



LIVING WITH A UROSTOMY

Frequently asked questions (FAQs) from
The British Association of Urological Surgeons (BAUS)

The aim of the leaflet is to provide you with detailed information about having a urinary diversion (or urostomy).

We have consulted specialist surgeons during its preparation, so 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/5uenh>

What should I expect before I leave hospital?

Once your urostomy has been fashioned, you have recovered sufficiently and are feeling confident managing your stoma, you will be discharged from hospital. Before you leave hospital, please ensure that you have:

- all the information booklets you require;
- your prescription exemption certificate (if applicable);
- stoma bags & equipment;
- prescription details & instructions;
- a contact number for your Stoma Nurse & Clinic;
- a discharge booklet; and
- a letter for your District Nurse and, if required, your local Stoma Nurse.



What happens after I leave hospital?

Your Stoma Sister will already have told your District Nurse that you have been discharged from hospital. A District Nurse will visit you at least once, usually within 48 hours of your discharge, and will remove your stents after 1-3 weeks.

We normally follow you up in the Stoma Clinic six to eight weeks after your

discharge from hospital. After that, we will continue to review you for as long as we all feel it necessary. If you have problems between clinic appointments, you can always contact the Stoma Clinic to arrange an earlier review.

Your Stoma Nurse may telephone you a few days after your discharge, to arrange a convenient follow-up appointment.

Please note: if you live outside the area where your surgery took place, you will normally be referred to your local Stoma Clinic for ongoing support and follow up.

How do I get my appliances & equipment?

Your stoma products are all available on prescription. Because your stoma is permanent, you are exempt from prescription charges. We will give you an exemption certificate for your GP to sign (unless you already qualify for one).

Before you are discharged, we will give you a card with the prescription code(s) for your stoma equipment. This is your personal record, and you should show it to your GP to get a prescription. The card may need to be altered by us at some point, so do not let your GP keep it. Once you have the prescription, you can get your supplies in two different ways:

- **From a chemist** - take your prescription to a chemist, as you would for any other medicines or tablets. Chemists do not normally stock stoma equipment so they will need to order it specially for you. This may take up to a week so order in advance when you are running low of supplies. If your chemist has any difficulty ordering your equipment, please contact your Stoma Nurse for advice; or
- **By direct delivery** - there are several delivery companies listed at the end of this leaflet (see page 8). You can register with them on the phone or over the internet. They will send your stoma equipment to you, free of charge.

You will need a prescription for this, which you should get from your GP and send on to them. If you cannot get a prescription, they will write to your GP and get it for you. They will also send you complimentary items such as dry wipes and scented disposal bags.

If you need to cut your bags to fit your stoma, they will deliver your equipment ready cut if you send them a template. Please allow six weeks before requesting this service, because your stoma needs to settle in size

and shape. If you are interested in this service and require additional support or advice, contact your Stoma Nurse.

Materials used for cleaning around your stoma (i.e. cleaning wipes) are available on prescription, and may be provided as a complimentary extra with some products. Your stoma nurse will be very happy to provide advice.

How do I change my stoma bag?

Collect all the necessary equipment (new bag, scissors, disposal bag, dry wipe/kitchen roll & warm water) and then:

- cut the new bag to the required size or shape (if necessary);
- empty the used bag down the toilet and reseal it;
- remove the soiled bag by peeling it off from the top;
- place the soiled bag in disposal bag;
- clean the skin and stoma using warm water and wipes. If you wish to use soap, a mild unperfumed soap is recommended and the skin should be rinsed thoroughly;
- dry the skin thoroughly by patting dry wipes or kitchen roll; check dryness with your hand;
- peel off the backing paper from the new bag and position it around your stoma, then press the bag firmly in place;
- wrap the used wipes and the soiled bag in newspaper and put them in a plastic bag; and
- knot or seal the top and place it with your household rubbish.

How do I use the night drainage system?

It is up to you whether you use the night drainage system. If you do, there are some points you should remember:

- always ensure that the bag is lower than the level of the bed;
- when connecting at night, do **not** empty the bag first - run some urine into the system to eliminate air pockets and help drainage;
- once disconnected, wash the bag with hot, soapy water (washing-up liquid or liquid soap); do **not** wash the bag with Milton, bleach or any other disinfectant; and
- change the night drainage bag and adaptor every week.

What questions do other patients ask?

