

Penile Cancer

Everything you need to know

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 useful information on how to cope with the issues involved.

www.orchid-cancer.org.uk



Special thanks to all the men who shared their experiences with Orchid as well as the specialist health teams at St Georges Tooting, UCLH, The Christie and Cancer Research UK.

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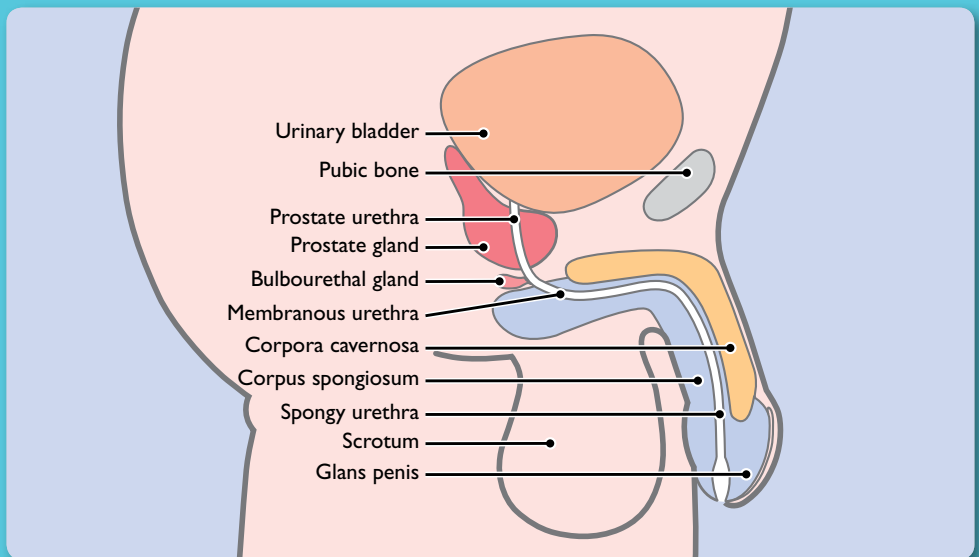


Section 1: Cancer of the penis

Cancer of the penis is very rare in the western world; there are about 500 cases in the UK each year. It is most often diagnosed in men over the age of 60 years however men in their 30s and 40s can also be affected. Research has suggested that 25% of

cases in the UK occur in males less than 50 years of age. Penile cancer is usually a slow growing cancer and if caught early before further spread the chances of survival are high. **Unfortunately most men tend to ignore potential penile cancer symptoms.**

Structure of the penis



The penis is made up of three chambers of spongy tissue that contain muscle, blood vessels and nerves. The **corpora cavernosa** makes up two of the chambers that are located on both sides of the upper part of the penis and expands to form the head of the penis, or **glans**. The **corpus spongiosum** surrounds the urethra or water pipe. The opening of this on the head of the penis is called the **meatus**.

Symptoms and signs

Symptoms of penile cancer may include the following. However there are also non cancerous conditions that can initially cause similar appearances. If you are concerned about a symptom or sign on this list, please talk with your doctor:

- ▶ A growth or ulcer on the penis, especially on the glans or foreskin, although these can also occur on the shaft.
- ▶ Changes in the colour of the penis.
- ▶ Skin thickening on 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 or growing bluish-brown flat 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).
- ▶ Irregular swelling at the end of the penis.

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

Causes and prevention

- ▶ Infection with a type of virus that causes penile warts (human papilloma virus or HPV) increases the risk of cancer of the penis. This is quite a common infection transmitted by sexual contact. Studies have indicated that nearly 50% of men who have penile cancer have the HPV virus. However there are over 100 types of HPV virus and only two have been linked with penile cancer. These are called HPV 16 and 18. Practising safe sex with a condom is thought to reduce the risk slightly.
- ▶ Uncircumcised men. Penile cancer is virtually unknown in men who have been circumcised as a child and circumcision may reduce the risk of HPV infection as well as the predisposition to chronic skin diseases associated with the penis and possible penile cancer. Adult men who are circumcised however, have no reduced risk of developing penile cancer.
- ▶ It is important for uncircumcised men to thoroughly clean underneath their foreskin.
- ▶ Some studies indicate that smoking may increase the chance of developing penile cancer probably because harmful chemicals in cigarettes such as benzene may damage the structure of penile cells. Urine will also contain chemical contaminants from the effect of smoking that may irritate the penile skin when they gather under the foreskin.
- ▶ Having a weakened immune system caused by certain type of medication or diseases such as HIV and AIDS.
- ▶ Phimosis - this is the inability to pull back the foreskin fully. It can occur as a result of skin irritation or inflammation and will reduce the ability to clean the penis thoroughly.

Section 2: Initial diagnosis



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

Circumcision

This is the removal of your foreskin and may be appropriate if only your foreskin appears to have been affected by a precancerous condition or cancer itself. Sometimes it will be the only treatment that you may need.

