

Penile Diagnosis

Information for patients



This booklet aims to give you information about penile cancer. We hope it will answer some of the questions that you, or those who care for you, may have at this time.

This booklet is not meant to replace discussions between you and your surgeon, but to act as a guide to accompany what is discussed.

Cancer of the penis is very rare, about 100 times less common than other cancers such as prostate and lung cancer.

An average local hospital will only see one to two cases every year, because the disease is so rare. Specialist centres have been developed to treat more cases per year, therefore improving the quality of treatment and expertise for the patient. St James's University Hospital in Leeds is one such centre, which sees around 50 cases a year.

Treatment of penile cancer can be very effective, and the 70-80% of men are cured completely, particularly if the disease is detected at an early stage.

What causes penile cancer?

As with many cancers we don't know the precise cause in most cases. We do know some facts:

- Penile cancer usually affects older men, most patients being over 60 years of age. However one in five will be under 40.
- It is much less common in men who have had their foreskin removed in early childhood (circumcised).

- It is sometimes associated with a skin condition which affects the foreskin, called Balanitis Xerotica Obliterans (BXO).
- It is sometimes associated with genital warts, which are often due to viral infection of the skin known as HPV.
- There is no genetic link that we are aware of, meaning it is not known to be passed on to your children or grandchildren.
- Your partner is not at risk of developing any form of cancer if you have been diagnosed with penile cancer and have been / are having sexual intercourse.

What are the symptoms and signs?

The first signs are usually on the foreskin, or behind the foreskin on the head of the penis (glans).

Typical signs are:

- A red, velvety patch.
- A raw area which may have a smelly discharge (oozing or leaking fluid).
- A wart-like growth or ulcer.
- Bleeding or discharge from beneath the foreskin, particularly if the foreskin is tight and does not retract.

All these may also be signs of less serious problems, but it is always wise to have symptoms like these checked out without delay.

What happens if it is suspected that the problem is a cancer?

Firstly you may need a biopsy to discover whether you do have penile cancer. This may be done either at your local hospital, or at St James's University Hospital . In some cases, particularly if the cancer is large, the diagnosis is very obvious and a biopsy is not needed. In other cases, if the cancer is small, it can be completely removed at the same time as the biopsy. In most cases, however, a biopsy is performed, allowing treatment to be planned once the biopsy results are known.

Having a biopsy

A biopsy involves the removal of a small piece of tissue for examination under a microscope to enable a diagnosis to be made. Most biopsies are performed under general anaesthetic (when you are asleep), but sometimes they can be done under local anaesthetic (freezing the area while you are awake). If your foreskin is tight your doctors may recommend that a circumcision is performed at the same time. Most men will leave hospital the same or following day.

What happens next?

Biopsies normally take approximately 2 week to be scientifically processed in the laboratory. If cancer is confirmed, you will then be referred to St James's University Hospital if you have not been seen there already.

The biopsy material and any other relevant information will be sent to St James's University Hospital and examined by the penile cancer team.

You will receive an appointment to see your consultant urologist or a member of their team including the clinical nurse specialist (CNS).

Your case will be discussed at the weekly Multidisciplinary Team (MDT) meeting so that your treatment can be planned.

What examinations and tests may I need?

When you are seen in the clinic the urologist will ask you questions about your symptoms and about any past medical problems. They will need to examine your penis, testicles and groins.

You will probably have routine blood tests depending on your type of cancer and your general state of health. Most men will have an MRI scan, which is generally performed following an injection of a drug (Alprostadil) into the penis. This injection produces a penile erection, which allows the medical team to more accurately determine the degree to which the tumour has (or hasn't) penetrated deeper tissues in the penis.

All men, except those with very small cancers, will have a CT scan at some stage. This may be delayed until after the cancer has been treated. This will show your medical team if there are any enlarged lymph nodes in your groin, which can be an area penile cancer can spread to.

Will I need an operation?

Most penile cancers are treated by surgery, so it is likely that you will need an operation of some sort. This will be fully discussed with you at your first clinic visit.

Are there any alternatives to surgery?

Small pre-cancerous growths can often be treated with drugs that are applied in the form of a cream to the abnormal area on the penis. The drugs that are commonly used are called Imiquimod and 5-fluoruracil. These are chemotherapy drugs which can cause some local irritation and discomfort on the penis, but will not cause any general side-effects such as hair loss. The team will discuss these drugs with you if your problem is suitable for this treatment.

