

Understanding Penile Cancer

A guide for people affected by cancer

This fact sheet has been prepared to help you understand more about penile cancer.

Many people look for support after being diagnosed with a cancer that is rare or less common than other cancer types. With rare types of cancer, sometimes finding a resource can be difficult. This fact sheet provides information about how penile cancer is diagnosed and treated, as well as where to go for additional information and support services.

Many people feel shocked and upset when told they have cancer. You may experience strong emotions after a cancer diagnosis, especially if your cancer is rare or less common like penile cancer. A feeling of being alone is usual with rare cancers, and you

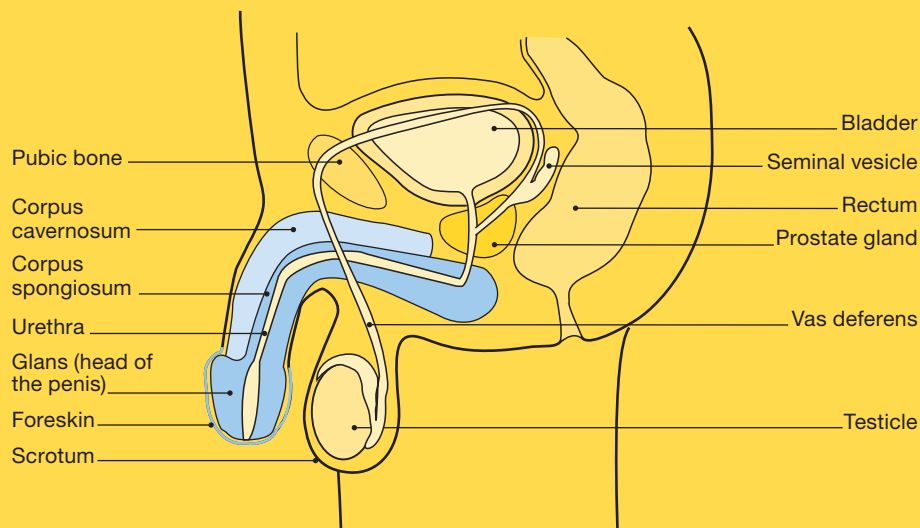
might be worried about how much is known about your type of cancer and how to manage it. You may also be concerned about the cancer coming back after treatment. Contacting local support services (see last page) can help overcome feelings of isolation and will give you information that you may find useful.

About the penis

The penis is the male external sex organ. It is also part of the urinary system. It is made up of different types of tissue such as skin, muscle, nerves and blood vessels. During sexual arousal, blood flows into the chambers of the penis and makes it hard and erect.

The penis also contains the urethra, a thin tube that carries urine from the bladder and semen from the testicles out of the body.

The Penis



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What is penile cancer?

Penile cancer is a rare type of cancer and occurs on the foreskin, the glans (head) of the penis, or on the skin of the penile shaft. It occurs mostly in uncircumcised men (men who still have foreskin around the head of the penis).

Cancer is a disease of the cells. Normally, cells multiply and die in an orderly way, so that each new cell replaces one that has been lost. Sometimes, however, cells become abnormal and keep growing, forming a mass or lump called a tumour or a sore called an ulcer. Some of these are malignant (cancerous) and can grow and spread to other parts of the body.

But not all growths are cancerous. Sometimes growths can develop on the penis that are abnormal but are not malignant (these are called benign tumours). These lesions look like warts or irritated patches of the skin. These can be caused by the human papillomavirus (HPV). It is important to discuss any growths you might have on your penis with your doctor as they might increase your risk of penile cancer.

There are several types of penile cancer, depending on the type of cell from which the cancer develops. Almost all penile cancers start in the surface layer of cells (called epithelium) of the penis.

- **Squamous cell cancer (SCC)** – the most common type of cancer of the penis. This cancer accounts for around 95% of cases and starts in the cells that cover the surface of the penis (squamous cell layer). Most of this type of cancer start on the foreskin (in men that have not been circumcised) or on the head of the penis (glans), but it can occur on the penile skin of the shaft as well.
- **Carcinoma in situ (CIS), penile intraepithelial neoplasia (PeIN)** – the earliest stage of squamous cell penile cancer where cancer cells are only found in the very top layer of the skin cells, and the cancer has not spread any deeper.