Wide local excision

Possible cancerous tissue will be removed from the affected area of your penis and a few millimetres of healthy tissue will be removed

from around the site to reduce the possibility of any potential cancerous cells from being left behind. This will be performed as a day case procedure.

Penile biopsy

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

These procedures can be performed using a general or local anaesthetic as a day case procedure meaning that you will be able to go home afterwards. The tissue samples removed will be examined for the presence of penile cancer:

After minor surgery

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

- ▶ You will have a dressing on your penis. This can usually be removed about 24 hours after the procedure. The stitches (sutures) you will have in your wound will be dissolvable but can take up to 2 weeks to fully dissolve.
- ▶ You can shower, normally after 24 hours, but it is important not to rub soap on the wound area. Dry the wound area by gently patting it with a clean towel/gauze pad. You can have a bath after 1 week.
- ▶ Your penis may be bruised and swollen after the operation. Take any painkillers you have been prescribed on a regular basis, (not just when you get pain) for the first 48 hours or until you feel comfortable. Always read the instructions to ensure you administer them correctly. Often simple Paracetamol combined with an anti-inflammatory medication (such as Ibuprofen) are particularly effective at reducing discomfort.
- ▶ Although these are minor procedures, it is important to take things easy for the first week. You should be able to return to work within a few days. However if you are being reviewed in an outpatient clinic or referred to an oncologist for possible further treatment or assessment; it may be a good idea to await these arrangements to be made before returning to work as you may need to take further time off.

- ▶ You may begin normal sexual activity again six weeks after your operation, as long as you feel comfortable.
- ▶ You should be given a follow up appointment within 2 weeks of your operation for the tissue, blood and scan results. At this time any further treatment will usually be discussed.

Pre-cancerous lesions

The following conditions which may affect the penis are usually regarded as pre cancerous and if left untreated may progress to penile cancer:

Bowenoid papulosis

This is a highly infectious disease which occurs in sexually active men, most commonly in men in their 30s. Again this condition is linked with HPV 16 virus.

Bowens disease/ Erythroplasia of Queryat also termed Carcinoma insitu.

This is a name that is given to cancer cells that are situated on the surface of the penis but have not progressed below the skin. However, if left untreated they are likely to progress to more invasive penile cancer. It usually has the appearance of a velvety red patch.

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

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

Topical Agents (Chemotherapy or Immunotherapy)

5-fluorouracil

This is a type of chemotherapy cream which is usually applied to the affected area of your penis for around 4 - 6 weeks. Chemotherapy works by destroying cancer cells. You will need to make sure that you wash your hands thoroughly if you do not use gloves to apply the cream. Chemotherapy will also affect some healthy cells on the penis and therefore the area treated may become inflamed, encrusted and sore. If this is the case you may be advised to use a steroid cream to help reduce some of 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

This is a type of immunotherapy. Unlike chemotherapy, immunotherapy stimulates the body's immune system to fight and possibly 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.

Both of 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 take further biopsies of the penis. A small section of skin from your thigh may be removed to create a skin graft and replace the removed tissue. Orchid has produced an information leaflet on this procedure. Please ask your healthcare team for the leaflet.

Cryotherapy

This technique uses liquid nitrogen at a temperature of between -20° C and -50° C to freeze the cells causing their death. The skin will later blister and peel. This procedure can 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. However it may take 2 - 3 months after treatment for any soreness 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 shone at them which can cause the cancer cells to die.

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

Once the tissue samples from your surgery have been analyzed by the histo-pathologist, (tissue specialist), it will be possible to determine what sort of penile cancer is present.

Squamous cell carcinoma

95% of penile cancer is squamous cell carcinoma. Squamous cells are skin cells that can become cancerous. They 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 other parts of the body and is usually treated aggressively. A rarer form of this cancer is called Verucous carcinoma, which tends to be less aggressive.

Basal cell penile cancer

Basal cells are skin cells from the outer lining of the skin which may become cancerous. 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 of melanoma cancer that affects the skin.

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.

Staging penile cancer

Staging is a way of describing how potentially aggressive a cancer is and how far it has spread locally or to other parts of the body. This can be determined by performing further tests such as:

Blood tests

Blood tests to measure the level of healthy blood cells in your body as well as blood tests to measure your kidney and liver function.

Fine needle aspiration using ultrasound scan

An ultrasound scan will be used to identify any enlarged lymph nodes around your groin area that may have been affected by possible cancer (see diagram on the next page). A biopsy using a surgical needle may 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.

Computerised Tomography (CT)

A CT scan checks for any signs that the cancer has spread to other areas of your body. The CT scan 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. You may be given a drink or injection of a dye that allows particular areas to be seen more clearly. Initially, this may make you feel hot all over. If you are allergic to iodine or have asthma you could have a more serious reaction to the injection, so it is important to let your doctor know beforehand. You will probably 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. Any scans you may need will be requested on a very urgent basis and will usually be performed within a few weeks of request.

