

Caring for a person with a stoma:

A practical guide for staff in nursing and residential homes and for home carers

www.ColostomyUK.org

Stoma helpline:

0800 328 4257



Colostomy UK

We are Colostomy UK. Here if you have questions, need support or just want to talk to someone who lives with a stoma.

Your voice on the bigger issues: advocates for your rights and campaigning to raise awareness of what matters to you; running projects to empower you; building communities to support you.

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Contents

Introduction	4
What is a stoma?	4
Why do people have stoma surgery?	4
Three main types of stoma	6
Caring for a person with a stoma	7
Stoma Bags	7
How to change a bag	8
Day-to-day life with a stoma	10
Common problems and concerns	11
Patient worries and concerns: physical and mental wellbeing	14
Further help:	17

Introduction

This publication is relevant to anyone who has the responsibility of caring for a person with a stoma. People with stomas are often known collectively as 'ostomates'. We use this term throughout. After briefly describing what a stoma is and why people have stoma surgery, the booklet goes on to cover the practical aspects of caring for someone with one. This includes everything from ordering their medical supplies and disposing of waste, to diet, changing a person's stoma bag and recognising some of the common problems ostomates suffer, such as sore skin. Consideration is then given to the worries and concerns that people with stomas have and how these can impact on their physical and mental wellbeing.

What is a stoma?

A stoma is a surgically created opening on the surface of the abdomen. In most cases the procedure involves the removal of a damaged or diseased part of the large intestine. The healthy part of the intestine is then brought out through the abdomen, allowing bodily waste to be collected in a bag or pouch.

Why do people have stoma surgery?

People of all ages and sexes have stoma surgery. This is because it is used in the treatment of many different illnesses and conditions. These include: cancer, inflammatory bowel disease (eg ulcerative colitis, Crohn's diseases etc), diverticular disease, new-born malformations, incontinence (arising from, for example child birth), chronic constipation, trauma (which causes damage to the bowel). Some people's stomas are permanent, others have temporary stomas which are later reversed.



Three main types of stoma

There are three main types of stoma:

Colostomy

This is the term used to describe an opening from the colon or large intestine. The stoma is usually sited on the left side of the abdomen. The output from a colostomy differs from person to person, but tends to be more solid and often resembles a 'normal' stool. A colostomy commonly functions between one and three times a day.

Ileostomy

This is the term used to describe an opening from the ileum or small intestine. Typically it is sited on the right of the abdomen. An ileostomy is more active than a colostomy, functioning three to six times a day and the output is looser.

Urostomy

This is the term used to describe a stoma for a person's urine. It is also sometimes referred to as an ileal conduit. A urostomy is formed by taking a piece of the patient's small intestine and attaching the ureters to it, forming a passageway for urine to pass through. One end of the tube is brought out through the abdomen to create the urostomy. Usually the person's bladder is removed too. A urostomy is normally on the right side of the abdomen. Unlike a colostomy or an ileostomy, a urostomy functions all the time.

What does a stoma look and feel like?

A stoma looks a bit like the inside of your mouth. It is soft to the touch, pinkish-red in colour and should be moist. When a person first has stoma surgery, it is normal for their stoma to be swollen. It can take a couple of months to reduce in size.



Caring for a person with a stoma

Stoma bags

There are five main types of stoma bag. Each type is made by a number of different manufacturers. The bag an ostomate uses is determined by the type of stoma they have and also by what they feel most comfortable wearing and most confident changing. The importance of the latter should not be underestimated.

- **One-piece bag:** has an adhesive flange which is attached directly to the skin. After use the bag is disposed of and a new one fitted.
- **Two-piece bag:** consists of an adhesive baseplate which is fitted around the stoma and then the bag either sticks or is clipped to this. Once used, the bag is removed and disposed of, and a fresh bag attached to the baseplate. The baseplate is designed to remain attached to the skin for several days.
- **Closed bag:** are mainly for formed motions. They are more commonly used by people with colostomies. They are usually changed several times a day. Some closed bags have a special liner which contains the motions and can be flushed down the toilet.
- **Drainable bag:** are mainly for more liquid motions. They are commonly used by people with ileostomies. They can be worn for longer than closed bags as they can be emptied through an outlet at the bottom of the bag and then resealed.
- **Urostomy bag:** are for collecting urine. They are worn by people who have had a urostomy. A urostomy bag is drainable and has a tap at the bottom.



