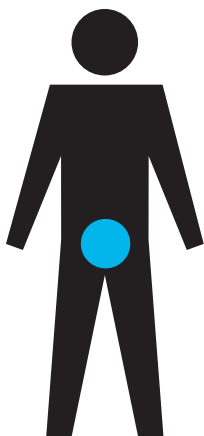




SPOTLIGHT ON

Active surveillance as a management for early prostate cancer



Introduction

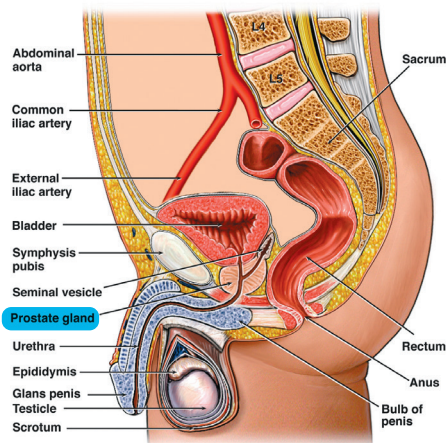
This booklet is to help explain more to you about a way to manage localised prostate cancer with Active Surveillance. The aim is to help you decide, in consultation with your consultant, clinical nurse specialist (CNS), and your family if Active Surveillance (AS) is right for you.

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 urologists, GPs and CNS will keep a close eye on your health and cancer with regular checkups, PSA tests and digital rectal examinations (DRE). Repeat MRI scans and biopsies may also be required. In this way, treatment is deferred until it becomes necessary or if you no longer want to manage your cancer in this way.

About the prostate

Only men (and those born biologically male) 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. As the prostate is inside the body, the tumour or cancer can't be seen and very often causes 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 early or localised 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 or you decide you no longer want to manage your cancer in this way.

During AS your cancer will be very carefully monitored. Your urologist or CNS will keep a close eye on your health and cancer with regular check-ups, PSA tests and digital rectal examinations (DRE). Repeat MRI scans and biopsies may also be required. 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 (incontinence, erectile dysfunction, bowel or bladder problems) 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 urologist.

Gleason score

The samples taken from your prostate during biopsy will be examined. Normal healthy prostate cells are roughly the same size and shape. As cancer grows, the cells change and become unusual in shape and size. The more unusual or abnormal the cancer cells are, the more likely the cancer is to be aggressive.

The pathologist decides which type of cell is most common and which is second most common. Each of these two cell types is given a number from 3 to 5. 3 means these cells are the most normal looking or least aggressive, whilst cells given a grade of 5 are the most abnormal looking or most aggressive. These numbers are added together to give a final score out of 10. The Gleason score is gradually being phased out in favour of the Prognostic Grade Group.

(For more information please see 'Early prostate cancer explained' pages 28,29)

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Prognostic Grade Group (PGG)

The samples taken from your prostate during biopsy will be examined to look at the cell pattern based on the Gleason Grading system. After grading the cancer with a Gleason score, the pathologist will assign a risk group to the prostate cancer by numbering from Grade 1 to Grade 5, with each of the grades having a likely outcome. Grade 1 will be the least aggressive and least likely to spread out-with the prostate while Grade 5 will be the most aggressive grade of prostate cancer.

(For more information please see 'Early prostate cancer explained' pages 28,29)

MRI Scans

An MRI scan uses a magnetic field and special computer software/programmes to produce detailed pictures of your prostate, surrounding tissues, bones and other organs. Standard MRI scans can be enhanced by using intravenous contrast that allows additional imaging parameters to be collected, which improve the ability of radiologists to identify abnormal areas in the prostate (e.g. diffusion weighted images, dynamic contrast enhancement).

Using these different parameters can highlight differences between healthy and unhealthy tissue. It's called multiparametric (mp) when 2 or more of these parameters are used. It may be that 4 different parameters are used to identify prostate cancer.

