Urostomy
A practical guide to stoma care

Putting you first
Foreword

Few people will have heard of a urostomy prior to finding out that they need surgery. Issues regarding bodily functions are rarely talked about, so few people facing this procedure often feel very alone. It may seem a daunting road ahead, but there are many sources of advice and support available to help you on the road to recovery.

I am frequently asked questions such as “What will my stoma be like?” or “What happens after surgery?” This booklet explains what to expect and provides hints and tips to enable you to get the best out of life. I am sure that you will find it very helpful.

Hazel Pixley
National Secretary
Urostomy Association
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It is a worrying time when you learn that you need to undergo major surgery. It can be particularly traumatic when you learn that as a result of that surgery your bodily functions will not be the same – that you will have an urostomy and will not be able to pass urine in the normal way, but will wear a ‘pouch’ on your abdomen.

Specialist stoma care nurses and medical staff offer understanding and support – and practical assistance. They have helped very many people through the same experience and back to a full, active and happy life.

Organisations such as the Urostomy Association are also invaluable sources of support and advice from fellow urostomists.

This booklet is intended to ‘fill in’ on some of the information you may have been unable to take in at the time of your surgery, to give you background information and practical advice.
How the urinary system normally works

In carrying out its functions, the body naturally produces wastes that collect in the blood.

The kidneys continuously filter the blood to remove the waste matter.

The resulting urine travels from the kidneys through the ureters to the bladder, where it is stored. It is then passed or excreted via the urethra.

With a Urostomy

When you have a urostomy, you will no longer pass urine in the usual way.

Instead the urine will come down the ureters from the kidneys and then be diverted by an ‘ileal conduit’ out to the surface via an opening (‘stoma’) on your abdomen.

The ileal conduit opens onto the surface of the skin as the urostomy. The stoma is usually situated on the right side of the abdomen.

A watertight pouch (with a tap at the bottom) is fitted over the stoma to collect the urine.
How is the stoma formed?

To create the stoma that opens onto the abdomen, the surgeon will usually isolate a short piece of your small intestine (‘ileum’) and use it to fashion a kind of tube or spout (known as an ‘ileal conduit’).

The rest of the small bowel or ileum will be rejoined so that your digestive system functions just the same as before.

The two ureters are ‘plumbed’ into the ileal conduit which then opens onto the abdomen. This is known as a urostomy (see page 5).

What does a urostomy look like?

A stoma is moist and pinkish in colour (similar to the inside of the mouth). It has little or no sensation, but it does have a good blood supply and may bleed slightly when touched. Because it is made from a piece of intestine, it will always continue to produce mucus and this shows up as threadlike matter in the urine collected in the stoma pouch.
In hospital

Before your operation

Members of the medical team will prepare you and advise you about your coming operation. In many hospitals specially trained senior staff – stoma care nurses – will be closely involved in your care and will make sure you have continued support in the hospital and when you return home. You may be given the chance to practice changing a urostomy pouch before you go into hospital. This will help you to become familiar with the process, making it easier for you after your operation.

Marking the site

The stoma is usually on the right hand side of the abdomen. The specialist stoma care nurse will usually discuss this with you and before the operation, mark the position where the stoma will be, as a guide for the surgeon. Your stoma will be permanent and you will always need to wear a stoma pouch.

After your operation

When you wake up, don’t be alarmed by the various tubes attached to you – these will be gradually removed during the following days.

The stoma will be covered by a transparent pouch. It will be swollen at first, but during the weeks after surgery it will shrink somewhat.

- During the operation two fine plastic tubes will be tucked into the stoma down into the ureters to hold the ureters open and make sure they are able to drain properly – once the swelling goes down the plastic tubes will gradually work their way out and be removed.

- Urine draining out of your stoma immediately after surgery will be blood-stained. It will gradually clear, but will remain discoloured for 2-3 weeks.

- The piece of intestine used to fashion the stoma will always continue to produce mucus as it did normally when it was part of the bowel. There is often quite a lot of mucus at first but the amount will gradually lessen.
Leaving hospital

Having a urostomy is major surgery, and you will probably stay in hospital for around 7-10 days. During this time, as you recover, the stoma care nurse will teach you how to care for your stoma. You will also be fitted with a more discreet type of pouch.

When you leave hospital you will be provided with a sufficient quantity of stoma supplies. Future supplies will be issued on prescription from your GP.

Blue disposal bags and wipes are supplied free to patients ordering supplies through the SecuriCare Home Delivery Service. For information call free on 0800 585125.

Your stoma care nurse will discuss this with you, will list out what you need and may also arrange for supplies to be delivered directly to your home. Whatever your age, you are exempt from prescription charges for stoma supplies. In England, if you are under 60 you will need to complete an exemption form FP92A.

