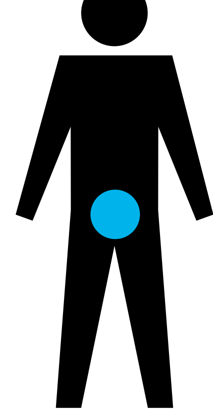
PROSTATE INFORMATION

SPOTLIGHT ON

Active surveillance as a management for early prostate cancer



Introduction

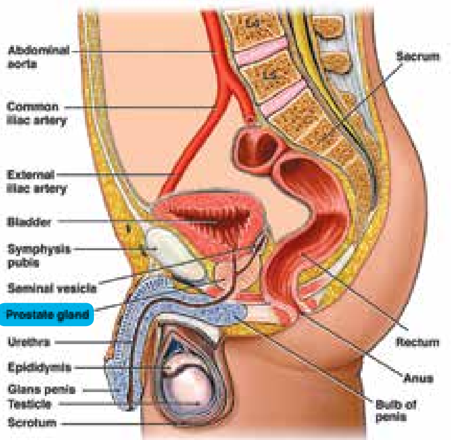
This booklet is to help explain more to you about a way to manage localised prostate cancer with Active Surveillance. The aim is to help you decide, in consultation with your consultant, clinical nurse specialist (CNS), and your family if Active Surveillance (AS) is right for you.

AS may be suggested to you as a way of managing your cancer if the side-effects of treatment will have a greater impact on your quality of life than the cancer.

AS means; there is no immediate treatment of the cancer but that doctors and CNS will keep a close eye on your health and cancer with regular checkups, PSA tests, digital rectal examinations (DRE) biopsies and MRI scans. In this way, treatment is deferred until it becomes necessary or if you no longer want to manage your cancer.

About the prostate

Only men have a prostate. It lies inside the pelvis, just below the bladder and in front of the back passage. It wraps around the tube called the urethra which allows urine to flow out of the body and semen to pass out through the penis. It supplies the thick clear fluid that mixes with sperm to form the ejaculate. It also makes Prostate Specific Antigen or PSA.



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What is prostate cancer?

Prostate cancer occurs when the cells in the prostate develop abnormalities, multiply and grow faster than normal. This causes a growth called a tumour. Tumours that can spread to other parts of the body are called cancers. As the prostate is inside the body, tumours affecting it can't be seen and very often cause no symptoms.

However, most prostate cancers grow slowly. At the moment, it is not known why some prostate cancers grow more slowly and others grow more quickly.

Some men won't even know they have prostate cancer, as it may not cause any symptoms, have any effect on or shorten their life.

Prostate cancer may be:

- *Early or localised:* when it is still within the prostate and has not spread to other parts of the body;
- *Locally advanced;* when it has spread just outside the prostate through the capsule (covering or outer wall) that surrounds the prostate or into the seminal vesicles that lie behind the prostate;
- *Advanced;* when cancer cells have spread away from the prostate through the bloodstream or lymph channels. On reaching a new site or sites, the cancer cells may start to grow causing another tumour or tumours. These are called secondary cancers (secondaries) or metastases.

What is active surveillance (AS)?

Active surveillance (sometimes called active monitoring) is a management option suitable for some men with low-risk prostate cancer because some prostate cancers grow more slowly than others and are non-aggressive. AS means that treatment is deferred, until such times that treatment becomes necessary.

During this time your cancer will be very carefully monitored. Your doctor or CNS will keep a close eye on your health and cancer with regular check-ups, PSA tests, DRE, prostate biopsies and MRI scans (usually delayed until after the effects of biopsies have resolved). If the cancer shows signs of becoming more aggressive or progressing, then curative treatment can be started.

Some men with localised prostate cancer will have a very slow growing cancer that will not normally threaten their life. These men may prefer to choose AS so avoiding the potential risk of side-effects associated with treatment, which may impact on the man's quality of life.

