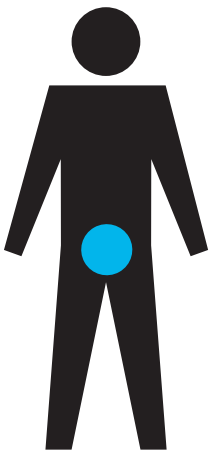
prostate scotland

SPOTLIGHT ON

Active surveillance as a management for early prostate cancer



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It is Prostate Scotland's aim to help all those affected by prostate disease and cancer, regardless of race, background, sexuality or gender identity.

This booklet is relevant for prostate cancer patients who are considering active surveillance.

This will include men, trans women and some non-binary people, although we do use the terms man/men/male within this booklet.

The information that follows about active surveillance for prostate cancer is meant as general guidance. As procedures may vary between health boards, ask for more advice from staff at the hospital you are attending. If you have been given specific guidance by the hospital, it is important that you follow their instructions.

The information contained in this leaflet has been developed by Prostate Scotland and reviewed by its advisory group of health professionals and patients. This leaflet is not intended to replace medical advice or seeing a doctor for specific illnesses or symptoms.

Introduction

This booklet is designed to provide you with information about active surveillance (AS) to manage localised prostate cancer. The aim is to help you decide, in consultation with your consultant, clinical nurse specialist (CNS) and your family, if AS is right for you.

The news that you have been diagnosed with prostate cancer will be a shock to you and your family. After being given your diagnosis, it's common not to take in everything the doctor has said.

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

AS is a way to manage prostate cancer by careful medical monitoring (see further information below). AS means that you won't have any immediate treatment, as treatment is postponed until you or your medical team feels it necessary because of your test results or you decide you no longer want to manage your cancer in this way.

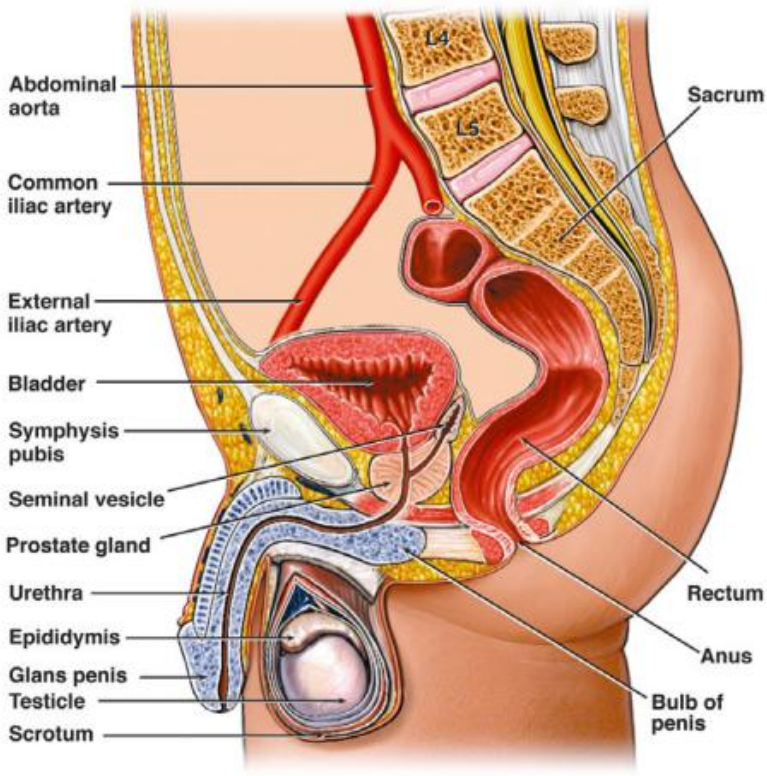
AS may be suggested as a way of managing your cancer if the side-effects of treatment are likely to have a greater impact on your quality of life than the cancer. It is suitable for some men, depending on test results (see further information below).

What is the prostate?

Only those born biologically male have a prostate. It starts out about the size of a pea then slowly grows to the size of a walnut by adulthood. Around the age of 40, it may start to enlarge, and this can cause problems when passing urine.