One-piece closed stoma bag



One-piece drainable stoma bag



Two-piece closed stoma bag and flange

How to change a bag

Getting ready

Make sure that you have everything you need to hand before you start (adhesive remover, new bag, baseplate, disposal sack, curved scissors, warm water and a towel). A stoma bag is best changed when it is about three-quarters full. Where possible, it is sensible to do changes in the bathroom. A bag can be changed when the ostomate is sitting down but, sitting down can cause the skin to crease and fold, making it trickier to get a good seal between the skin and the baseplate or adhesive flange. Thus, if the ostomate is able to stand for bag changing, this is often preferable. Alternatively, if this is not possible, then changing could be carried out with them lying flat on a bed.

Step one: the template

Begin by checking whether the hole in the adhesive flange/baseplate has been pre-cut to the size and shape of the ostomate's stoma. Pre-cutting is something offered by most suppliers of stoma bags. If it has not been pre-cut use a template to mark the outline of the stoma and, using curved scissors, trim to the correct shape. Getting this right is important. If the hole is too large, then the skin around the stoma will become sore and irritated through contact with the bag's contents. If the hole is too small, then it may rub against the stoma, causing it to swell.



Fig. 1: Correct



Fig. 2: Incorrect

Step two: remove the used flange/baseplate and/or bag

Start by spraying adhesive remover (if required) sparingly along the top edge of the flange or baseplate. Then, remove by peeling away from the skin, top to bottom. As you do this, you should support the skin with your finger. Gently clean the stoma and surrounding skin with warm water and



dry it thoroughly. You should pat dry, rather than rubbing dry. Check the skin around the stoma for any early signs of soreness or irritation. Do not use soaps or baby wipes as these often contain perfume or moisturisers, which can irritate the skin. They can also adversely affect the adhesion of the new flange or baseplate.

Step three: apply new flange/baseplate and/or bag

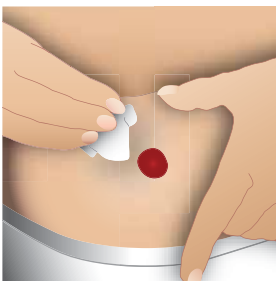
Stick the lower half of the flange or baseplate beneath the stoma and then roll it up and over the stoma. Hold in place for at least 30 seconds to make sure that the seal is secure. If the patient is using a two-piece appliance, then attach the bag to the base plate.

Step four: disposal of used bags

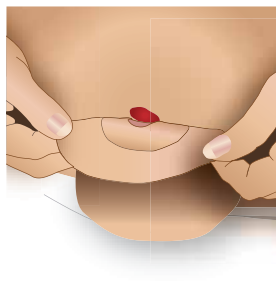
Seal the used bag and used flange/baseplate in a disposal bag. These are often provided free by suppliers. A nappy disposal bag is also suitable. In a nursing or care home, this can then be disposed of with other clinical waste.

Outside of the nursing or care home setting it is advisable to check if your local authority operates a clinical waste collection service. If this service is not available in your area, the used bag and contents can be treated in the same way as a nappy: wrapped up well and put in the dustbin. Prior to doing this, consideration should be given to disposing of the bag contents in the toilet.

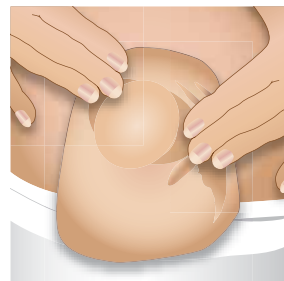
As was mentioned on page 7, some closed bags have a special liner which contains the motions and can be flushed down the toilet.



Step 2



Changing a stoma bag



Step 3

Day-to-day life with a stoma

Obtaining bags and related medical supplies

Stoma bags and related medical supplies are obtained by prescription. Everyone living in the UK who has a permanent stoma is entitled to free prescriptions, whatever their age. However, those under the age of 60 will need to apply for a medical exemption certificate. Application is made using the form **FP92A** (obtainable from hospital or GP surgery).

People with temporary stomas are not automatically entitled to free prescriptions (although they may qualify if their personal circumstances meet other criteria). Full up-to-date details about prescriptions (including eligibility for free prescriptions) can be found at: <https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs>

If the person you are caring for is not entitled to free prescriptions then it may be cheaper to pay for a pre-payment certificate. Up-to-date information can be found at: <https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/prescription-prepayment-certificates-ppcs>

Prescriptions can either be taken to a chemist or sent to a specialist supplier who will fulfil and deliver the order. This process is now often carried out electronically. The stoma care nurse or GP will be able to advise you what system operates in your area.

There are many suppliers and so it is worth recording their details and the product codes of supplies in the space provided at the back of this booklet. Most suppliers also offer a free template cutting service (see page 8). Again, the stoma care nurse or GP will be able to advise.

