



# Healthcare services for urological cancers

## Introduction

The National Institute for Clinical Excellence (known as NICE) has issued guidance on the organisation of healthcare for people with a urological cancer. The guidance recommends which healthcare professionals should be involved in treatment and care, and the types of hospital or cancer centre that are best suited to provide that healthcare – this type of guidance is called ‘service guidance’.

It’s important to appreciate that many service guidance recommendations require large-scale changes in the way that a section of the NHS works. Although such changes can’t be made overnight, the NHS is working to put all the guidance recommendations into practice.

**The key recommendations from the urological cancer service guidance are summarised in the following sections.** More information on these and the other recommendations is given in the full version of *Improving Outcomes in Urological Cancers*, and this is available from the NICE website ([www.nice.org.uk](http://www.nice.org.uk)). The full report also includes a summary of the evidence that was considered when the recommendations were being prepared.

Although service guidance does sometimes refer to appropriate forms of investigation and treatment, it doesn’t provide detailed information on these areas. More detailed information on investigations and treatment for urological cancers can be obtained elsewhere (NHS Direct Online, [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk), is a good starting point, with links to other sources of information on urological cancers). People with concerns about their own health should contact their GP or cancer team.

## Urological cancer

Urological cancer is a general name for a group of cancers. These are:

- bladder cancer
- prostate cancer
- kidney cancer
- testicular cancer (cancer affecting the testicle, sometimes also called the testis)
- cancer of the penis (also known as penile cancer).

Men and women of all ages can be affected by a urological cancer, though women cannot get cancers of the penis, testis or prostate.

## Key recommendations

### People should be treated by a multidisciplinary team

A multidisciplinary team is one that includes professionals with different skills. The NICE cancer service guidance recommends that a person with a urological cancer should be cared for by a multidisciplinary team of healthcare professionals. This is because the diagnosis, treatment and care of a person with a urological cancer can be very complex and is best provided by bringing together people with all the necessary skills, knowledge and experience.

Teams that deal with the more common forms of urological cancer and treatments are based in the cancer units at local general hospitals; these are called local urological cancer teams. Teams that care for

people whose cancer is less common or whose treatment requires certain specialist skills are based at specialist cancer centres at other hospitals; these are known as specialist urological cancer teams.

### **Local urological cancer teams**

Local teams diagnose most urological cancers, provide treatment for some types of cancer, and refer people on to the specialist urological cancer teams if necessary. The local team is also responsible for providing information, advice and support for patients and their carers during their illness. Finally, the local team communicates with the individual's GP and other professionals involved in the patient's care.

#### ***Who should be in the local team?***

The healthcare professionals who work as part of a local urological cancer team should all have a particular interest in urological cancers and their treatment.

The NICE guidance says that all local urological cancer teams should normally include, as a minimum:

- a lead doctor, usually a consultant urologist (urologists are surgeons who have specialised in treating conditions affecting the urinary system)
- at least two urologists
- a nurse who has been trained to provide support and information for people with urological cancer – he or she may also be able to carry out some investigations and treatments
- a radiologist with experience and training in urological cancers (radiologists are doctors who use X-rays and related techniques to show the cancer and sometimes also to treat it)
- a pathologist with experience in urological cancers (pathologists look at samples taken from the cancer and provide crucial information about the specific type of cancer and how advanced it is)
- an oncologist (doctor) with experience in radiotherapy (treatment using x-rays) and chemotherapy (treatment using cancer medicines)

- a palliative care specialist (palliative care is concerned with relieving pain and discomfort).

### **Specialist urological cancer teams**

Specialist teams provide specialist care and treatment for people whose cancer is less common or who require specialist treatment for other reasons. These teams liaise with the local urological cancer team, the person's GP and other professionals if necessary.

Specialist teams are based at specialist cancer centres. These are usually at major hospitals, which might be some distance from the patient's home and local hospital.

#### ***Who should be in the specialist cancer team?***

The healthcare professionals who work as part of a specialist urological cancer team should all have an interest in those urological cancers and types of treatment that are specifically dealt with by the specialist team rather than the local team.

The NICE guidance says that all specialist urological cancer teams should normally include, as a minimum:

- at least two urologists with specialist knowledge and experience of treating the relevant types of urological cancer
- at least one oncologist with experience in certain specific types of treatments available through this team
- a radiologist with specialist experience and training in imaging and treating specific urological cancers
- a specialist nurse who can provide support and information on the particular types of urological cancer and treatments with which the specialist team deals
- a pathologist with specific experience in urological cancers
- palliative care and pain management specialists.

### **The roles of the teams**

Depending on the type of cancer and the treatment needed, people with a urological cancer may receive all

or most of their healthcare from the local urological cancer team or the specialist urological cancer team. The decision about whether a person should be treated by a local team or a specialist team depends on the cancer that a person has and the particular types of treatment that may be necessary. Treatment options will be discussed and agreed between members of the team and the patient.

