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. If you have any questions or concerns, please speak to a doctor or nurse caring for you.

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 prostate cancer treatments. Also, active surveillance does not interfere with your everyday life like undergoing treatment does.
Issues associated with active surveillance
We do not know how many men on active surveillance will eventually need treatment such as surgery or radiotherapy. However, a research study over ten years found that about one in four men (25%) 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
- potential side effects of repeat biopsies
- a 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 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)
- **robotic radical prostatectomy** (surgery to remove your prostate either through an incision or cut in your abdomen or using robotic instruments and several keyholes)

However for a very low grade, low volume cancer, external beam radiotherapy and robotic surgery may not be appropriate

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 doctor or nurse will discuss this with you, but typically your programme will run to the following schedule:

**Three weeks after biopsy:**
You will return to the clinic for the results of your biopsy.

If the biopsy shows that the cancer is of a low enough risk for monitoring, we will enrol you on to the active surveillance programme which will include
1. An invitation to an active surveillance seminar
2. Regular PSA checks (every six months) once at your GP and once at the hospital
3. Regular MRI scans, usually every two years
4. Regular biopsies, usually between two to three years

If your PSA blood test reaches a defined limit (which we will specify) your GP should notify the prostate team.

If subsequent biopsies show more cancer than expected, your doctor will advise on which treatments might be suitable and whether any further investigations are necessary before you decide on a course of action.

Usually active surveillance runs until between the ages of 75 and 80 years. After this age the MRI and biopsies will be dropped from the programme and you will only have the PSA monitoring.
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 the prostate cancer specialist nurses (details below).

Useful sources of information
Prostate Cancer UK  w: www.prostatecanceruk.org

Contact us
If you have any questions or concerns about active surveillance, please contact the prostate cancer specialist nurses,  t: 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

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

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
  t: 020 7188 3514 (complaints)  e: 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

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

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, please get in touch.
  t: 0800 731 0319  e: members@gstt.nhs.uk  w: www.guysandstthomas.nhs.uk/membership