do anything to prepare for them?
- How long will it take to get the results? What will they tell you?

Information and support after your diagnosis

Your care team

You should be given the name and contact details of a clinical nurse specialist who can help and support you throughout your treatment and care. The clinical nurse specialist should have experience and training in caring for people with bladder cancer. They will be in contact with the other professionals involved in your care. You should be able to go to your clinical nurse specialist with any questions you have about your treatment and care, and for help with concerns or problems.

Throughout your treatment and care, you should be offered chances to talk with members of your care team about the kinds of information and support that are right for you and, if you wish, your partner, family or carer. Your care team should offer to talk with you when you're first diagnosed with bladder cancer, after you've had your first treatment, if there is a change in your bladder cancer or it comes back after treatment, if you change your treatment or if you have cancer that can't be cured.

During these talks your care team should discuss with you:

 the type of cancer you have and its stage and grade (for more information see <u>types</u> of bladder cancer)

- the treatments you could have
- any side effects you might get from your treatments
- if you smoke, stopping smoking and the support you can get to help you stop (see <u>other NICE guidance</u> for details of our guidance on smoking cessation)
- how the cancer or the possible treatments might affect your sexual health and the way you feel about your body, and where to find information about these that is specifically designed for either men or women
- your diet and lifestyle, including physical activity
- where to find more information about bladder cancer and bladder cancer support groups
- going back to work after your treatment
- getting financial support such as free prescriptions or compensation if you are not able to work.

Other people who can offer support

You and, if you wish, your partner, family or carer, should be offered opportunities to talk with other types of healthcare professionals throughout your treatment and care. For example, if you wish, you should be able to talk with professionals who can give emotional support and counselling to help with anxiety, stress or depression. You should also be offered opportunities to talk with other people who've had the same treatments you might have.

Questions to ask your care team

- Who will I be able to talk to about my tests and treatment?
- Is there any support I can have if I decide to make changes to my lifestyle, such as becoming more physically active, changing my diet or stopping smoking?
- What other kinds of support will be available?

• Will my GP be involved? If so, what will they do?

For family members, partners or carers

- What can I/we do to help and support the person with bladder cancer?
- Is there any additional support that I/we as carer(s) might benefit from or be entitled to?
- Can we talk to the clinical nurse specialist?

Treating non-muscle-invasive bladder cancer

Non-muscle-invasive bladder cancer (cancer that has not grown into the muscle wall of the bladder) is divided into 3 categories. These categories describe how likely it is that the cancer will spread to the muscle wall or further, or will come back after it's been treated. The 3 categories are called:

- low-risk non-muscle-invasive bladder cancer
- intermediate-risk non-muscle-invasive bladder cancer
- high-risk non-muscle-invasive bladder cancer.

The types of tests and treatments you should be offered for non-muscle-invasive bladder cancer depend on which of these 3 categories it's in.

If you have non-muscle-invasive bladder cancer, you should be told whether it is low-risk, intermediate-risk or high-risk.

Treating low-risk non-muscle-invasive bladder cancer

If the tissue samples that were removed during your TURBT operation turn out to be

low-risk bladder cancer, you may not need more treatment because the cancer will have been removed. For information about the TURBT operation see <u>taking tissue samples for</u> <u>testing</u>.

You should be offered a cystoscopy to check your bladder 3 months later, and another one 9 months after that. If there is no sign of cancer at either of these check-ups you should be discharged back to your GP. For more information about cystoscopy see <u>looking inside the bladder</u>.

If your cancer comes back, you may be offered a treatment called fulguration, which uses an electric current to destroy the cancer. You may be offered fulguration if you have been free of cancer for at least 6 months and your new cancer is small.

Treating intermediate-risk non-muscle-invasive bladder cancer

You should be offered a course of at least 6 doses of <u>chemotherapy</u> with a drug called mitomycin C. The drug is a liquid that is put into your bladder through a thin tube called a catheter.

You should be offered a cystoscopy to check your bladder 3 months, 9 months and 18 months after you finish your chemotherapy, then once a year after that. For more information about cystoscopy see <u>looking inside the bladder</u>.

