

Penile Cancer

What you need to know

Revised 5th Edition

ORCHID 
FIGHTING MALE CANCER

A diagnosis of penile cancer can be physically and psychologically devastating for a man. As it is a very rare cancer few people have heard about it and men do not talk about it.



““ Four years after my treatment I still run a business with over fifty employees. Taking into account all their partners, families and friends, cancer; by the law of averages, could sadly strike my workforce many times. I often have to offer advice to my employees, and I am sure they often think that if I can survive cancer then they also have an equal chance.””

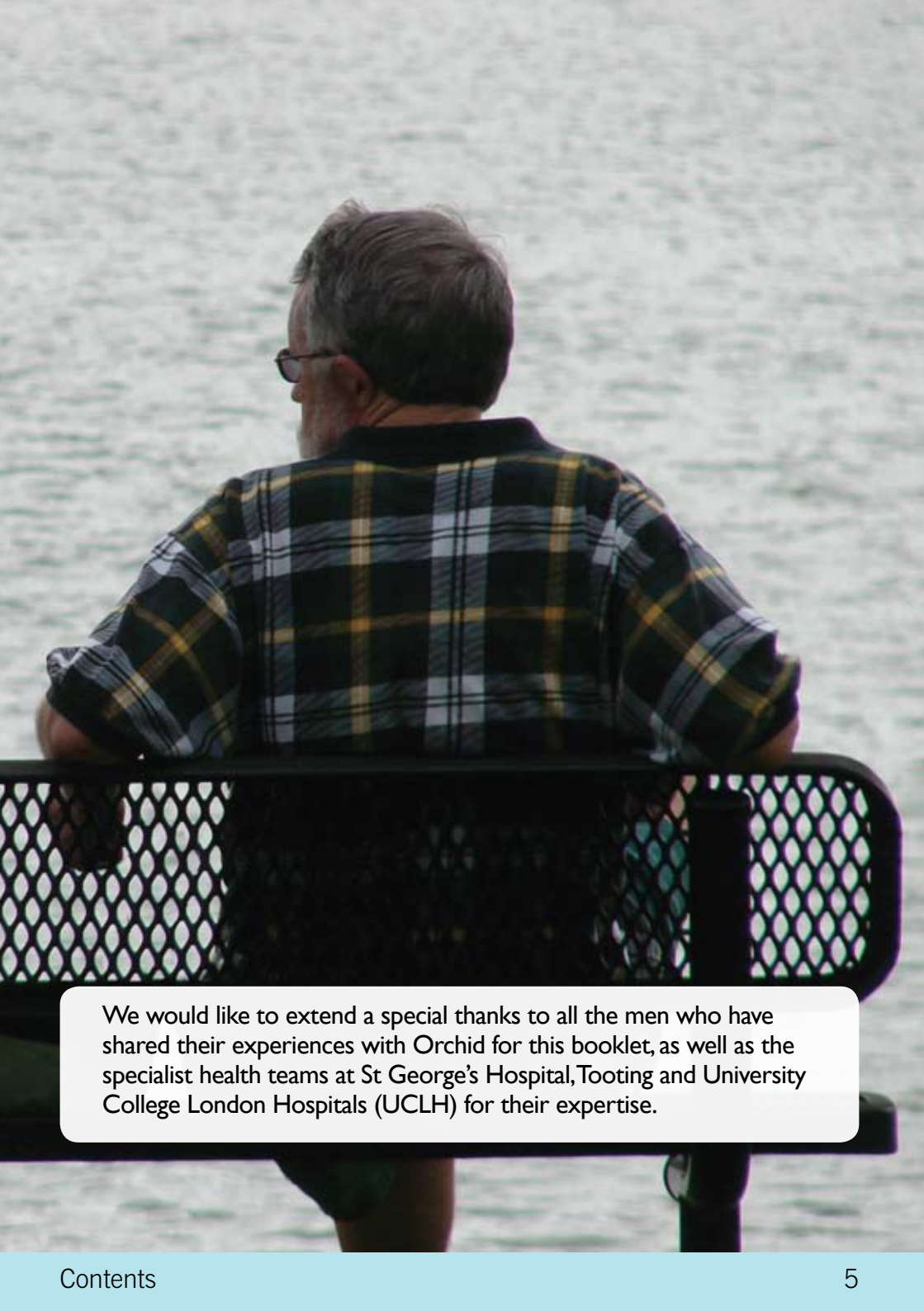
This booklet has been written to help men through a diagnosis of penile cancer and hopefully provide them with information which may help them through their journey.

www.orchid-cancer.org.uk

ORCHID 
FIGHTING MALE CANCER

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We would like to extend a special thanks to all the men who have shared their experiences with Orchid for this booklet, as well as the specialist health teams at St George's Hospital, Tooting and University College London Hospitals (UCLH) for their expertise.

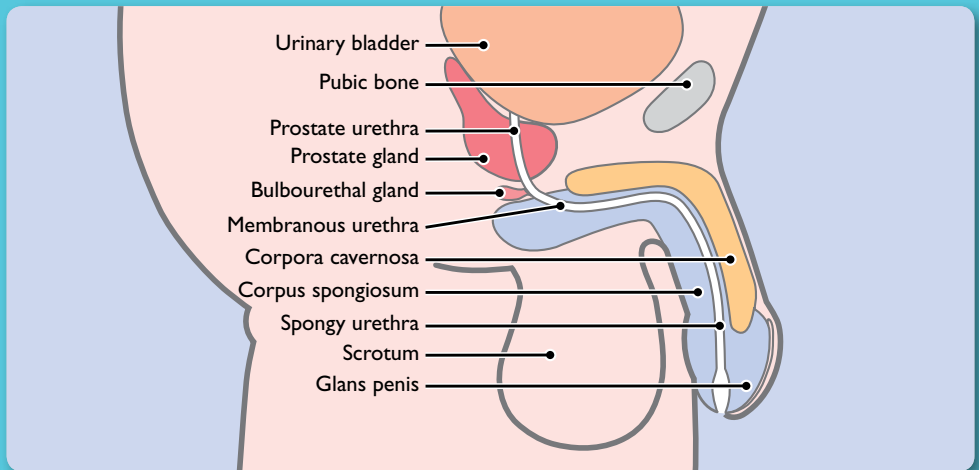
Section 1: Cancer of the penis

Cancer of the penis is very rare in the western world; there are over 700 cases in the UK each year. It is most often diagnosed in men over the age of 60 although it can affect younger men.

Penile cancer is usually a slow growing cancer and if caught early the chances of survival are high.

Unfortunately many men tend to ignore symptoms of penile cancer.

Structure of the penis



Symptoms

Symptoms of penile cancer may include the following:

- ▶ A growth or ulcer on the penis, especially on the glans or foreskin.
- ▶ Changes in the colour of the penis.
- ▶ Skin thickening on the penis.