Other rarer types of penile cancer include:

- **basal cell carcinoma (BCC)** – another type of skin cancer that can develop in deeper cells of the squamous cells in a layer of skin.

- **adenocarcinoma** – a type of cancer that develops in the sweat glands in the skin of the penis.
- **melanoma of the penis** – a type of cancer that develops in the pigmented skin cells that give the skin its colour.
- **penile sarcoma** – a very rare type of cancer that develops in the deeper tissues of the penis such as the blood vessels, muscle, fat or connective tissue in the penis.

How common is penile cancer?

Penile cancer is rare with around 103 Australians diagnosed each year (this is about 0.8 cases per 100,000 people).¹ It is more likely to be diagnosed in men over 50 years of age but can also occur in younger men.

What are the risk factors?

The cause of penile cancer is not known in most cases. However, there are several risk factors:

- **Human papillomavirus (HPV) infection.** This common group of viruses are spread through sexual contact. Some types of HPV increase the risk of certain cancers. Most people with HPV do not develop cancer but HPV infection is found in about half of all penile cancers. Some types of HPV can cause genital warts, which increase the risk of developing penile cancer.
- **not being circumcised.** Penile cancer is more common in men who are not circumcised. Circumcision is the surgical removal of the foreskin that covers the end of the penis. This procedure is commonly performed on newborn boys for medical, cultural and religious and reasons. Men who have a tight foreskin that is hard to pull back (phimosis) for washing sometimes notice a secretion under the foreskin that becomes a smelly substance (smegma). While smegma doesn't necessarily cause penile cancer, it can irritate and inflame the penis, which can increase the risk of cancer.
- **smoking.** Chemicals found in cigarettes and other forms of tobacco can damage cells in the body, including cells in the penis, which can increase your risk of developing penile cancer.
- **age.** The risk of penile cancer increases with age and is more common in men over 50 years of age.

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- **certain skin conditions.** Men who have skin conditions such as psoriasis or lichen sclerosus may have a higher rate of penile cancer.
- **HIV/AIDS.** Infection with the human immunodeficiency virus (HIV) causes acquired immune deficiency syndrome (AIDS) and men who contract HIV have a greater risk of developing penile cancer as their immune system is less able to fight off cancer.
- **pre-malignant lesions/conditions.** If left untreated, these can become cancerous.
- **exposure to ultraviolet (UV) radiation.** From either sunlight or UV lamps.
- **Blood tests** – a full blood count (to measure your white blood cells, red blood cells and platelets), tumour markers (to measure chemicals produced by cancer cells) and to check if you have an infection.
- **Biopsy** – the removal of some tissue from the affected area or region for examination under a microscope. In penile cancer, the following biopsies may be used:
 - a punch biopsy or elliptical excision of the affected region to remove tissue. This procedure is generally performed under a local anaesthetic.
 - a fine needle aspiration biopsy where a local anaesthetic is used to numb the area then a thin needle is inserted into the tumour or lymph node under ultrasound or CT guidance.
 - a sentinel lymph node biopsy (under local anaesthetic) to see if cancer cells have spread to lymph nodes near the penis
 - removal of the lymph nodes from one or both sides of the groin to see if the cancer has spread. This operation is performed under a general anaesthetic and the nodes are removed through small cuts in the groin.

What are the symptoms?

People with penile cancer may experience a range of different symptoms. Having any of these symptoms does not mean a man has penile cancer but if you experience any of these symptoms you need to discuss them with your doctor.