If the chemotherapy hasn't helped and your cancer has come back, your care should be referred to <u>a specialist urology multidisciplinary team</u>.

If the cancer hasn't come back after 5 years of check-ups, you may be discharged back to your GP.

Treating high-risk non-muscle-invasive bladder cancer

If you have high risk non muscle invasive bladder cancer, you should be offered another TURBT operation as soon as possible and no later than 6 weeks after your last TURBT (for more information about the TURBT operation see<u>taking tissue</u> <u>samples for testing</u>). You may also be offered more<u>CT scans</u>or<u>MRI scans</u>. The TURBT operation and the scans are to double-check how far your cancer has grown before you and your care team talk about possible treatments.

To treat your cancer you should be offered a choice of either:

- a course of treatment with a vaccine called BCG or
- an operation to remove your bladder (called a cystectomy).

A <u>urologist</u> who carries out both types of treatment and a clinical nurse specialist should discuss both treatment options with you. They should talk to you about the stage of your cancer and how likely it is to spread. They should tell you how well these treatments have worked for other people and what the risks of each treatment are. They should also explain the effect each treatment might have on your general health and your quality of life, including your sex life, and how you might feel about your body after treatment.

Having treatment with BCG

BCG (short for Bacille Calmette-Guérin) is a vaccine for tuberculosis and is also used to help stop some kinds of bladder cancer from spreading or coming back again. The BCG is a liquid that is put into your bladder through a thin tube called a catheter. If the BCG treatment doesn't work and your cancer is still there or comes back after treatment, or if the side effects of the BCG are too strong for you to carry on with it, your care should be referred to a specialist urology multidisciplinary team.

After your treatment you should be offered a cystoscopy to check your bladder:

- every 3 months for the first 2 years, then
- every 6 months for the next 2 years, then

• once a year after that.

For more information about cystoscopy see looking inside the bladder.

Having an operation to remove your bladder (cystectomy)

If you decide to have your bladder removed, you will need to have a new way of storing urine and passing it out of your body. There are different procedures for this and you should be offered a choice of procedures that are suitable for you. In one type of procedure a small opening called a 'stoma' is made in your abdomen, and the urine drains out through the stoma into a waterproof bag worn outside your abdomen. There are other types of procedures that don't involve a bag worn outside the body, although they are not suitable for everyone.

A surgeon who specialises in treating bladder cancer, a clinical nurse specialist and a nurse who looks after people who've had these procedures (often called a stoma care nurse) should explain the options and discuss them with you.

Chemotherapy after having your bladder removed

You may be offered <u>chemotherapy</u> with a combination of drugs if the operation to remove your bladder shows that your cancer has spread into the muscle and is now muscle-invasive bladder cancer. This is called 'adjuvant' chemotherapy. You should have an opportunity to talk about the possible advantages and disadvantages of this chemotherapy with an <u>oncologist</u> who treats people with bladder cancer.

For more information seetreating muscle-invasive bladder cancer.

After you've had your bladder removed, you should be offered check-ups that may include:

- CT scans 6 months after your bladder has been removed and once a year after that, to check whether the cancer has come back or there are any problems with your kidneys
- blood tests at least once a year to check whether your body is absorbing enough vitamin B and how well your kidneys are working

• if you're a man, tests to check your <u>urethra</u> once a year for 5 years.

After any type of treatment for non-muscleinvasive bladder cancer

Tell your GP straight away if there is blood in your urine, or you have problems urinating, after any type of treatment for non-muscle-invasive bladder cancer. They should refer you to a specialist without delay.

Questions to ask your care team

About non-muscle-invasive bladder cancer

- Can you tell me more about the difference between low-risk, intermediate-risk and high-risk non-muscle-invasive bladder cancer?
- How will I know if the cancer has come back after my treatment? What should I look out for?
- Is there anything I can do to reduce the chance of the cancer coming back?
- What will happen if the cancer does come back?
- Who should I call if I have problems urinating or there's blood in my urine?