- ▶ Irregular swelling at the end of the penis.
- ▶ Persistent discharge with foul odour beneath the foreskin.
- ▶ Blood coming from the tip of the penis or under the foreskin.
- ▶ Unexplained pain in the shaft or tip of the penis.
- ▶ Irregular lesions or marks beneath the foreskin or on the body of the penis.
- ▶ Reddish, velvety rash beneath the foreskin.
- ▶ Small, crusty bumps beneath the foreskin.
- ▶ Any of the above symptoms with unexplained lumps in the groin (enlarged lymph nodes) see page 13.

Cancer can develop anywhere on the penis but the most common places are under the foreskin and on the glans.

There are also a number of non-cancerous conditions that may cause similar symptoms. If a man is concerned about any of these symptoms, he should seek medical advice.

Risk factors and prevention

There is no one factor which leads to penile cancer but there are some conditions which appear to increase the risk.

▶ Human Papilloma Virus (HPV)

There are over 140 different types of HPV virus which are spread by direct skin to skin contact. Common types cause warts and verrucas. Around 40 types of HPV are transmitted via sexual intercourse.

There are a number of strains of HPV virus which are considered high risk viruses (including types 16 and 18 most commonly). These can infect the anus, penis, throat and cervix and are linked with the development of some cancers in these areas. The body's immune system is usually able to kill the virus, however sometimes in rare instances the virus can persist for

many years without causing any symptoms and then develop into cancer or pre-cancerous conditions. Practising safe sex using a condom can help reduce the risk of HPV as well as Sexually Transmitted Infections (STIs).

- ▶ Penile cancer is virtually unknown in men who have been circumcised in early childhood. Circumcision may reduce the risk of HPV infection as well as the predisposition to chronic skin diseases associated with the penis which may increase the risk of penile cancer. However, adult men who are circumcised have no reduced risk of developing penile cancer:

It is important for uncircumcised men to thoroughly clean underneath their foreskin to reduce potentially harmful substances accumulating which may increase the risk of penile cancer.

- ▶ Phimosis - this is the inability to pull back the foreskin fully. It can occur as a result of skin irritation or inflammation or be present from birth. It will reduce the ability to clean the penis thoroughly or notice abnormal changes.
- ▶ Some research indicates that smoking may increase the chance of developing penile cancer although the exact cause of this association is not fully understood.
- ▶ Having a weakened immune system caused by certain type of medication or diseases such as HIV and AIDS.
- ▶ Lichen sclerosus et atrophicus (Balanitis Xerotica Obliterans; BXO). This is the formation of white lesions which can lead to phimosis in uncircumcised men. It is found in a small percentage of men with penile cancer but has not been definitively linked as a causative factor in its development.

Section 2: Initial diagnosis



If penile cancer is present or suspected then one of the following procedures may be performed.

Penile biopsy

A special type of surgical needle will be used to obtain a sample of tissue from around the abnormal area of the penis.

Circumcision

This is the surgical removal of the foreskin and may be appropriate if only this area has been affected by a pre-cancerous condition or cancer itself. Sometimes it will be the only treatment needed.

Wide local excision

Pre-cancerous or cancerous tissue will be removed surgically from the affected area of the penis and a few millimetres of healthy tissue will also be removed to reduce the possibility of any potential cancerous cells from being left behind.

These procedures can be performed using a general or local anaesthetic as a day case procedure meaning that men will be able to go home afterwards. The tissue samples removed will be examined for the presence of abnormal cells by medical scientists.

After minor surgery

In general the following guidelines may be useful to follow after any minor penile surgery:

- ▶ There will be a surgical dressing on the penis. This can usually be removed after 24 hours. The stitches (sutures) left in the wound will be dissolvable but can take up to 2 weeks to fully dissolve.
- ▶ Men can normally shower after 24 hours, but it is important not to rub soap or other perfumed toiletries on the wound area until it has healed. The wound can be dried by gently patting it with a clean towel/gauze pad. A bath can be taken after one week.
- ▶ The penis may be bruised and swollen after the operation. Pain killers should be taken on a regular basis as prescribed and not just when pain is present.
- ▶ Although these are minor procedures, it is important to take things easy for the first week. Men should be able to return to work within a few days. However, if they are being reviewed in an outpatient clinic or referred to a specialist for possible further treatment or assessment; it may be a good idea to wait for these arrangements to be made before returning to work.
- ▶ Normal sexual activity can begin six weeks after the operation, as long as a man feels physically comfortable.

- ▶ Men should be given a follow-up appointment after their operation for the results. At this time any further treatment which may be needed will be discussed.

Pre-cancerous lesions

The names or terms used to describe pre-cancerous lesions can be confusing. The correct medical term is PeIN3 (Penile Intraepithelial Neoplasia 3) but there may be other names for these conditions that the medical team may use.

Bowenoid papulosis

This is an HPV related lesion, typically a small plaque which may form on the penile shaft. It rarely progresses to penile cancer and can usually be treated by simple surgical removal or other minor surgical techniques.

Bowens disease/ Erythroplasia of Queryat

Bowens disease is found on the shaft skin of the penis and is not associated with the HPV virus (see page 7). Erythroplasia of Queryat is found on the glans or foreskin of the penis and is more likely to progress to penile cancer.

The treatments listed on page 10 may be used to treat these types of lesion.



Orchid has a **Male Cancer Helpline** manned by specialist nurses

freephone **0808 802 0010**

or email helpline@orchid-cancer.org.uk

Treatments for pre-cancerous penile lesions (also some early stage penile cancers)

Topical Agents (Chemotherapy or Immunotherapy)

5% – fluorouracil (Effudex™)

This is a type of chemotherapy cream which is usually applied to the affected area of the penis for around 4 - 6 weeks. Chemotherapy works by destroying cancer cells. Chemotherapy will also affect some healthy cells on the penis and therefore the area treated may become inflamed, encrusted and sore. If this happens a steroidal cream may be prescribed to help reduce these symptoms. Soreness can sometimes last for a few months, however, it is important to continue treatment if possible for the full duration of the recommended period. This type of chemotherapy will not cause hair loss.

Imiquimod cream (Aldara™)

This is a type of immunotherapy. Unlike chemotherapy, immunotherapy stimulates the body's immune system to fight and sometimes regress cancerous cells. It can be used if chemotherapy cream has not worked fully. Treatment is usually applied for 4 - 6 weeks.

For both of the above treatments it may be necessary to use a barrier cream to protect areas around the treatment site.

The above treatments may not be suitable for patients with a weak immune system.

Glans resurfacing

This is a surgical technique to remove the surface tissue of the glans and sometimes take further biopsies. A small piece of skin from the thigh may be used as a skin graft to replace the tissue. Orchid has produced an information leaflet called *Glans resurfacing and Glansectomy* on this procedure.

Cryotherapy

This technique uses liquid nitrogen at a temperature of between -20° C and -50° C to freeze the cancer cells. The skin will later blister and peel. This procedure may leave a small scar.