Diet

In most cases, people with stomas can quickly return to their usual eating and drinking habits after surgery. Sometimes patients are given dietary advice to avoid certain foods as they can cause watery stools or wind for example. But this is patient specific. Generally speaking people with stomas, just like everyone else, should eat a healthy and balanced diet, unless advised otherwise by a healthcare professional.



Colostomy UK's booklet *Healthy eating: Nutritional guidelines for people who have a stoma* provides more detailed information. This can be downloaded free from our website. Alternatively contact us and we will send you a copy.

Bathing and showering

An ostomate's bag can be left in place or taken off while they are in the bath or taking a shower. Water cannot get into the bag or the stoma. If the ostomate prefers to remove their bag, then it is a good idea to schedule baths and showers to coincide with times when the stoma is less likely to be active (eg before, rather than after a meal).

Common problems and concerns

Listed below are some of the problems people with stomas experience. If you are in any doubt, you should always seek medical advice.

Diarrhoea

If a large section of the colon has been removed, or the colon removed entirely, it is likely that motions will always be fairly liquid. It may be easier to use a drainable bag. If motions are usually formed then an episode of diarrhoea could be due to a stomach upset, stress and/or emotional upset or medication. If diarrhoea persists, then you should contact the stoma care nurse or GP.

Constipation

Lack of fruit and fibre in a person's diet can lead to constipation, which can be caused by not drinking enough fluids. It can also be the side effect of medication. If a person's stoma has not worked for several days or there is any pain or vomiting then you should seek medical advice. Unless prescribed by a doctor or stoma care nurse, you should not give an ostomate suppositories or enemas.

Leakage

It is not normal for stoma bags to leak. When they do, it is time to consult the stoma care nurse. It may be that the size of the stoma has changed and thus requires measuring for a new template. Similarly, changes in a person's weight and/or body shape can cause leakage. The stoma care nurse will be able to suggest alternative bags or accessories to resolve the problem.

Sore skin

If the skin around the stoma becomes red and inflamed this can be due to damage caused to the skin when removing the flange/baseplate. Using an adhesive remover may help to prevent this. With a two-piece or drainable bag, the flange/baseplate remains in place for several days, which reduces damage to the skin.

Sore skin can also result from contact between the contents of the bag and the skin. Stomas can change in size and shape, so check the size of the stoma every few months to make sure the hole in the flange/baseplate fits snugly around the stoma (see fig 1, page 8).

If the problem persists, then it is time to consult a stoma care nurse.

Pancaking

This occurs when, instead of dropping to the bottom of the bag, the motion collects around the stoma and may seep between the flange and the skin. One of the reasons for this happening is insufficient air in the bag, which leads to the sides of the bag sticking together. It may help to cover the bag's filter with a sticky patch, to prevent gas escaping from the bag. Another solution is to add a small piece of crumpled tissue to the bag to keep the sides apart. Lubricating the inside of the bag with baby oil, or one of the special lubricants available from stoma suppliers can also help the motion to drop to the bottom of the bag.



Ballooning

This occurs when gas expelled from the stoma collects inside the bag, causing it to inflate. Most bags have a filter on them, which allows gas to escape. Occasionally, this filter will become blocked, leading to ballooning. This can happen for example if the filter gets wet. Hence, when bathing it's a good idea to cover the filter with a sticky patch (supplied with bags). When ballooning occurs, it is a signal to change the bag. If ballooning occurs on a regular basis it may be worth trying a different bag (either type of bag or manufacturer of bag, or both). The ostomate's stoma care nurse will be able to advise.

Bleeding

A stoma can bleed if it is rubbed too hard. It is also likely to bleed more easily, if the ostomate is taking anticoagulant drugs (eg Warfarin or aspirin). If the stoma bleeds and does not stop, or the blood is coming from inside the stoma, you should consult a stoma care nurse, without delay.

Rectal discharge

It is normal for ostomates who still have their rectum in place to pass clear or putty-coloured mucus out through their anus. This occurs because the lining of the bowel produces mucus as a lubricant to assist the passage of food and waste. Even though motions will now pass out through the stoma, the rectum continues to produce mucus, although the amount may decrease over time. You can read more in **Colostomy UK's** booklet: *Rectal discharge following stoma surgery*. Download a copy from our website, alternatively e-mail: info@ColostomyUK.org or call us **0118 939 1537** and we will send you one.

Rectal discomfort

After stoma surgery some ostomates still experience the sensation of rectal fullness and feel as if they need to pass a motion in the normal way. Sitting on the toilet and relaxing the muscles in this area may provide some relief. Other coping strategies and treatment options are discussed in **Colostomy UK's** booklet: *Pain and discomfort following stoma surgery*. Download a copy from our website, alternatively e-mail: info@ColostomyUK.org or call us **0118 939 1537** and we will send you one.