Where is it?

The prostate is inside the pelvis, just below the bladder and in front of the rectum (back passage). It wraps around the urethra, a tube which allows urine to flow out of the bladder and semen to pass out through the penis. The prostate can't be seen or checked from outside the body.



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What does the prostate do?

It supplies a thick, clear fluid that mixes with sperm to form semen. This fluid helps to nourish and protect sperm during sexual intercourse. The prostate also makes PSA, a protein that makes semen more fluid and so helps sperm to move more easily.

What is prostate cancer?

Prostate cancer happens when the cells in the prostate become abnormal, multiply and grow faster than normal in an uncontrolled way. This causes a growth called a tumour. As the prostate is inside the body, this growth can't be seen and often causes no symptoms. Most prostate cancers grow slowly. Some people won't even know they have prostate cancer, as it may not cause any symptoms or shorten their life.

Prostate cancer may be:

- **Early or localised:** It is still within the prostate and has not spread to other parts of the body.
- **Locally advanced:** It has spread just outside the prostate through the capsule (covering) 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. These metastases are most often found in lymph nodes in the pelvis or in bone.

What do test results mean?

You will hear many different terms and numbers when your medical team discuss your results. These can be difficult to keep track of so you might want to record them in the Prostate Scotland logbook, a notebook or on your smartphone.

Gleason score / ISUP grade

A doctor, called a pathologist, will be sent the small samples taken from your prostate during your biopsy. These are examined under a microscope to look at the cells.

Normal healthy prostate cells are roughly the same size and shape. As cancer grows, the cells change, become unusual, 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 or spread outside the prostate.

The pathologist decides which type of cancer cell is most common, and which is second most common. Each of these two cell types is then given a number/score from 3 to 5.

3 means these cells are the most normal looking or least aggressive, whilst cells scored as 5 are the most abnormal looking or most aggressive. These numbers are added together to give a final score out of 10. This is your Gleason score.

You may hear the Gleason score mentioned, but it has been replaced by the International Society of Uropathologists (ISUP) score. The ISUP score simplifies the Gleason score into 5 Grade Groups.

ISUP Grade 1 will be the least aggressive and least likely to spread to outside the prostate while Grade 5 will be the most aggressive grade of prostate cancer and more likely to spread.

Gleason Score	ISUP Grade
2-6	1
7 (3+4)	2
7 (4+3)	3
8 (4+4 or 3+5 or 5+3)	4
9-10 (4+5 or 5+4 or 5+5)	5

Staging

This is the word used to describe the size of the cancer and whether the cancer has spread outside the prostate to the bones or other parts of the body. It is called the TNM system. It is made up of:

- The letter **'T'** for **tumour** followed by a number.
- The letter **'N'** for **lymph** nodes.
- The letter **'M'** fo**r metastasis** or metastases.

What does the T stage mean?

T1	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 digital rectal examination. 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: The tumour is still inside the prostate.	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 during a digital rectal examination. This type of tumour is still inside the prostate. This is also called early or localised prostate cancer.

T3a: The tumour has broken through the capsule of the prostate. **T3b:** The tumour has spread into the seminal vesicles.	The tumour is breaking out through the wall of the prostate. This will be seen during a scan or can be felt when your prostate was examined during a digital rectal examination. If there is no evidence that the cancer has spread elsewhere in the body, then this is called locally advanced prostate cancer.
T4: The tumour is invading other organs or bone.	The cancer has spread to nearby organs in the body, such as the rectum, 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 site (secondaries) or metastasis. It is still prostate cancer.

What does the 'N' stage mean?

The 'N' stands for lymph nodes. Lymph nodes help fight infection. Prostate cancer can spread to lymph nodes near the prostate or to lymph nodes in other parts of the body. So, the 'N' shows whether cancer has been found in the lymph nodes. This is measured during an MRI scan. As a guide:

- NX: the lymph nodes were not checked.
- N0: cancer cells have not spread to lymph nodes near the prostate.
- N1: the cancer has spread to the lymph node(s) near the prostate.