Full details of how to contact your stoma care nurse for information and advice will be given to you and you will also have an appointment for your first check-up at the hospital. Your GP will be notified of your return home.

When you return home

Support is available from your stoma care nurse and/or community nurse. The stoma care nurse can be contacted by phone and may hold regular stoma clinics. The nurse will give you full details.
Your stoma care nurse will show you a selection of pouches and accessories available. There are basically two types of pouches – ‘one-piece’ and ‘two-piece’. Whatever the type, all pouches need to be emptied several times during the day and therefore have a small soft ‘tap’ at the bottom for this purpose.

**One-piece pouches**

These simple pouches are very popular. They are fixed around the stoma by means of a skin friendly hydrocolloid, self-adhesive flange. When changing a pouch for a fresh one (usually every other day), the whole pouch is gently removed and a new one applied in its place.

The type of flange and precise means of attaching the pouch vary with different types and makes, so it is worth experimenting to find one that suits you, your skin and your way of life. The material the pouches are made from also varies.

The most modern ones are very fine, soft and discreet, with a backing that is comfortable next to the skin. Most manufacturers are happy to provide free samples for you to try – and you can also keep up with the latest developments this way.

**Two-piece pouches**

These pouches have a flange (or baseplate) that fits round the stoma and stays in place for several days, with separate pouches that are attached to it. The baseplate is usually changed once or twice a week.
Using your pouch

**Aperture sizes**
The size of a stoma varies in diameter and stoma pouches are available with different sized apertures or holes. Most manufacturers supply a measuring device. Find the correct sized measuring ring which fits comfortably and snugly round the stoma, without touching it or cutting in. If the stoma is irregularly shaped, it is best to cut your own pattern to fit, using the measuring device as a basis, or using pouches with printed cutting guides. Alternatively call the SecuriCare careline on 0800 585 125 for assistance. For those with limited dexterity SecuriCare offer an ultrasonic pouch cutting facility.

In the months after surgery the stoma size usually reduces slightly. Check carefully to ensure a good fit – many problems with leakage or skin soreness are caused by using a pouch with the wrong size aperture.

**Night time**
To avoid getting up in the night to empty your pouch, you can add on extra capacity by means of a ‘night bag’. This is attached via a long tube to the tap at the bottom of your usual pouch. You can either place the night bag on a stand or hang it out of the end of the bed resting in a bowl or bucket. The night bag should be cleansed daily and changed five to seven days. Some night bags are ‘single use’ only. It is advisable to check that you have been supplied with the re-usable type.

Some people prefer to use a leg pouch at night (and some also do this in the day).
Changing your pouch and protecting your skin

When changing your pouch
As a urostomy functions continuously, it is important to get everything ready before you remove the pouch – and to get on with it when you do!

If you are removing a one-piece pouch, or the baseplate of a two-piece system, do so carefully and gently. The importance of taking care of the skin around the stoma to avoid soreness cannot be emphasised too much. Clean gently with water, dry, and use non-sting barrier wipes to protect the skin before applying another pouch/baseplate. (Don’t worry if your stoma bleeds slightly when it is touched – this is quite normal).

Protecting your skin
Various accessories can be obtained free on prescription – including extension flanges for extra security, washers, seals, pastes and powders – and your stoma care nurse will go through these with you. Free disposal bags (to put used stoma pouches in), belts and deodorants are also available.
You must drink plenty of fluids

One of the main concerns with a urostomy is the possibility of urinary infections. To help avoid this it is very important to:

- Drink plenty of fluids – a total of 2-3 litres per day (that’s the equivalent of 10-11 large glasses or 13 mugs of liquid)

This ensures you keep the system flushed through and working properly (and helps to flush out bacteria).

Cranberry juice has been shown to be helpful in avoiding urinary infections. If you don’t like it, you can also obtain cranberry tablets from chemists and health food stores. **N.B. Avoid cranberry juice if you are taking Warfarin.**

Dietary observations

When you have a urostomy there are no dietary restrictions and you should continue to have a normal diet. But please note:

- It is quite normal for your urine to smell after eating fish or asparagus!
- Beware – after eating beetroot the urine (and sometimes stools) will often be pink in colour!
- Urine crystals sometimes form in the stoma. These can be dissolved using a cloth dampened with white vinegar. Drinking cranberry juice will help to reduce the formation of crystals (**Avoid cranberry juice if you are taking Warfarin**). 

Travelling

A urostomy will not prevent you from taking trips in the U.K. or abroad by land, sea or air.