Individuals will usually see a particular member of the cancer team, depending on the treatment they are receiving, with input from other health professionals, such as radiographers, when needed. (Radiographers are involved in imaging areas of the body and treating patients using radiation therapy.) The team nurses have a particularly important role in supporting patients with urological cancer at all stages of diagnosis and treatment.

Individuals may also move between teams to receive the best mix of care. For example, people with bladder or prostate cancer might receive most of their healthcare from the local team. But if they need an operation to completely remove their prostate (known as a radical prostatectomy) or bladder (known as a radical cystectomy), the surgery will be carried out at a cancer centre by urologists from a specialist team. This is because these operations are quite complex, and it has been recommended that they are performed only by a team that carries out these procedures regularly, and does a number of the same operations each year.

### ***The patient's GP***

Most people will also see their own GP or other members of their primary care team such as community nurses. The GP and the patient's urological cancer team will keep each other updated on the person's treatment and progress and any changes in his or her circumstances.

### **Team members should have appropriate clinical skills**

NICE recommends that members of urological cancer teams have the specialist skills needed for the type of patients that they will see. For example, only urologists who are experienced in performing some of the more specialised operations should carry out those operations – these urologists will work as part of the specialist cancer teams (this is covered in the next section).

### **Radical surgery for prostate and bladder cancer should be carried out by specialist teams**

'Radical' in the title of an operation means that it involves removing all or most of the organ affected by the cancer (bladder or prostate) and sometimes some of the surrounding structures. For example, a radical prostatectomy involves removing the whole prostate gland and the structures called seminal vesicles that lie behind it – this might be recommended for some men with prostate cancer. Similarly, a radical cystectomy might be recommended for some people with bladder cancer – this operation involves removing the bladder.

Radical prostatectomies and radical cystectomies require certain skills and experience. Because of this, NICE has recommended that these operations are only carried out by a specialist team that does at least 50 of either or both procedures each year.

Not all hospitals currently perform this number of operations and the number of operations carried out by urologists within teams varies considerably. So, while the teams build up their experience, NICE recommends that those urologists who carry out fewer than five radical prostatectomies or radical cystectomies a year refer people needing these operations to selected urologists working in the specialist teams.

### **Information and support should be improved**

The NICE guidance recommends that people with a urological cancer should be provided with good-quality information on all aspects of their condition, the tests that might be offered, and the treatment options. All members of the cancer teams should be trained to communicate effectively with patients and their family members and carers and to be aware of all the important issues. Patients (and family members if appropriate) should receive clear, helpful written information.

The aim is that when the doctor and patient have to decide on the next step, the patient knows all the options and the possible consequences of those options.

NICE has suggested that this information could be combined in an information pack that could be produced at a local level and kept by the patient. Such a pack could contain details of the patient's disease and treatment, information about the cancer team(s) responsible for the patient's care and treatment, and a diary in which the patient can write down symptoms and any other information that might be helpful in future discussions with the doctor or nurse.

Other forms of support that should be available to people with a urological cancer include counselling and information on organisations that can offer advice or support in specific areas.

### **More research is needed on treatment**

Some people with urological cancers will be faced with the need to consider different treatment options. Some of the key issues for the doctor and patient when discussing treatment options are the relative success of different treatments for an individual patient, and the side effects and long-term consequences of the different options. So a patient might ask "what option has the most chance of being successful?" or "how will I feel if I have treatment x compared with treatment y?" Sometimes the doctor will be able to talk about the results of research that has been done, which might help the individual to reach a decision about treatment. But in some circumstances the doctor cannot provide all the answers because the necessary research has not yet been carried out or completed.

NICE has therefore recommended that doctors and other healthcare professionals working in this area support research projects into treatments for

urological cancer and discuss taking part in research studies with their patients. These research projects are usually clinical trials that aim to show the best forms of treatment for specific medical conditions.

People asked to participate in clinical trials should receive a full explanation of what clinical questions a trial is designed to answer and what participating in the trial involves. They should receive written information about what taking part will involve, have time to decide if they want to participate or not and be given the opportunity to ask further questions if they need to before they make a decision. While it is hoped that people will want to participate, they should have the opportunity to decide not to take part. Deciding not to participate doesn't affect other aspects of treatment and care.

## **Further information**

It's important to remember that your local services may be a little different from those described here – the NICE cancer service guidance sets out the way that the urological cancer services should develop over the coming years.

If you have any questions about your health or the health of a member of your family or a friend, speak to your GP. If you or a relative or friend has a urological cancer and you have questions about the information here, or about treatment and healthcare in general, talk to a member of the urological cancer team. In addition, further information on urological cancers and support groups is available from NHS Direct (which you can access on the Internet at [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)).

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Copies of this document can be obtained from the NHS Response Line by telephoning 0870 1555 455 and quoting reference N0139. The full guidance, reference N0138, has also been published and a CD with all documentation including the research evidence on which the guidance is based is available.

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