

URETEROLYSIS for RETROPERITONEAL FIBROSIS (RPF)

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 short URL below it into your web browser.

http://rb.gy/6rkzq

KEY POINTS

- Retroperitoneal fibrosis (RPF), also known as chronic periaortitis, forms at the back of your abdominal cavity and can block your ureters (the tubes that carry urine from your kidneys to your bladder)
- Ureterolysis is used to free your ureters from the blockage caused by the RPF
- In most patients, the procedure involves open surgery through a long incision in your abdomen, but it can sometimes be done by laparoscopic (keyhole) surgery
- To try and prevent further obstruction, we wrap your ureters in omentum (the fatty envelope from inside your abdomen) or in a synthetic material
- The procedure is usually reserved for patients in whom medical treatment has been unsuccessful
- Care of patients with RPF is multi-disciplinary with physicians, expert surgeons and other specialists collaborating in your care

What does this procedure involve?

Freeing your ureters from scar tissue at the back of your abdomen to relieve the blockage and restore urine drainage from your kidneys. To prevent recurrence, we wrap your ureters in omentum (a sheet of fatty

Published: Jul 2023 **Leaflet No:** E23/122 **Review due:** Oct 2026 © British Association of Urological Surgeons Limited

tissue found in your abdomen); if your omentum has been removed or is too small to use, we may wrap the ureters in a synthetic material.

In some centres, if the appropriate level of expertise is available, ureterolysis is performed using a "keyhole" technique (laparoscopic or robotically-assisted). The long-term results of keyhole surgery for RPF are not yet known.

What are the alternatives?

- **Medical treatment** using anti-inflammatory drugs or immunosuppressive treatment (e.g. steroids)
- **Permanent percutaneous nephrostomy** to relieve the obstruction by draining your kidneys externally
- <u>Ureteric stenting</u> to relieve the obstruction by draining your kidneys internally; <u>long-term stents</u> need to be changed regularly

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.

Use of omentum to prevent recurrence of fibrosis

We may provide you with a pair of TED stockings to wear, and give you a heparin 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 carry out the procedure under a general anaesthetic
- we may give you an injection of antibiotics before the procedure, after you have been checked for any allergies
- we make a long incision in your abdomen (from top to bottom) and free the ureters throughout their entire length from the RPF

Published: Jul 2023 Leaflet No: E23/122 Review due: Oct 2026 © British Association of Urological Surgeons Limited

- we use your omentum to wrap around the ureters (pictured above);
 this prevents further obstruction by the fibrosis
- if keyhole surgery is used, you will only have four to six small punctures in your abdomen
- we put a catheter in your bladder through your urethra (waterpipe) to monitor your urine output; this is usually removed after five to seven days
- we usually put stents into your ureters during the procedure and, occasionally, we may also put external nephrostomy tubes into one or both kidneys; the stents and/or nephrostomies are usually removed a few weeks after the surgery
- we normally leave a drain inside your abdomen in case there is any urinary leak; this is removed after three or four days
- we close your wound with absorbable stitches, tissue glue or staples

Following major abdominal surgery, some urology units have introduced Enhanced Recovery Pathways. These actually start before you are admitted to hospital. After your surgery, they are designed to speed your recovery, shorten your time in hospital and reduce your risk of re-admission.

We will encourage you to get up and about as soon as possible. This reduces the risk of blood clots in your legs and helps your bowel to start working again. You will sit out in a chair shortly after the procedure and be shown deep breathing/leg exercises. We will encourage you to start drinking and eating as soon as possible.

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	
Abdominal bloating and shoulder-tip pain, due to irritation by carbon dioxide gas (if keyhole surgery has been used)	All patients	

Temporary insertion of ureteric stents which need later removal	Almost all patients
Bleeding requiring blood transfusion or a further procedure	Between 1 in 10 & 1 in 50 patients
Kidney function may not improve after the procedure	Between 1 in 10 & 1 in 50 patients
Recurrence of the blockage requiring further surgery	Between 1 in 10 & 1 in 50 patients
Inadvertent injury to adjacent structures (which may be unrecognised) requiring further surgery	Between 1 in 10 & 1 in 50 patients
Need for conversion from keyhole to open approach due to unexpected findings, bleeding or injury to adjacent organs	Between 1 in 10 & 1 in 50 patients
Unexpected finding of cancer or a generalised inflammatory disease causing the obstruction	Between 1 in 50 & 1 in 250 patients
Infection, pain or hernia of the wound requiring further treatment	Between 1 in 50 & 1 in 250 patients
Inability to ejaculate due to operative nerve damage (males only)	Between 1 in 50 & 1 in 250 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)

What is my risk of a hospital-acquired infection?

Published: Jul 2023 **Leaflet No:** E23/122 **Review due:** Oct 2026 © British Association of Urological Surgeons Limited

Your risk of getting an infection in hospital is between 4 & 6%; this includes getting *MRSA* or a *Clostridium difficile* bowel infection. This figure is higher if you are in a "high-risk" group of patients such as patients who 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 around the wounds which may last several days
- any discomfort in your wound or abdomen can be relieved by simple painkillers
- mild discomfort on passing urine once your catheter has been removed
- you will be given advice about your recovery at home
- you have had a large operation it will be several weeks before you have recovered completely from the procedure
- your appetite will be poor at first but will gradually improve over the first two to three weeks
- any antibiotics or other tablets you may need will be arranged & dispensed from the hospital pharmacy
- you will be given a copy of your discharge summary and a copy will also be sent to your GP
- a follow-up appointment will usually be arranged for you before you leave hospital
- you will be told when your ureteric stents (or nephrostomy tubes)
 will be removed; if you have not, you should contact your urologist or specialist nurse for further information

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;
- access your local <u>NHS Smoking Help Online</u>; or
- 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 <u>contact the DVLA</u> 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 <u>Department of Health (England)</u>;
- 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

DISCLAIMER

Whilst we have made every effort to give accurate information, there may still be errors or omissions in this leaflet. BAUS cannot accept responsibility for any loss from action taken (or not taken) as a result of this information.

PLEASE NOTE: the staff at BAUS are not medically trained, and are unable to answer questions about the information provided in this leaflet. If you have any questions, you should contact your Urologist, Specialist Nurse or GP in the first instance.