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 scar tissue, or whether cancer cells are still present. They are not always necessary, but you can discuss with your doctor whether one would be useful in your case. A PET scan uses low-dose radioactive sugar to measure the activity of cells in different parts of the body.

A very small amount of a mildly radioactive substance is injected into a vein, usually in your arm. Areas of cancer which are usually more active than surrounding tissue then show up on the scan. It is not usually used on a routine basis but may be performed after initial treatment.

Magnetic Resonance Imaging (MRI)

This test may be recommended to provide further information about your disease and may be performed prior to, and during treatment. It builds up cross-sectional pictures of your body. Some people are given an injection of dye into a vein in the arm to improve the image. During the scan you will be asked to lie very still on a couch inside a long chamber for up to an hour. This can be unpleasant if you don't like enclosed spaces; if so, it may help to mention this to your specialist team. MRI scanning is also very noisy, but you will be given earplugs.

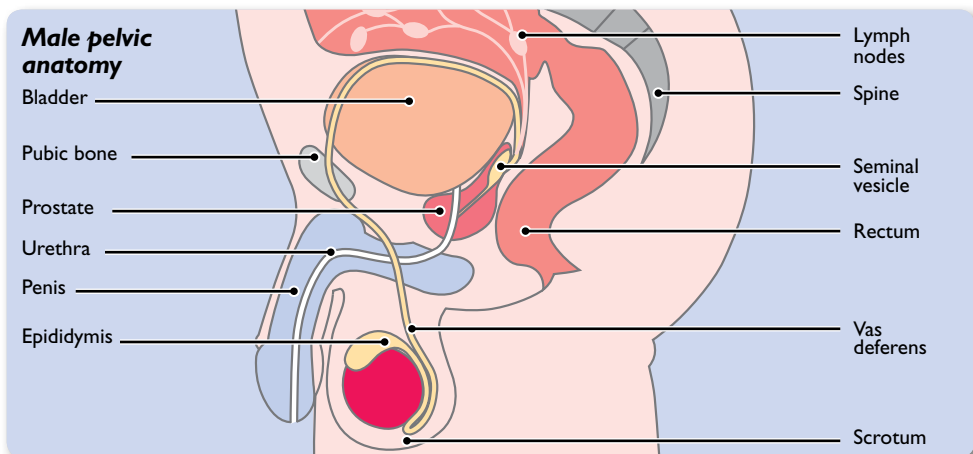
The chamber is a very powerful magnet, so before entering the room you should remove any metal belongings.

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

Sentinel lymph node biopsy

This biopsy is performed to find out if cancer cells have spread to areas beyond the penis. It is not a procedure that is available in every part of the country and you may need to be referred to a specialist centre that provides it. To perform this, your surgeon will remove the sentinel lymph node (the lymph node nearest the cancer) which is situated under the skin in your groin area. If cancer is detected in this lymph node then it is possible that it has spread to other lymph nodes or parts of the body. Providing that you feel well enough you will be allowed home following the procedure.

- ▶ You will need to have a family member or friend who can make sure you are alright for the next 24 hours.
- ▶ Dressings on your biopsy site can be removed after 48 hours when you should be able to bath or shower normally. Use a clean towel or gauze dressing to pat dry the wound area.
- ▶ You may have small metal surgical clips or dissolvable stitches in the wound site. Clips will usually be removed after 10 - 14 days.
- ▶ You will be given the results of your biopsy a few weeks later where any further treatment will be discussed with you.



Planning your treatment

Once you have had all the necessary investigations and the results of any further tests are known it will be possible to ascertain if your cancer is localised or if there is any evidence of possible spread to areas away from your penis. Any further treatment will be based on these results and decided by a specialist team of urologists, oncologists and other health professionals.

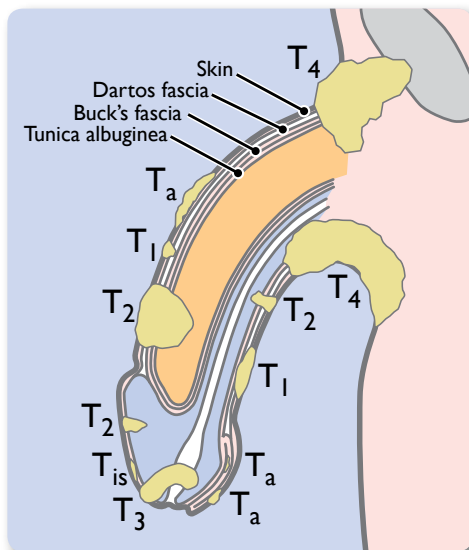
The TNM system

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 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;

Lymph nodes are part of the body's natural drainage system and are essential for a healthy immune system. They act as filters, which eliminate waste substances, from the body's natural processes. Waste products travel along the lymphatic drainage system where they collect at lymph nodes, which act as filters. If one lymph node does not manage to filter out these substances they will travel to the next lymph node. Cancer is able to travel through the lymphatic system in the same way and become deposited in other areas of the body, (see Male pelvic anatomy 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 lymph nodes on either side of the groin which have been affected.
- N3** Lymph nodes in the abdomen have been affected.