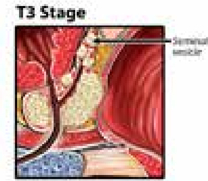
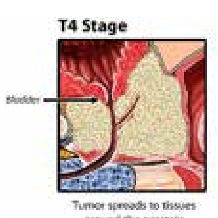
In some circumstances, active surveillance may also be considered for men with intermediate-risk prostate cancer who wish to defer treatment; this would need to be discussed with your consultant.

What does low risk and intermediate risk mean?

Result	Low risk	Intermediate risk	High risk
Gleason score	6 The cancer is likely to remain in the prostate and grow slowly (be less aggressive).	7 There is an increased chance of the cancer breaking out of the prostate and spreading to other parts of the body.	8 - 10 There is a greater risk that the cancer will grow quickly (more aggressive) and may have already spread outside the prostate to the bones or other parts of the body.
PSA level ng/ml	10 or lower	10 - 20	More than 20

The Gleason score measures the aggressiveness of your tumour. Although the scale goes from 1 to 5 the pathologist (the person examining your biopsy samples) will only report on grades of 3, 4 and 5.

The two most common grades found in the tumour samples are added together to give your score. So a Gleason 6 (3+3) means that the two most common grades were a 3. A Gleason 7 (3 +4) indicates that the most common pattern was a 3, the second most common a 4.

Stage	Image	Description
T1	T1 Stage Tumor is NOT palpable by digital rectal exam (DRE)	The tumour is too small to be seen during a scan and the doctor will not have been able to feel it when your prostate was examined during a DRE . This type of tumour shows up when the samples of tissue taken during the biopsy are looked at under the microscope. This is called early or localised prostate cancer.
T2 T2a The tumour is smaller than half of one of the lobes in the prostate T2b The tumour is bigger than half of one of the lobes in the prostate T2c The tumour is in both lobes but is still inside the prostate	T2 Stage Tumor is palpable by digital rectal exam (DRE)	The tumour will be seen during a scan and the doctor will have been able to feel a lump or hard area when your prostate was examined. This type of tumour is still inside the prostate. This is also called early or localised prostate cancer.
T3 T3a The tumour has broken through the capsule (outer wall) of the prostate T3b The tumour has spread into the seminal vesicles		The tumour will be seen during a scan and the doctor can feel it breaking out through the wall of the prostate.This type of tumour has spread outside the prostate to areas around the prostate, but not any other areas in the body. This is called locally advanced prostate cancer.
T4		The fixed or invasive tumour has spread into the bones or nearby organs in the body, such as the back passage, bladder or pelvic side wall. This is called advanced prostate cancer. Where the cancer has spread to other areas in the body and started to grow, the new site is called a secondary (secondaries) site or metastases.

When might active surveillance be suggested?

- When cancer is found in the early stages, it's still inside the prostate and is thought to be low-risk of progression or non- aggressive. It **may** be an option for some men with intermediate-risk prostate cancer;
- For men aged under 75 with a life expectancy of 10 years or more;
- For men over 70, if the cancer is unlikely to grow fast enough to cause any problems;
- For younger men who have concerns that the side-effects of treatment may have a greater impact on their quality of life than the cancer. They may prefer to put off the risk of potential side-effects for as long as possible (deferred radical treatment);
- For men with a PSA of less than 10;
- Gleason score of 6 (3+3), Stage T1 as first choice treatment;
- Gleason score of 6 (3+3), Stage T2a/b consider alongside prostatectomy and radiotherapy options
- Gleason score of 7 (3+4). Stage T2b/c In this case other treatment options will most likely be recommended but AS may be considered if the man wants to defer treatment.

There may be additional local guidelines that you may have to meet in order that AS would be considered as a suitable management choice for you. These might include thinking carefully about what your prostate biopsies showed. Ask your consultant or clinical nurse specialist (CNS) if there are specific guidelines for AS in the hospital that you attend.

How would I be monitored?

The information that follows about active surveillance is meant as general guidance. As there is more than one approach, procedures and treatment may vary slightly from hospital to hospital, ask for more advice from staff at the hospital you are attending. If you have been given any specific guidance by the hospital then it is important that you follow their instructions.

