

Patient information

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.

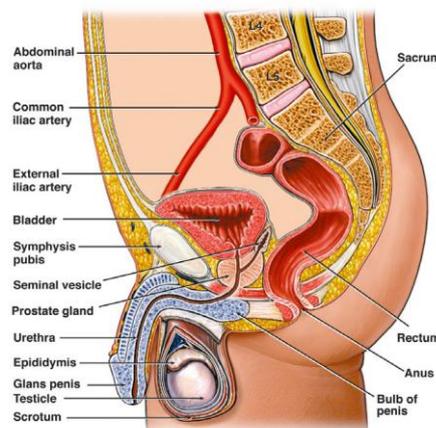
AS means there is no immediate treatment of the cancer, but that urologists, CNS and GPs will keep a close eye on your health and cancer with regular checkups, PSA tests and, potentially, digital rectal examinations (DRE). Repeat MRI scans and biopsies may also be required. In this way, treatment is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

The news that you have been diagnosed with prostate cancer may have come as a shock to you and your family and something that you were not expecting to hear.

It's normal to have a wide range of feelings or emotions – fear, worry, sadness, guilt, anxiety, stress, feeling very low and depressed. Although all these feelings are quite normal, they can have a huge impact on your life and on your family. The first step is to let someone from your health care team know that you're having difficulty in coping with everything that is going on. You will find information on the emotional impact of prostate cancer later in this booklet.

About the prostate

Only those born biologically male (assigned male at birth) subsequently referred to as 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 in an uncontrolled, erratic way. 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's 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 incorrectly 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. In some Health Boards, your follow up appointment may be by a phone call or video link depending on the protocol in your Health Board. (Protocol means that there are rules for the correct procedures to follow for the medical team looking after your care)

Although the protocol may differ in health boards you will usually have regular PSA tests. Digital rectal examinations (DRE), MRI scan every 2/3 years and potentially biopsy may also be part of your follow up.

If the cancer shows signs of becoming more aggressive or progressing, then a radical treatment can be started. (radical means treatment given that aims to cure a disease)

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, all of which may impact on the man's quality of life.

In some circumstances, AS 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 are 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 and grow faster in an uncontrolled way. 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. Grade 3 means these cells are the 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 International Society of UroPathologists (ISUP) **or** Cambridge Prognostic Group.

International Society of Urothologists (ISUP)

The samples taken from your prostate during biopsy are 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.

ISUP 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 and more likely to spread.

Cambridge Prognostic Group (CPG)

This is another way of categorising the risk of the cancer progressing (see table below), which includes information about the PSA and local stage of the prostate cancer.

The Grade, ISUP group, and CPG (if used) are important numbers to remember, and you might hear these terms mentioned a lot.

You can record these in the Prostate Scotland logbook or in the Prostate Scotland Cancer Navigator App in the 'My personal journal' section.

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 greatly improved by using intravenous contrast. (a special 'dye' introduced into a vein that shows up veins, arteries and internal organs more clearly on scan images).

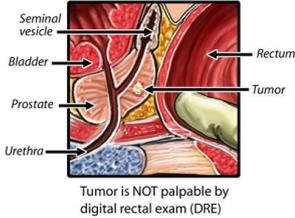
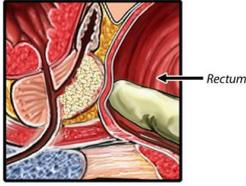
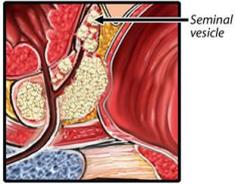
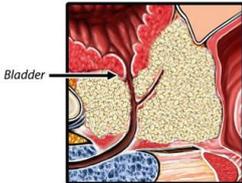
Using different contrasts, enables radiologists to better identify abnormal areas in the prostate and can highlight differences between healthy and unhealthy tissue.

It's called multiparametric (mp) when 2 or more of these contrasts/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')

Cancer risk scores compared.