M - This stands for metastases

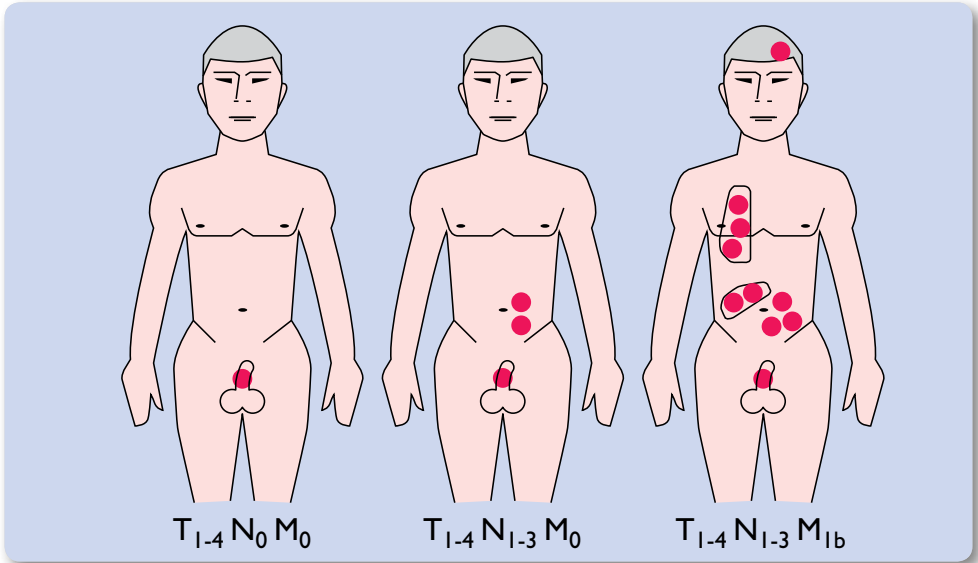
The spread of cancer to other organs or areas in the body.

M0 There is no evidence that the cancer has spread to other organs.

M1a The cancer has spread to the lungs or distant lymph nodes furthest away from the penis.

M1b Organs such as the liver or brain have been affected.

Using this system, doctors can assign a particular stage to the penile cancer by combining the T, N, and M classifications as illustrated in the diagram below.



Record your staging:

Your TNM stage T N M

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 your family. Let them know what is happening so that they can help with any arrangements that need to be made while you are having treatment (childcare, work etc.).
- ▶ While you are being treated and afterwards, you will need to take some time off work. **Keep any correspondence / letters and contact details of the health professionals you meet or procedures that you undergo as proof of your treatment in case your employer wants evidence. It may also be a good idea to talk to your human resources department** and inform them of your current situation and the fact that you are likely to need some time off. Think about working from home if possible. Although the hospital where you have been treated can issue you with a sick certificate to cover your stay they will not provide you with a long term sick certificate. **You will have to get one from your G.P.**

The following websites have a great deal of information with regard to work related issues and are well worth a visit if you think you may get problems. **If you are self employed and have to stop working due to your illness you should be entitled to Employment and Support Allowance (visit; www.gov.uk/incapacity-benefit) providing you have been paying National Insurance contributions previously.**

You may also be entitled to other benefits or rebates if you are going to be off of work for some time.

Macmillan cancer support:

www.macmillan.org.uk

or phone **0800 808 1234**

Citizens Advice Bureau:

