

UNDERSTANDING

Active Surveillance

for prostate cancer

A guide for men with prostate cancer,
their partners and their families.



Prostate Cancer
Foundation of Australia

Active Surveillance for prostate cancer

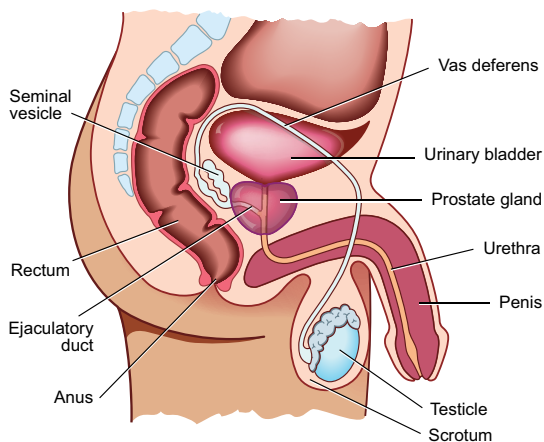
What is prostate cancer?

The prostate is a small gland located below the bladder and in front of the rectum in men. It surrounds the urethra, the passage that leads from the bladder, out through the penis through which urine and semen pass. The prostate gland is part of the male reproductive system (see diagram).

The prostate produces some of the fluid that makes up semen, which enriches and protects sperm. The prostate needs the male hormone testosterone to grow and develop. Testosterone is made by the testicles.

The prostate gland is about the size of a walnut and it is normal for it to grow as men age. Sometimes this can cause problems, such as difficulty with passing urine.

The male reproductive system



Prostate cancer occurs when abnormal cells develop in the prostate. These cells have the potential to continue to multiply, and possibly spread beyond the prostate. Cancers that are confined to the prostate are called **localised** prostate cancer. If the cancer extends into the surrounding tissues near the prostate or into the pelvic lymph nodes, it is called **locally advanced** prostate cancer. Sometimes it can spread to other parts of the body including other organs, lymph nodes (outside of the pelvis) and bones. This is called **advanced** or **metastatic** prostate cancer. However, most prostate cancers grow very slowly and about 96% of men survive at least 5 years after diagnosis, particularly if diagnosed with localised prostate cancer.

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Active Surveillance for prostate cancer

1. Introduction

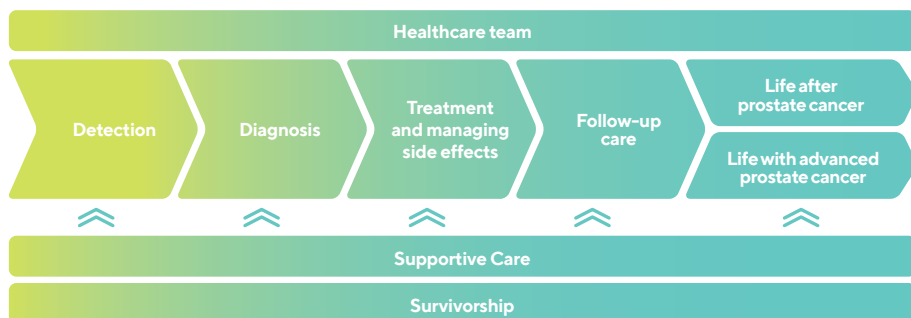
This booklet is for men who have decided to have Active Surveillance management for prostate cancer. It is also designed for men who are in the process of deciding on their treatment option, if your specialist has recommended that Active Surveillance is a suitable option. It could be helpful for significant people in your life, such as your partner, family and friends, to read this booklet. It contains information about Active Surveillance and what this involves.

Your cancer experience

After being diagnosed with prostate cancer, it's common for you to see several health professionals with different expertise who work together as a healthcare team (sometimes called a multidisciplinary team). The team includes health professionals who are involved in diagnosing your cancer, treating your cancer, managing symptoms and side effects, and assisting you with your feelings or concerns during your cancer experience.

The cancer experience is not the same for everybody, even with the same type of cancer. Depending on the grade (the cancer aggressiveness) and stage (the extent of spread) of your prostate cancer and other underlying medical conditions, your experience may be quite different to someone else's.