Result	Low risk	Intermediate risk	High risk
PSA level ng/ml	10 or lower (or appropriate for the size of their prostate)	10 - 20	More than 20
ISUP grade (or CPG)	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 the prostate
Stage	T1 -T2a	T2b -T2c	T3 -T4

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 urologist/CNS 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 urologist/CNS 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.</p> <p>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 urologist/CNS 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.</p> <p>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. It is still prostate cancer though.</p>

When might AS be suggested?

- ISUP Grade Group 1 or Gleason score of 6 (3+3), Stage T1 or T2a, Stage T1 as first choice of treatment.
- ISUP Grade1 or Gleason score of 6 (3+3), Stage T2a/b consider alongside prostatectomy and radiotherapy options
- When cancer is found in the early stages, is still inside the prostate and is thought to be low risk of progression ISUP Grade Group 2 or Gleason 7 (3+4).
- For men whose PSA is appropriate for the size of their prostate.
- 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).

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. Ask your urologist or 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
Enrolment in AS	After initial tests have confirmed prostate cancer.
Year 1	<p>Measure PSA every 3 - 4 months by your GP or by the urology team. (please see information below about getting a PSA test) This will be carefully monitored for any repeated rises in PSA.</p> <p>You will have a follow up every 12 months either by attending the urology department or by telephone or video call</p> <p>DRE (digital rectal examination) will be considered every 12 months. DRE may not be undertaken in all health board areas.</p> <p>Around 12-18 months you will have an MRI scan.</p> <p>If the urology team notice any changes with your PSA, MRI scan or DRE, then you may be advised to have a repeat biopsy.</p> <p>(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.)</p>

<p>Year 2-4</p>	<p>Measure PSA every 3 – 6 months, depending on your individual circumstances.</p> <p>DRE every 12 months. DRE may not be undertaken in all health board areas.</p> <p>MRI scan every 3 – 5 years.</p> <p>(Some health boards will carry out MRI routinely but not normally more often than every 2 years, but others may only carry out MRI if there are changes in PSA and or DRE - this depends on local protocol.)</p>
<p>Year 5 +</p>	<p>Measure PSA every 6 months*</p> <p>DRE every 12 months DRE may not be undertaken in all health board areas.</p>

It is recommended that you get a PSA test before your appointment with the urologist or CNS, so they have an up-to-date PSA level. Arrangements to have this PSA test done may vary between health boards. If your PSA is usually done at your GP practice before your hospital appointment, please remember to make the appointment with your GP so the urologist or CNS has the result available. In other areas your PSA may be done in a hospital hub in the community. It's best to check arrangements with the urologist or CNS

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 they think 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 either with your GP, at the hospital community hub or as advised by the urologist or CNS

The Prostate Scotland Cancer Navigator App has section specifically for appointments. You can input appointments, times and whether it is a hospital, GP, CNS. As the App gives a reminder, you need never miss or forget an appointment.

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. Recent studies have shown that for the majority of men whichever treatment is chosen for early prostate cancer there is an equal impact on the risk of dying from prostate cancer around 15 years after treatment.

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

You will have regular 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. Depending on the health board these follow-up appointments might be face-to-face, a telephone call or a video call.

You will be monitored with regular MRI scans according to your local hospital guidelines. A prostate biopsy may be suggested if your urologist notes changes in your PSA, DRE, MRI or if they think 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 urologist, CNS or GP notices 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.

It is likely that your CNS or urologist will investigate further with repeat MRI and may consider biopsy to investigate the possible reasons for the rise in the PSA.

To help keep a record of your appointments, blood results, CPG, Gleason score, results, you may find that the Prostate Logbook or the Prostate Scotland Cancer Navigator App is very handy.

Changes in your MRI scan

If your scan shows changes indicating that your cancer is perhaps growing.

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 ISUP (or CPG) or Gleason has changed.

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

Changes in your general health

If you unexpectedly develop or become ill with another condition.

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).
- Focal therapy (HIFU, Cryotherapy, Nanoknife) is available privately in England or via the PART Trial (a clinical trial in NHS Lothian)

For more information on these treatments please see 'Early prostate cancer explained'.