www.citizensadvice.org.uk

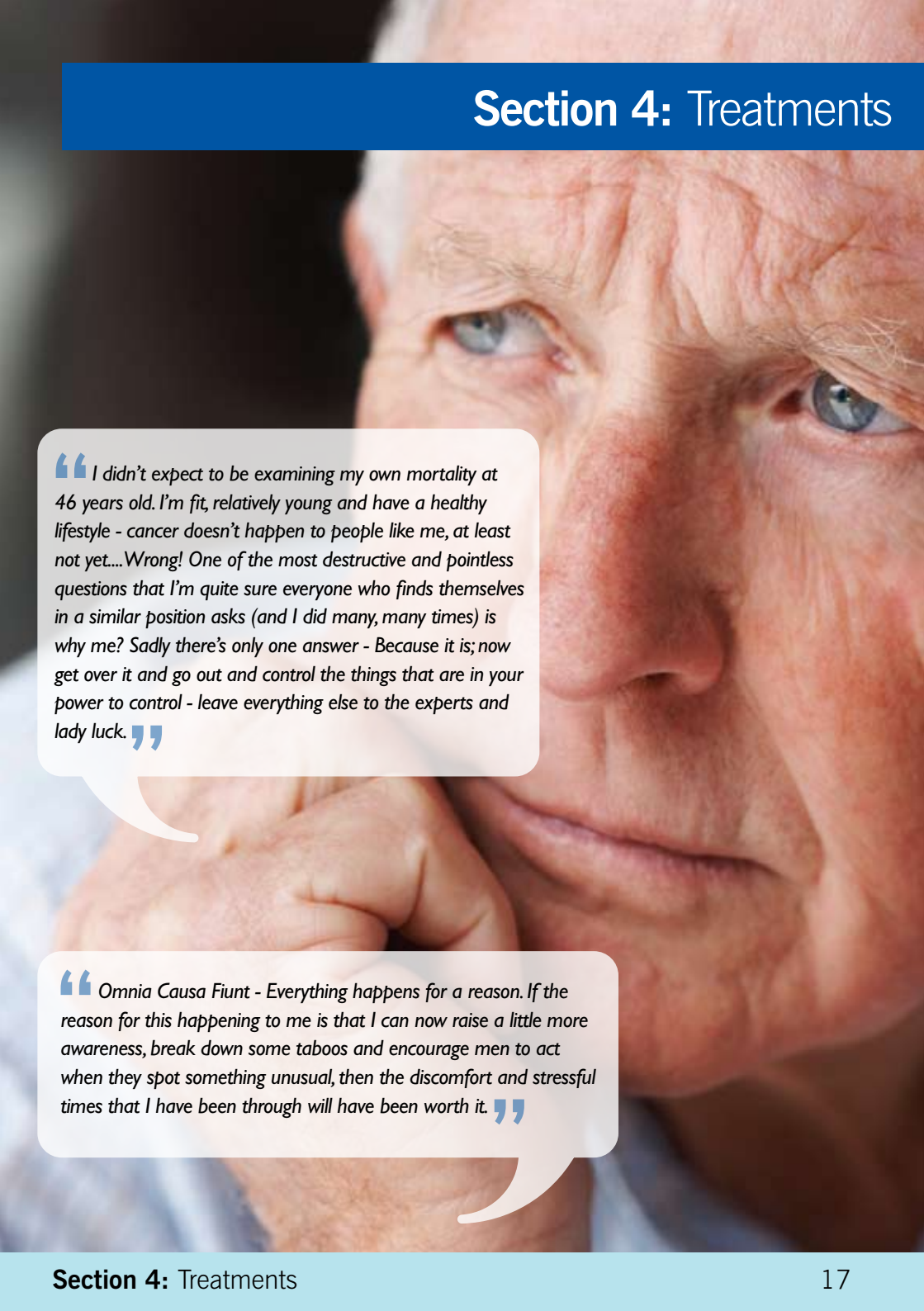
or phone **0207 833 2181**

Government benefit enquiry line:

www.direct.gov.uk

or phone **0800 882 200**

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. ”

There are a number of treatment options for penile cancer which will ultimately depend on the nature of your particular cancer and stage. In the UK, surgery remains the most common option for penile cancer. The aim of the surgery is not only to treat the cancer but also to ensure that **surgery is kept to a minimum and your penis preserved as much as possible**. Surgery today is very advanced and there are many new techniques available.

To make sure that you receive the best and most advanced treatment techniques you will be referred to a specialist centre called a **Supra-Network**. There are several penile supra-networks around the UK. As penile cancer is rare these centres will contain very

experienced surgeons and oncologists who will specialise in treating penile cancer and who can offer you the best treatment for your condition. The supra-network will also have specialist nurses who will be able to guide you through your treatment and offer support.

Orchid has produced information on the different types of treatment for penile cancer and your specialist centre should be able to provide you with one that describes your particular treatment. Ask your specialist nurse for the correct information and store it with this booklet for your reference.



Tips:

- ▶ It is a good idea to ask your surgeon or health professional to give you as much information as possible with regard to the possible change in appearance of your penis following surgery. This will help you prepare for any change in your body image.
- ▶ Ask your specialist nurse to discuss the treatment you are having and what to expect immediately after, and in the long term following treatment. If possible try and involve your partner and family as they will be affected by the changes too.
- ▶ If you are having difficulty in preparing for your treatment ask your specialist team about counselling or contact some of the organisations listed in the next section of this booklet. In some cases it may be possible for them to put you in contact with someone who has had a similar treatment.

Your treatment option:

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. ”

Your 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. You 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 you are not coping with your 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 too.



Tips:

- ▶ Being given a diagnosis of penile cancer is emotionally and mentally devastating. Following your diagnosis you should let your family know of any planned treatment and how it may affect you 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 different types of cancer and be able to help you decide which treatment you may opt for. They may also be able to find information on your behalf from the internet or organisations such as Orchid.
- ▶ Often the information that you will be given at diagnosis will be overwhelming and you may not fully appreciate the implications of what is said until later on. It is a good idea therefore to take someone with you to your hospital who can help remember the information you have been given and support you.
- ▶ If you do not feel that you can talk to your family about your diagnosis you may like to contact the following organisations who may be able to offer support:

Macmillan cancer support: www.macmillan.org.uk

or phone **0808 808 0000**. Counsellors and nurses are available who can advise you.

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, provided by Cancer Research. Nurses will be online every Thursday between 2.00pm and 3.00pm.