What will happen if I do not have any treatment?

If you do have cancer and no treatment is given it will continue to grow. It may also spread to other parts of your body. **All cancers are easier to treat if detected early.**

What is involved with surgery?

This depends on the size and position of your cancer, and on your general state of health. The exact nature of any proposed operation will be discussed with you before you and your consultant make a joint decision to go ahead. You will also be given further written information relating to your specific surgical procedure and aftercare when you are seen by the nurse specialist.

What support is available to me?

The Clinical Nurse Specialist (CNS) is an experienced urology nurse who works with the other members of the team to provide high quality medical and psychological care for men with penile cancer and their families.

The CNS is there to clarify any information and discuss matters important to you. It is very important that you are able to have your questions answered and concerns discussed and the CNS will make every effort to ensure this. You will be given a contact telephone number for the CNS so that you are able to contact him or her, should you have any worries or need further information when at home. The CNS will be on hand to co-ordinate any treatment and investigations throughout your treatment and follow up care. His or her responsibilities include: providing informational support; counselling; and ward visits during in-patient stays. Your on going follow-up will be arranged at St James's University Hospital.

Contact numbers:

- **Victoria Washington - Urology Nurse Specialist:**
0113 206 4594 / CNS Team 0113 206 6792
(Monday to Friday 8am - 4pm)
- **Mr. Eardley / Mr Kayes / Mr Elmamoun Secretary:**
0113 206 6994 (Monday to Friday 9am - 5pm)

Any questions?

If you have any worries or questions, please contact the Urology Clinical Nurse Specialist.

It is important that you make a list of all medicines you are taking and bring it with you to all your follow-up clinic appointments. If you have any questions at all, please ask your surgeon, oncologist or nurse. It may help to write down questions as you think of them so that you have them ready. It may also help to bring someone with you when you attend your outpatients appointments.

Leeds Cancer Support

Leeds Cancer Support complements care provided by your clinical team. We offer access to information and a wide range of support, in a welcoming environment for you, your family and friends. We can be found in the information lounges in Bexley Wing and also in the purpose built Sir Robert Ogden Macmillan Centre.



The Sir Robert Ogden Macmillan Centre

The Centre is on the St James's Hospital site and offers a variety of support services including counselling, support groups and complementary therapies. These therapies include Reiki, relaxation and visualisation, hand and foot massage and many others. You can just drop in for a coffee and a chat anytime. Open from 10am - 4pm Monday to Friday.

Health Talk support service

Health talk is an online service where you can find information and support by seeing and hearing patients real life experiences.

In co-ordination with researchers from the Centre for Men's Health at Leeds Metropolitan University who spoke to 27 men in their own homes. You can explore what these people felt about issues such as symptoms, treatment, body image and sex. We hope you find the information helpful and reassuring.

<http://www.healthtalk.org/peoples-experiences/cancer/penile-cancer/topics>

Contact numbers for Leeds Cancer Support

Leeds Cancer Support Information Centre

Level 1 Outpatients Department

Tel: (0113) 206 8816 Open from 10am - 4pm.

Information Lounge

Level -2 Radiotherapy Department

Tel: (0113) 206 7603 Open from 8.30am - 6.00pm

The Sir Robert Ogden Macmillan Centre

Tel: (0113) 206 6498 Open from 10am - 4.00pm

All the above services can be emailed on:

leedsth-tr.Cancersupport@nhs.net

Where can I find more Information?

- **Macmillan Cancer Support**
Freephone: 0808 808 1021
Website: www.macmillan.org.uk
- **Orchid Male Cancer Support**
Website: www.orchid-cancer.org.uk
- **The Cancer Research UK website**
www.cancerresearchuk.org

Health Talk support service

<http://www.healthtalk.org/peoples-experiences/cancer/penile-cancer/topics>

For details of local cancer support groups and organisations, please ask your CNS who will be able to explore these for you.

References:

- Orchid male cancer support 2017. Partial Penectomy
- Orchid male cancer support 2017. Total Penectomy
- The Christie Patient Information Service May 2015
CHR/SUR/600/17.06.08 version 4
- <http://www.healthtalk.org/peoples-experiences/cancer/penile-cancer/topics>

Questions / Notes

A series of 22 horizontal dotted lines intended for writing questions or notes.



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