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 checkups 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 your treatment is deferred. The cancer is only treated if and when treatment becomes necessary or you wish to have treatment, so avoiding any 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 may need to have additional biopsies.
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 can carry on with everyday life as before without any impact due to your prostate cancer.	You may worry that you are not doing anything. AS is not for everyone. 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

<p>Even if your cancer starts to grow, then there are still options for treatment to try to cure it.</p>	<p>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.</p> <p>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.</p>
<p>While your cancer is being monitored new and better treatments may become available.</p>	<p>You will need to attend your GP and urology department (or by telephone/video calls) to have regular check-ups, PSA tests, DRE and mpMRI scan or biopsy depending on local hospital guidelines.</p> <p>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.</p>

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 (RARP)

The operation removes the whole prostate, part of the urethra inside the prostate and seminal vesicles. Radical prostatectomy is done by robotic assisted minimal access surgery.

RARP 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 RARP, the PSA level should be practically undetectable. There will be regular checkups 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. The number of fractions is decided for each patient individually, and so the length of treatment can vary between 5 and 20 days.

Stereotactic Body Radiation Therapy

SBRT is a type of external beam radiation treatment but uses a tracker system to monitor any movement of the prostate. SBRT delivers very precise and higher doses of radiation from outside the body. This works in the same way as other radiotherapy treatments to damage the cancer cells.

The dose of each fraction of radiotherapy is larger than with traditional EBRT. As a result, the treatment dose is delivered in 5 large doses of radiotherapy over 5 days.

SBRT is not suitable for everyone and may not be available in all hospitals.

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. If the prostate is large, hormone therapy may be given in combination with brachytherapy 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 urologist 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, MRI scans, 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 another way of monitoring prostate cancer. It is **not** the same as Active Surveillance. Your urologist or GP may suggest WW when they think that:

- The prostate cancer is likely to be slow growing and would not affect how long you will live.
 - You have another health condition which means that you wouldn't be well enough to have another type of radical/major treatment.
 - You are of an age where there is no clear evidence that treating the prostate cancer would help you to live longer.
- It means that you wouldn't have any active treatment for the prostate cancer.

The GP, Practice Nurse or sometimes the urology hospital team will review the PSA level around every 6-12 months. In some circumstances, the man will only have his symptoms checked and won't have his PSA checked.

If tests show that the cancer may be changing and starting to grow, then the GP, urologist or CNS may talk to him about treatment. The treatment would not be aimed at curing the cancer. It would be aimed at controlling the cancer.

Is there anything I can do when on AS?

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). Avoid focusing in on any one food that is thought to be or have 'cancer fighting' properties.

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. Perhaps replacing butter with a polyunsaturated spread or an olive oil spread.

3. Fruit and vegetables

Try to include at least 5 portions each day. This means 5 portions of fruit and vegetables in total, not 5 portions of each. It doesn't matter whether these are fresh, tinned, dried or frozen. 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 avoid having 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 number of times and 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. Try using a 'spray' 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.

6. *Cooking methods*

Cooking foods at a very high temperatures and charring foods can change the food and may produce some cancer-causing substances to be formed on foods. Avoid very well-done or brown charred meats. This also applies to foods cooked on an open flame or barbecued.

7. *Vitamin D supplements*

There is some evidence that Vitamin D supplements may reduce the progress of prostate cancer in men on active surveillance so you may wish to take supplements which are available as tablets or an oral spray. Speak to your urologist or CNS, before taking any supplements and ensure you buy these from a reliable source.

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 number of calories you eat and at the same time take more exercise each day.

To reduce the number of calories you eat follow a healthy diet and also cut down or cut out sugar, sugary drinks, sweets, chocolate, cakes, puddings, fried foods, chips, 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 weight. There are lots of people to help you get started. Your GP may refer you to a weight loss clinic, there may be specialist exercise programmes at your local leisure centre or join a local walking group.

There are a couple of exercise videos on our website to help you make a start with exercising if you haven't taken any exercise for a wee while.