Laser ablation

Laser therapy is the use of a very powerful beam of light to kill cancer cells. Laser surgery can be used along with a small incision to destroy these cells. This can cause some minor pain and bleeding but is usually well tolerated. It may take 2 - 3 months after treatment for any discomfort to fully settle.

Photodynamic therapy

This is a newer treatment that is still being fully assessed. Light sensitive chemicals are applied to the affected area and left for a few hours. A special type of light is then used to target and kill the cancer cells.

Mohs microsurgery

This is a special surgical technique which may be used for some types of penile cancer:

Small slices of cancerous tissues are removed and examined under a microscope. This is repeated until all the cancerous tissue has been removed.

Section 3: Staging of penile cancer

“ I was completely stunned when I was told. As far as I was concerned, everybody else got cancer – not me. I was fit and healthy. Why should I get cancer? People don't even know of penile cancer, it is so rare. I kept thinking of how this might end, although I knew that my inbuilt resilience would help me rationalise my circumstances. This proved to be the case as during treatment I felt that I got stronger and better able to cope as I came to terms with what was going on and got a better understanding of treatment and the way forward. ”

“ I remember I had originally gone to my GP about four years ago now with what had looked like a boil or wart-like growth near the end of my foreskin. My GP was a bit annoyed that I had not approached him sooner (the growth had been emerging for about two or three months). He immediately referred me to a urology specialist and I was operated on quite quickly to have it removed. ”

Types of penile cancer

Squamous cell carcinoma

95% of penile cancer is called squamous cell carcinoma. Squamous cells are skin cells that can become cancerous on any part of the penis but usually develop on or under the foreskin.

This type of cancer has the potential to spread to other areas around the penis and sometimes the urethra. A rarer form of this cancer is called Verucous carcinoma, which generally tends to be less invasive and less aggressive.

Basal cell penile cancer

Basal cells are skin cells from the outer lining of the skin. Less than 2% of penile cancers are basal cell cancers.

Melanoma

This cancer sometimes occurs on the surface of the penis and is the same as the type that affects other areas of the body.

Sarcoma

About 1% of penile cancers are sarcomas, which are cancers that develop in the tissues that support and connect the body, such as blood vessels, muscle and fat.

Other types of cancer such as cancer of the bladder and urinary tract, as well as squamous cell carcinoma can also begin in the urethra or invade it and then affect the penis. They will often be treated in a similar way.

Staging penile cancer

Staging is a way of describing how far cancer may have spread. This can be determined using one or more of the following tests decided by the specialist team.

Computerised Tomography (CT)

A CT scan checks for any signs that the cancer has spread to other areas of the body. It takes a series of x-rays, which are fed into a computer to build up a three-dimensional picture of the inside of the body and takes from 10 to 30 minutes. Men may be given a drink or injection of a dye that allows particular areas to be seen more clearly. They will usually be able to go home as soon as the scan is over. The scan is painless, but it will mean lying still for 10 - 20 minutes.

Positron Emission Tomography (PET)

This may be used to find out whether penile cancer has spread beyond the penis or to examine any residual areas of abnormality that remain after treatment to see whether they are dead tissue, or whether cancer cells may still be present. A PET scan uses low-dose radioactive sugar to measure the activity of cells in different parts of the body. It is not usually used on a routine basis as it is not always necessary but may be performed after initial treatment.

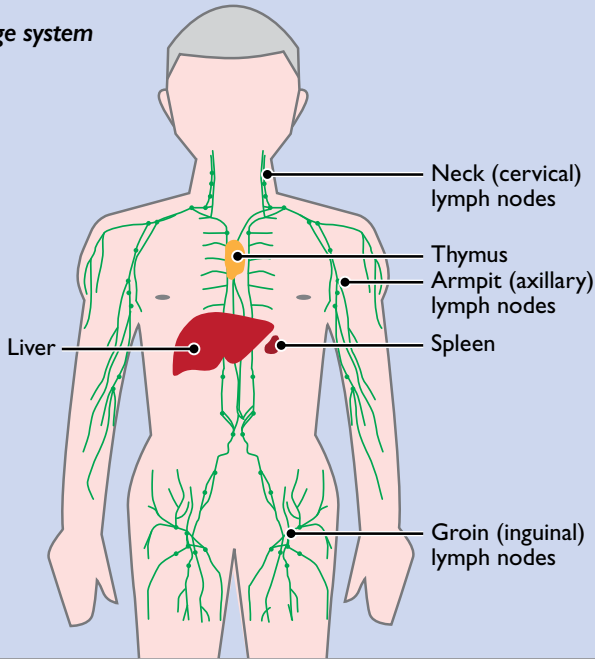
A very small amount of a mildly radioactive substance is injected into a vein, usually in the arm.

Magnetic Resonance Imaging (MRI)

This test may be recommended and may be performed prior to, or during treatment. It builds up a cross-sectional medical image of the body. During the scan men will be asked to lie very still on a couch inside a confined chamber for up to an hour. MRI scanning is noisy, and ear plugs will be provided.

Sometimes an injection may be given into the penis to cause an erection which can help provide more detail of the area affected by cancer.

Lymphatic drainage system



Lymph nodes

The human body is covered by a special type of drainage system called the lymphatic drainage system (see diagram). This system is responsible for transporting excess fluid from the organs and tissues of the body as a fluid called lymph. Lymph fluid will contain various types of cells and substances that are no longer needed. The lymph fluid will pass through small nodules or nodes that act as filters removing these substances. Cancer cells can also travel in the lymph fluid and as a result may affect other areas of the body.

The lymph nodes that tend to be affected by penile cancer are those in the groin region and sometimes the pelvis.

The following procedures may be performed to determine if lymph nodes have been affected by penile cancer:

Fine needle aspiration using ultrasound scan

An ultrasound scan will be used to verify enlarged lymph nodes in the groin region which may have been felt on physical examination. A biopsy using a surgical needle will be taken. The cells that are obtained will be sent for laboratory analysis to determine if they are cancerous or not. This is performed under a local anaesthetic. If cancer is found in the lymph nodes then these will usually be removed by an operation (see Orchid's information leaflet: *Lymph node dissection*).

Dynamic sentinel lymph node biopsy

This is performed to find out if cancer cells have spread to lymph nodes in the groin region which may not be obvious during a physical examination.

A local anaesthetic will first be applied to several areas of the penis and a radioactive dye will then be injected into it. Special x-rays will be taken of the area to visualise the lymph nodes in the groin. Once the lymph node nearest to the cancer has been identified the area will be marked and a surgical plaster will be applied. This procedure may take several hours.

An operation requiring a general anaesthetic will then be performed usually later on the same day and a blue dye will be injected into the penis. The dye will be absorbed by the lymph nodes and a special camera will be used along with the x-rays from the previous procedure to identify the sentinel lymph nodes which will then be removed by a small surgical incision.

If cancer is detected in the sentinel lymph node then it is possible that it has spread to other lymph nodes and a subsequent operation may need to be performed to remove these lymph nodes.