Cancer Buddies Network: www.cancerbuddiesnetwork.org

A registered charity enabling patients, carers, or family and friends affected by cancer to make contact.

Cancer information Service (Wales): www.cancerinformation.org.uk

or phone **01792 655 025 / 01639 642 333 / 01267 679 149**.

Volunteer counsellors are available who can discuss your diagnosis with you.

Cancer Aid and Listening Line (CALL) (Greater Manchester):

www.canceraid.co.uk Helpline: **0845 123 2329** Website Emotional support and home-based practical help for people living with cancer; their carers and families.

Tenovus Cancer Information Centre (Wales): www.tenovus.org.uk

Helpline: **0808 808 1010**. Funds support and counselling services for cancer patients and their families through a team of nurses, counsellors and social workers.

Support Groups

Unfortunately due to the very nature of the disease, men do not readily talk about their experience to other men. Orchid is particularly interested in providing a “buddy” service for men to talk to other men who have experienced penile cancer. If you are interested in providing such support to other men on a confidential basis either by email or phone calls please contact the nurses at Orchid.

Please phone **0203 465 5766** or email nurse@orchid-org.uk

Postal Address:

Orchid, St Bartholomew's Hospital, London EC1A 7BE

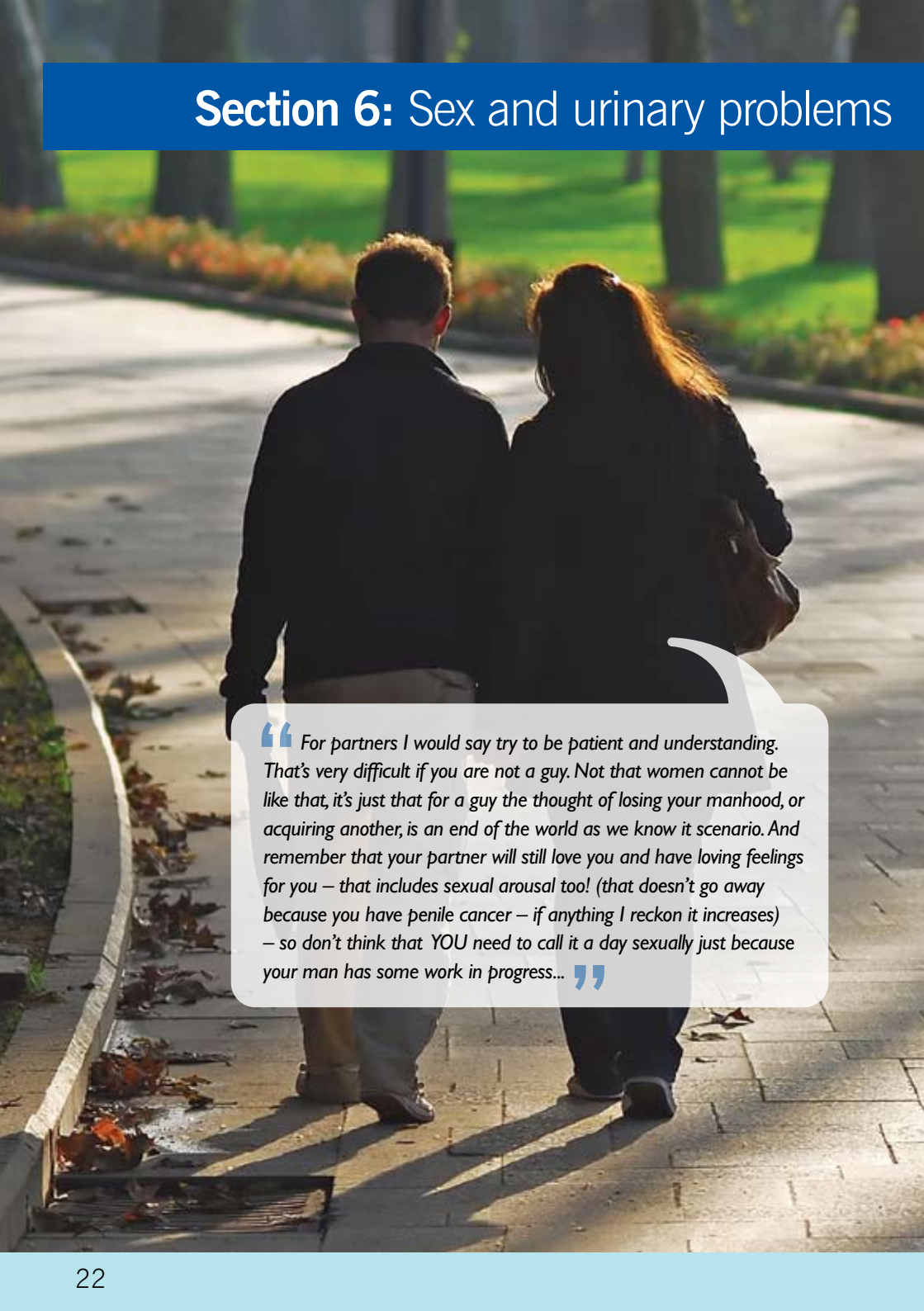
To read about men's experiences of penile cancer:

www.orchid-cancer.org.uk

For information, support and video clips of men discussing their treatment for penile cancer please go to:

www.healthtalkonline.org

Section 6: Sex and urinary problems

A photograph of a man and a woman walking away from the camera on a paved path. The man is on the left, wearing a dark jacket and light-colored trousers. The woman is on the right, wearing a dark jacket and dark trousers, carrying a brown bag. They are walking on a path with fallen leaves, and a green lawn and trees are in the background. The lighting suggests it's late afternoon or early morning.