Symptoms may include:

- a growth or sore on the head of the penis (the glans), the foreskin or on the shaft of the penis that doesn't heal in a couple of weeks.
- bleeding from the penis or under the foreskin
- a smelly discharge under the foreskin
- a hard lump under the foreskin
- changes in the colour of the skin on the penis or foreskin
- thickening of the skin on the penis or foreskin that makes it difficult to pull back the foreskin
- pain in the shaft or tip of the penis
- swelling at the tip of the penis
- a rash on the penis or a persistent red patch of skin that does not go away
- lumps in the groin due to swollen lymph nodes.

Diagnosis

If your doctor thinks that you may have penile cancer, they will talk to you about your medical history, perform a physical examination and suggest that you have certain tests. If the results of these tests suggest that you may have penile cancer, your doctor will refer you to a specialist called a urologist for further tests. These tests may include:

- **Ultrasound scan** – high-frequency soundwaves are used to create pictures of the inside of your body. For this scan, you will lie down, and a gel will be spread over the affected part of your body. A small device called a transducer is moved over the area by an ultrasound radiographer.
- The transducer sends out soundwaves that echo when they encounter something dense, like an organ or tumour. The ultrasound images are then projected onto a computer screen. An ultrasound is painless and takes about 15–20 minutes.
- **CT (computerised tomography) or MRI (magnetic resonance imaging) scans** – special machines are used to scan and create pictures of the inside of your body. Before the scan you may have an injection of dye (called contrast) into one of your veins, which makes the pictures clearer. During the scan, you will lie on an examination table. For a CT scan, the table moves in and out of the scanner; the scan takes

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about 10 minutes. For an MRI scan, the table slides into a large metal tube that is open at both ends; the scan takes about 30–90 minutes to perform. Both scans are painless. With an MRI, you may need an injection into the penis with a drug to make it erect. This makes it easier to find a cancer in the penis.

- **PET (positron emission tomography)–CT scan** – a scan combined with a CT scan where you are injected in your arm with a glucose solution containing some radioactive material. Cancer cells show up brighter on the scan because they absorb more glucose than normal cells do.

Finding a specialist

Rare Cancers Australia have a directory of health professionals and cancer services across Australia: rarecancers.org.au.

Grading and staging of penile cancer

If cancer cells are found during any of your tests, your doctor will need to know the tumour grade and stage so your team of health professionals can develop the best treatment plan for you. The grade of the cancer lets your doctor know how quickly the cancer might grow and spread while the stage of the cancer describes its size and whether it has spread.

Grading

Penile cancer is graded from 1 to 3 with 1 being the lowest grade and 3 being the highest grade. Low-grade means that the cancer cells are slow growing and less likely to spread. High-grade means that the cancer cells grow more quickly and are more likely to spread.

Staging

Staging describes where the cancer is and how far the cancer has spread. Knowing the stage helps doctors plan the best treatment for you. There are several staging systems for penile cancer, but the one most commonly used is the TNM staging system.

TNM staging system

T (tumour)	describes the size and extent of the main tumour. Refers to if the cancer is in situ or penile intraepithelial neoplasia (Tis) and in only the top layer of skin; is like a wart (Ta) but only in the top layer of skin; has grown into tissue just below the top layer of skin but not any further (T1a); has grown into blood vessels, lymph vessels or nerves in the layers of the penis (T1b); has spread into the spongy tissue of the penis and/or the urethra (T2); has grown more deeply into the penis and/or urethra (T3); has spread further into the penis, urethra or scrotum (T4)
N (nodes)	describes if cancer has spread to nearby lymph nodes. No spread (N0) or spread to one or more lymph nodes (N1, N2, N3)
M (metastasis)	describes if cancer has spread to other parts of the body. No spread (M0) or spread to other organs or bones (M1)

Treatment

You will be cared for by a multi-disciplinary team of health professionals during your treatment for penile cancer. The team may include a urologist, a surgeon, a radiation oncologist (to prescribe and coordinate a course of radiation therapy), a medical oncologist (to prescribe and coordinate a course of systemic therapy which includes chemotherapy), a radiologist, specialist nurses and allied health professionals such as a dietitian, social worker, psychologist, physiotherapist and occupational therapist.

