PENECTOMY (SUBTOTAL or TOTAL) FOR PENILE CANCER

Information about your procedure from
The British Association of Urological Surgeons (BAUS)

This leaflet contains evidence-based information about your proposed urological procedure. We have consulted specialist surgeons during its preparation, so that it represents best practice in UK urology. You should use it in addition to any advice already given to you.

To view this leaflet online, scan the QR code (right) or type the shortened URL below it into your browser.

https://bit.ly/4bQaj3b

KEY POINTS

- The aim of this operation is to remove the cancer completely from your penis
- Either all or most of your penis will be removed; the extent of the procedure depends on how much of your penis is invaded by the cancer
- Your urethra (waterpipe) will be brought out on to your perineum (the area between your testicles and your back passage)
- You will still have full control over passing urine, but you will need to sit down to empty your bladder

What does this procedure involve?

We make an incision at the base of your penis and extend it down to the top of your scrotum. The penis is then separated from your urethra (waterpipe) before being removed. Your urethra is brought out on your perineum, between your back passage and your scrotum.

The scrotum with the testicles still in place is lifted up and fixed to the skin overlying the pubis. This means that you will be flat at the front and will need to sit down to pass urine.

The procedure is performed under a general anaesthesia. A small drain and bladder catheter are usually left in place. The drain will usually be removed after a few days; the catheter may stay for 5 - 7 days.

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What are the alternatives?

- **Do nothing** - this is rarely recommended and is only offered for advanced cancer involving the penis. There are rarely any useful options apart from surgery.

What happens on the day of the procedure?

Your urologist (or a member of their team) will briefly review your history and medications, and will discuss the surgery again with you to confirm your consent.

An anaesthetist will see you to discuss the options of a general anaesthetic or spinal anaesthetic. The anaesthetist will also discuss pain relief after the procedure with you.

We may provide you with a pair of TED stockings to wear, and we may give you an injection to thin your blood. These help to prevent blood clots from developing and passing into your lungs. Your medical team will decide whether you need to continue these after you go home.

Details of the procedure

- we normally use a full general anaesthetic and you will be asleep throughout the procedure
- you will be given an injection of antibiotics before the procedure, after you have been checked for any allergies
- a **subtotal** penectomy involves removing most of your penis, while a **total** penectomy involves removal of all the penis.
- your urethra (waterpipe) is brought out through the perineum
- we use absorbable sutures throughout, which normally disappear within two to three weeks
- we usually put a catheter in your bladder through your new urethral opening to drain urine while the area is healing
- you will have a dressing where the penis was previously located, to limit any bruising or swelling
- The catheter will be removed when your wounds have healed; this is usually after 5 - 7 days.

Are there any after-effects?

The possible after-effects and your risk of getting them are shown below. Some are self-limiting or reversible, but others are not. We have not listed very rare after-effects (occurring in less than 1 in 250 patients) individually. The impact of these after-effects can vary a lot from patient to patient; you

should ask your surgeon's advice about the risks and their impact on you as an individual:

After-effect	Risk
Swelling, bruising & discomfort around the operation site	 Almost all patients
You will not be able to have penetrative sexual intercourse	 Almost all patients
Bleeding from the operation site requiring further surgery or blood transfusion	 Almost all patients
Sensation of your penis still being present (only if you have had **subtotal** penectomy)	 Between 1 in 3 & 1 in 10
Narrowing of the new urethra which may require further surgery	 Between 1 in 3 & 1 in 25
Incomplete cancer removal requiring further treatment	 Between 1 in 4 & 1 in 20
Post-operative mortality (death)	 Between 1 in 10 & 1 in 30
Infection in the surgical area requiring antibiotic treatment	 Between 1 in 10 & 1 in 50 patients
Need for further cancer treatment	 Between 1 in 10 & 1 in 50 patients
Anaesthetic or cardiovascular problems possibly requiring intensive care (including chest infection, pulmonary embolus, stroke, deep vein thrombosis, heart attack and death)	 Between 1 in 50 & 1 in 250 patients (your anaesthetist can estimate your individual risk)

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What is my risk of a hospital-acquired infection?