Men will usually be allowed home within 24 hours of the procedure.

Tips

- ▶ Men will need to have a family member or a friend who can check their progress recovering for 24 hours after the procedure.
- ▶ Dressings on the biopsy site can be removed after 48 hours and it should then be possible to bath or shower normally. Use a clean towel or gauze dressing to pat dry the wound area.
- ▶ There may be small metal surgical clips or dissolvable stitches in the wound site. Clips will usually be removed after 10 - 14 days.
- ▶ Once the results of the biopsy are known any further treatment which may be needed will be discussed.

Planning treatment

Once results of the investigations and surgery are known it will be possible to determine whether the cancer is localised or has spread to other areas of the body. Any further treatment will be based on these results and decided by a specialist team of urologists, oncologists and other health professionals in a Multi Disciplinary Team Meeting (MDT). Men with penile cancer will be referred for treatment at a specialist centre where an experienced surgical team will perform penile sparing surgery. These centres are called supranetworks.

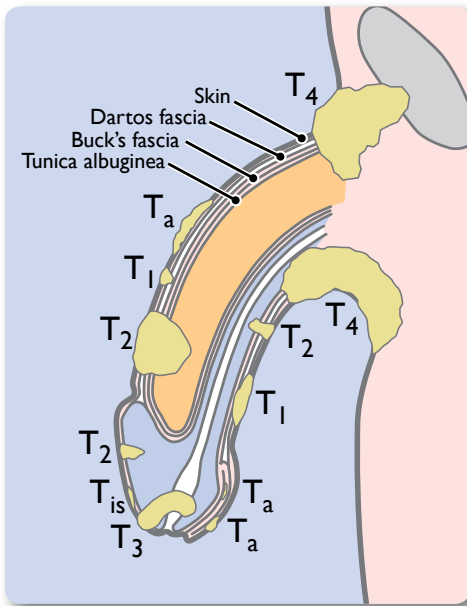
The TNM system

Like many cancers, penile cancer is staged using several methods. One of the most common is called the **TNM** system where:

T - stands for tumour size

This can be given a value of 1 - 4 indicating how big the cancer size is.

- T_{is}** The cancer has not invaded below the superficial (surface) layer of skin. It has not spread to lymph nodes or distant parts of the body.
- T_a** Wart-like growth that is superficial and has not spread to any other areas.
- T_{1a}** A low-grade cancer has grown just below the superficial layer of skin. It has not spread to lymph nodes or distant parts of the body.
- T_{1b}** Higher grade cancer that has affected surrounding tissue and blood vessels but is still superficial.



- T₂** The cancer has grown into blood or lymph vessels and/or into the internal chambers of the penis and/or the urethra.
- T₃** The cancer has grown no further than the urethra.
- T₄** The cancer has grown into nearby tissues.

N - Stands for lymph nodes;

The human body is covered by a special type of drainage system called the lymphatic drainage system (see diagram). This system is responsible for transporting excess fluid from the organs and tissues of the body as a fluid called lymph. Lymph fluid will contain various types of cells and substances that are no longer needed. The lymph fluid will pass through small nodules or nodes that act as filters removing these substances. Cancer cells can also travel in the lymph fluid and as a result may affect other areas of the body (see lymphatic drainage system diagram on page 13).

- N0** Lymph nodes do not contain cancer cells.
- N1** There is a lymph node in the groin which has been affected.
- N2** There are multiple lymph nodes on one or both sides of the groin which have been affected.
- N3** Lymph nodes in the pelvis have been affected or lymph nodes in the groin that have been severely affected.

M - This stands for metastases

The spread of cancer to other organs or areas in the body.

- M0** There is no evidence that cancer has spread to other organs.
- M1** The cancer has spread to other areas of the body.

Stage grouping

Once the T, N, and M categories have been assigned, this information is combined to assign an overall stage from 0 to IV. This is known as stage grouping. These stages are illustrated in the table and diagrams on the next two pages.

Stage 0: Tis or Ta, N0, M0

The cancer is only in the top layers of the skin (Tis or Ta) and has not spread to lymph nodes (N0) or distant sites (M0).

Stage I: T1a, N0, M0

The cancer has grown into tissue just below the top layer of skin but has not grown into blood or lymph vessels, and it is grade 1 or 2 (T1a). It has not spread to lymph nodes (N0) or distant sites (M0).

Stage II: Any of the following

T1b, N0, M0: The cancer has grown into tissue just below the top layer of skin and is either high-grade (grade 3 or 4) or has grown into blood or lymph vessels (T1b). It has not spread to lymph nodes (N0) or distant sites (M0).

OR T2, N0, M0: The cancer has grown into at least one of the internal chambers of the penis (the corpus spongiosum or corpora cavernosum) (T2). The cancer has not spread to lymph nodes (N0) or distant sites (M0).

OR T3, N0, M0: The cancer has grown into the urethra (T3). It has not spread to lymph nodes (N0) or distant sites (M0).

Stage IIIa: T1 to T3, N1, M0

The cancer has grown into tissue below the top layer of skin and may have grown into the corpus spongiosum, the corpus cavernosum, or the urethra (T1 to T3). The cancer has also spread to a single groin lymph node (N1). It has not spread to distant sites (M0).

Stage IIIb: T1 to T3, N2, M0

The cancer has grown into tissue below the top layer of skin and may have grown into the corpus spongiosum, the corpus cavernosum, or the urethra (T1 to T3). It has also spread to 2 or more groin lymph nodes (N2). It has not spread to distant sites (M0).

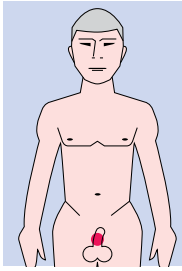
Stage IV: Any of the following

T4, any N, M0: The cancer has grown into the prostate or other nearby structures (T4). It may or may not have spread to groin lymph nodes (any N). It has not spread to distant sites (M0).

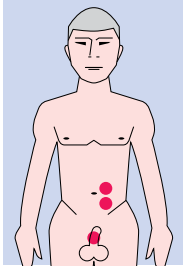
OR Any T, N3, M0: The cancer has spread to lymph nodes in the pelvis **OR** the cancer in the groin lymph nodes has grown out of a lymph node and into the surrounding tissue (N3). The cancer has not spread to distant sites (M0).

OR Any T, any N, M1: The cancer has spread to distant sites (M1).

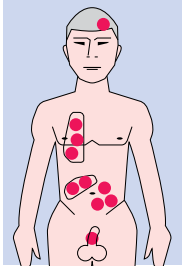
Examples of stages



Stages 0/1/II



Stages IIIa/IIIb



Stage IV

Grading

A grade of cancer can be given to determine how potentially aggressive the cancerous cells are. This works by identifying how abnormal the cancerous cells look compared to normal healthy cells:

G1: Describes cells that look more like normal tissue cells.

G2: The cells are somewhat different from normal cells.