About high-risk non-muscle-invasive bladder cancer

- Will I have a specialist urology multidisciplinary team? Who is on the team and what do they do?
- Can you tell me about the advantages and disadvantages of BCG treatment compared with removal of the bladder (cystectomy)?
- Is there some other information that I can have about BCG treatment and cystectomy (like a leaflet, DVD or a website I can go to)?

- Can I talk to someone who has had BCG treatment and someone who has had cystectomy?
- Are there any other options for treatment?
- If I have BCG treatment now, will I still be able to have a cystectomy later?
- What options would I have for storing and draining urine if I have my bladder removed? Can I talk to people who have had these options?
- What support can I have after my treatment?
- Will I need to have check-ups every year from now on?
- What will happen if the cancer spreads?

Treating muscle-invasive bladder cancer

You may be offered a <u>CT scan</u> or an <u>MRI scan</u> to help find out whether the cancer has grown beyond the muscle and if so, how far it has grown.

If they are suitable for you, you should be offered treatment with a choice of either:

- an operation to remove your bladder, called a cystectomy (for more information see having an operation to remove your bladder) or
- <u>radiotherapy</u> together with drugs called radiosensitisers, which help the radiotherapy to work better.

A <u>urologist</u> who does operations to remove the bladder, an <u>oncologist</u> and your clinical nurse specialist should discuss both options with you. They should tell you what's likely to happen if you have either type of treatment, or if you choose not to have treatment. They should explain the effect each treatment might have on your general health and your quality of life, including your sex life. They should tell you what the risks of each treatment are, and how well the treatments have worked for other people.

Chemotherapy before having your bladder removed or starting radiotherapy

If it's suitable for you, you should be offered <u>chemotherapy</u> with a combination of drugs before you have your bladder removed or start radiotherapy. This is called 'neoadjuvant' chemotherapy. You should have an opportunity to talk about the possible advantages and disadvantages of this chemotherapy with an oncologist who treats people with bladder cancer.

After having your bladder removed (cystectomy)

For more information see having an operation to remove your bladder.

After having radiotherapy

After your radiotherapy has finished, you should be offered a cystoscopy to check your bladder:

- every 3 months for the first 2 years then
- every 6 months for the next 2 years then
- every year after that.

For more information about cystoscopy see looking inside the bladder.

You may also be offered <u>CT scans</u> of your abdomen, pelvis and chest 6 months, 1 year and 2 years after your radiotherapy has finished, and scans of your upper <u>urinary tract</u> every year for 5 years.

Questions to ask your care team

• How does radiotherapy compare with cystectomy? What are the advantages and disadvantages of each?

- Will you offer me chemotherapy before I start my radiotherapy or have my cystectomy? How will this be decided?
- Are there any other options for treatment?
- Can I talk to someone who has had these treatments?
- Is there some other information (like a leaflet, DVD or a website I can go to) about these treatments that I can have?
- How will I know if the cancer has come back after my treatment? What should I look out for?
- Is there anything I can do to reduce the chance of the cancer coming back?
- What will happen if the cancer does come back?

Treating locally advanced or metastatic bladder cancer

If you have bladder cancer that has spread to other parts of your body, your <u>oncologist</u> should talk to you about what is likely to happen in the future. They should discuss the advantages and disadvantages of having treatment, including what might happen if you decide not to have treatment for your cancer. They should also offer you treatment to relieve symptoms caused by your cancer (for more information see <u>relieving cancer</u> <u>symptoms</u>).

Chemotherapy

You should be offered a course of <u>chemotherapy</u> with a combination of drugs.

Your oncologist should check your health regularly while you are having chemotherapy. They should offer you treatments to help relieve side effects of chemotherapy. They should stop the chemotherapy if the side effects are too strong or the chemotherapy isn't helping. If your first course of chemotherapy doesn't help, your oncologist should discuss another course of chemotherapy with you. They should talk to you about the advantages and disadvantages of having a second course of chemotherapy, including what might happen if you decide not to have it.