Discussion with your doctor will help you decide on the best treatment for your cancer depending on the type of penile cancer you have, if the cancer has spread, your age and general health. The main treatments for penile cancer include surgery, radiation therapy and chemotherapy. These can be given alone or in combination. Many people may have concerns about how the treatment could affect their sexuality and fertility. It is important to discuss these issues with your doctor before treatment begins.

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Surgery

Surgery is the main treatment for penile cancer. A surgeon will remove the tumour as well as some surrounding healthy tissue, called a margin. The extent and type of surgery depends on the location and the grade and stage of the tumour. Your surgeon will discuss the type of operation you may need (see table below). In most cases, any physical changes to your penis after an operation can be corrected with reconstructive surgery.

- For a free copy of Cancer Council's booklet *Understanding Surgery* visit your local Cancer Council website or call 13 11 20.

Other treatments for penile cancer

Some early-stage, low-grade penile cancers, especially carcinoma in situ (where the cancer is only in the top layers of skin), can be treated with techniques other than surgery. These include laser treatment, cryotherapy, radiation therapy and topical therapy. These treatments are called penile sparing techniques and cause the least damage to the penis. Discuss your options with your doctor.

Laser treatment

If the cancer is very small and only on the surface of the penis, laser therapy may be used to kill cancer cells. Laser therapy uses powerful beams of light to destroy the cancer cells and can be used for tumours with lower staging (see TNM staging system on previous page) instead of surgery.

Photodynamic therapy (PDT)

Photodynamic therapy uses special drugs, called photosensitising agents, along with light to kill cancer cells. The drugs only work after they have been activated or turned on by the light. In penile cancer the drugs are put on the skin and after a period of time, light is applied to the area. The procedure is usually painless and less invasive than surgery.

Cryosurgery

Cryosurgery uses liquid nitrogen to freeze and kill the cancer cells. The procedure may sting and cause slight discomfort. The treated skin will blister and peel over following days and may leave a scar. Sometimes several treatments are needed.

Surgical procedures

Circumcision	Used when cancer is only on the foreskin. The foreskin of the penis is surgically removed.
Simple excision	The affected area of the penis and a small margin are removed surgically. If the tumour is small, the skin can be stitched back together.
Wide local excision	The tumour is removed along with a larger amount of normal tissue. If there is not enough skin left to cover the area, skin may be taken from another part of the body (a skin graft) to cover it.
Glans resurfacing	Used when the cancer is in situ and in only the top layer of skin. The surface tissue from the glans or head of the penis is removed. A skin graft may be needed to replace tissue removed.
Partial or total glansectomy	Removal of part or all of the head of the penis (the glans). The amount of tissue removed will depend on the extent of the cancer.
Partial or total penectomy	Removal of part or all of the penis and reconstruction of the urethra. In a total penectomy, the urethra is passed through to the perineum.
Lymph node surgery	<p>You may need nearby lymph nodes in the groin to be removed to check for the spread of cancer. This may be done during penile surgery or at a separate time. There are four types of lymph node surgical procedures all of which need to be performed by a urologist:</p> <ul style="list-style-type: none"> • Dynamic sentinel lymph node biopsy to see if cancer cells have spread to lymph nodes near the penis. If positive, further surgery (dissection) is needed to remove more lymph nodes. • Modified inguinal node dissection where some, but not all the lymph nodes in the groin, are removed. If positive, a full dissection will be performed. • Radical inguinal node dissection. If lymph nodes in the groin are involved, all the nodes in this area will be removed. • Pelvic lymph node dissection. If nodes are involved or a high risk of being involved, the pelvic lymph nodes will also be removed.

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Radiation therapy

Radiation therapy (also known as radiotherapy) uses high energy x-rays to destroy cancer cells. The radiation comes from a machine outside the body. It may be used for penile cancer:

- to treat smaller penile cancers instead of surgery
- after surgery, to destroy any remaining cancer cells and stop the cancer coming back
- if the cancer cannot be removed with surgery
- at the same time as chemotherapy to help shrink the tumour before surgery to make it easier to remove with less damage to the penis
- if the cancer has spread to other parts of the body (e.g. palliative radiation for the management of pain).