G3: Describes tumour cells that look very much like each other, but don't look very much like normal cells.

G4: The tumour cells barely look like normal cells.



Tips:

- ▶ **Plan ahead.** Try and involve all of the family. Let them know what is happening so that they can help with any arrangements that need to be made while treatment is taking place (childcare, work etc.).
- ▶ During and after treatment, time off work will be needed. **Keep any correspondence / letters and contact details of the health professionals that have been met or procedures that have been performed as proof of treatment.** It may also be a good idea to talk to the human resources department if available and inform them of the current situation and the fact that some time off is likely to be needed. Think about working from home if possible. Although the hospital where the treatment has been undertaken can issue a sickness certificate to cover the stay, they will not provide a long term sickness certificate. **One will have to be obtained from a G.P.**

The following websites have a great deal of information with regard to work related issues and are well worth a visit.

Macmillan cancer support: www.macmillan.org.uk or phone **0808 239 9485**

Citizens Advice Bureau: www.citizensadvice.org.uk or phone **03444 111 444**

Government benefit enquiry line: www.direct.gov.uk or phone **0345 712 3456**

Section 4: Treatments

“ I didn't expect to be examining my own mortality at 46 years old. I'm fit, relatively young and have a healthy lifestyle - cancer doesn't happen to people like me, at least not yet....Wrong! One of the most destructive and pointless questions that I'm quite sure everyone who finds themselves in a similar position asks (and I did many, many times) is why me? Sadly there's only one answer: Because it is; now get over it and go out and control the things that are in your power to control - leave everything else to the experts and lady luck. ”

“ Omnia Causa Fiunt - Everything happens for a reason. If the reason for this happening to me is that I can now raise a little more awareness, break down some taboos and encourage men to act when they spot something unusual, then the discomfort and stressful times that I have been through will have been worth it. ”

Treatment options

Glansectomy +/- split skin graft

This involves removing the surface tissue of the glans while taking biopsies from deeper within the penile tissue to check for cancer in other areas of the penis. A small section of skin will usually be removed from the thigh to act as a skin graft and will be used to replace the area of tissue that has been removed.

Partial penectomy

This is a surgical procedure to remove part of the penis. During this process a section of skin may be taken from another area of the body to replace some of the tissue removed (skin graft). It is very important that men and their partners discuss this surgery with the specialist health team to ensure that they know exactly what to expect with regard to the appearance of the penis afterwards.

Total penectomy

This is an operation to remove the whole of the penis. The urethra will be surgically reshaped to form a special urinary drainage passage called a perineal urethrostomy. This will mean that a man will need to sit down to pass urine. It's very important that men discuss this surgery with their specialist healthcare team to ensure that they know exactly what to expect after the operation.

Inguinal (groin) lymph node dissection

This is an operation which involves removing the lymph nodes from one or both sides of the groin if it is found that they contain cancer. It is performed under a general anaesthetic and will typically take 2 - 3 hours to complete. An incision into the groin is made and the lymph nodes are surgically removed. A similar procedure can be used to remove lymph nodes in the pelvis.

Radiotherapy

Radiation therapy is the use of high-energy x-rays to kill cancer cells and can be directed at cancer from outside of the body (external beam radiotherapy) or from within the body (brachytherapy). Both can be used to treat penile cancer which has not spread beyond the penis as an alternative to surgery. External beam radiotherapy can also sometimes be used to treat cancer which has spread to other areas of the body.

Chemotherapy

Chemotherapy is the use of cancer killing drugs (cytotoxic) injected into the bloodstream (systemic chemotherapy). It is usually used to treat more advanced penile cancer but can be used after some localised treatments to reduce the risk of cancer returning.

Orchid has several different leaflets which discuss individual treatments which can be requested by phoning **0808 802 0010** or emailing **nurse@orchid-cancer.org.uk**.



Men and their partners should:

- ▶ Ask the surgeon or specialist team to give as much information as possible with regard to the possible change in appearance of the penis following surgery and in the long term.
- ▶ Most regional centres will have a specialist nurse who will provide information and support and men should make sure they have these contact details. Involve a partner and family too.
- ▶ If preparing for treatment is proving difficult, ask the specialist team about counselling or contact some of the organisations listed in the next section of this booklet.

Section 5: Life, during and after treatment

“ The support of my wife, family and friends has been vital in giving me the strength to deal with the uncontrollable aspects. ”

“ For guys it is often very difficult to share intimate information and experience. I cannot imagine anything more intimate for a guy than talking about problems with his penis and fearing losing his manhood. ”

Feelings

Most people feel overwhelmed when they are told they have cancer, even if the chance of cure is very high. Many different emotions arise, which can cause confusion and frequent changes of mood. Men may experience all of the feelings that are associated with being diagnosed with penile cancer, such as fear, resentment and anger.

This does not mean however, that they are not coping with their illness.

Reactions differ from one person to another - there is no right or wrong way to feel. These emotions are part of the process that many people go through in trying to come to terms with their illness. Partners, family members and friends often experience similar feelings and frequently need as much support and guidance in coping with their own feelings.

Orchid currently offers a telephone counselling service for men affected by penile cancer. For further information please contact the **Orchid Male Cancer Helpline** on **0808 802 0010** or email nurse@orchid-cancer.org.uk.



Tips:

- ▶ Being given a diagnosis of penile cancer is emotionally and mentally devastating. Following diagnosis men should let their family know of any planned treatment and how it may affect them in the coming weeks or months. Although it may be hard to share this type of information many people including younger people are, these days, more likely to have some knowledge of cancer. They may also be able to find information on the internet or from organisations such as Orchid.
- ▶ Often the information that will be given to men at diagnosis will be overwhelming and a man may not fully appreciate the implications of what is said until later on. It is a good idea therefore to take someone along who can help remember the information being given and offer support such as a partner or family member.

Online support;

Macmillan cancer online support: www.macmillan.org.uk

or phone **0808 239 9485**. Counsellors and nurses are available who can offer advice.

Cancer Chat: www.cancerchat.org.uk Nurse contact **0808 800 40 40** Monday to Friday, 9am to 5pm. An online forum for people affected by cancer to share information and experiences.

Online support groups:

Facebook

Penile Cancer Awareness and Support; a closed support group for which requests can be made to join: <https://www.facebook.com/groups/penilemelanoma/>

Support groups

A monthly support group meets on the first Tuesday of every month and at University College Hospital, London. This group is open to men who have been treated for penile cancer within the London area. Further details can be obtained by emailing nurse@orchid-cancer.org.uk

Unfortunately, due to the very nature of the disease, men do not readily talk about their experience to other men. Orchid is always interested in organising meetings for those who have been affected by penile cancer. Please contact the nurses at Orchid.