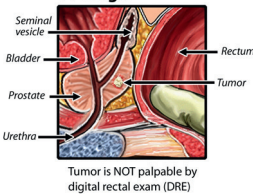
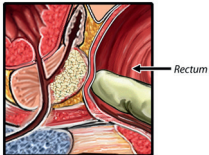
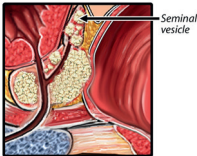
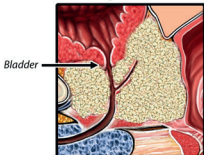
(For more information please see 'Early prostate cancer explained' 19,20)

Cancer risk scores compared

Result	Low risk	Intermediate risk	High risk
PGG	1	2-3	4-5
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.	8 - 10 There is a greater risk that the cancer will grow quickly (be more aggressive) and may possibly have spread outside of the prostate.
PSA level ng/ml	10 or lower	10 - 20	More than 20

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Staging of prostate cancer

<p>T1</p>	<p>T1 Stage</p>  <p>Tumor is NOT palpable by digital rectal exam (DRE)</p>	<p>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 .</p> <p>This type of tumour shows up when the samples of tissue taken during the biopsy are looked at under the microscope.</p> <p>This is called early or localised prostate cancer.</p>
<p>T2</p> <p>T2a The tumour is smaller than half of one of the lobes in the prostate</p> <p>T2b The tumour is bigger than half of one of the lobes in the prostate</p> <p>T2c The tumour is in both lobes but is still inside the prostate</p>	<p>T2 Stage</p>  <p>Tumor is palpable by digital rectal exam (DRE)</p>	<p>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.</p>
<p>T3</p> <p>T3a The tumour has broken through the capsule (outer wall) of the prostate</p> <p>T3b The tumour has spread into the seminal vesicles</p>	<p>T3 Stage</p>  <p>Tumor extends out of capsule to seminal vesicles but no other organs</p>	<p>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.</p> <p>This is called locally advanced prostate cancer.</p>
<p>T4</p>	<p>T4 Stage</p>  <p>Tumor spreads to tissues around the prostate</p>	<p>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.</p>

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 PGG1. It **may** be an option for some men with intermediate-risk prostate cancer PGG2;
- For men who are medically fit otherwise;
- 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 (incontinence, erectile dysfunction, bowel or bladder problems) for as long as possible (deferred radical treatment);
- For men with a PSA of less than 10;
- Gleason score of 6 (3+3) PGG1, Stage T1 or T2a, 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). PGG2, stage T2b. 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 MRI scan or prostate biopsy showed. Ask your urologist or CNS if there are specific guidelines for AS in the hospital that you attend.

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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	My hospital does
Enrolment in AS	After initial tests have confirmed prostate cancer.	
Year 1	Measure PSA every 3 months* DRE (digital rectal examination) every 12 months At the end of the first year repeat MRI and/ or biopsy (Recent changes in NICE guidelines suggest that if all test results are thought to be satisfactory at this point, then routine repeat biopsy is unnecessary.)	
Year 2- 4	Measure PSA every 3 months* DRE every 12 months	
Year 5+	Measure PSA every 6 months* DRE every 12 months	

*Your PSA will usually be done at your GP practice before your hospital appointment so the urologist has the result available. Please remember to make the appointment with your GP.

Further **routine** biopsies are not now recommended. Repeat biopsies are now usually done if the urologist or CNS notes changes in your PSA test, DRE or if he/she thinks a biopsy is necessary.

However, depending on the guidelines followed in your local area, biopsies **may** be planned and done at certain times.

In certain areas, you may have regular follow up MRI scans.

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 will likely 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, CNS, 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 urologist or CNS. At these appointments the urologist or CNS will ask how you are, ask about symptoms, check the result of your latest PSA test and potentially carry out a DRE. You will be monitored with regular MRI scans according to your local hospital guidelines. A prostate biopsy may be done if your urologist notes changes in your PSA, DRE or if he/she thinks a biopsy is necessary.

The CNS is an important point of contact if you need to ask questions, if you have any worries and for more help and advice.

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 or if you decide you no longer want to manage your cancer by AS.

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.

A rise in your PSA level may indicate that the cancer is changing, and that AS is no longer suitable. However, if the PSA does rise, the clinical team may look at how quickly it is rising (known as PSA Velocity) and also how the level compares to the size of your prostate (known as PSA Density) before deciding if AS is still the right choice for you.

To help keep a record of your appointments, blood results, Gleason score PGG and test results, you may find that the Prostate Log Book is very handy.

You can ask your urologist 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

During a DRE the urologist or CNS may notice changes to your prostate. This could be a change in size or shape, a lump or hardened area. In this situation, the urologist or CNS will most likely organise further tests such as an mpMRI scan or possibly a biopsy depending on local hospital guidelines.

Your Gleason score or PGG 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 urologist 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 (robotic assisted radical prostatectomy)
- Radical radiotherapy. This treatment is to kill the cancer cells. It may be given by external beam radiotherapy, brachytherapy, external beam radiotherapy with seed boost, stereotactic body radiation. Hormone therapy may also be used in combination with EBRT, brachytherapy, stereotactic body radiation therapy (SBRT).