“ For 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 your penis and its function including normal sexual intercourse. For some older men this may not be a cause for concern but for sexually active men it raises a number of possible problems.

Included in this section is some guidance on what to expect and tips on how to help you adjust to the change in your sexuality. It is very important that both you and your partner are aware of these issues, and work through them together.

Surgery

If you have had a wide local incision to remove an area of cancer then the area affected will be swollen and tender following surgery. Once the wound has healed there will be some scarring at the site of the operation and your penis may be a slightly different shape. However you should still be able to have an erection and maintain sexual intercourse as you were prior to surgery.

If you have had a glansectomy and skin graft then the glans which is the most sensitive part of your penis will not be present. However the nerves and blood supply which control erections will usually be left intact and you should be able to have sexual intercourse as you did prior to surgery although it will take some time for the swelling from your surgery to resolve. It may also take a while for you adjust mentally to the appearance of your penis.

If you have had a partial penectomy (surgery to remove part of your penis) you should 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. Again it is likely to take some time for you to adjust fully to the appearance of your penis.

If you have had a total penectomy (surgery to remove the entire penis) then normal sexual intercourse will not be possible. You may feel less of a man and worry that you will not be able to fulfil your partner's sexual needs. In this situation it is vital that you talk to your partner and explore other ways of maintaining a satisfactory sex life. Some partners may have already lost interest in sex due to age or life changes and will not be concerned about maintaining an active sex life. Sometimes hugging, kissing or petting can be just as fulfilling as penetrative sex. You will still have sensitive zones around your body that may allow you to have similar sensations and cause sexual arousal.

The use of adult toys such as massagers and vibrators may bring equal pleasure to both you and your partner. Adult films/pictures or role playing may also achieve similar results and fulfilment. Although you may feel 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.

You may find that talking to your partner is difficult or not enough and you may need further counselling. There are a number of specialist counsellors (psychosexual counsellors) who can often help in this situation. You and your partner will both need to participate in this type of counselling. It is likely that your specialist team will know of a local counsellor that you 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:

Tablets and injections

Some men may associate any change in their ability to get an erection with their treatment for the penile cancer however it is important to understand that there are a number of other conditions and lifestyle factors that can effect this which are not related, such as high blood pressure, diabetes and cardio vascular disease.

Medication such as Viagra and similar tablets may help your erections. However **physical sexual stimulation** needs to be used to make this successful. Other treatments include injections that can be used to give you an erection. If you suffer from heart conditions or are on nitrate or anticoagulant medication these treatments may need to be used with caution. **Ask your consultant or specialist nurse if these may be options for you.**

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

or phone **0844 8030 240**

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

Find a Therapist: www.cpdirectory.com

Urinary problems

Surgery

Surgery to your penis will cause swelling and possibly inflammation. This swelling may put pressure on your urethra or “water pipe” which may cause you to experience problems passing urine. Swelling may cause your urinary stream to weaken or sometimes your urinary stream to “spray”. This swelling will settle in time and if you are experiencing difficulties in passing urine then this may improve as your body heals. However, if you find that you spray when urinating and it is bothersome to you, there is a funnel that you can get on a prescription from your GP. You place it over the penis when urinating and it directs the spray. It is washable and you can take it anywhere with you.

Your GP will need to know that this is available from :

Beambridge Medical Ltd

It's called a Male Funnel cost £12.37

Prescribing Code 6-35

Chemist's PIP Code 262-5960

www.beambridgemedical.com

Similar products can be found on **amazon.co.uk**

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

Men may be anxious following surgery that their normal daily routine at work or general lifestyle will be adversely affected by changes in their urinary habits as a result of surgery or treatment. Some men may also find it difficult to get used to physical changes in the appearance of their penis making it mentally difficult or awkward to get back into their normal urinary pattern. Some men may associate any change in their voiding pattern with their treatment however it is important to understand that there are a number of other conditions and lifestyle factors that can alter this pattern which are not related to treatment. For instance many men may have already noticed changes to their urinary pattern prior to any treatment that they have had. This can occur for a number of reasons such as prostate enlargement which occurs naturally in many men over the age of 50. Any conditions that make a man need to pass urine more frequently may therefore exacerbate mental anxiety caused by their treatment for penile cancer.