As protocols or guidelines may vary throughout Scotland, a typical approach might be:

Timing in years	Tests	In my hospital
Enrolment in AS	MRI scan. (after effects of biopsies have resolved – this can take up to 6 months)	
Year 1	Measure PSA every 3-4 months* DRE every 6 months Repeat prostate biopsy within the first year, or later if very low risk	
Years 2- 4	Measure PSA every 3-6 months* DRE every 6 – 12 months Repeat biopsy at 3 years	
Year 5 and every following year	Measure PSA every 6 months DRE every 12 months Repeat biopsy at 5 years and every 2 years thereafter	

* PSA may be undertaken in the GP practice or hospital clinic. The measurement allows calculation of PSA doubling time. For more information about this see pages 10 and 11.

So, as you can see AS does involve close monitoring of your cancer and will mean that you have regular appointments with your GP practice and follow-up visits and tests at the hospital to ensure that the cancer does not progress whilst under surveillance.

Remember to make dates for follow-up PSA blood test appointments which are likely to be with your GP or practice nurse. If you have an appointment to attend the hospital for follow-up you might be asked to have a PSA test done at your GP practice before attending hospital so the consultant or CNS has an up-to-date PSA level.

Making the decision

Although being diagnosed with prostate cancer might be scary, there is no need to panic or rush into making a hasty decision. Take your time to read about all the choices of treatment that are suitable for you. Think about what is important to you, the advantages and drawbacks of each treatment and how these might affect you and your lifestyle now and in the future. It's far better to choose your treatment carefully now, rather than rushing ahead with a treatment which may not be best for you in the long run. It's very useful to talk over treatment with the urologist, oncologist, clinical nurse specialist, your partner and family. In many areas, there are support groups where you can talk to men and their partners who are willing to share their experiences with others and it may be particularly valuable to talk to other men who are newly diagnosed. For more information on treatments there is a booklet available from Prostate Scotland called, 'Early prostate cancer explained', which will give you lots of information on tests, treatment and making decisions about treatment.

Will I have to attend hospital and who would I see?

You will have regular hospital appointments for check-ups throughout the time your prostate cancer is being monitored usually with the consultant or CNS. Most likely at these appointments you will have a PSA test done (or this may be arranged at your GP practice prior to your appointment so the result is available at your hospital clinic appointment), a general examination and DRE. A prostate biopsy will be done at regular intervals according to the guidelines in the hospital that you attend, it is probable that you will have an MRI scan at some stage.

In some areas prostate biopsies will be done by the urology consultant who is looking after you. However, in many areas, your prostate biopsy will be done

by a CNS or urology nurse practitioner. The CNS are an important point of contact if you need to ask questions, if you have any worries and for more help and advice.

Why will I have a follow up prostate biopsy?

The tissue samples from the biopsy are sent to a lab to be examined to check on your Gleason score and to check whether your cancer/tumour has changed and become more aggressive or increased in volume or size.

Gleason Score

The samples taken from your prostate are examined under a microscope to look at the cells. The specialist doctor (pathologist) looking at the cells decides which type of cell is most common and which is the second most common. Each of these two cell types is then given a score from 1 to 5. These numbers are added together to give a final score out of 10. This will be between 6 and 10. The pathologist will in fact only report on grades of 3, 4 and 5.

For active surveillance to be a suitable way to manage your prostate cancer, your Gleason Score should be 6 (grades 3+3) and the biopsy doesn't show any or perhaps a very small amount of grade 4. In this case your Gleason Score might be 7 (grades 3+4).

It's very important not to miss any appointments for blood tests, examinations and hospital appointments.

When will I need to consider another form of treatment?

Having all the checks done regularly, will show if or when your cancer starts to progress by becoming more aggressive.

Treatment can be started if the cancer shows these signs:

PSA level increasing

Your PSA will be checked regularly. A single, one-off rise in your PSA level may be due to other reasons, such as an infection. If your doctors notice that the level is continuing to go up, they will look at how quickly and by how much it has gone up.