Inevitably, patients and their families often have many questions about

having a urostomy. Below are some of the commoner questions asked:

Will my friends and family be able to see that I am wearing a bag?	No
Do I need to tell my friends and family?	It is entirely up to you. No-one need know unless you wish them to
Will I get depressed?	All patients, men and women, can feel “down in the dumps” after any form of surgery. This is very common and your Stoma Nurse will help you through any difficulties you may have
Do I need to eat a special diet?	Generally, no, although a well-balanced diet is recommended. You may have a poor appetite at first, so we recommend small, frequent meals until your appetite returns. You should drink plenty of fluids (at least 2 litres per day)
Can I drink alcohol?	Yes
Will I smell unpleasant?	No. All the bags are odour-proof. If you do smell urine (other than when you are emptying or changing your bag), it usually means there is something wrong with the stoma bag: either it has not been cleaned sufficiently or there is a leak somewhere. You should change the bag if this occurs
Will I need to pay prescription charges?	No. You will be medically exempt from charges
Will I have to wear the bag all the time?	Yes, but you can remove it for bathing or showering

Will I need to carry a lot of equipment with me?	No. But you should carry a spare bag, a disposal bag and dry/wet wipes in case you need to change your bag
Where should I store my bags?	In a cool, dry place, out of direct sunlight
Will I be able to work?	Yes, once you have recovered sufficiently and your GP is happy with your progress
Will I need to change my job?	Not normally
Will my partner reject me?	If you had a good, stable relationship before the surgery, there should not be any problems. Your Stoma Nurse can talk to you & your partner about this, either together or separately
Will I be able to have sex?	Your urologist or Stoma Nurse can discuss this with you
Can I travel and go on holiday?	Yes
Can I travel by air?	Yes. Your Stoma Nurse can give you some travel tips & advice
Will I be able to bathe and swim?	Yes, your bags are waterproof. Some companies provide patterned swimwear for stoma patients. Please contact your Stoma Nurse for more information
Will I be able to wear normal clothes?	Yes. Some companies provide special clothes for ostomates (e.g. high-waisted trousers). Your Stoma Nurse can provide you with more information

Can I play sport?	Yes, usually 2-3 months after your surgery. For high-impact sports such as squash or rugby, you should consider wearing a stoma shield
Can I wear a seatbelt?	Yes. You can buy a device from most car accessory shops which relaxes the seatbelt without affecting its safety mechanism
Will I get sore skin?	Not normally, especially if you look after your stoma carefully. If the skin does get sore, contact your Stoma Nurse
When can I drive?	Not for at least 6 weeks after your surgery, depending on your insurance company
How can I find out about new products and developments?	Most Stoma Clinics hold “open days” where companies bring along the latest products for you to see; your Stoma Nurse will invite you to attend these
Will my bag leak?	Not normally, but you may occasionally get faulty bags which leak. It can also occur if the shape and size of your stoma changes, or if you let the bag get too full. If you keep getting leakages, please contact your Stoma Nurse; if you ignore them, you may lose confidence and your skin could get very sore

Will I be able to have children?	If your bladder has been removed, you will not be able to have children (in men, the prostate and sperm-carrying channels are removed with the bladder; in women, the womb & ovaries are usually removed). If your urostomy was constructed without your bladder being removed, you may still be able to father children or get pregnant. Your Stoma Nurse can advise you about this
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Are there any other important points?

- **Bleeding from the stoma:** your stoma may bleed slightly when you clean it. This is nothing to worry about. It may also bleed if your appliance is too tight or rubs/irritates. If you get repeated bleeding, you should contact your Stoma Nurse
- **Mucus plugs:** the bowel used to make your urostomy will continue to produce mucus (which you can see as a white, sticky deposit in the tubing or when you empty your bag). It is not a sign of infection but it can block the drainage valve or the night drainage tubing. Gentle “milking” the tubing normally dislodges any plugs of mucus. Taking Vitamin C supplements can reduce the amount of mucus production by your stoma
- **Certain foods** may give your urine an unusual smell (e.g. asparagus, fish, onions, garlic & some spices)
- **Drinking cranberry juice**, 200 ml each day, can help keep your urine free from infection. If you take regular Warfarin, you must check with your GP before drinking cranberry juice
- **Beetroot**, as well as red fruit and some fruit drinks, can turn your urine red
- **Some drugs** can change the smell and colour of your urine
- **Follow-up:** you will need prolonged follow up with blood tests and scans of the kidneys to check that they are draining freely
- **Kidney failure:** a urostomy can, in the long term, lead to a reduction in function of your kidneys. In rare cases your kidneys may fail to work adequately. This may occur many years after your surgery and may lead to dialysis, or even kidney transplantation

Are there any support groups for urostomates?

Yes. The main support group is the [Urostomy Association](https://urostomyassociation.org.uk/) which provides help and advice through its website.