Your prostate cancer experience



As the diagram above shows, it can be useful to think of the cancer experience in different stages: detection, diagnosis, treatment, follow-up care and either life after cancer or life with advanced prostate cancer. Take each stage one at a time so that you can break down what might feel like an overwhelming situation into smaller, more manageable steps.

From the moment prostate cancer is detected, your healthcare team will focus on survivorship – every aspect of your health and wellbeing while you are living with cancer and beyond. Survivorship also includes your family and loved ones.

2. What is Active Surveillance?

Active Surveillance is a treatment option for men with low risk and some intermediate risk prostate cancers. It involves following a program in which you are monitored for any changes in your cancer.

The aim of Active Surveillance is to avoid unnecessary immediate treatment and to find the best time to start treatment in the future if it is necessary.

If you have Active Surveillance, your cancer is closely monitored for any symptoms or signs the disease is progressing. These signs may include:

- an increase in the size of the cancer determined by mpMRI
- an increase in the grade of the cancer determined from a repeat biopsy
- a significant rise in the PSA level.

Most cancers never progress and do not need any further treatment. But if the cancer is seen to be progressing, treatments like surgery or radiation therapy may be recommended.

There is now strong evidence that it is safe for men with low-risk prostate cancer to be regularly and carefully monitored. Active Surveillance can delay the need for treatment for several years in some men and others may avoid ever needing to have active treatment for their prostate cancer.

Who can have Active Surveillance?

You may be offered Active Surveillance if you have low risk prostate cancer that meets all the below criteria:

- low grade prostate cancer – ISUP Grade Group 1 (Gleason score of less than or equal to 3+3=6)
- PSA levels less than or equal to 10ng/ml and
- early stage cancer that is localised within the prostate – tumour stage T1 to T2a.
- A score of PI-RADS 3 or less determined by multiparametric MRI (mpMRI)
- A PSA density (PSAD) score of 0.15µg/L or less.

Some men with intermediate risk prostate cancer ISUP Grade Group 2 disease, may also be offered Active Surveillance if 10% or less of their cancer is Gleason pattern 4.

Your specialist may also recommend Active Surveillance for other reasons particular to your situation. More information about prostate cancer grading, staging and risk can be found in *Prostate cancer – a guide for newly-diagnosed men* downloadable at prostate.org.au

Active Surveillance for prostate cancer

Benefits of Active Surveillance

- The cancer is closely monitored. Clinical trials have shown this to be a very safe method of treatment.
- Avoids or delays the side effects associated with radical treatments (e.g. surgery or radiation therapy).
- Radical treatment may never be needed if monitoring suggests the cancer is not growing or spreading.

Possible side effects of Active Surveillance

- There is a small chance of pain, bruising and bleeding from the biopsy.

Things to consider

- Some men worry about not doing anything to treat the cancer.
- Regular digital rectal examinations and biopsies are needed.
- There is always a risk that a progressing prostate cancer may not be identified.

Watchful Waiting

Watchful Waiting is different from Active Surveillance. While Active Surveillance aims to monitor low-risk prostate cancer and offer curative treatment if the cancer shows signs of progression, Watchful Waiting focuses on maintaining quality of life by monitoring the cancer and treating symptoms if they occur. Curative treatment is not usually planned.

You may choose Watchful Waiting if you are older, have other significant health conditions, or your life expectancy means the cancer is unlikely to cause problems during your lifetime.

If you choose Watchful Waiting, your healthcare team (such as your GP, specialist, Prostate Cancer Specialist Nurse and other health professionals) will work with you to develop a monitoring plan that reflects your individual needs and preferences. The plan may include PSA tests, clinical reviews and, where appropriate, imaging or other investigations.

If your cancer begins to cause symptoms, treatment may be recommended to help control the cancer and relieve symptoms. Depending on your situation, this may include hormone therapy (androgen deprivation therapy), palliative radiotherapy or other treatments recommended by your healthcare team.

3. Deciding to go on Active Surveillance

Being fully informed will help you make the best decision for you about Active Surveillance. Ask your urologist to explain what is involved, the benefits, the risks and why it is a good option for you.