For more information on these treatments please see Early prostate cancer explained pages 51 - 95.

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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, your clinical team will carefully monitor your cancer to check if it is progressing
You avoid any risk of potential side-effects (incontinence, erectile dysfunction, bowel or bladder difficulties) that you might get from other types of curative 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 being monitored by AS 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 and urology department to have regular check-ups, PSA tests, DRE and mpMRI scan or biopsy depending on local hospital guidelines. 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. You can chat over these treatments with your CNS urologist or oncologist. Unlike AS, these treatments may bring with them some unwanted side-effects such as incontinence, erectile dysfunction, bladder or bowel difficulties.

Robotic assisted radical prostatectomy

The operation removes the whole prostate, part of the urethra and seminal vesicles. Radical prostatectomy is usually done by robotic assisted minimal access surgery or less commonly now by a laparoscopic (keyhole) or open procedure.

Radical prostatectomy involves a very short hospital stay, if recovery goes well, a general anaesthetic and a catheter for about 1 - 2 weeks. This can vary in different hospitals and with the type of surgery. After a radical prostatectomy, the PSA level should be practically undetectable. There will be regular check-ups and PSA levels will be measured after about 6-8 weeks.

Radiotherapy

This can be given in two ways:

External Beam Radiotherapy (EBRT)

A special machine called a linear accelerator produces high energy x-ray beams which are then very carefully and accurately focused on the prostate. The treatment can also cover a small area around the gland, including the seminal vesicles, in case the cancer has spread to these areas.

Treatments are very carefully planned and given in doses called fractions. For radical radiotherapy to the prostate, it is becoming more common for men with low or intermediate risk to be given higher doses over a shorter period often 20 days.

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Stereotactic Body Radiation Therapy

This is similar to EBRT above but uses a tumour tracking system to very accurately deliver larger doses of radiation to the prostate over a shorter period of time.

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?

Watchful waiting

Watching waiting (WW) is monitoring your prostate cancer but in a slightly different way than Active Surveillance. WW may be suggested as appropriate when the urologist or GP believes that:

- The prostate cancer is unlikely to affect overall life expectancy;
- The man may have another health condition which means that he wouldn't be well enough to have another type of treatment
- He is of an age where there is no clear evidence that treating the prostate cancer would bring life expectancy benefits.

It means that the man won't have any active treatment for his prostate cancer. The GP, Practice Nurse or sometimes the urology hospital team will look after him by doing a check- up usually around every 6-12 months.

Is there anything I can do?

Many men worry when they are diagnosed with prostate cancer but forget about taking care of the rest of their health so you may want to think about some lifestyle changes.

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 red meats more than 2-3 times per week, and not to have processed meats such as sausages and meat pies very often.

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.

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 GP may refer you to a weight reduction clinic.

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

Unless you've been told not to drink alcohol, it's best to keep alcohol within the sensible drinking guidelines, trying to have a couple of 'alcohol free' days each week.

For more information on sensible drinking guidelines go to www.drinkaware.co.uk Helpful sections include 'Understanding unit guidelines', 'Should you take a break from alcohol' and 'How much alcohol is too much'.

Smoking

Smoking can affect your health in many ways so the best advice is to give up. Giving up can be difficult and it may be worth discussing this with your local pharmacist, GP, or local stop smoking advisor or cessation clinic.

Smokeline is the national stop smoking service for Scotland. Smokeline advisors give free advice and information about how to stop smoking, can offer advice on quitting, support during cravings, information on using NRT and signpost to local services. Free stop smoking services are provided by every health board in Scotland. Call 0800 84 84 84 to find out more.

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 and some groups run a buddy scheme. 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 and details of Prostate Cancer Support Groups throughout Scotland please see our website <https://www.prostatescotland.org.uk/?s=support+groups>

For more information...

If you have any questions, then you can speak to your hospital urologist, CNS 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.

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Organisation	Website	Contact number	Helpline available
Prostate Scotland	www.prostatescotland.org.uk	0131 603 8660	Telephone information service (not a helpline) 0300 666 0236
NHS 24	www.nhs24.com	111	✓
Prostate Cancer UK	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	0808 800 4040	✓
UCAN Care Centre Ward 209, Aberdeen Royal Infirmary	www.ucanhelp.org.uk	01224 550333 (voicemail) For men in Aberdeen area	
Webmd	www.webmd.com		
Patient UK	www.patient.co.uk		
Medicine net	www.medicinenet.com		

NOTES:



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