

Understanding NICE guidance

Information for people who use NHS services

Prostate cancer

NICE 'clinical guidelines' advise the NHS on caring for people with specific conditions or diseases and the treatments they should receive.

This booklet is about the care and treatment of men who have suspected or diagnosed prostate cancer in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for men who have prostate cancer but it may also be useful for their partners, families or carers or for anyone with an interest in the condition.

The booklet aims to help you understand the care and treatment options that should be available in the NHS. It does not describe prostate cancer or the tests or treatments for it in detail. A member of your healthcare team should discuss these with you. There are examples of questions you could ask throughout this booklet to help you with this. Some sources of further information and support are on the back page.

Contents

Your care	3
Prostate cancer	4
Suspected prostate cancer	4
Diagnosed prostate cancer	5
Palliative care	7
Follow-up	7
More information	8
About NICE	8

The advice in the NICE guideline covers the tests, treatment, care and support that men who have suspected or diagnosed prostate cancer should be offered.

It does not specifically look at the care of men with rare cancers of the prostate (for example, small-cell carcinoma and rhabdomyosarcoma).

Your care

Your treatment and care should take into account your personal needs and preferences, and you have the right to be fully informed and to make decisions in partnership with your healthcare team. To help with this, your healthcare team should give you information you can understand and that is relevant to your circumstances. All healthcare professionals should treat you with respect, sensitivity and understanding and explain prostate cancer and the treatments for it simply and clearly.

The information you get from your healthcare team should include details of the possible benefits and risks of particular treatments and management options. You can ask any questions you want to and you can choose to be involved in decisions about your treatment and care as your treatment progresses and as your condition or circumstances change. Your own preference for a particular treatment is important and your healthcare team should support you in your choice of treatment options wherever possible.

Your treatment and care, and the information you are given about it, should take account of any religious, ethnic or cultural needs you may have. It should also take into account any additional factors, such as physical or learning disabilities, sight or hearing problems, or difficulties with reading or speaking English. Your healthcare team should be able to arrange an interpreter or an advocate (someone who supports you in putting across your views) if needed.

If you agree, your partner, family and carers should have the chance to be involved in decisions about your care. Family members and carers also have the right to the information and support they need in their role as carers.

If people are unable to understand a particular issue or are not able to make decisions for themselves, healthcare professionals should follow the advice that the Department of Health has produced about this. You can find this by going to the Department of Health website (www.dh.gov.uk/consent). Your healthcare professional should also follow the code of practice for the Mental Capacity Act. For more information about this, visit www.publicguardian.gov.uk

Some treatments may not be suitable for you, depending on your exact circumstances. If you have questions about the specific treatments and options covered in this booklet, please talk to a member of your healthcare team.

If you think that your care does not match what is described in this booklet, please talk to a member of your healthcare team.

Prostate cancer

Prostate cancer is one of the most common cancers in men. The prostate is a small gland near a man's bladder, which makes a fluid called semen. When a man has prostate cancer, the cells in the prostate gland do not grow normally, but instead form lumps (also known as tumours).

Prostate cancer is more likely to occur in older men. It tends to grow slowly, sometimes over many years, and may not necessarily affect a man's general health. When prostate cancer spreads to other parts of the body it is called 'advanced' or 'metastatic' cancer.

Suspected prostate cancer

Some men have signs or symptoms that lead their healthcare professional to suspect that they may have cancer. NICE has produced a guideline specifically on the care that people with suspected cancer should be offered before they are referred to specialist care (see www.nice.org.uk/CG027).

What your GP should do

If your symptoms suggest that you may have prostate cancer, your GP should offer you a digital rectal examination. This involves a healthcare professional feeling inside your rectum with a finger to check for anything unusual on the surface of the prostate. Your GP should also offer you a blood test to measure your level of a protein called prostate specific antigen (or PSA for short). The levels of this protein in the blood are often higher in men with prostate cancer, but there may be other reasons for raised PSA levels.

Referral to specialist care

If your GP feels further investigation is needed, they should refer you for a consultation with a specialist.

You may be offered a prostate biopsy. This involves taking small samples of your prostate and checking them for cancer under a microscope. This test helps healthcare professionals identify whether a man has prostate cancer and whether the cancer is likely to cause him harm.

Deciding whether to have a prostate biopsy

Your healthcare professional should talk with you about whether a prostate biopsy is appropriate for you.

To help you make a decision about a biopsy, your healthcare professional should discuss with you the risks and benefits of having a biopsy and the results of previous tests (including the digital rectal examination, PSA test and any previous biopsy results). They should also discuss with you your risk factors, including increasing age and whether you are from a black African or black Caribbean ethnic background. Your healthcare professional should also discuss with you the implications for you if it turns out that the biopsy shows cancer of the prostate which is not likely to cause symptoms or affect your life expectancy.

You should be given as much support, time and information as you need to help you make the decision. If you decide to go ahead with a prostate biopsy, a team of healthcare professionals who specialise in cancer will review the results.