There are two ways to have radiation therapy for penile cancer:

- external beam radiation therapy
- brachytherapy

External beam radiation therapy

This is the most common way to have radiation therapy for penile cancer and uses carefully focused beams of radiation aimed at the tumour from a machine. A course of radiation therapy needs to be carefully planned. During your first consultation session you will meet with a radiation oncologist. At this session you will lie on an examination table and have a CT scan in the same position you will be placed in for treatment. The information from this session will be used by your specialist to work out the treatment area and how to deliver the right dose of radiation. Radiation therapists will then deliver the course of radiation therapy as set out in the treatment plan.

Men who are not circumcised will have their foreskin removed first before radiation therapy begins. This is to stop swelling and tightening of the foreskin during treatment which could lead to further problems.

Radiation therapy does not hurt and is usually given in small doses to minimise side effects five days a week for a period of about six weeks. Each treatment only lasts a few minutes but there is also setting-up time. A plastic block or mould is used to hold the penis in the exact same position for each treatment and shields may be used to protect your groin and testicles.

Brachytherapy

Brachytherapy, also known as internal radiation, involves placing radioactive material inside your body either directly into the tumour or next to the tumour. It allows doctors to deliver higher doses of radiation to more specific areas of the body and usually has fewer side effects than external beam radiation.

- For a free copy of Cancer Council's booklet *Understanding Radiation Therapy* visit your local Cancer Council website or call 13 11 20.

Chemotherapy

Chemotherapy (sometimes just called "chemo") is the use of drugs to kill or slow the growth of cancer cells. You may have one chemotherapy drug, or a combination of drugs. This is because different drugs can destroy or shrink cancer cells in different ways.

Your treatment will depend on your situation and stage of the tumour. Your medical oncologist will discuss your options with you.

Chemotherapy is usually given through a drip into a vein (intravenously) or as a tablet that is swallowed. Sometimes for low grade carcinoma in situ cancers, a cream can be applied topically (see below).

Chemotherapy is commonly given in treatment cycles which may be daily, weekly or monthly. For example, one cycle may last three weeks where you have the drug over a few hours, followed by a rest period before starting another cycle. The length of the cycle and number of cycles depends on the chemotherapy drugs being given.

Topical chemotherapy

For low grade carcinoma in situ, lower doses of chemotherapy can be used on the skin in the form of a cream. The cream is applied often twice a day for several weeks to the affected area on the penis and does not cause the side effects people often have with intravenous or tablet chemotherapy. Circumcision is recommended before starting treatment. There is a slight risk of recurrence with this treatment so you must have regular follow-up appointments with your doctor.

- For a free copy of Cancer Council's booklet *Understanding Chemotherapy* visit your local Cancer Council website or call 13 11 20.

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Clinical trials

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment. Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time.

For more information on clinical trials, visit australiancancertrials.gov.au.

► For a free copy of Cancer Council's booklet *Understanding Clinical Trials and Research* visit your local Cancer Council website or call 13 11 20.

Complementary therapies and integrative oncology

Complementary therapies are designed to be used alongside conventional medical treatments (such as surgery, chemotherapy and radiation therapy) and can increase your sense of control, decrease stress and anxiety, and improve your mood.

Some Australian cancer centres have developed "integrative oncology" services where evidence-based complementary therapies are combined with conventional treatments to create patient-centred cancer care that aims to improve both wellbeing and clinical outcomes.

Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

► For a free copy of Cancer Council's booklet *Understanding Complementary Therapies* visit your local Cancer Council website or call 13 11 20.