Carry a travel kit, packed in a small pouch or toilet bag, containing: clean stoma pouches, tissues, barrier wipes if used, scissors and plastic disposal bags. You can then empty or change your pouch wherever there is access to a toilet and handbasin. SecuriCare provide you with a free travel pack when you place your first order.
If you are travelling by air, pack a good supply of stoma pouches and accessories in your hand luggage in case your suitcases go astray. SecuriCare provide you with a travel certificate in foreign languages explaining about urostomies. Check your travel insurance to make sure it does not preclude any pre-existing conditions or have any age limits.

**Urinary diversion**
If you still have your bladder in place (i.e. you have had a urinary diversion, but not a bladder removal or cystectomy), the bladder will need to be washed out regularly, usually at fortnightly intervals. You may be shown how to do this yourself, or the district nurse may carry out the procedure for you. Your stoma nurse will advise.

**Sexual problems**
Impotence in men, and other sexual problems, often occur after bladder surgery. You will be counselled by medical staff and may also be referred to a urology nurse specialist. Younger men undergoing surgery should also be offered sperm banking.

Do not despair if you do experience erection problems, but speak to an adviser – there are many helpful solutions such as penile implants, injections, tablets, vacuum pumps etc.

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**Urostomy Association**

Central Office:
18 Foxglove Avenue
Uttoxeter
Staffordshire ST14 8UN
Telephone: 0870 770 7931
Fax: 0870 770 7932

The Careline operated by SecuriCare provides a friendly and efficient information and advice service to patients and carers.

The team is experienced in all makes of stoma pouches and accessories as well as Welland products and will be delighted to help with any product queries, requests for information or advice on stoma care.

**Careline 0800 585 125**
Your questions answered

Will people be able to tell I have a urostomy?
The answer to that is NO – today’s stoma pouches are very slim and discreet. Wear what you like and what’s comfortable (see below for sportswear). Have you ever seen anyone who you thought looked as though they had a urostomy?

When should I change my pouch?
A urostomy functions continuously and the pouch has to be emptied several times a day, using the tap at the bottom of the pouch. A pouch should be changed for a new one every other day.

What about sports?
No problem – carry on swimming, dancing, playing games, gardening or whatever you enjoy doing most. Patterned one-piece costumes disguise any slight bulges for women, while men might prefer fairly high-waisted boxer type shorts. Baggy T-shirts are great cover-ups, particularly over leotards for ladies’ keep-fit.

Whom should I tell?
It’s entirely up to you and is a very personal decision.

Baths and showers?
Yes, with the pouch in place as a urostomy functions all the time. Water will not go into your stoma even in the bath.

‘Leaks’?
Leaks shouldn’t happen! Check to make sure the pouch is applied properly and that you are using pouches with the correct size aperture. Pouches vary in the degree of security offered, so try other types if you continue to have problems. Consult your stoma care nurse.

I think I may have a urinary infection?
If you think you may have a urinary infection it is very important to contact your doctor immediately for treatment. To obtain a specimen, change your pouch and then take a specimen from the first lot of urine in the fresh pouch. Signs of possible infection are smelly urine, cloudy urine and/or increased mucus.

Will my life insurance be affected?
All insurance companies you deal with should be notified about your urostomy.
Associations and support groups

**Urostomy Association**
18 Foxglove Avenue
Uttoxeter, Staffordshire
ST14 8UN
Telephone: 0870 7707931

**Colostomy Association**
2 London Court, East St
Reading RG1 4QL
Freephone: 0800 3284257

**ia – the Ileostomy and Internal Pouch Support Group**
Peverill House
1-5 Mill Road, Ballyclare
Co. Antrim BT39 9DR
Freephone: 0800 0184724

**CancerBACUP**
3 Bath Place,
Rivington Street
London EC2 3JR
Freephone: 0808 808000

**Macmillan Cancer Relief**
89 Albert Embankment
London SE1 7UQ
Freephone: 0808 8082020

**Royal Association for Disability and Rehabilitation (RADAR)**
12 City Forum, 250 City Rd
London EC1V 8AF
Telephone: 020 7250 3222

**NASPCS**
(National Advisory Service to Parents of Children with a Stoma)
51 Anderson Drive, Darvel
Ayrshire KA17 0DE
Telephone: 01560 322024

**Relate National Marriage Guidance**
To find your nearest Relate
Telephone: 0300 100 1234

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**Websites**

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<tr>
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<td><a href="http://www.colostomyassociation.org.uk">www.colostomyassociation.org.uk</a></td>
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<td><a href="http://www.cancerbacup.org.uk">www.cancerbacup.org.uk</a></td>
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<td><a href="http://www.naspcs.co.uk">www.naspcs.co.uk</a></td>
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<td>SecuriCare (Medical) Ltd</td>
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<td><a href="http://www.uagbi.org">www.uagbi.org</a></td>
<td>Urostomy Association</td>
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We would like to thank the following for their invaluable assistance in reviewing this booklet:

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