Your risk of getting an infection in hospital is between 4 & 6%; this includes getting *MRSA* or a *Clostridium difficile* bowel infection. Individual hospitals may have different rates, and the medical staff can tell you the risk for your hospital. You have a higher risk if you have had:

- long-term drainage tubes (e.g. catheters);
- bladder removal;
- long hospital stays; or
- multiple hospital admissions.

What can I expect when I get home?

- you will get some swelling and bruising of your penis which may last several days
- you will be discharged with a catheter in your bladder; we will show you how to manage it at home
- you will be given advice about your recovery at home
- you will be given a copy of your discharge summary and a copy will also be sent to your GP
- any antibiotics or other tablets you may need will be arranged & dispensed from the hospital pharmacy
- a follow-up appointment will be made for you to have your dressings and catheter removed.

It usually takes up to 14 days until the results of the pathology analysis are available; these will be discussed in a multi-disciplinary team (MDT) meeting before any further treatment decisions are made. We will let both you and your GP know the results.

A subtotal/total penectomy operation can affect how you feel about your body and your sexual confidence. Whilst this may be very distressing, it is normal and understandable. It may be helpful to discuss these feelings with close friends or your partner(s).

In addition, support is available from your cancer specialist nurse, your surgeon or a psychosexual counsellor. Your hospital team will be able to arrange this is if required or requested.

Is it possible to rebuild my penis?

Yes – this can be done using a procedure called a phalloplasty.

This is a major operation which can be performed at The Andrology Centre in London, but only after you have been cancer-free for 12 months, and you

are fit enough for the surgery. It usually involves three separate stages, the first of which may take up to 10 hours to complete.

Further details about phalloplasty can be provided by your penile surgeon (or click the link above).

General information about surgical procedures

Before your procedure

Please tell a member of the medical team if you have:

- an implanted foreign body (stent, joint replacement, pacemaker, heart valve, blood vessel graft);
- a regular prescription for a blood thinning agent (e.g. warfarin, aspirin, clopidogrel, rivaroxaban, dabigatran);
- a present or previous MRSA infection; or
- a high risk of variant-CJD (e.g. if you have had a corneal transplant, a neurosurgical dural transplant or human growth hormone treatment).

Questions you may wish to ask

If you wish to learn more about what will happen, you can find a list of suggested questions called "Having An Operation" on the website of the Royal College of Surgeons of England. You may also wish to ask your surgeon for his/her personal results and experience with this procedure.

Before you go home

We will tell you how the procedure went and you should:

- make sure you understand what has been done;
- ask the surgeon if everything went as planned;
- let the staff know if you have any discomfort;
- ask what you can (and cannot) do at home;
- make sure you know what happens next; and
- ask when you can return to normal activities.

We will give you advice about what to look out for when you get home. Your surgeon or nurse will also give you details of who to contact, and how to contact them, in the event of problems.

Smoking and surgery

Ideally, we would prefer you to stop smoking before any procedure. Smoking can worsen some urological conditions and makes complications more likely after surgery. For advice on stopping, you can:

- contact your GP or access your local NHS Smoking Help Online;
- ring the Smoke-Free National Helpline on **0300 123 1044**.

Driving after surgery

It is your responsibility to make sure you are fit to drive after any surgical procedure. You only need to contact the DVLA if your ability to drive is likely to be affected for more than three months. If it is, you should check with your insurance company before driving again.

What should I do with this information?

Thank you for taking the trouble to read this information. Please let your urologist (or specialist nurse) know if you would like to have a copy for your own records. If you wish, the medical or nursing staff can also arrange to file a copy in your hospital notes.

What sources have we used to prepare this leaflet?

This leaflet uses information from consensus panels and other evidence-based sources including:

- the Department of Health (England);
- the Cochrane Collaboration; and
- the National Institute for Health and Care Excellence (NICE).

It also follows style guidelines from:

- the Royal National Institute for Blind People (RNIB);
- the Information Standard;
- the Patient Information Forum; and
- the Plain English Campaign.

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