Complementary therapy	Clinically proven benefits
acupuncture	reduces chemotherapy-induced nausea and vomiting; improves quality of life
aromatherapy	improves sleep and quality of life
art therapy, music therapy	reduce anxiety and stress; manage fatigue; aid expression of feelings
counselling, support groups	help reduce distress, anxiety and depression; improve quality of life
hypnotherapy	reduces pain, anxiety, nausea and vomiting
massage	improves quality of life; reduces anxiety, depression, pain and nausea
meditation, relaxation, mindfulness	reduce stress and anxiety; improve coping and quality of life
qi gong	reduces anxiety and fatigue; improves quality of life
spiritual practices	help reduce stress; instil peace; improve ability to manage challenges
tai chi	reduces anxiety and stress; improves strength, flexibility and quality of life
yoga	reduces anxiety and stress; improves general wellbeing and quality of life



Alternative therapies are therapies used *instead* of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

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Nutrition and exercise

If you have been diagnosed with penile cancer, both the cancer and treatment will place extra demands on your body. Research suggests that eating well and exercising can benefit people during and after cancer treatment.

Eating well and being physically active can help you cope with some of the common side effects of cancer treatment, speed up recovery and improve quality of life by giving you more energy, keeping your muscles strong, helping you maintain a healthy weight and boosting your mood.

You can discuss individual nutrition and exercise plans with health professionals such as dietitians, exercise physiologists and physiotherapists.

- ▶ For free copies of Cancer Council's booklets *Nutrition and Cancer* and *Exercise for People Living with Cancer* visit your local Cancer Council website or call 13 11 20.

Side effects of treatment

All treatments can have side effects. The type of side effects that you may have will depend on the type of treatment and where in your body the cancer is. Some people have very few side effects and others have more. Your specialist team will discuss all possible side effects, both short and long-term (including those that have a late effect and may not start immediately), with you before your treatment begins.

One issue that is important to discuss before you undergo treatment is fertility, particularly if you want to have children in the future.

- ▶ For a free copy of Cancer Council's booklet *Fertility and Cancer* visit your local Cancer Council website or call 13 11 20.

Penile cancer and its treatment can sometimes lead to long-term, life-changing side effects. Your doctors will try to use penile-sparing treatments where possible but in some cases, this is not an option. Most men will still be continent (able to control urine flow) after surgery but if the surgery has removed part or all of the penis, how you urinate may change. If your urethra was reconstructed, you may have to sit down to urinate.

Common side effects	
Surgery	Erectile dysfunction, pain, discomfort, altered appearance, bleeding, trouble urinating, swelling, itching, lymphoedema if lymph nodes have been removed
Radiation therapy	Scar tissue formation in the penis and urethra may cause problems urinating, sexual problems, fatigue, nausea and vomiting, skin reaction, loss of fertility, lymphoedema, slight risk of developing other cancers in the future
Chemotherapy	Fatigue, loss of appetite, nausea and vomiting, bowel issues such as diarrhoea, hair loss, mouth sores, skin and nail problems, increased chance of infections, loss of fertility

Having penile cancer treatment can affect your self-image and also your ability to have sex. Changes to how your penis looks can cause decreased interest in sex as well as embarrassment. Some men may worry that they won't be able to satisfy their partner. Sometimes depression and anxiety can make you want to avoid sex. You and your partner, if you have one, may wish to have counselling to help understand the impact the treatment has had on your sexuality and explore other ways of enjoying intimacy and sexual satisfaction. Ask your GP for a referral.

After a partial penectomy, the remaining part of the penis can still become erect with arousal and penetration may be possible. Intercourse, however, is not possible after a total penectomy. But sexual pleasure is still possible after a total penectomy so it's important to talk to a counsellor, sex therapist or psychologist who can give you support and advice.

Surgical reconstruction of the penis might be possible after a total penectomy. Talk to your doctor to see if this might be an option for you.

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Making decisions about treatment

It can be difficult to know which treatment is best for you. It is important that you speak with a specialist team before making your decision. Ask them to give you a clear plan of your treatment options, including written information about side effects. Some people prefer to seek several opinions before feeling confident to go ahead with the treatment. If you are confused or want to check anything, ask your specialist questions. This will make sure you have all the information you need to make decisions about treatment and your future that you are comfortable with.

You may have to attend many appointments. It's a good idea to take someone with you. They will be able to listen, ask questions and remember what the doctor says.