Support and information can also be obtained from your GP, Prostate Cancer Specialist Nurses and/or prostate cancer support group members.

It can also be very helpful to discuss treatment options with your partner or a family member and take them along to your appointments.

Here are some questions you can ask your urologist or members of your healthcare team about Active Surveillance.

- What do the tests tell us about my cancer?
- How do you know it hasn't spread?
- What would happen if I don't start treatment straight away?
- What are my options for treatment?
- What are the pros and cons of each option in my case?
- Are there other factors I need to consider before deciding?
- What is the risk that my cancer will progress and become more harmful?
- What are the risks of delaying treatment?
- How will Active Surveillance affect me daily?
- How often will I need to have PSA tests, MRI and/or a biopsy?
- What are the costs involved with Active Surveillance?
- How long will I be on Active Surveillance?
- What happens if my cancer starts to grow?
- How likely is it that I will need active treatment in the future?

More information on different treatment options can be found in *Prostate cancer – a guide for newly-diagnosed men* downloadable at **prostate.org.au**

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4. What does Active Surveillance involve?

Active Surveillance can be different for different men. Your doctor will advise you on your specific Active Surveillance monitoring protocol. It is important to keep track of your appointments and not to miss regular tests that have been scheduled for you.

Active Surveillance will involve:

- PSA testing at regular intervals
- digital rectal examination (DRE) at regular intervals
- mpMRI prostate scans at regular intervals
- repeat biopsies at regular intervals.

If your test results suggest that your cancer could be growing, you may be offered further tests to check on the cancer. If any changes are found, you could be advised to have active treatment that aims to cure the cancer.

Active Surveillance is continuing to be studied and protocols might change as new evidence becomes available. This could affect which tests are required and how often they need to be repeated. As they are developed, new tests may be offered to help predict whether treatment is needed or not.

PSA monitoring during Active Surveillance

Your PSA will be checked at regular intervals. PSA levels can fluctuate over time, even if your cancer isn't changing. Rather than relying on a single PSA result, your doctor will look at the pattern of your PSA levels over time, together with the results of your other tests, to decide whether further investigation is needed.

In the past, doctors placed greater emphasis on PSA velocity and PSA doubling time (how quickly your PSA level rises or how long it takes to double). While these measurements may still be considered as part of your overall assessment, research has shown they are not reliable enough on their own to determine whether your cancer is progressing. Today, they are interpreted alongside other important information, including MRI scans, biopsy results and clinical examination.

Your doctor or specialist may also calculate your PSA density (PSAD). PSA density combines your PSA blood test result with the size of your prostate measured on multiparametric magnetic resonance imaging (mpMRI). A higher PSA density may indicate a greater likelihood that clinically significant prostate cancer is present or that your cancer is changing, and can help guide decisions about whether further testing or treatment is needed.

No single test determines whether Active Surveillance remains the right option for you. Your doctor will consider your PSA levels, PSA density, mpMRI findings, biopsy results and clinical examination together to build the most accurate picture of your prostate cancer over time.

Digital rectal examination (DRE)

A DRE is when a doctor inserts a gloved, lubricated finger into the rectum (back passage) to feel the size of the prostate and check if there are any abnormalities. Occasionally a cancer can be felt this way, but not always.

Multiparametric magnetic resonance imaging (mpMRI)

An mpMRI is a specialised scan that provides detailed images of the prostate to help identify areas that may contain clinically significant prostate cancer. Most men will have an mpMRI scan when they first start Active Surveillance to make sure the cancer hasn't spread outside the prostate. Your doctor will usually recommend having repeat mpMRI scans as part of your routine surveillance plan, especially if your PSA test or DRE have changed. The scan will sometimes be done before a biopsy or as an alternative to the repeat routine biopsy.

Biopsy

All men need a biopsy at diagnosis to determine if they are suitable for Active Surveillance. Once you start Active Surveillance, you will require further biopsies. Your doctor will advise you on how often you will need to have a biopsy.