If your PSA level doubles in less than 3 years (called your PSA doubling time) then your doctor may advise you to consider having a different type of treatment. It may be a sign that your prostate cancer is becoming more aggressive.

If your PSA rises, even though it doesn't actually double, it may be that your doctor advises that active surveillance is no longer a suitable management for your prostate cancer.

To help keep a record of your appointments, blood results, Gleason score and test results, you may find that the Prostate Log Book is very handy. You can ask your doctor or CNS for a copy, download from our website www.prostatescotland.org.uk or call us and a copy can be sent to you.

Changes in DRE

Changes may be felt by the doctor or CNS during a physical examination of your prostate. This could be a change in size or shape, a lump or hardened area. In this situation, they may organise a prostate biopsy depending on how the prostate feels or an MRI scan depending on local guidelines.

Your Gleason score has changed

If a repeat prostate biopsy shows an increase in the amount of cancer, this suggests that the cancer is becoming more aggressive.

What if I change my mind about having AS as my management choice?

You can change your mind and opt for another treatment at any time. Talk to your consultant or CNS. They will be able to advise you on the next steps and which other treatments may be suitable for you.

Other treatments include:

- Surgery to remove the prostate (radical prostatectomy)
- Radiation treatment to kill the cancer cells. This may be by external beam radiotherapy (EBRT) or brachytherapy. Hormone therapy may also be used in combination with EBRT or brachytherapy.

What advantages and drawbacks are there to think about with active surveillance?

Because you will not be having any immediate, active treatment for your prostate cancer and instead your cancer will be monitored by regular check-ups and tests, you may want to think about the advantages and drawbacks of managing your prostate cancer by AS.

Advantages	Drawbacks
With AS your prostate cancer is carefully monitored and only treated if and when treatment becomes necessary, so avoiding potential side-effects of treatment that can impact on your quality of life and the risk of over treatment.	Although AS does not cure your cancer, it manages it while you watch if it gets more aggressive.
You avoid any risk of potential side-effects that you might get from other types of treatment.	You may worry that you are not doing anything. You will have to be willing to live with some uncertainty and doubt about your cancer and what is going on.
Your prostate cancer may grow so slowly that other treatments may never be needed.	There is a very small risk that a slow-growing cancer may suddenly grow and spread outside the prostate capsule while you are waiting and so you could reduce the possibility of your cancer being treated with curative intent. This could then reduce the types of treatment available for you, increase the risk of side-effects and may make it longer for you to recover after treatment.
While your cancer is being monitored new and better treatments may become available.	You will need to attend your GP or hospital to have regular check-ups, PSA tests, DRE and prostate biopsies. You will need to remember to make appointments and keep a record of test results, in other words taking an active part in the monitoring of your cancer.

If Active Surveillance is not for you...

There are other treatment options available which may be suitable for you now or in the future. Unlike AS, these treatments may bring with them some unwanted side-effects such as incontinence and erectile dysfunction. You can chat over these treatments with your CNS or consultant.

Radical Prostatectomy

The operation removes the whole prostate and cancer which is contained within the prostate. Radical prostatectomy involves a hospital stay of about 1 - 5 days (depending on the surgical approach and if recovery goes well), a general anaesthetic and a catheter for about 2 weeks. After a radical prostatectomy, the PSA level will be extremely low and there will be regular check-ups and PSA levels will be measured.

Radiotherapy

This can be given in two ways:

External Beam Radiotherapy (EBRT)
High energy x-ray beams from outside the body are aimed at the prostate to kill the cancer cells in the prostate. These beams pinpoint areas to be treated. Treatments are carefully planned and will usually be given 5 days a week for between 4 - 8 weeks. Hormone therapy may be given in combination with radiotherapy.

Brachytherapy

This is a type of radiotherapy where tiny metal seeds which emit radiation are placed into the prostate, working to kill cancer cells from inside the body. The position and exact number of these 'seeds' are worked out carefully. The seeds are put in place during an operation with a general anaesthetic and possibly an overnight hospital stay. Hormone therapy may be given in combination with brachytherapy if the prostate is large to make the implant technically easier.