What does the 'M' stage mean?

The 'M' stands for metastasis (one other cancer site) or metastases (when there are several other cancer sites). This is the term used to measure the spread of the cancer in the body. As a guide:

- M0: The cancer has not spread to other parts of the body.
- M1: The cancer has spread to other parts of the body e.g. lymph nodes away from the pelvis, bone or other organs.

CPG

You may also hear Cambridge Prognostic Group or CPG mentioned. To help with making choices about treatment, your ISUP score, your PSA and the stage of your cancer can be combined to give a CPG. The CPG categorises the likelihood of the cancer spreading and whether the cancer may shorten your life. Other prognostic tools are available, but this is the most commonly used and is endorsed by the National Institute for Health & Care Excellence (NICE). The following table summarises the Cambridge Prognostic grouping.

Cambridge Prognostic Group	Criteria
1	Gleason score 6 (grade group* 1) and PSA less than 10microgram/L and Stages T1–T2
2	Gleason score 3+4=7 (grade group* 2) or PSA 10–20microgram/L and Stages T1–T2
3	Gleason score 3+4=7 (grade group* 2) and PSA 10–20microgram/L and Stages T1–T2 or Gleason 4+3=7 (grade group* 3) and Stages T1–T2
4	One of: Gleason score 8 (grade group* 4), PSA more than 20microgram/L, Stage T3
5	Two or more of: Gleason score 8 (grade group* 4), PSA more than 20 microgram/L, Stage T3 or Gleason score 9–10 (grade group* 5) or Stage T4

In addition, the clinicians involved in your care may discuss or show you the Predict Prostate tool, which can be used to calculate individual prognosis for men with prostate cancer. Such tools can be used to help with decision making around the benefits and potential risks of the various treatments.

What exactly is AS?

AS (sometimes incorrectly called active monitoring) is a management option suitable for some men with early or localised prostate cancer thought to be slow growing and non-aggressive.

During AS your cancer will be very carefully monitored. Your urologist or CNS will keep a close eye on your cancer and general health with regular check-ups. Your follow-up appointments may be in-person or by telephone or video, depending on your health board.

Although the protocol may vary between different health boards, you will likely have regular investigations which may include PSA tests, digital rectal examinations (DRE), MRI scans and potentially biopsies (see further information below).

If the cancer shows signs of progressing, then a treatment aiming to cure the cancer can be started.

Some men may prefer to choose AS to avoid the potential risk of side-effects (incontinence, erectile dysfunction, fatigue, etc) associated with treatments, all of which may impact on quality of life.

When might AS be suggested?

- For patients in Cambridge prognostic group 1 as a first choice of treatment.
- For patients in Cambridge prognostic group 2 AS may be suggested alongside prostatectomy and radiotherapy options.
- For some patients in Cambridge prognostic group 3, AS may be discussed if the patient wished to defer treatment.
- For patients whose PSA is appropriate for the size of their prostate.
- For patients who are medically fit otherwise.
- For younger patients who have concerns that the side-effects of treatment may have a greater impact on their quality of life than the cancer.

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 is the cancer monitored?

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

Timing in years after commencing AS	Tests
Year 1	Measuring PSA every 3–6 months. Possibly a DRE every 12 months. Possibly an MRI scan if there is concern the cancer may be progressing.
Years 2-4	Measuring PSA every 3–6 months. Possibly a DRE every 12 months. Possibly an MRI scan if there is concern the cancer may be progressing.
Years 5 +	Measuring PSA every 6 months (assuming everything appears stable). The possibility of a DRE every 12 months.

It is usually recommended that you get a PSA test before each 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. It's best to check arrangements with the urologist or CNS.

Further routine biopsies are now not usually recommended. Repeat biopsies are now generally only done if the urologist or CNS notes changes in your PSA test, DRE or if they think a biopsy is necessary for a specific clinical reason.

As you can see AS involves close monitoring of your cancer and means that you will have regular appointments with your GP practice and hospital team to ensure that the cancer does not progress whilst under surveillance.