THE UROSTOMY ASSOCIATION (UA)

The UA mission statement outlines its main aims as:

- assisting those who are about to undergo or who have undergone surgery which results in a urinary diversion;
- improving the quality of life of people who have undergone urinary diversion surgery and those who care for them; and
- undertaking such research as the membership feels is necessary to enhance the life of members.

The association is supported by volunteers and relies on an annual subscription from its members.

Contact: Hazel Pixley, Chief Executive Officer
Urostomy Association
2 Tyne Place, Mickleton
Chipping Camden
Glos GL55 6UG

Telephone: +44(0)1386 430140

Email: info@urostomyassociation.org.uk

Website: <https://urostomyassociation.org.uk/>

Companies offering delivery of stoma care products

<p>Alphamed Limited 324-338 Bensham Lane, Thornton Heath, Surrey, CR7 7EQ Freephone: +44(0)800 515 317 www.amcaregroup.co.uk/</p>	<p>Amcare 24 Tinsley Close, Claypole, Newark, NG23 5BS Freephone: +44(0)800 855 050 www.convatec.com</p>
<p>Bullens 85-87 Kempston Street, Liverpool, L3 8HE Freephone: +44(8)00 269 327 www.bullens.com</p>	<p>Charter Healthcare Peterborough Business Park, Peterborough, PE2 6FX Freephone: +44(0)800 132 787 www.charter-healthcare.co.uk</p>

<p>Clinimed & Welland Cavell House, Kanvess Beech Way, Loudwater, High Wycombe, HP10 9QY Freephone: +44(0)800 360 100 www.clinimed.co.uk</p>	<p>Fittleworth (for Hollister products) Unit L, Rudford Industrial Estate, Ford Arundel, West Sussex, BN18 4DS Freephone: +44(0)800 378 846 www.fittleworth.com</p>
<p>Oakmed Limited 54 Adams Avenue, Northampton, NN1 4JL Freephone: +44(0)800 592786 www.oakmed.co.uk</p>	<p>Pelican Healthcare Cardiff Business Park, Cardiff, CF14 5WF Freephone: +44(0)800 052 7471 www.pelicanhealthcare.co.uk</p>
<p>Rapidcare (Southern Surgical) Unit 8, Stanley Centre, Kelvin Way, Crawley, RH10 2SE Freephone: +44(0)800 181 901 www.rapidcare.co.uk</p>	<p>Respond Plus 1 Carlton Business Park, Carlton, Notts, NG4 3AA Freephone: +44(0)800 220 300 www.respondplus.co.uk</p>
<p>Salts Medilink 226 Longmore Road, Shirley, Solihull, B90 3ES Freephone: +44(0)800 626 388 www.salts.co.uk/</p>	<p>Speed Services 91 South Street, Bishop's Stortford, Herts, CM23 3AL Telephone: +44(0)1279 654 172</p>

Companies manufacturing stoma care equipment

<p>Braun Thorncliff Park, Sheffield, S35 2PW Freephone: +44(0)800 163 007 www.bbraun.co.uk</p>	<p>Bullens 85-87 Kempston Street, Liverpool, L3 8HE Freephone: +44(8)00 269 327 www.bullens.com</p>
<p>Clinimed & Welland Cavell House, Kanvess Beech Way, Loudwater, High Wycombe, HP10 9QY Freephone: +44(0)800 360 100 www.clinimed.co.uk</p>	<p>Coloplast Limited Peterborough Business Park, Peterborough, PE2 6FX Freephone: +44(0)800 220 622 www.coloplast.co.uk</p>
<p>Convatec Harrington House, Milton Road, Ickenham, Uxbridge, UB10 8PU Freephone: +44(0)800 282 254 www.convatec.com</p>	<p>Dansac James Hall, Parsons Green, Saint Ives, Cambs, PE27 4AA Telephone: +44(0)1480 484300 www.dansac.co.uk</p>
<p>Pelican Healthcare Cardiff Business Park, Cardiff, CF14 5WF Freephone: +44(0)800 052 7471 www.pelicanhealthcare.co.uk</p>	<p>Salts Medilink 226 Longmore Road, Shirley, Solihull, B90 3ES Freephone: +44(0)800 626 388 www.salts.co.uk/</p>

<p>Hollister Rectory Court, 42 Broad Street, Wokingham, Berks, RG40 1AB Telephone: +44(0)800 521 377 www.hollister.com/uk/</p>	<p>Oakmed Limited 54 Adams Avenue, Northampton, NN1 4JL Freephone: +44(0)800 592786 www.oakmed.co.uk</p>
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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](#).

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.