Please phone **0808 802 0010** or email nurse@orchid-cancer.org.uk

Postal Address:

Orchid, 60 Gray's Inn Road, London WC1X 8AQ

To read about men's experiences of penile cancer: www.orchid-cancer.org.uk

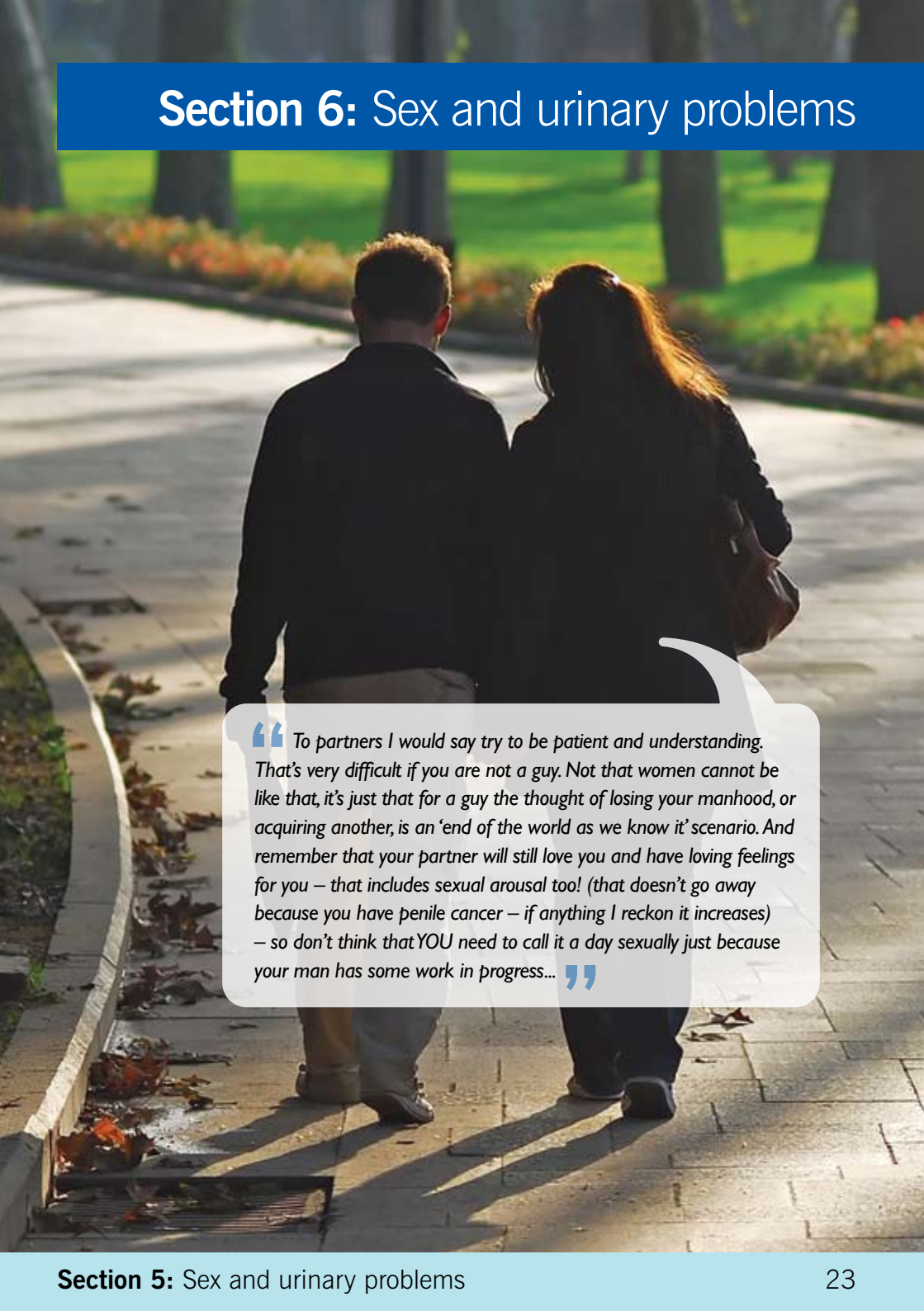


Orchid has a **Male Cancer Helpline** manned by specialist nurses

freephone **0808 802 0010**

or email helpline@orchid-cancer.org.uk

Section 6: Sex and urinary problems



“ To partners I would say try to be patient and understanding. That’s very difficult if you are not a guy. Not that women cannot be like that, it’s just that for a guy the thought of losing your manhood, or acquiring another, is an ‘end of the world as we know it’ scenario. And remember that your partner will still love you and have loving feelings for you – that includes sexual arousal too! (that doesn’t go away because you have penile cancer – if anything I reckon it increases) – so don’t think that YOU need to call it a day sexually just because your man has some work in progress... ”

Naturally one of the most difficult issues to address following surgery is the effect that any treatment will have on the appearance of the penis and its function including sexual intercourse.

Included in this section is some guidance on what to expect and tips which may help men adjust to their sexuality. It is very important that both a man and his partner are aware of these issues, and work through them together.

Surgery

For men who have had a wide local incision the penis will be swollen and tender following surgery. Once the wound has healed there will be some scarring at the site of the operation and the penis may be a slightly different shape. However a man should still be able to have an erection and maintain sexual intercourse as he was prior to surgery.

For men who have had a glansectomy and skin graft, the glans which is the most sensitive part of the penis will appear different. However, the nerves and blood supply which control erections will usually be left intact and men should be able to have sexual intercourse as they did prior to surgery, although it will take some time for swelling from surgery to resolve. It may also take a while to adjust mentally to the appearance of the penis.

Men who have had a partial penectomy (surgery to remove part of the penis) may still be able to have penetrative sex. Past research studies have suggested that over 50% of men who have had partial penectomy could still maintain an erection suitable for intercourse. Again it is likely to take some time for them to adjust fully to the appearance of their penis.

For men who have had a total penectomy (surgery to remove the entire penis) normal sexual intercourse will not be possible. They may feel less of a man and worry that they will not be able to fulfil their partner's sexual needs. In this situation it is useful to talk to their partner and consider exploring other ways of maintaining a satisfactory sex life. Sometimes hugging, kissing or petting can be just as fulfilling as penetrative sex. Men will still have sensitive zones around their body that may allow them to have similar sensations and cause sexual arousal.

The use of adult toys such as massagers and vibrators may bring equal pleasure to both men and their partners. Adult films/pictures or role playing may also achieve similar results and fulfilment. Although it may be felt that there may be some stigma attached to these types of sexual gratification, many people all over the world make use of these methods to enhance their sex life.

Men may find that talking to their partner is difficult or not enough and they may need further counselling. There are a number of specialist counsellors (psychosexual counsellors) who can often help in this situation. A man and his partner will both need to participate in this type of counselling. It is likely that the specialist team may know of a local counsellor who could be referred to and it is therefore worth discussing this possibility with them. Contact details of some of these organisations can be found on the next page.

Advice and counselling organisations:

College of Sexual and Relationship Therapists: www.cosrt.org.uk

or phone **020 8543 2707** or email info@cosrt.org.uk

Postal address: The Administrator, COSRT, PO Box 13686, London SW20 9ZH.

