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Having an open cystectomy and formation of a urostomy

Department of Urology

Information for patients

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Introduction

Your consultant has recommended that you have a cystectomy (removal of your bladder) following your recent diagnosis of bladder cancer. This leaflet aims to give you an outline of the procedure.

The team looking after you

The team looking after you is known as the Multidisciplinary Team, or MDT. The MDT is a team of health care professionals who are experts in the care and treatment of people with bladder cancer.

Your MDT will have met to discuss the most appropriate treatment for yourself. Your doctor will discuss your treatment plan with you.

Your operation

You may have your operation as part of the Enhanced Recovery Programme. If this is the case, you will be given further information about this at your pre-assessment visit as you will need to follow a special plan to speed up your recovery from surgery.

The operation to remove your bladder is carried out whilst you are asleep, under general anaesthetic. Once your bladder has been removed, your kidneys will continue to make urine and this urine needs to be diverted.

This leaflet gives you brief information about formation of a urostomy (stoma). Further information will be given to you by the stoma nurses who will see you before you come into hospital.

How will I pass urine after the operation?

During the operation the surgeon caries out a procedure called a ‘urinary diversion’. After the operation your urine will pass through a small piece of bowel, called a stoma, and into a bag on your abdomen. The stoma nurse will give you further information about this when you meet them.

What are the possible complications?

As with all operations, there are associated risks. These include:

- Chest infection, which can result from reduced activity and difficulty in breathing deeply because of the wound.
- Wound infection which may delay healing and require treatment with antibiotics. In rare cases, further surgery is necessary.
- Bleeding, which may mean that you need to have a blood transfusion.
- Deep vein thrombosis (DVT): there is a small risk of clots in the leg veins, which occasionally travel to the lungs and cause breathing difficulty (pulmonary embolus). Heparin (blood-thinning) injections will be given to you, starting before the operation, to minimise risk.
- Paralytic ileus, can result in the muscle movement that pushes food along your intestines stop working and you may need a longer stay in hospital..
- Urine infection, which may require treatment with antibiotics.
- Men: impotence (lack of an erection)

  Dry orgasm with no semen produced
- Women Narrowing and dryness of the vagina may result in pain or difficulty with sexual intercourse

You will have time to discuss all these risks with the doctors and nursing staff before you consent to your operation.
The Macmillan booklet “Understanding muscle-invasive and advanced bladder cancer” has more information, including diagrams. Ask your key worker for a copy or contact Macmillan Cancer Support on 0808 808 00 00.

How am I prepared for my operation?

As part of your preparation your bowel needs to be emptied before surgery.

In order to do this you will be given an enema on the morning of your operation. This will make you empty your bowels. You will not be allowed to have anything to eat although you will be encouraged to drink plenty of clear fluid.

A stoma nurse will visit you and put a mark on your abdomen where your urostomy will be sited. This needs to be done whilst you are awake to ensure that it goes in the most suitable place for you.

What happens after my operation?

As this is major surgery, you are likely to be transferred to the High Dependency Unit where you will be cared for until you are ready to go back to the ward.

You will have:

A drip (an intravenous infusion)

This may be in your neck, hand or arm. It replaces any fluids that you may have lost during surgery or by fasting. You may also have a blood transfusion through this drip. You will not be allowed to eat or drink for a few days after your operation as you need time to heal inside. Once your bowels start working again, you will be allowed to have small amounts of water. As you recover, we will gradually

What happens after my operation? (continued)

Pain relief

You will have some form of pain relief. This will be explained to you before your operation. If you need more information, please ask to speak to a member of the Pain Team.

Wound

You will have a wound on your abdomen. There will be at least one drain into the wound, to drain fluid from the operation site.

Stoma bag

You will have a stoma bag on your abdomen, collecting urine from the new urostomy. A stoma nurse will teach you how to look after your urostomy.

Stents

You will have two temporary fine plastic tubes (stents) which help the urine to drain from the kidneys Into your stoma bag. These stents will remain in until healing takes place, and are normally removed before you go home.

Preparing to go home

You will usually be in hospital for about seven to ten days. You will be discharged when you are eating and drinking, mobile, your bowels have opened and the stoma nurses are happy that you can change your stoma bag independently. The stoma nurse will ensure that you have everything that you need for your urostomy when you get home, and will explain how to obtain further supplies.

The ward nurses will arrange for a district nurse to visit you at home whilst you are recovering. We will give you a letter for your GP and will make sure that you have a supply of any medication that you have been prescribed.

What happens when I go home?

Formation of a urostomy is major surgery and it will take you several months to recover fully. The stoma nurse will arrange to see you when you have been discharged home.

Exercise
You should go for short gentle walks, but avoid too much exercise and heavy lifting. Expect to feel tired for a few weeks and take an afternoon rest if necessary.

Eating and drinking

You may find that your appetite is reduced for a few weeks. Gradually build up to your normal diet by eating little and often.

Driving
Do not drive for four to six weeks.

Return to work
Your consultant will advise you about going back to work.

Sex
When you feel ready you can resume sexual activity. However, this is a very personal matter and will depend on the extent of your surgery. Treatments for bladder cancer may have a direct effect on your sex life. Please discuss any worries that you may have with your consultant or specialist nurse.

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Further information

This booklet has been designed to answer many of your questions, but of course you may have others.

If you have any questions you would like to ask before you come into hospital, you can contact the specialist nurses or the ward directly, using the numbers below:

Stoma Nurses

Telephone: 0116 258 4455 (Monday to Friday 8:00 am to 4:00 pm)

Urology Oncology Nurse Specialists (Key Workers)

Telephone: 0116 258 4637 (Monday to Friday 9:00 am to 4:30 pm)

Outside these hours:

Urology Emergency Admissions

Telephone: 0116 258 4247

Other sources of information and support

Urostomy Association

Website: www.urostomyassociation.org.uk

Action Bladder Cancer UK

Telephone: 0300 302 0085
Website: www.actionbladdercanceruk.org

Fight Bladder Cancer

Telephone: 01844 351621

Website: www.fightbladdercancer.co.uk

Macmillan Information and Support Centre, Leicester Royal Infirmary

Telephone: 0116 258 6189 (Monday to Friday 8.30am to 4.00pm)

Macmillan National Support Line

Telephone: 0808 808 0000 (7 days a week 8am to 8pm)

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
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Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email equality@uhl-tr.nhs.uk

LEICESTER'S RESEARCH

Leicester's Hospitals is a research active trust so you may find research happening on your ward or in your clinic. To find out about the benefits of research and become involved yourself, speak to your clinician or nurse, call 0116 258 8351 or visit www.leicestersresearch.nhs.uk/patient-and-public-involvement