Patient worries and concerns: physical and mental wellbeing

It is important to remember that when a person has stoma surgery it is usually because they have been very unwell for some time. It is major surgery too, which alters the way in which the patient's body functions. In the post-operative period, ostomates often feel emotionally overwhelmed. It also takes them time to come to terms with what they have been through. The amount of time this takes varies from ostomate to ostomate. Some, never fully adjust to life with a stoma. Ostomates commonly worry about body image and how they 'look', even though their condition is 'hidden'. Many also harbour concerns that they might 'smell' or that their bag might leak. In extreme cases this can lead to isolation and problems with mental health. In caring for a person with a stoma it is important to aware of these things and seek the help of a healthcare professional if you become concerned.





Research shows that being physically and mentally active benefit a person's physical and mental wellbeing. Ostomates are no different. The central aim of **Colostomy UK's** 'Active Ostomates®' initiative is to support the physical and mental wellbeing of ostomates. 'Active Ostomates®' is constantly developing and with each year that passes we add more activities, challenges and events. Some are delivered via support groups, such as **Chair Yoga** and our **Creative Minds Arts** sessions. Others are things that people can do in the comfort of their own home, such as the medically-approved exercises, which form part of our booklet: *Active ostomates: Sport and fitness after stoma surgery*. You can download this resource, which won 'highly commended' at the British Medical Association Patient Information awards in 2017, from our website. Alternatively e-mail: **info@ColostomyUK.org** or call us **0118 939 1537** and we will send you one.

To find out more about Active Ostomates and how the person you are caring for might get involved and benefit, we recommend you visit our website. This is the place to find the most up-to-date information.

Other considerations – Dementia

Caring for an ostomate who develops dementia, or caring for a person with dementia who then goes on to have stoma surgery, can be challenging. It is for this reason that **Colostomy UK** have partnered with Dementia UK to produce a booklet called: *Caring for a person with a stoma and dementia*. You can download a copy from our website, alternatively e-mail: **info@ColostomyUK.org** or call us **0118 939 1537** and we will send you one.





Further help

Care workshops

Colostomy UK run workshops for professional carers and family carers. These are delivered by healthcare professionals and expand on the many issues covered in this booklet. Our care workshops and this booklet complement one another. To find out more please visit our website, e-mail: info@ColostomyUK.org or call us **0118 939 1537**.

Signposts

- **Carers UK**
Information on benefits, rights and services available to carers.
Website: www.carersuk.org
- **Carerstrust**
Provide support for carers and the people they care for.
Website: www.carers.org

Support from Colostomy UK

We hope that you have found this booklet useful. There are lots of other ways in which we can help and support you:

We provide:

- A stoma helpline: **0800 328 4257**.
- Support literature and factsheets about all aspects of *Living with a stoma*.
- *Tidings*, a quarterly magazine full of the latest news, articles by healthcare professionals, product information and real-life stories from other ostomates.
- A private Facebook group for supporting each other and exchanging hints and tips.
- A website that provides practical information, details of open days and a directory of organisations, support groups, products and services.

We also have over 100 volunteers that have or have had a stoma(s), so if you still have any concerns or questions please get in touch and we can arrange for one of them to contact you.



Patient Profile: An at a glance reference guide for carers and ostomates

Name: (Mr/Mrs/Miss/Ms) _____

Address: _____

_____ Postcode: _____

NHS No: _____ Date of Birth: _____

Telephone No: _____

Hospital/Outpatients attended: _____

About the Stoma:

Stoma Type: Colostomy Ileostomy Urostomy

Stoma Size: _____ (mm) Template: Yes/No _____

Medical supplies used:

Date: _____ Name/Type of supply _____ Item Code: _____

Manufacturer's Name & Tel No: _____

Supplier/Delivery Company:

Date: _____ Name of Supplier _____ Tel No: _____ Order Ref: _____

Main Contacts:

Colostomy UK: **24-hour stoma helpline: 0800 328 4257** Tel No: **0118 939 1537**

Stoma Nurse: _____ Tel No: _____

GP/Practice: _____ Tel No: _____

Consultant/Surgeon: _____ Tel No: _____

Pharmacist: _____ Tel No: _____

Medical Helplines:

NHS Direct (England): **www.nhsdirect.nhs.uk** Tel No: **111**

NHS Direct (Scotland): **www.nhs24.com** Tel No: **111**

NHS Direct (Wales): **www.nhsdirect.wales.nhs.uk** Tel No: **0845 4647**

Colostomy UK's flagship magazine *Tidings*, is hailed by ostomates and healthcare professionals alike for the support and information that it provides readers with on a quarterly basis.

Visit our website or call us to sign up for your free copy.

How to contact us

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