The CNS is an important point of contact at all times if you have any questions or worries and need further help and advice.

Remember that if you are on AS it's very important not to miss any appointments for blood tests, examinations and hospital appointments.

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 further information on prostate cancer treatments and the decision-making process download *Early Prostate Cancer Explained* from www.prostatescotland.org.uk/resources

When might another form of treatment be needed?

Being monitored regularly should show if the cancer starts to grow and become more likely to spread, which would indicate treatment might be necessary. Signs that a treatment might be needed include:

PSA level increasing

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 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 scans and may consider biopsy to investigate the possible reasons for the rise in PSA.

MRI scan results

If your scan shows changes indicating that your cancer is growing, your urologist or CNS may suggest other treatment options.

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.

Changes in your general health

If you unexpectedly develop or become ill with another condition.

Changing your mind about AS

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).
- Radiotherapy.
- Brachytherapy.
- Hormone therapy.

Each treatment will have advantages and side-effects which will need carefully consideration. Your urologist or CNS will discuss these with you in detail.

For further information on different treatments download *Early Prostate Cancer Explained* from www.prostatescotland.org.uk/resources

What advantages and drawbacks are there to think about with AS?

Advantages	Drawbacks
With AS your prostate cancer is carefully monitored and treatment is put off until it becomes necessary or you decide you no longer want AS.	AS does not treat your cancer but the urology team will carefully monitor your cancer to check if it is progressing. You will need to remember to make appointments and keep a record of test results, taking an active part in the monitoring of your cancer.

Advantages	Drawbacks
You avoid any risk of potential side-effects (incontinence, erectile dysfunction, bowel or bladder difficulties) that you might get from treatments aimed at curing your prostate cancer. You can carry on with everyday life as before without any impact due to your prostate cancer treatment.	You may be anxious 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. Even if your cancer starts to grow, then there are still options for treatment to try to cure it.	There is a very small risk that a slow-growing cancer may suddenly grow and spread outside the prostate while you are on AS, so you could reduce the possibility of your cancer being treated with the aim of curing it. 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 have regular check-ups which may include PSA tests, DRE, MRI scans or biopsies.

Questions you may wish to ask your medical team about active surveillance

- Is AS a suitable option for me?
- If I choose AS now, can I change my mind later?
- Is it safe for me to put off treatment?
- If I wait, will this limit my choices in the future?
- What indications are there about the aggressiveness of my prostate cancer?
- Can you explain what the risks are likely to be?
- Between check-ups, are there any signs or symptoms I should look out for?
- Which tests would I have to monitor the cancer?

- How often would I need to have the tests and who would do these?
- How would we know if my prostate cancer is getting worse?
- What treatment might be offered to me if the cancer starts to grow?
- Are there other suitable treatment choices that I could think about now?
- Is there someone that I can talk to who has made this choice?

Watchful waiting

You may also hear about watchful waiting (WW). This 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 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 urology team will review your PSA level every 6–12 months. Alternatively, you may be on symptomatic follow-up only, where it is felt that PSA readings would not change the management of your care. This would be discussed with you by your team.

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

What can you do to help your health when on AS?

Being diagnosed with prostate cancer can be extremely stressful and it can be easy to forget about taking care of the rest of your health. However, it is important to try to look after your general health and wellbeing as much as possible.

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, the following section on possible lifestyle changes might help or you can ask your CNS or GP for more information.

Healthy diet

A healthy diet is good for your overall health and wellbeing. Try to eat a wide variety of foods from all food groups, including plenty of fruit and vegetables, wholegrains and fibre. In general, it's best to avoid focusing in on any one food that is thought to have 'cancer fighting' properties. **If you're on a special medical diet always follow the advice given by your dietitian.**

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.

Dairy foods

You may want to start using low or reduced-fat types such as semi-skimmed milk and low-fat yoghurts. Consider replacing butter with a polyunsaturated or olive oil spread.

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.

Protein foods

These are foods such as red and white meat, fish, eggs, cheese, 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, such as mackerel, trout, sardines, kippers or tuna, once a week.