There is more information on these treatments in our booklet 'Early prostate cancer explained' which can be found on our website or by calling us for a copy.

How do I decide if managing my cancer this way is the right choice for me?

Before choosing active surveillance, you may have some questions to ask your doctor or CNS.

A list of possible questions is given below. Think about what you would like to know, so perhaps you need only to ask a few of these or you may have questions of your own.

- Is active surveillance a suitable option for me?
- If I choose active surveillance now, can I change my mind later on?
- Is it safe for me to put off treatment?
- If I wait, would this limit my treatment choices in future?
- What indications are there about the aggressiveness of my prostate cancer?
- Between check-ups, are there any signs or symptoms I should look out for and let you know about?
- Why do you think this might be the best option for me?
- Can you explain what the risks are likely to be?
- Which tests would I have – PSA, DRE, prostate biopsy, scans, anything else?
- How often would I need to have the tests or check-ups and who would do these?
- How would we know if my prostate cancer is getting worse?
- How quickly and to what level would my PSA need to rise before you would think about an alternative treatment for me?
- What treatment might be offered to me if the cancer starts to grow?
- How quickly would I be able to have the treatment?
- Are there other suitable treatment choices that I could think about now?
- Why might active surveillance be better for me than a radical prostatectomy, external beam radiotherapy or brachytherapy?
- What is the outlook for me?
- Is there someone that I can talk to who has made this choice?

ACTIVE SURVEILLANCE AS A MANAGEMENT FOR EARLY PROSTATE CANCER

Watchful waiting

This is different from active surveillance and is generally an option for older men, or for those who have significant other health problems and who will most likely not need radical treatment such as surgery or radiotherapy for their prostate cancer but may still, in future, be treated with hormone therapy alone.

These men will still have tests and examinations done such as DRE, PSA blood test and will be asked about their symptoms. If DRE and PSA levels show changes or symptoms become troublesome then the doctor will talk over suitable treatments as appropriate with them.

Is there anything I can do?

Lifestyle changes

You may like to be more involved in helping with your health care by looking at some of the lifestyle choices that you make. Suitable changes that you make to your lifestyle may help improve your general health and well-being.

Think about your lifestyle – do you have a healthy diet, do you take enough exercise, do you smoke, do you drink and if so how much?

If you're not too sure about any of these, then perhaps the following section on possible changes that you could make to your lifestyle will help or ask your CNS for more information.

Healthy diet

A healthy diet is good for your overall health and wellbeing – so what does a healthy diet mean? All you need to do is eat sensibly, choosing a wide variety of foods. (If you're on a 'special diet' then you should follow advice given by your dietitian)

Simply choose a variety of foods from each group, each day.

1. Starchy foods

Starchy foods include bread, rice, noodles, pasta, potatoes, oats, breakfast cereals, pitta bread, tortillas, chapattis. Try to have wholemeal or wholegrain varieties where possible and have potatoes with skins on.

2. Milk and dairy foods

Use low or reduced fat types whenever you can such as semi-skimmed milk and low fat yoghurts.

3. Fruit and vegetables

Try to include at least 5 portions of these each day. It doesn't matter whether these are fresh, tinned, dried, frozen or fresh fruit juice. Choose a variety of different types and colours of fruit and vegetables as different coloured fruit and vegetables have their own special combination of minerals and vitamins.

4. Protein foods

These are foods such as meats, fish, eggs, cheese, chicken, turkey, beans and lentils. Choose lean cuts of meat, trim off any excess fat and avoid using the frying pan or chip pan to cook these. It's best not to have too many processed meats such as sausages and meat pies.

Try to have fish twice a week and if possible have an oily fish once a week such as mackerel, trout, sardines, kippers or tuna.

5. Fats and sugars

These are foods that you really need to watch in your diet.