It may help to take a list of questions with you, take notes (especially about anything you are unfamiliar with) or ask the doctor if you can record the discussion (many mobile phones have a recording function or you can use the CAN.recall app – visit rarecancers.org.au for more information). There are some suggestions for questions you could ask at the end of this sheet.

► For a free copy of Cancer Council's booklet *Cancer Care and Your Rights* visit your local Cancer Council website or call 13 11 20. Cancer Council's podcast *Making Treatment Decisions* can be downloaded from your local Cancer Council website.

Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. There is no right way to feel if you have been diagnosed with a less common cancer such as penile cancer. Feeling a range of emotions is normal and you may feel overwhelmed, anxious, fearful, angry, sad or lonely.

Many people need emotional support before, during and after treatment. Adjusting to living with visible scars, changes to your physical appearance, changes to your lifestyle and bodily function can be hard and take time. If this is affecting you or likely to affect you, it's important to seek help.

It can help to talk things through with a counsellor, psychologist, friend or family member. Talk to your medical team or call Cancer Council 13 11 20 about what support services are available in your local area.

► For a free copy of Cancer Council's booklet *Emotions and Cancer* visit your local Cancer Council website or call 13 11 20.

Practical and financial support

After a cancer diagnosis, many people worry about how they will manage the financial impact of having cancer. The Australian Government offers several benefits that can help you access medical treatments, tests, prescription medicines and other medical supplies at a lower cost such as the Medicare Safety Net, The PBS Safety Net and Medicare benefits for allied health services

There are also programs that provide financial help for transport costs, accommodation and even utility bills and council rates. Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

For additional income, you may be able to access your superannuation early in certain circumstances, or claim on insurance policies such as income protection, trauma, and total and permanent disability (TPD).

If you are struggling financially, talk to your doctor as they may suggest ways to reduce your treatment costs or they might be able to keep seeing you as a public patient.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

Managing your ability to work or study, particularly during cancer treatment, is important to consider and will depend on your personal situation.

► For free copies of Cancer Council's booklets *Cancer and Your Finances* and *Cancer, Work & You* visit your local Cancer Council website or call 13 11 20.

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Life after treatment

Once your treatment has finished, you will have regular check-ups to confirm that the cancer hasn't come back. Ongoing surveillance for penile cancer involves a schedule of ongoing tests, scans and physical examinations. Let your doctor know immediately of any health problems between visits.

Some cancer centres work with patients to develop a "survivorship care plan" which usually includes a summary of your treatment, sets out a clear schedule for follow-up care, lists any symptoms to watch out for and possible long-term side effects, identifies any medical or emotional problems that may develop and suggests ways to adopt a healthy lifestyle going forward. Maintaining a healthy body weight, eating well and being physically active are all important.

If you don't have a care plan, ask your specialist for a written summary of your cancer and treatment and make sure a copy is given to your GP and other health care providers.

► For a free copy of Cancer Council's booklet *Living Well After Cancer* visit your local Cancer Council website or call **13 11 20**.

Relationships and sexuality

If penile cancer is diagnosed early, treatments can often be used that may have little effect on your sex life. Doctors will always try to give you the treatment that preserves as much of your penis as possible. Some treatments for penile cancer, however, can cause long-term, life-changing side effects.

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as the treatment you have had and the side effects of the treatment. Often treatment for penile cancer can affect your self-confidence and the way you think about sex. Changes to the way your penis looks can cause embarrassment, depression and anxiety, and you may feel like avoiding sex.

Your doctor will explain to you any possible effects your treatment may have on your sex life. If you have had early-stage cancer, treatment is unlikely to have any direct effect. It is usually safe for you to have sex as soon as your treated area heals and that you feel ready for it. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

► For a free copy of Cancer Council's booklet *Sexuality, Intimacy and Cancer* visit your local Cancer Council website or call 13 11 20.

If the cancer comes back

For some people, penile cancer does come back after treatment, which is known as a recurrence. If the cancer does come back, treatment will depend on where the cancer has returned in your body and may include a mix of surgery, radiation therapy and chemotherapy.