<https://www.prostatescotland.org.uk/help-and-support-for-you/exercise-video>

In some areas of Scotland, we offer a 12-week exercise and wellbeing programme called Prostate FFIT. This is a specially designed programme for those with prostate cancer. For more information check our website

<https://www.prostatescotland.org.uk/help-and-support-for-you/prostate-ffit>

If you haven't exercised for a long time, then you will need to build this up gradually. Always check with your GP, CNS or urologist 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 (nicotine replacement therapy) 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.

The emotional impact of prostate cancer.

In addition to managing the physical side-effects of prostate cancer and treatments, it can sometimes be hard to deal with how you are feeling. There are however many things that you can try to help you manage. Everyone is different and not everyone will be affected, or by the same feelings.

Some people making a treatment decision, going through treatment or after treatment might feel worried about whether they are making or have made the right treatment choice, worried about the side-effects they are experiencing from treatment or about getting their PSA or scan results. Sometimes people's moods and how they are feeling can be affected as they go through treatment. And for some if their treatment has finished, they may feel relief, but also fearful of the cancer coming back. Some people may find their moods and how they are feeling may go up and down. All these feelings are normal.

What kind of feelings are we talking about?

Some people going through or after treatment may at times have:

Low mood or feeling depressed.

How having a low mood or being depressed might make you might feel:

- Very sad, or very low for most of the day and these feelings persist.
- Not having the energy to do things that you took for granted before.
- Losing interest in hobbies, not taking part in activities that you used to enjoy, not feeling up to see family and friends.
- Feeling very tired yet having trouble sleeping.
- Having trouble focusing or concentrating and perhaps not able to make decisions.

Feeling anxious

Being anxious can affect you in many ways:

- Feeling very worried all the time and finding it difficult to let go of these thoughts.
- It can make it hard for you to carry out everyday jobs and not able to take care of yourself.
- Being very restless, feeling on edge for a lot of the time or jumpy.
- Feeling tired, short tempered, touchy.
- Feeling shaky or trembling

Feelings of panic

Panic attacks are severe/strong feelings of being anxious or scared. You feel as though you have very little control over them and these can be very scary. These can come on at any time and sometimes for no apparent reason.

For instance, panic attacks may mean that:

- Your heart rate shoots up, and you feel the beats almost pounding in your chest.

- You feel hot and sweaty.
- You feel shaky or numb or tingly.
- You feel dizzy, light-headed or feel you might faint.
- It's difficult to catch your breath and you take very small quick breaths or feel that you have difficulty in breathing.

Coping with these feelings

Just like with everything else in life, people find different ways of helping them cope with these feelings. Some people try new activities that they never thought they would enjoy so don't rule anything out.

Here are some ideas for you to think about. Not all of these will be for you but maybe give some a try.

Getting more information.

For some men and their family, it helps to know more about everything that is going on, so they feel more in control and more knowledgeable when they go to see the urologist, oncologist, CNS or GP. They have a better grasp of what they are being told during their consultation and can ask questions about anything they don't understand. When searching for more information use reputable/trustworthy websites for example:

<https://www.prostatescotland.org.uk/>
<https://www.cancerresearchuk.org/>
<https://www.macmillan.org.uk/>
<https://prostatecanceruk.org/>
<https://www.maggies.org/>
<https://www.samh.org.uk/>

Prostate Scotland Cancer Navigator App is free to download from Google play or the App store
<https://www.prostatescotland.org.uk/help-and-support-for-you/prostate-scotland-cancer-navigator-app>

Remember too that your CNS, urologist, oncologist and GP can provide you with more information and answer your questions.

Talking it out

For some men talking to their partner or spouse or their family and friends provides them with the support that they need. They feel comfortable and at ease showing how they feel – sad, teary, angry etc

Other men might find it easier to talk someone from the team looking after him – the CNS, urologist, oncologist and GP.

The important thing to realise is that you're not alone – others have had similar feelings and thoughts. There are Prostate Cancer Support Groups throughout Scotland where you can talk to other men who have already been on or still on the same journey as you are right now. Some of the groups run a 'buddy scheme' and you can talk to someone who has had/is having the same treatment as you. (see the Prostate Scotland website for more details).