Sexual Advice Association: www.sda.uk.net

or phone **020 7486 7262** or email info@sexualadviceassociation.co.uk Monday, Wednesday and Friday 9am to 5pm.

Postal address: The Sexual Advice Association, Suite 301, Emblem House, London Bridge Hospital, 27 Tooley Street, London SE1 2PR.

Counselling Directory: www.counselling-directory.org.uk

Postal address: Counselling Directory, Coliseum, Riverside Way, Camberley, Surrey GU15 3YL

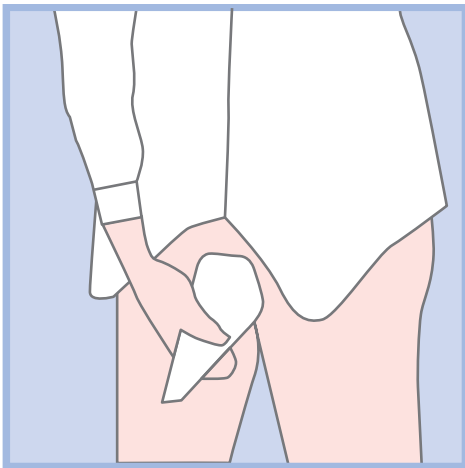
Find a Therapist: http://counsellor.directory/cgi-bin/cd_index.pl

Urinary problems

Surgery

Surgery to the penis is likely to cause swelling and possibly inflammation of the penis. This may exert pressure on the urethra and cause the urinary stream to spray. It will usually settle in time and symptoms should improve as the body heals. However, if this proves bothersome, there are several types of disposable urinary funnel which can be purchased (see diagram below). Examples of these can be found online (the internet), from popular shopping websites.. Similar non-disposable devices are available on prescription and men should ask their GP or Practice nurse for details of these.

It is also possible to purchase a special key (**RADAR Key**) which allows anyone with a medical condition which has affected their urinary pattern to make use of otherwise locked or inaccessible toilets in the UK. It can be ordered from Disability Rights for a small fee. (www.disabilityrightsuk.org/radar-nks-key or **020 7250 8191**)



A 'Just Can't Wait' toilet card can also be obtained from the Bladder and Bowel Foundation again for a small fee which is universally recognised and may allow men access to toilets in the same way. (<https://www.bladderandbowelfoundation.org/just-cant-wait-card-introduction/> or by phoning **01926 357220**)

Orchid also has similar cards available which can be ordered by phoning the **Orchid National Male Cancer Helpline** on **0808 802 0010**.

A similar problem can occur following radiotherapy treatment due to minor tissue damage. Sometimes additional surgery can be undertaken to improve these symptoms.

Men may be anxious following surgery that their normal daily work routine or lifestyle will be adversely affected by changes in their urinary habits as a result of treatment. It is important to understand that there are a number of other conditions which can affect the passage of urine such as an enlarged prostate gland or bladder weakness which are not related to treatment.

If men experience problems such as urinary frequency or trouble passing urine they should discuss these symptoms with their specialist healthcare team.

Urinary Catheter

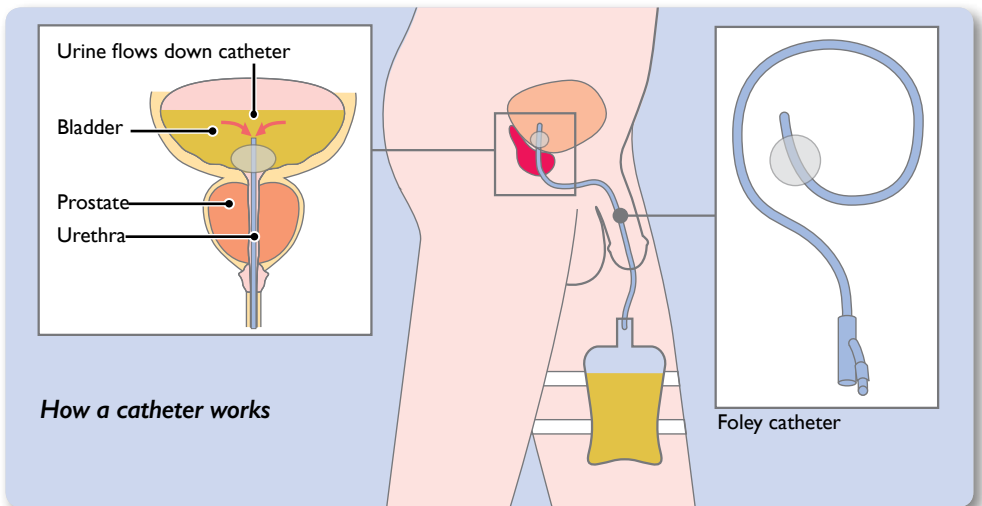
Some types of surgery for penile cancer will require a catheter (urinary drainage tube) to be inserted. This will need to remain in place for several days. The information below is designed to help with its management.

A catheter is a plastic tube that drains urine from the bladder. It will be connected to a leg drainage bag which can be left in place for up to a week. A bigger bag can be attached to the leg bag for drainage at night.

The catheter is held inside the bladder by a small balloon that is inflated with sterile water following insertion. It will therefore not usually come out unless properly removed by deflating the balloon. The balloon tends to rest over a sensitive area of nerves in the bladder which may be irritated by its presence and these nerves are connected to nerves in the penile area. This irritation may make a man feel as if he needs to pass urine

urgently and sometimes force a small amount of urine from around the catheter: Using a strap or tape to fix the join of the catheter to the thigh or top of the leg to prevent it from pulling or dragging may be of help.

- ▶ Men should clean around the penis as instructed by the specialist team and should avoid any toiletries which may cause skin irritation and delay the healing process.
- ▶ The catheter should not be pulled or tugged.
- ▶ It is very important to drink 2 - 3 litres of fluid daily to flush the urine through and water based drinks tend to prevent bacteria forming which will help prevent urinary infection.
- ▶ When emptying or connecting catheter bags, hands should always be washed thoroughly with soap and water before and after the procedure.





Follow-up

Once men have finished their treatment for penile cancer they will need to be reviewed on a regular basis in the outpatient clinic to monitor their progress and check that the type of treatment that they have had has been effective. This type of follow-up will vary and the specialist team will decide on the follow-up plan which might include further scans or other investigations.

Important contact numbers:

Urology unit/ward contact no.:

Oncologist contact no.:

Specialist nurse contact no.:

Consultant urologist contact no.:

Community nurse contact no.:

How is Orchid helping?

Awareness

Raising awareness of penile cancer is very difficult as some men do not know that cancer can affect the penis and very few men will talk openly about the condition. Orchid has created informative Z-cards highlighting the signs and symptoms of penile cancer, testicular and prostate cancer.