Relieving cancer symptoms

Problems urinating

If urinating is painful, there is blood in your urine, or you need to urinate very often or during the night, you should be offered <u>radiotherapy</u>, which may help to relieve your symptoms.

Pain in your lower back or kidneys

Pain in your lower back or kidneys may be caused by a blockage in your ureter (the tube that carries urine from the kidneys to the bladder). You may be offered a procedure to drain the kidneys to help ease the pain. This could be an external drainage tube into the kidney (called a nephrostomy) or a splint (called a stent) placed between the kidney and the bladder.

Your <u>urologist</u> should discuss the treatment options with you. They should talk to you about what is likely to happen in the future and the advantages and disadvantages of treatment, including not having treatment.

Severe and painful bleeding from your bladder

You may be offered radiotherapy or a treatment called embolisation, in which the blood vessels that supply the bladder are blocked, to stop the bleeding.

Pain in your pelvic area

You may be offered radiotherapy, chemotherapy or treatment with a drug to block the pain.

Questions to ask your care team

- What is meant by locally advanced cancer? What does it mean for me?
- What is meant by metastatic cancer? What does it mean for me?
- What are the advantages and disadvantages of having chemotherapy?
- How likely is it to work? What happens if it doesn't work?
- What might happen if I decide not to have any treatment?
- What will you be able to do for me if I get painful symptoms from the cancer?
- Is there support available for people with this type of bladder cancer?

If your bladder cancer can't be cured

If your cancer can't be cured you should be told about a service called palliative care. This service offers support and practical help, including pain relief. If you agree, you should be referred to a palliative care team.

A member of the <u>urology multidisciplinary team</u> should discuss with you how your cancer is likely to progress in the future. They should also talk to you about the treatments you could have to help ease your symptoms and pain. For details of our guidance on supportive and palliative care for adults with cancer see <u>other NICE guidance</u>.

Questions to ask your care team

- What is palliative care? Who provides it?
- Can I have palliative care at home?
- Is there support available for my family, partner or carers?
- What will you be able to do for me if I have painful symptoms?

Medical terms explained

Chemotherapy

A treatment that uses anticancer drugs to destroy cancer cells

CT (computerised tomography) scan

A scan that makes a picture of a part of the body by taking a series of X-rays

MRI (magnetic resonance imaging) scan

A scan that makes a picture of a part of the body using magnetic fields and radio waves

Multidisciplinary team (MDT)

A specialist team of healthcare professionals with different kinds of skills and experience

Oncologist

A doctor who treats cancer with drugs or radiotherapy

Pathologist

A doctor who examines tissue samples

Radiologist

A doctor who carries out and examines scans of the body

Radiotherapy

A treatment that uses high-energy rays to destroy cancer cells

Specialist urology multidisciplinary team

A specialist team of healthcare professionals with different kinds of skills and experience who manage more complicated types of bladder cancer

Urethra

The tube that carries urine out of the body

Urinary tract

The kidneys, ureters (tubes that run from the kidneys to the bladder), bladder and urethra

Urologist

A doctor who diagnoses and treats problems in the urinary tract

Urology multidisciplinary team

A specialist team of healthcare professionals with different kinds of skills and experience who manage problems in the urinary tract

Sources of advice and support

- Action on Bladder Cancer <u>www.actiononbladdercancer.org</u>
- Bladder and Bowel Foundation, 0845 345 0165 www.bladderandbowelfoundation.org
- Fight Bladder Cancer www.fightbladdercancer.co.uk
- Urostomy Association, 01889 563191 <u>www.urostomyassociation.org.uk</u>

You can also go to <u>NHS Choices</u> for more information.

NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

Other NICE guidance

- Patient experience in adult NHS services (2012) NICE guideline CG138
- <u>Smoking cessation services</u> (2008) NICE guideline PH10
- Brief interventions and referral for smoking cessation (2006) NICE guideline PH1
- Improving supportive and palliative care for adults with cancer (2004) NICE guideline CSGSP

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Accreditation