Fats and sugars

Try to limit these foods in your diet by reducing the number of times and amount of fatty or sugary 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. Try using a 'spray' oil. 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 ask to see a dietitian.

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.

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.

Maintaining a healthy weight

Being overweight can bring with it many health problems so, if appropriate, you may want to think about trying to lose weight. 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 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 for further advice.

Exercise

Recent studies have all pointed to the benefit of taking regular exercise. Aim for 30 minutes of moderate exercise, 5 times a week. Moderate exercise can include going for a brisk walk, swimming, mowing the lawn, doing the gardening or washing the car. This can 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 and your GP can give you advice. There may be specialist exercise programmes at your local leisure centre or you could think about joining 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 GP, CNS or urologist before starting to exercise.

Alcohol intake

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

For more information 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 GP, pharmacist, or local stop smoking advisor or cessation clinic.

Quit Your Way Scotland is the national stop smoking service for Scotland. Advisors give free advice and information about how to stop smoking, support during cravings, information on using nicotine replacement therapy (NRT) and signpost to local services.

Call **0800 848484** or visit **www.nhsinform.scot/care-support-and-rights/nhs-services/helplines/quit-your-way-scotland/** 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 be hard to deal with how you are feeling.

You might feel worried about whether you are making or have made the right treatment choice, worried about side-effects or anxious about waiting for results.

Your moods might be affected as you go through treatment. It is also common to experience a fear of cancer returning after treatment, or a fear of cancer progressing if you have opted for active surveillance or watchful waiting. Increased fear around follow-up scans or PSA testing is also common. All these feelings are normal, and there are ideas below to help you cope.

If you feel overwhelmed by these feelings, or they are getting in the way of you living your life, make an appointment with your GP and tell them how this is affecting you emotionally.

How might you be impacted?

Low mood or feeling depressed:

- Persistent very sad or low feeling for most of the day.
- 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 seeing family and friends.
- Feeling very tired yet having trouble sleeping.
- Having trouble focusing and perhaps not able to make decisions.

Feeling anxious:

- Feeling worried all the time and finding it difficult to let go of these thoughts.
- Difficulty carrying out everyday jobs and caring for yourself.
- Being very restless, on edge or jumpy.
- Feeling tired, short tempered or irritable.

Feelings of panic: Panic attacks are severe feelings of being anxious, scared or out of control, and these can be frightening. These can come on at any time for no apparent reason. 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, numb or tingly.
- You feel dizzy, light-headed or faint.
- You feel short of breath.

Coping with these feelings

Different people find different ways of coping with these feelings. For many people, taking back some element of 'control' over their prostate cancer journey can help them navigate the emotional impact. This could be:

- Taking an active part in treatment decision-making.
- Sourcing extra information online.
- Joining a support group.
- Volunteering to help others.
- Choosing to pursue a healthier diet.
- Taking gentle exercise.

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 will be for you but maybe give some a try.

Getting more information: Some men like to learn more about everything that is going on, to feel more in control, more knowledgeable at appointments and to have a better understanding of what medical teams are talking about. When searching for more information online use reputable websites such as:

- www.prostatescotland.org.uk
- www.cancerresearchuk.org
- www.macmillan.org.uk
- prostatecanceruk.org
- www.maggies.org
- www.samh.org.uk

Remember that your medical team can provide you with more information so don't be afraid to ask questions at your appointment.

Talking it out: The important thing to realise is that you're not alone – others will have had similar feelings and thoughts.

For some men talking to their partner, family and friends provides the support they need. They feel comfortable and at ease showing how they feel.

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

There are prostate cancer support groups throughout Scotland where you can talk to other men who are on a similar journey. Some of the groups run a 'buddy scheme' and you can talk to someone who has had / is having the same treatment as you.