Information

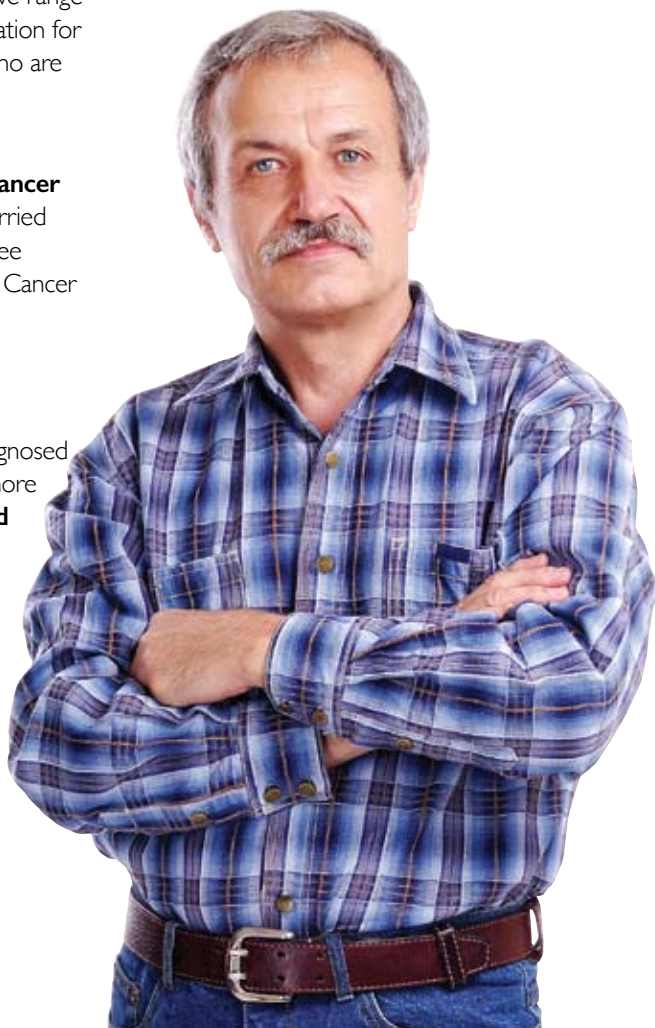
Orchid has produced a comprehensive range of penile cancer booklets and information for men who have been diagnosed or who are being treated for penile cancer.

Support

Orchid provides a **National Male Cancer Telephone Helpline** for anyone worried or affected by male cancer. This is a free service and is staffed by Orchid Male Cancer Information Nurse Specialists.

Telephone Counselling Service

Orchid offer a telephone counselling service for anyone who has been diagnosed with testicular or penile cancer. For more information please phone the **Orchid National Male Cancer Helpline** freephone **0808 802 0010**.



Support groups

University College Hospital

235 Euston Rd, Bloomsbury, London NW1 2BU

First Tuesday of every month.

For further details please email nurse@orchid-cancer.org.uk

Facebook

Penile Cancer Awareness and Support; a closed support group for which requests can be made to join.

<https://www.facebook.com/groups/penilemelanoma/>

Useful contacts throughout the UK and Ireland

Macmillan

One of the most comprehensive cancer websites available includes excellent resources on support and financial advice.

Helpline (UK only): **0808 800 1234**

(freephone) Mon to Fri, 9am to 8pm

Telephone: **020 7696 9003**

Write to:

Macmillan Cancer Support,
89 Albert Embankment,
London SE1 7UQ

www.macmillan.org.uk

Cancer Research UK information and support

Admin telephone number: **020 7242 0200**

Cancer Research UK Nurse Helpline:

freephone **0808 800 4040**

www.cancerresearchuk.org

Health talk Online website

The cancer section of this website contains video and audio clips of people with the main types of cancer, so that men can share in their stories. A great section, with online interviews of penile cancer survivors.

There is an adult cancer section at www.healthtalkonline.org

Maggie's Cancer Caring Centres

Help centres, run by professionals, who can discuss any aspect of cancer. Also run support groups and weekly sessions in relaxation, stress management, nutrition and health.

Telephone: **0141 341 5675**

Email: enquiries@maggiescentres.org

Write to:

The Stables,

Western General Hospital, Crewe Road,
Edinburgh EH4 2XU

www.maggiescentres.org

Rarer Cancers Forum

The Rarer Cancers Forum website has several message boards so people with less common or rarer cancers can get in touch with each other. Friends and families of people with rarer cancers can also use the message boards to share their experiences, give support or get advice from people in similar situations. The website also offers general advice and information.

www.rare-cancer.org/forum

Northern Ireland

Action Cancer

A charity which offers one to one counselling.

Telephone: **028 9080 3344**

Fax: **028 9080 3356**

Email: info@actioncancer.org

Write to:

1 Marlborough Park,

Belfast BT9 6XS

www.actioncancer.org

The Ulster Cancer Foundation

Provides a cancer information helpline, information and resource centre, public and professional education. Rehabilitation programmes and support groups for patients and relatives.

Telephone: **0800 783 3339** (helpline)

Telephone: **028 9066 3281** (admin)

Email: info@ulstercancer.org

Write to:

40-44 Eglantine Avenue,

Belfast BT9 6DX

www.ulstercancer.org

Scotland

Tak Tent Cancer Support Scotland

Offers information, support, education and care for cancer patients, their relatives and friends, and health professionals. Details of support groups throughout Scotland.

Telephone: **0141 211 0122**

(resource/information centre)

Email: tak.tent@care4free.net

Write to:

Flat 5, 30 Shelley Court, Gartnavel Complex,
Glasgow G12 0YN

www.taktent.org.uk

Wales

Tenovus, the cancer charity

Provides an information service on all aspects of cancer, and practical and emotional support for cancer patients and their families. Freephone Cancer Helpline staffed by nurses, social workers and counsellors.

Telephone: **02920 482 000**

Freephone helpline: **0808 808 10 10**

Write to:

43 The Parade,

Cardiff CF24 3AB

www.tenovus.com

Ireland

Irish Cancer Support

Irish cancer website, with numerous links to support and information.

www.cancer.ie/support

Resources...

For further information and support on male cancer, please visit the Orchid website at www.orchid-cancer.org.uk

Orchid has produced a series of leaflets and factsheets on specific issues relating to male cancer which can be downloaded from the website.

Orchid has a
Male Cancer Helpline
manned by specialist nurses on
freephone **0808 802 0010**
or email
helpline@orchid-cancer.org.uk

Written and edited by:

**Orchid Cancer Appeal and
Orchid Editorial Board**
March 2017

To be reviewed November 2023

References to sources of information used in this booklet are available from Orchid. If you would like to comment on the information included in the booklet or make suggestions about future editions Orchid would like to hear your feedback.

Orchid is the UK's leading charity dedicated to supporting men and their families who are affected by male-specific cancers: testicular, prostate and penile.

Established in 1996 by a young testicular cancer patient and the oncologist who saved his life, Orchid works to improve the lives of people affected by male cancers through a world class research programme, educational campaigns and raising awareness and an extensive support service.

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