In some cases of advanced cancer, treatment will focus on managing any symptoms, such as pain, and improving your quality of life without trying to cure the disease. This is called palliative treatment.

Palliative care involves health professionals from a range of disciplines caring for your physical, practical, emotional and spiritual needs. Palliative care can be provided in your home, in a hospital, in a palliative care unit or hospice, or in a residential aged care facility. Services vary because palliative care is different in each state and territory. Speak to your GP, community nurse or cancer specialist about the palliative care services appropriate for you.

When cancer is no longer responding to active treatment, it can be difficult to think about how and where you want to be cared for towards the end of life. But it's essential to talk about what you want with your family and health professionals, so they know what is important to you. Your palliative care team can support you in having these conversations.

► For free copies of Cancer Council's booklets *Understanding Palliative Care*, *Living with Advanced Cancer* and *Facing End of Life* visit your local Cancer Council website or call 13 11 20. You can also listen to our podcast series *The Thing About Advanced Cancer*.

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Questions for your doctor

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your list.

- What type of penile cancer do I have?
- How far has the cancer spread? What stage of cancer do I have?
- Have you treated this type of cancer before?
- Can you recommend another doctor so I can get a second opinion?
- What are the treatment options for me? What do you recommend and why?
- What are the possible risks and side effects of my treatment? How will these be managed?
- What impact will the treatment have on my continence, sexual function and fertility?
- How long will the treatment take?
- Is this treatment covered by Medicare/private health insurance? Will there be extra expenses?
- Are there any complementary therapies that might help me?
- If the cancer comes back, how will I know?

If you are thinking of taking part in a clinical trial, here are some questions you could ask:

- What are the possible benefits and risks to me?
- What is being tested and why?
- How many people will be involved in this trial?

Reference

1. Australian Institute of Health and Welfare 2019. Cancer in Australia 2019. Cancer series no.119. Cat. no. CAN 123. Canberra, AIHW.

A web-based resource for Australians with less common cancers project is a Cancer Australia Supporting people with cancer Grant initiative, funded by the Australian Government. Website: canceraustralia.gov.au

Acknowledgements

This information has been developed with help from health professionals and people affected by penile cancer. It was reviewed by: Gregory Bock, Urology Cancer Nurse Coordinator, WA Cancer and Palliative Care Network, North Metropolitan Health Service, WA; Dr Mikhail Lozinskiy, Consultant Urologist, Royal Perth Hospital, WA; Caitriona Nienaber, 13 11 20 Consultant, Cancer Council WA; Prof Manish Patel, Urological cancer surgeon, University of Sydney, Westmead and Macquarie University Hospitals, Sydney, NSW; Walter Wood, Consumer; Dr Carlo Yuen, Urologist, St Vincent's Hospital, Sydney, Conjoint Senior Lecturer UNSW.

Note to reader

Always consult your doctor about matters that affect your health. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this fact sheet.

Support services

- Beyond Blue: support for depression and anxiety. Visit beyondblue.org.au or call **1300 22 4636**
- Cancer Council: visit your local Cancer Council website (see below for details) or call **13 11 20**
- Checkyourtackle: support for male orientated cancers such as penile cancer. Visit www.checkyourtackle.com
- Rare Cancers Australia: rarecancers.org.au or call **1800 257 600**
- Talk to your GP, nurse or social worker about what is available in your area.

Where to get help and information

Call Cancer Council **13 11 20** for more information about penile cancer. Trained health professionals can listen to your concerns, provide information, and put you in touch with local services and support groups. Ask for free copies of booklets that may be relevant to you, or download digital versions from your local Cancer Council website:

ACT..... actcancer.org
 NSW cancercouncil.com.au
 NT..... cancer.org.au/nt
 QLD cancerqld.org.au
 SA..... cancersa.org.au
 TAS cancertas.org.au
 VIC..... cancervic.org.au
 WA cancerwa.asn.au
 Australia..... cancer.org.au



For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.