Molecular testing

There are new tests being developed that can analyse the genetic makeup of the prostate cancer in the biopsy samples. These tests might help to predict which cancers are more likely to require treatment and which cancers might have an even lower risk of needing treatment. These tests are not routinely recommended now, but they might become a more regular part of Active Surveillance as further evidence becomes available.

Biological markers

Biological markers are molecules found in body fluids such as blood, urine and semen that can show signs of a disease. There are several tests being developed or recently introduced that measure prostate health by analysing biological markers in the urine and semen. There is not enough evidence yet for them to be used to monitor men on Active Surveillance programs.

It's vital to keep up with routine monitoring of your prostate cancer. If you don't, you increase the risk that changes to your prostate cancer may not be detected, which could lead to advanced disease and lower prospects for long-term survival.

You can use the table in Section 10 Tracking your test results on pages 16 and 17 to keep track of your results and the plan for you.

Active Surveillance for prostate cancer

5. Who should move from Active Surveillance to treatment?

Active Surveillance has been shown to be a safe option for men with lower risk prostate cancer to either avoid or delay the need for treatment. Men who remain on Active Surveillance have the same chance of living for 10 years as they would if they had chosen to have surgery or radiation therapy.

The length of time men remain on Active Surveillance programs is variable and many men may never need treatment. Some reasons men move from Active Surveillance to treatment include:

- increase in cancer grade – the biopsy results show that the grade of the tumour has increased
- increase in cancer size/growth – determined by a PSA level increase, results from a biopsy and/or mpMRI scan results
- anxiety – some men can feel very anxious because they are afraid their cancer will grow.

If you are on Active Surveillance and are thinking about starting treatment, understanding as much as you can about prostate cancer and the different treatment options can help you decide which option is best for you. Ask your doctor and/or Prostate Cancer Specialist Nurse for as much information as you need. It can also be helpful to discuss your options with your partner, family and/or close friends. Speaking to people at your local prostate cancer support group or our Prostate Cancer Specialist Nurse on 1800 22 00 99 can also help you decide.

For information and support, visit PCFA on prostate.org.au
or call us on **1800 22 00 99**.

6. Looking after yourself on Active Surveillance

Psychological wellbeing

If you have prostate cancer, it is normal to have a wide range of feelings and emotions such as shock, sadness, anxiety, anger, fear and frustration. You may also experience physical effects of stress like nausea, stomach upsets, feeling irritable or on edge, and trouble sleeping. Some days will be worse than others.

It can help to talk through your problems with a partner or good friend, gather information and advice from trusted sources, and focus on keeping well.

If you are distressed and having trouble managing, talk to your GP or a member of your healthcare team. You could join one of our support groups, speak with our Prostate Cancer Specialist Nurses or read our resources at prostate.org.au.

Prostate Cancer Counselling Service

Our Prostate Cancer Counselling Service (PCCS) can help you with the psychological and emotional impacts of the disease. You can access the free service at any point – whether you or someone you love has been impacted by prostate cancer. Call **1800 22 00 99** and talk to one of our Prostate Cancer Specialist Nurses about a referral.

Feeling distressed and urgently need help?

**Call Lifeline 13 11 14 or
Beyond Blue 1300 22 4636.**

Organisations providing information and support are listed on page 13.

Active Surveillance for prostate cancer

Physical activity and exercise

Physical activity is very important for maintaining and improving your physical and psychological health. It is important to do some physical activity most days, if not everyday.

Targeted exercises can help slow the progression of your prostate cancer, reduce the side effects of treatments and enhance your recovery. Exercise can also improve your quality of life and help with anxiety and depression.

The most effective forms of exercise are:

- cardiorespiratory exercise such as fast walking, jogging, cycling and swimming
- resistance training exercises such as lifting weights, stair climbing and high intensity resistance workouts.

Diet and nutrition

A healthy, balanced diet can improve your strength, vitality and wellbeing, help you manage your cancer experience, and improve your outcomes from treatment.

For the best diet:

- eat plenty of fruit and vegetables, wholegrain foods and lean meat, fish, poultry and low-fat dairy
- avoid animal fats, processed meals, biscuits, cakes and pies, salt and added sugars
- drink plenty of water
- limit alcohol.
- stop smoking.