There are organisations who provide confidential support to let men talk about what they are going through, for example:

<https://www.maggies.org/>
<https://www.cancersupportscotland.org/>

Prostate Cancer UK Specialist Nurses tel 0800 074 8383
 Macmillan cancer support line call 0808 808 00 00

Cancer research UK, Nurse helpline 0808 800 4040

For some men once they have come to terms with their diagnosis and treatment, like to share their personal stories with others, often to stress the importance of early diagnosis and for men not to bury their head in the sand. This can be through talking to work colleagues, family, friends, sharing their story in the press etc

Here you will find great examples of men sharing their stories. If you don't feel ready to talk about your own experience, it can still be useful to hear other men talk about their experience of prostate cancer, and the videos below allow you to listen without needing to join a group.

<https://www.theinfopool.co.uk/personal-stories>

Keeping track

Some men like to keep a record of their cancer journey from PSA test results to treatments and side-effects. If this is something you would consider then the Prostate Scotland Cancer Navigator App is free to download from Google play or the App store and has a special section where you can do just that including keeping track of your fatigue as well as levels of anxiety. For others it may be as simple as keeping a notebook handy or using the Prostate Scotland Log Book.

You could also try writing down your feelings, worries and concerns and think about any practical things you could do to help yourself.

Time out

Would time away and just forgetting about everything help for a wee while? Trying a new hobby that you've thought about doing for a long time but never got round to it?

- Getting back to a hobby or activity that you enjoyed before - a game of golf, bowls or darts.
- Mending the fence, cutting the grass, putting up the shelf.
- Visiting gardens or historical sites that you've always put off.
- Visiting museums, art galleries, listening to music, trying to paint or sketch, write short stories or poetry, go dancing.
- Trying yoga, meditation, Tai Chi.

There are so many things out there that you might never have tried so give them a go and have fun!

Looking after yourself.

It's all too easy to fall into the trap of thinking about your diagnosis so much that you forget to look after you. Try to have a good diet with plenty of fresh fruit and vegetables. Sleep is important too. Talk to your CNS, Urologist, Oncologist or GP if you're having trouble sleeping.

Some people may be tempted to try and escape it all by drinking too much alcohol or using drugs. This is never a good idea. Alcohol and unprescribed drugs may make how you're feeling worse and might affect the treatment that you are on.

Look out for our 'Living Well with Prostate Cancer' 6-week course run in partnership with Maggie's Centres throughout Scotland, Ayrshire Cancer Support, UCAN (in Aberdeen)

<https://www.prostatescotland.org.uk/support-services>

This website is well a worth a look as it is dedicated to giving support at every stage of your journey. They offer a range of workshops and classes providing advice and guidance around the physical changes you may experience while undergoing treatment.

<https://lookgoodfeelbetter.co.uk/support/men/> <https://lookgoodfeelbetter.co.uk/workshops/>

Getting active

Speak to your CNS, Urologist, Oncologist or GP first to make sure you are fit enough to exercise. Research has shown that exercising when you have prostate cancer can make a difference:

- It might relieve some of the side-effects of treatment.
- It may help slow the risk of progression of prostate cancer.
- It might improve prostate cancer survival.
- Overall, it may improve your mood and relieve some stress, tension and anxiety.

If you've been used to regular exercise, you might be keen to get going again. If exercising is completely new to you then doing a small amount of exercise is better than not doing anything so don't feel daunted about getting started.

Try going for a walk, playing golf or going bowling, washing the car, doing the weeding, walking up the stairs – all these things and more count towards having some exercise.

Prostate Scotland have an exercise video on our website specifically designed for men with prostate cancer so grab your trainers and give it a go!

<https://www.prostatescotland.org.uk/news/prostate-cancer-exercise-video>

In some areas we also offer Prostate FFIT, a 12-week exercise and wellbeing programme for men living with prostate cancer. This programme is run at football grounds in partnership with the SPFL at Trust. This programme is available free of charge.