If you were experiencing problems such as urinary frequency or trouble passing urine prior to your treatment for penile cancer then it may be worth discussing these symptoms with your specialist healthcare team.

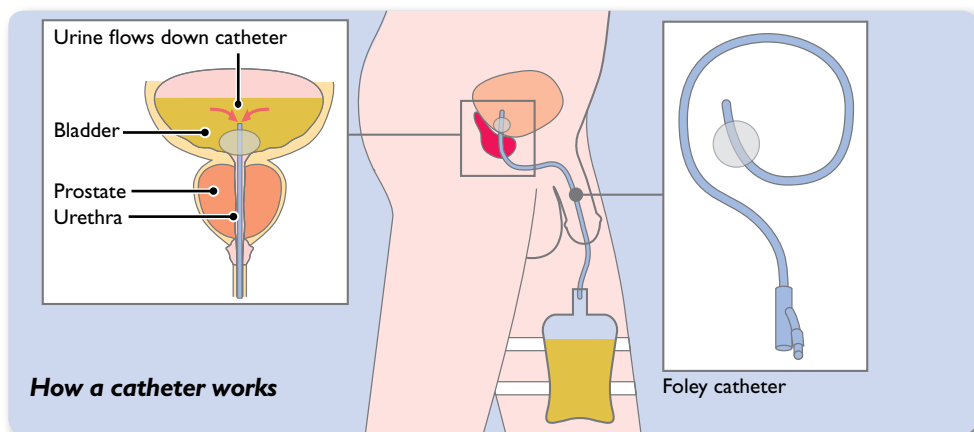
Catheters

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 you with its management.

A catheter is a plastic tube that drains urine from your 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 your bladder by a balloon that is inflated 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 your bladder which will be irritated by its presence and these nerves are connected to ones in your penis. This irritation may make you feel as if you are bursting to pass urine and sometimes the nerves in the bladder will go into a spasm which may force a small amount of urine from around the catheter. This is normal and is due to your bladder trying to reject a foreign body. Using a strap or tape to fix the join of the catheter to your thigh or top of the leg may help.

- ▶ Clean the area around the drainage tube with soap and water twice a day.
- ▶ Do not pull or tug at the catheter.
- ▶ Unless you have been instructed otherwise you can have a shower or bath with the catheter in place.
- ▶ Do not use powders or lotions around the catheter or penis entry site.
- ▶ If you find the catheter is leaking do not put tissues around the penis, only use clean preferably sterile gauze.
- ▶ 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 can lead to infection.
- ▶ When you are emptying or connecting catheter bags always wash your hands thoroughly with soap and water before and after the procedure.





Follow up

Once you have finished your treatment for penile cancer you will need to be reviewed on a regular basis in the outpatient clinic to monitor your progress and check that the type of treatment that you have had has been effective. This type of follow up will vary depending on the type of treatment that you have undergone. Your specialist team will inform you of this follow up plan which might include further scans or other investigations. It is a good idea to make sure that you discuss your follow up plan with your healthcare team and have their contact details should you need to get in touch with them at any time.

Important contact numbers

Urology unit/ward contact no:

Oncologist contact no:

Specialist nurse contact no:

Consultant urologist contact no:

Community nurse contact no:

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**

Write to:

Cancer Research UK,
Angel Building, 407 St John Street,
London EC1V 4AD

www.cancerresearchuk.org

Cancer52

A combination of rare cancer charities dedicated to increase awareness of the less common cancers which make up 52% of all cancers.

www.cancer52.org.uk

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 you 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

Penny Brohn Cancer Care

(formerly the Bristol Cancer Help Centre)

Provides a programme of complementary care - The Bristol Approach to people with cancer and their loved ones.

Helpline: **0845 123 23 10**

Mon to Fri, 9.30am to 5pm

Switchboard: **01275 370 100**

Email: **helpline@pennybrohn.org**

Write to:

Chapel Pill Lane, Pill,
Bristol BS20 0HH

www.pennybrohncancercare.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.rarercancers.org.uk/

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

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This image shows a blank sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

Resources...

For further information and support on male cancer, please visit the Orchid website at www.orchid-cancer.org.uk or call 0203 465 5766.

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

You may find these factsheets helpful:

- ▶ **HIV and Testicular Cancer**
- ▶ **Vitamin D** and Prostate Cancer
- ▶ **Prostate Cancer: The Big Question**
- ▶ **Prostate Cancer: The Familial Link**
- ▶ **Diet and Lifestyle**
- ▶ **Testicular Cancer and Your Fertility**
- ▶ **Hereditary Prostate Cancer**
- ▶ **Prostate Cancer: The PSA Blood Test**

Low-down, Orchid's newsletter features the latest news and developments in male cancer including research, treatments, new services and events.

Written and edited by:

**Orchid Cancer Appeal and
Orchid Editorial Board**
October 2012

**References to sources of
information used in this booklet
are available from Orchid.**

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.



ORCHID

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info@orchid-cancer.org.uk www.orchid-cancer.org.uk

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