Active surveillance for low to intermediate risk prostate cancer

What does active surveillance mean?

Active surveillance is a way of monitoring prostate cancer that is contained within the prostate (localised prostate cancer) and with a low chance of progressing. It is an alternative to initiating immediate treatment.

The aim of active surveillance is to avoid treatment unless there are signs of the cancer progressing. This is so that you can avoid, for as long as possible, any side effects of treatment. Many studies have shown that with a rigorous active surveillance programme, there is no detrimental effect for patients or an increased chance of cancer spreading.

Who is eligible for active surveillance?

Men diagnosed with low risk prostate cancer, that is a prostate specific antigen (PSA) equal to or less than 10ng/ml, Gleason grade sum score 6 and clinical stage T1-T2 and cancer involving less than 50% of the number of cores.

or

Low volume intermediate risk cancer, that is PSA 10-20ng/ml, Gleason7 and T1-T2.

There are a few other factors such as age, family history or other illness that may also be important when considering active surveillance.

What does active surveillance involve?

An active surveillance programme may vary slightly from patient to patient, depending on your specific circumstances. Your nurse or doctor will discuss this with you, but typically your programme will have the following schedule:

- After you have been enrolled to active surveillance all patients will be seen in an active surveillance clinic at three months.
- All patients will have a repeat PSA, magnetic resonance image (MRI) scan of prostate (if not already done) and may be recommended to have a repeat biopsy to ensure there is only low risk disease or low volume intermediate risk disease in the prostate. This biopsy may be another transrectal biopsy or a transperineal biopsy.
- If the scans and repeat biopsy confirm low risk disease then a regular plan of three monthly PSA will be initiated and a personalised plan of follow up arranged.
- Typically this will involve PSA blood tests which can be done at your GP and we will ask you to keep a record of these results. This may also be supplemented by online or other tools to keep a track of your PSA.
- A hospital review at 6-12 months in clinic.
- A repeat MRI at 12 months and consideration of a further biopsy. If the PSA, scans and biopsy (if undertaken) remain stable then active surveillance will be continued.
Thereafter to continue regular PSA blood tests indefinitely, 12 monthly clinic appointments and repeat assessment with scans and re-biopsy at two to four yearly intervals.

Triggers for re-investigation or active treatment may include:
1. Evidence of a significant rise in the PSA (typically three consecutive PSA rises)
2. Any change in MRI scans and/or examination findings
3. Patient preference for change
4. Increase in tumour volume on repeat biopsies

**Are there any risks with active surveillance?**

**Changes to your cancer**
There is a chance that your cancer could grow. But the tests used to monitor your cancer aim to find any changes early enough to start treatment. The monitoring plan described above is designed to be as rigorous and robust as possible to detect early any potential change in the cancer. There is always a small chance that changes may be missed. Talk to your nurse or doctor about your own specific risks as an individual.

**Changes to your health**
There is a chance that your general health could change, which would make some treatment (particularly surgery) unsuitable for you, if the cancer did grow. However there are many very effective options to treat prostate cancer.

**Concerns about active surveillance (psychological impact)**
Active surveillance isn’t for everyone. You might find it difficult not to have any treatment for prostate cancer, and worry that it will change or spread. If you are worried talk to your doctor or nurse. You do not have to stay on active surveillance if you do not want to.

**Side effects from repeat biopsies of the prostate**
On an active surveillance programme you will require repeat prostate biopsies as part of the monitoring. Prostate biopsies do however have a small risk of infection and bleeding and this risk will apply for each biopsy episode though all steps will be taken to minimise this risk.

**What are the advantages of active surveillance?**
1. As you won’t have any treatment while on active surveillance, you will avoid the side effects.
2. Active surveillance doesn’t interfere with your everyday life as much as treatment might do.
3. If tests show that your cancer is growing, there are treatments available that can still cure it.

**What are the disadvantages of active surveillance?**
1. You might need to have more prostate biopsies which can cause side effects, and which some men find uncomfortable and painful.
2. Your general health could change, which might make some treatments unsuitable for you if you need them.
3. Your cancer might grow more quickly than expected, but the chance that this will happen is small.

4. Not having treatment can cause high levels of worry in patients about the possibility of their cancer growing.

**What to expect after deciding to have active surveillance?**

1. You do not need to change your lifestyle or activities.

2. Your first appointment will be in three to four months from the diagnosis.

3. You need to have your PSA done prior to this appointment, at your GP surgery.

4. You may have an MRI scan before the first appointment or the MRI is sometimes organized from the appointment (if not done before).

5. At your first appointment, the MRI results or organising an MRI scan, along with repeat biopsy and type of biopsy and as well as follow up plans will be discussed.

6. At all times you will have ready contact with your prostate cancer nurse specialist who you can talk to if you have any concerns or worries. You can also come off surveillance and have active treatment at any point if you are worried.

**What are the alternatives to active surveillance?**

Other treatment options for localised cancer 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)

- **Radical prostatectomy** (removal of the entire prostate gland)

**Who can I contact for more help or information?**

**Oncology nurses**

- **Uro-oncology nurse specialist**
  01223 586748

- **Bladder cancer nurse practitioner (haematuria, chemotherapy and BCG)**
  01223 274608

- **Prostate cancer nurse practitioner**
  01223 216897 or bleep 154-620

- **Surgical care practitioner**
  01223 348590 or 256157 or bleep 154-351

**Non-oncology nurses**

- **Urology nurse practitioner (incontinence, urodynamics, catheter patients)**
  01223 274608 or 586748 or bleep 157-237

- **Urology nurse practitioner (stoma care)**
  01223 349800
Urology nurse practitioner (stone disease)
01223 349800 or bleep 152-879

Patient advice and liaison service (PALS)
Telephone:
+44 (0)1223 216756 or 257257
+44 (0)1223 274432 or 274431
PatientLine: *801 (from patient bedside telephones only)
E mail: pals@addenbrookes.nhs.uk
Mail: PALS, Box No 53
Addenbrooke's Hospital
Hills Road, Cambridge, CB2 2QQ

Chaplaincy and multi faith community
Telephone: +44 (0)1223 217769
E mail: chaplaincy@addenbrookes.nhs.uk
Mail: The Chaplaincy, Box No 105
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Hills Road, Cambridge, CB2 2QQ

MINICOM System ("type" system for the hard of hearing)
Telephone: +44 (0)1223 217589

Access office (travel, parking and security information)
Telephone: +44 (0)1223 596060

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