Limit the amount of fatty foods that you eat. If using spreads, try a spread low in saturated fat and use only small amounts of polyunsaturated or monounsaturated oil to cook with and try to utilise polyunsaturated or monounsaturated oil.

Sugar and sugary foods – cut down or cut out the amount of sugar you add to foods and keep sweets, chocolate, cakes, biscuits and puddings to an occasional treat.

If you would like more information, speak to your CNS or perhaps you could ask to see a dietitian.

Your weight

Being overweight can bring with it many health problems so, if appropriate, you may want to think about shedding those extra pounds. The best way to do this is to cut down the amount of calories you eat and at the same time take more exercise each day. (see exercise section overleaf)

To reduce the amount of calories you eat follow a healthy diet and also cut down or cut out sugar, sugary drinks, sweets, chocolate, cakes, puddings, fried foods, crisps and take-aways. If you are very overweight your doctor may refer you to a dietitian.

Exercise

Recent studies have all pointed to the benefit of taking regular exercise. Aim for 30 minutes of moderate exercise every day, 5 times a week. Moderate exercise can include going for a brisk walk, swimming, mowing the lawn, doing the gardening or washing and polishing the car. This may help with your general health and feeling of wellbeing and may help if you need to lose some weight. There are lots of people to help you get started; your doctor may refer you to a physiotherapist, there may be specialist exercise programmes at your local leisure centre or join a local walking group.

If you haven't exercised for a long time then you will need to build this up gradually. Always check with your doctor before starting to exercise.

Alcohol intake

As long as you've not been told otherwise, keep alcohol intake to a moderate amount and ask your doctor about it if you're at all unsure. It's best not to go over the sensible drinking limits and have a couple of 'alcohol free' days each week.

Smoking

Smoking can affect your health in many ways so the best advice is to give up smoking. There are many people and organisations out there who can help you to stop. Your GP or clinical nurse specialist may be able to give you more information or let you know who to contact about this.

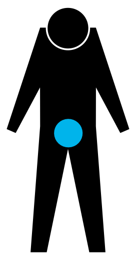
Support for you and your family...

There may be a prostate cancer support group in your area where you can talk to other men (and often their family) who have been diagnosed with prostate cancer. These support groups may provide you with additional information. Often these men share their experiences of when they were diagnosed with prostate cancer, how they decided on treatment and about the various types of treatment they are having or have had.

For more information...

If you have any questions, then you can speak to your hospital consultant, specialist nurse or GP. It may also help to look at the following websites or contact the organisation by phone or email. These organisations also have information leaflets available and some offer telephone helplines which you can contact for support or to answer your questions.

Organisation	Website	Contact number	Helpline available
Prostate Scotland	www.prostatescotland.org.uk	0131 603 8660	Telephone information service (not a helpline) 0300 666 2036
NHS 24	www.nhs24.com	111	✓
Prostate Link UK	www.prostate-link.org.uk		
Prostate Cancer UK (Includes some support group contact details)	www.prostate-cancer.org.uk	0141 314 0050	✓ 0800 074 8383
Macmillan Cancer Support	www.macmillan.org.uk	0808 808 0000	✓
Cancer Research UK	www.cancerresearchuk.org		✓
Edinburgh and Lothian Prostate Cancer Support Group West Lothian group	www.elprostatecancersupport.co.uk Email charliehogg@blueyonder.co.uk	0131 208 3067 01506 845 981	✓
Prostate Cancer Support Group, Maggie's Dundee	email Lynn.Downie@maggiescentres.org	01382 632999	
UCAN Care Centre Ward 209, Aberdeen Royal Infirmary	www.ucanhelp.org.uk	01224 550333 (voicemail) For men in Aberdeen area	
Maggie's Gartnavel General Hospital, 1053 Great Western Road Glasgow G12 0YN	glasgow@maggiescentres.org	0141 357 2269	
Webmd	www.webmd.com		
Patient UK	www.patient.co.uk		
Medicine net	www.medicinenet.com		



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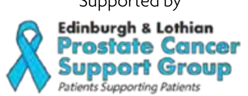

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