Questions you might like to ask about a biopsy

- Do I need this test and what does it involve?
- What are the risks and benefits of the test?
- When will I get the results?
- What if I decide not to have the test?

Diagnosed prostate cancer

Using the results of your tests, your healthcare professional should be able to confirm whether or not you have cancer cells in your prostate.

Your healthcare professional should work out and discuss with you what stage of prostate cancer you have and how quickly it is likely to progress. There are three stages of prostate cancer, depending on where the cancer is in your body.

Localised prostate cancer: cancer that is only in the prostate and has not spread.

Locally advanced prostate cancer: cancer that is in the prostate and has spread to surrounding tissues.

Metastatic (or advanced) prostate cancer: cancer that is in the prostate and has spread to the lymph nodes, bones or other parts of the body.

Depending on the stage of your cancer and your preferred treatment options, you may be offered a scan (for example, a scan of your pelvis or bones) to give your healthcare professional a picture of where the cancer is in your body.

Deciding on treatment

If you have prostate cancer, your healthcare professional should discuss your treatment options with you. You should be given the information you need about prostate cancer (including useful websites such as www.prostate-link.org.uk). You should also be given information on the treatments available, their side effects and ways of dealing with the side effects (see page 7) in order to make decisions about your treatment and care.

Your healthcare professional should support you in making a decision about treatment, taking into account the risks and benefits and the effects of the different treatments on your quality of life. They may use a questionnaire to help you make decisions.

Managing prostate cancer

Below are the treatment and management options that are recommended by NICE, some of which may be appropriate for you depending on the stage of your disease, how quickly your cancer is likely to progress and your preference. These options may be offered in combination and at different stages during your treatment.

Watchful waiting: treatment is offered only when symptoms develop.

Active surveillance: regular testing, with treatment only if and when necessary.

Radical prostatectomy: surgery to remove the prostate.

Radical external beam radiotherapy: radiation treatment directed at the prostate from outside the body to destroy cancer cells.

Brachytherapy: radiotherapy treatment directed at the cancer from within the prostate. A substance that gives off radiation is placed in the prostate and the radiation destroys cancer cells.

Hormonal therapy: medicines that reduce the production or block the effects of hormones which cause the cancer cells to grow.

Orchidectomy: removal of the part of the testicles that produces the hormone testosterone which helps the cancer cells to grow.

Chemotherapy: treatment with drugs to destroy cancer cells.

Palliative care: aims to relieve the symptoms of cancer. This includes treatments for pain relief and practical support.

There may be other treatments that are appropriate for you. Please talk to your healthcare professional if you need further information or contact the organisations listed at the end of this booklet.

You should not be offered **high-intensity focused ultrasound (HIFU)** or **cryotherapy** unless you are involved in a good quality research study.

Side effects

Your healthcare professional should talk with you about the side effects you may experience from the different treatment options.

Some prostate cancer treatments can affect your sex life or fertility. You should be able to talk with a healthcare professional about erection problems or about how your treatment is affecting your sex life. There are drugs and devices which may help with problems in getting and maintaining an erection. Sperm storage is an option if you are concerned about losing your fertility.

Some prostate cancer treatments can make it harder to control urination (passing water). Your healthcare professional should discuss this with you and provide you with access to specialist continence services.

If you are taking hormonal therapy, regular resistance exercise, with weights, can help to reduce tiredness.

Questions you might like to ask about treatments

- Why might this particular treatment be suitable for me?
- What are the side effects of this treatment?
- Will this treatment affect my sex life or fertility?
- Are there any other treatments available to me?

Palliative care

Palliative care helps to relieve some of the symptoms of cancer but does not cure it. Palliative care includes more than hospice care. For instance, it can include pain relief and practical support to help men deal with their symptoms. Men with metastatic prostate cancer should have the opportunity to discuss palliative care options with their healthcare professional at any stage.

Follow-up

You should be offered follow-up appointments after your treatment. Your healthcare professional should talk with you and your partner or carer about how often and where follow-up appointments should take place. You should be able to talk with a member of your healthcare team whenever you need to, and in particular if there are changes in your disease or symptoms.

More information

The organisations below can provide more information and support for people with prostate cancer. Please note that NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- Cancerbackup, 0808 800 1234
www.cancerbackup.org.uk
- PCaSO – Prostate Cancer Network, 0845 650 2555
www.pcaso.com
- PSA Prostate Cancer Support Association, 0845 601 0766
www.prostatecancersupport.info
- The Prostate Cancer Charity, 0800 074 8383
www.prostate-cancer.org.uk

NHS Direct online (www.nhsdirect.nhs.uk) may also be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further information and support.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider the best available evidence on the condition and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals working in the field. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This booklet and other versions of this guideline aimed at healthcare professionals are available at www.nice.org.uk/CG058. The versions for healthcare professionals contain more detailed information on the care and treatment you should be offered.

You can order printed copies of this booklet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N1458).

We encourage NHS and voluntary sector organisations to use text from this booklet in their own information about prostate cancer.