You can find more information about support groups at **www.prostatescotland.org.uk/help-and-support-for-you/support-groups**

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

- www.maggies.org
- www.cancersupportscotland.org
- Prostate Cancer UK specialist nurses' helpline: 0800 074 8383
- Macmillan cancer support line call: 0808 808 0000
- Cancer Research UK nurse helpline: 0808 800 4040

Some men like to share their personal stories with others, often to stress the importance of early diagnosis and for men not to ignore symptoms and risks. This can be through talking to work colleagues, family, friends, or even sharing their story in the press.

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; videos on the website below allow you to listen without needing to join a group: **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. You can use a smartphone for this, or it can be as simple as keeping a notebook handy.

You could 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 for a short while help?

- Get 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 fancied.
- Visiting museums, art galleries, listening to music, trying to paint or sketch, writing short stories or poetry.
- Trying something new like dancing, yoga, meditation or Tai Chi.

Looking after yourself: It's all too easy to think 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 medical team if you're having trouble sleeping.

Some people may be tempted to try and escape by drinking too much alcohol or using drugs. This is never a good idea. Alcohol and unprescribed drugs may make you feel worse and might affect your treatment.

Consider attending one of our 'Living Well with Prostate Cancer' courses run in partnership with Maggie's Centres throughout Scotland, and Ayrshire Cancer Support in Ayr and Kilmarnock (see more information below).

Visit **https://lookgoodfeelbetter.co.uk** for support at every stage of your journey. They offer a range of workshops and classes providing advice around the physical changes you may experience while undergoing treatment.

Getting active: Speak to your urologist, oncologist, CNS or GP to make sure you are fit enough to exercise. Research has shown that exercising when you have prostate cancer might:

- Relieve some of the side-effects of treatment.
- Help slow the risk of progression of prostate cancer.
- Improve prostate cancer survival.
- 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 or walking up the stairs instead of taking the lift.

Above all if you're struggling to cope, 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

As you deal with the impact of your prostate cancer diagnosis you may find you and your family need extra support.

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. Your CNS or GP should be able to advise on what support groups there are in your area.

Prostate Scotland COMPASS support services

COMPASS is our comprehensive range of support services to help men and their families navigate prostate cancer. These services are specifically designed for all men affected by prostate cancer, wherever they are on their journey. They complement the excellent care received from medical experts and offer the opportunity to meet others in a similar situation.

Living Well with Prostate Cancer: Our Living Well with Prostate Cancer 6-week course is free and run in partnership with all Maggie's Centres across Scotland, as well as Ayrshire Cancer Support in both Ayr and Kilmarnock. Men meet others in a similar situation, while hearing from experts on all aspects of living with prostate cancer, from managing urinary problems to financial advice and everything in between.

Prostate FFIT: We've teamed up with the SPFL Trust to run our unique Prostate FFIT (Football Fans in Training). A free, 12-week health and wellbeing programme, it is an invaluable opportunity to meet others and share experiences. Men learn about different types of exercise, diet and nutrition, in a relaxed, fun environment.

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

Other sources of help

The following organisations also offer information, advice and support. Some offer nurse-led telephone helplines.

Cancer Research UK
www.cancerresearchuk.org
0808 800 4040

Look Good Feel Better
lookgoodfeelbetter.co.uk/workshops
01372 747500

Macmillan Cancer Support
www.macmillan.org.uk
0808 808 0000

Maggie's
www.maggies.org/our-centres
0300 123 1801

NHS 24
www.nhs24.scot
111

Prostate Cancer Research Infopool
www.theinfopool.co.uk
0203 735 5444

Prostate Cancer UK
prostatecanceruk.org
0800 074 8383

Scottish Action for Mental Health
www.samh.org.uk
0141 530 1000

UCAN
www.ucanaberdeen.com
01224 550333

Please note Prostate Scotland is not responsible for the content of any of the external websites.

PROSTATE SCOTLAND

Our Work

All our awareness materials, introductory guides, explanatory guides and 'Spotlight on' guides 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 donating.

This booklet has been produced by Prostate Scotland with input and advice from its expert advisory group PAGES. All PAGES members have been asked to declare any potential conflict of interests. Further details can be requested be emailing jennifer.fallon@prostatescotland.org.uk

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