Information on wellbeing, diet and exercise can be found in *Understanding health and wellbeing with prostate cancer* downloadable at prostate.org.au

7. Where to get more information and support

Prostate Cancer Foundation of Australia (PCFA)

1800 22 00 99 or (02) 9438 7000 (freecall)

**Email: enquiries@pcfa.org.au
prostate.org.au and pcfa.org.au**

Beyond Blue: The National Depression Initiative – providing information about, and support for, anxiety and depression.

1300 22 46 36

www.beyondblue.org.au

Cancer Council Australia: providing professional telephone and online support, information and referral service.

13 11 20

www.cancer.org.au

Dietitians Australia: find an accredited practising dietitian.

(02) 6189 1200

Email: info@dietitiansaustralia.org.au

www.dietitiansaustralia.org.au/find-an-apd

Exercise & Sport Science Australia (ESSA): find an accredited exercise physiologist.

(07) 3171 3335

Email: info@essa.org.au

www.essa.org.au/find-aep

Lifeline Australia: personal crisis support and suicide prevention.

13 11 14 (24-hour service)

www.lifeline.org.au

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9. Glossary

Dietitian – A health professional who specialises in human nutrition.

General practitioner (GP) – A family doctor. Your GP is the first person you see if you're sick. They can refer you to other medical specialists.

Multidisciplinary team – A team approach to cancer treatment and planning.

Prostate Cancer Specialist Nurse – An experienced registered nurse who has received additional training to make them an expert nurse in prostate cancer care.

Prostate specific antigen (PSA) – A protein in the blood that is produced by cells in the prostate gland. The PSA level is usually higher than normal when prostate cancer is present.

Psychologist – A health professional who provides emotional, spiritual and social support.

Quality of life – A person's overall appraisal of their situation and wellbeing – whether they have symptoms and side effects, how well they can function, and their social interactions and relationships.

Radical prostatectomy – An operation to remove the prostate gland and seminal vesicles.

Radiation therapy (radiotherapy) – The use of radiation, usually X-rays or gamma rays, to kill cancer cells or injure them so they cannot grow or multiply.

Radiation oncologist – A doctor who specialises in treating cancer using radiation therapy.

Side effect – Unintended effects of a drug or treatment.

Stage – The extent of a cancer and whether the disease has spread from an original site to other parts of the body.

Support group – A group of people who provide emotional caring and concern, practical help, information, guidance, feedback and validation of the individual's stressful experiences and coping choices.

Survivorship – The health and life of a person beyond diagnosis and treatment for cancer. Survivorship issues may include follow-up care, late effects of treatment, secondary cancers, and quality of life factors.

Urethra – The tube that carries urine and semen out through the penis and to the outside of the body.

Urologist – A surgeon who treats people with problems involving the urinary system, including the kidney, bladder, prostate and reproductive organs.

Active Surveillance for prostate cancer

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Active Surveillance for prostate cancer

You may wish to use this note section to record your progress or questions you may have about your symptoms following treatment.

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PROSTATE CANCER FOUNDATION OF AUSTRALIA (PCFA)

We are Australia's leading community-based organisation for prostate cancer research, awareness, and support. As the nation's predominant charity fund for Australian-based prostate cancer research, we exist to protect the health of existing and future generations of men in Australia and to improve quality of life for Australian men and families impacted by prostate cancer.

Our vision is a future where no man dies of prostate cancer and Australian men and their families get the support they need.

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For a full list of contributors and reviewers, please visit the PCFA website: prostate.org.au

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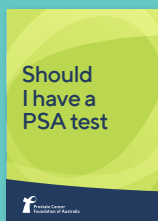
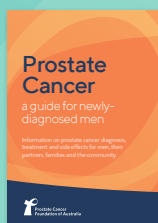
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Email: enquiries@pcfa.org.au

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PCFA develops materials based on the best available evidence and advice from recognised experts. However, it cannot guarantee and assumes no legal responsibility for the currency or completeness of the information.

Printable versions of these resources may also be downloaded from our website prostate.org.au or pcfafa.org.au



If you would like further information, please contact **PCFA** on **1800 22 00 99** or email enquiries@pcfafa.org.au