

# Active surveillance for prostate cancer

This leaflet aims to answer any questions you may have about active surveillance (monitoring) of your prostate cancer. It gives you information on why this may be suitable for you, its risks and benefits and what to do if you change your mind and decide you want treatment for your cancer. More detailed information is available from your specialist.

## What is active surveillance?

Active surveillance is a process of monitoring men diagnosed with prostate cancer, which aims to avoid or delay unnecessary treatment in men with low volume, low risk prostate cancer. Some prostate cancers are detected at an early stage following a prostate biopsy which tests for increased levels of prostate-specific antigens (PSA) in the blood. In some of these cases the cancer may never progress or cause any symptoms - in other words, some men with prostate cancer will never need any treatment.

Treatments for prostate cancer can cause side effects which can affect your quality of life. By monitoring the cancer through an active surveillance programme, you can avoid or delay these side effects. The most common side effects include problems getting and keeping an erection (erectile dysfunction) and problems controlling or passing urine (incontinence).

## Who is suitable for active surveillance?

Active surveillance is suitable for men with low to intermediate risk, low volume, early stage prostate cancer that is contained within the prostate gland (often referred to as localised prostate cancer). High risk cancers (with a Gleason score of eight or above) are not suitable for active surveillance.

Men with low to intermediate risk cancer will usually have a PSA level of less than 10ng/ml and a Gleason score of seven or less (please see the leaflet, **How Prostate Cancer is diagnosed** by the charity, **Prostate Cancer UK**). The biopsy result should show that there was cancer in less than half of the samples taken. Your specialist will discuss whether it is an option for you.

## What are the benefits?

There is no physical treatment involved, so there are none of the physical side effects associated with other prostate cancer treatments. Also, active surveillance does not interfere with your everyday life like undergoing treatment does.

## What are the risks?

We do not know how many men on active surveillance will eventually need treatment such as surgery or radiotherapy. However, a recent research study over ten years found that about one in three men go on to have treatment. Of this number, most men will have treatment because tests show that their cancer has changed, although some men decide that they want to have treatment anyway, even when there is no sign of any change.

Other risks of active surveillance include:

- becoming anxious or worrying about the cancer changing
- the need to have more prostate biopsies
- the small chance that the cancer may grow more quickly than expected and become more difficult to treat.

## What are the alternatives?

Other treatment options for localised cancer (cancer that has not spread outside the prostate gland) may include:

- **brachytherapy** (a form of internal radiotherapy which involves implanting 'seeds' of radioactive material directly into your prostate gland under a general or spinal anaesthetic)
- **external beam radiotherapy** (beams of radiation to destroy the cancer cells)
- **open / robotic radical prostatectomy** (surgery to remove your prostate either through an incision or cut in your abdomen or using robotic instruments and several keyholes)

## If I decide to follow the active surveillance programme, what can I expect?

The surveillance programme may vary slightly from patient to patient, depending on how often you will need your PSA monitored. Your nurse or doctor will discuss this with you, but typically your programme will run to the following schedule:

### Three weeks after biopsy:

You will return to a special clinic for the results of your biopsy.

- If the transperineal biopsy shows that the cancer is of a low enough a risk for you to be on an active surveillance programme, we will arrange shared-care follow up with your GP. Your PSA levels will need to be checked every six months.
- If your PSA blood test reaches a defined limit (which we will specify) your GP will refer you back to the hospital for review.
- If the transperineal biopsy shows more cancer than expected, your doctor will advise on which treatments might be recommended and whether any further investigations are necessary before you decide on a course of action.
- You will be given the contact details of a specialist nurse (key worker) so that you can contact them if you have any questions or queries at any point.

### Six months after diagnosis:

- You will have a further PSA test and a review with a doctor (often your GP) or specialist nurse to discuss the results.
- If you have not already had one, an MRI scan will be arranged for you.

### One year after diagnosis:

- You should have another PSA blood test taken just prior to your hospital appointment.
- At this time you will be reviewed by the specialist nurse in clinic.
- You will also have a rectal examination at this appointment.

- A decision will be made as to whether you will continue on surveillance with your GP and when you will next be reviewed at the hospital.
- If the nurse has any concerns, she will ask one of the prostate consultants to review you when you are in the clinic.

### **18 months after diagnosis:**

- At 18 months you should be reviewed by your GP and should have another blood test.
- If your PSA blood test reaches a defined limit (which we will specify) your GP will refer you back to the hospital for review. If not, you will continue with the active surveillance programme.

### **Two years after diagnosis:**

- You may need another transperineal prostate biopsy, although this will depend on your PSA levels, the rectal examination, an up to date MRI scan and how you feel about this.
- If you have another transperineal prostate biopsy you will come back to the prostate cancer clinic to see one of the prostate cancer team.
- If the biopsy shows that your cancer is stable we will continue the active surveillance programme.

## **What if I change my mind about being on active surveillance?**

If at any point you change your mind about remaining on active surveillance, please contact one of the specialist nurses (Anna Ashfield or Netty Kinsella) on 020 7188 7339.

## **Contact us**

If you have any questions or concerns about active surveillance, please contact Anna Ashfield or Netty Kinsella on **020 7188 7339** (Monday to Friday, 9am to 5pm).

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)

### **Pharmacy Medicines Helpline**

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

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

### **Patient Advice and Liaison Service (PALS)**

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

**t:** 020 7188 8801 at St Thomas'    **t:** 020 7188 8803 at Guy's    **e:** [pals@gstt.nhs.uk](mailto:pals@gstt.nhs.uk)

### **Language Support Services**

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

**t:** 020 7188 8815    **fax:** 020 7188 5953