<https://www.prostatescotland.org.uk/help-and-support-for-you/prostate-ffit>

Above all if you're struggling to cope, then please talk to someone. Your CNS, Urologist, Oncologist and GP are great sources of help along with the many voluntary organisations out there.

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/help-and-support-for-you/support-groups>

Other organisations who provide information and some provide support include:

Maggie's Centres in Scotland

Maggie's Centres provide support for anyone diagnosed with cancer and also for their family. To find a Maggie's Centre near you visit: www.maggies.org/our-centres/

<https://www.theinfopool.co.uk/personal-stories>.

<https://lookgoodfeelbetter.co.uk/workshops/>

www.samh.org.uk support for men and their families

For more information...

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

Organisation	Website	Contact number	Helpline available
Prostate Scotland	www.prostatescotland.org.uk	0131 603 8660	Telephone information service (not a helpline)
NHS 24	www.nhs24.com	111	✓
Prostate Cancer UK	www.prostatecanceruk.org	0800 074 8383	✓
Macmillan Cancer Support	www.macmillan.org.uk	0808 808 0000	✓
Cancer Research UK Cancer Information	www.cancerresearchuk.org	Nurses 0808 800 4040	✓
UCAN Ward 209, Aberdeen Royal Infirmary	www.ucanhelp.org.uk	Tel 01224 550333 (voicemail) Support for men in the Aberdeen area	

Prostate Scotland

Other booklets from Prostate Scotland that you may find useful:

'Early prostate cancer explained'

<https://www.prostatescotland.org.uk/wp-content/uploads/resources/Early-prostate-cancer-explained.pdf>

'Deciding on treatment – A step on your journey' <https://www.prostatescotland.org.uk/wp-content/uploads/resources/Early-prostate-cancer-explained-deciding-on-treatment.pdf>



COMPASS is our support and wellbeing service helping men and their families across Scotland navigate their prostate cancer journey.

We currently offer:

- **Prostate Scotland Cancer Navigator App.**

This is available and free to download from the Apple Store or Google play. This includes information on treatment decision making, the ability to record your consultation (with permission), appointment and medication diaries, monitor side-effects and much more.

<https://www.prostatescotland.org.uk/help-and-support-for-you/prostate-scotland-cancer-navigator-app>

- **A ‘Living Well with Prostate Cancer’ course.**

This is a 6-week course run in partnership with Maggie’s Centres throughout Scotland, Ayrshire Cancer Support and UCAN. It’s suitable for everyone diagnosed with prostate cancer. The course takes a look at fatigue, urinary problems, side-effects and how to minimise them, erectile dysfunction and relationships, eating well and the practicalities of living with prostate cancer.

- **Prostate FFIT**

In some areas of Scotland, we offer a 12-week exercise and wellbeing programme called Prostate FFIT. This is a specially designed programme for those with prostate cancer. Each week there is an exercise session but in addition, the course builds your knowledge on diet, nutrition and making healthier lifestyle choices. For more information check our website <https://www.prostatescotland.org.uk/news>

- **Online exercise programme**

Our special online exercise programmes for those living with prostate cancer are particularly relevant for those on hormone therapy. Available on our website www.prostatescotland.org.uk/help-and-support-for-you/exercise-video

Please check with your CNS, oncologist, urologist or GP that these programmes are suitable for you before starting to exercise.

For more information visit <https://www.prostatescotland.org.uk/help-and-support-for-you>

Our work

All our awareness materials, introductory guides, explanatory guides and ‘Spotlight on’ guides such as this booklet are available free of charge to people and their families and all healthcare settings. If you found the booklet helpful, you can help us reach many more people with awareness and information about prostate disease and prostate cancer by:

- Obtaining and wearing a Prostate Scotland badge
- Volunteering some of your time
- Taking part in or organising a fundraising event or making a donation.

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The information contained in this leaflet has been developed by Prostate Scotland and reviewed by its Advisory Group of doctors, nurses and patients.

This leaflet is not intended to replace medical advice or seeing a doctor for specific illnesses or symptoms.

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