Supporting and empowering ostomates

Colostomy UK

How will a colostomy affect me?

Information for patients before stoma surgery

www.ColostomyUK.org

Stoma helpline:

0800 328 4257

365 DAYS

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.

This booklet seeks to address concerns that you, a family member, or carer might have about a colostomy. Your surgeon or stoma care nurse will also be able to answer questions that you have both pre and post–operation.

Contact us

Write to:
Colostomy UK
100 Berkshire Place
Winnersh
Wokingham
Berkshire
RG41 5RD

Adminline:
Tel: 0118 939 1537

Stoma helpline:
0800 328 4257

E–mail
hello@ColostomyUK.org

Website:
www.ColostomyUK.org

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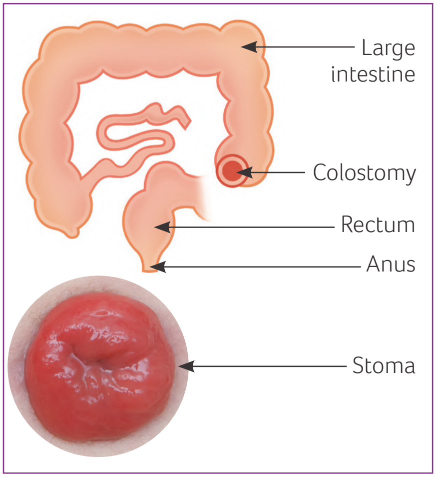
What is a colostomy?

A colostomy is an operation to divert one end of your colon (which is a part of your bowel) through a surgically created opening in your abdomen. This opening is known as a 'stoma'. A removable colostomy bag is then attached to it, which will collect your faeces (poo). Just like before your operation, the consistency of your faeces will vary. Likewise you can still become constipated or have diarrhoea. You will pass urine as usual.

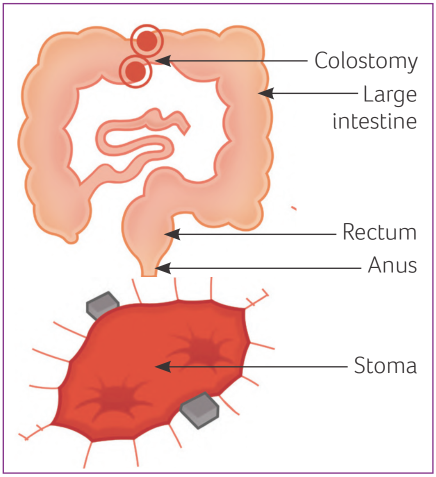
What will it look and feel like?

Your colostomy will either be an end or a loop colostomy (see diagram below), your surgeon or stoma care nurse will tell you which you will be having and explain the differences. Colostomies are normally situated on the left–hand side of the abdomen. They are usually referred to as a stoma and that's the term we will be using from now on. A stoma looks a bit like the inside of your mouth and is soft to the touch. It will be pinkish–red in colour and should be moist. At first, your stoma may be swollen and could take a couple of months to reduce in size.

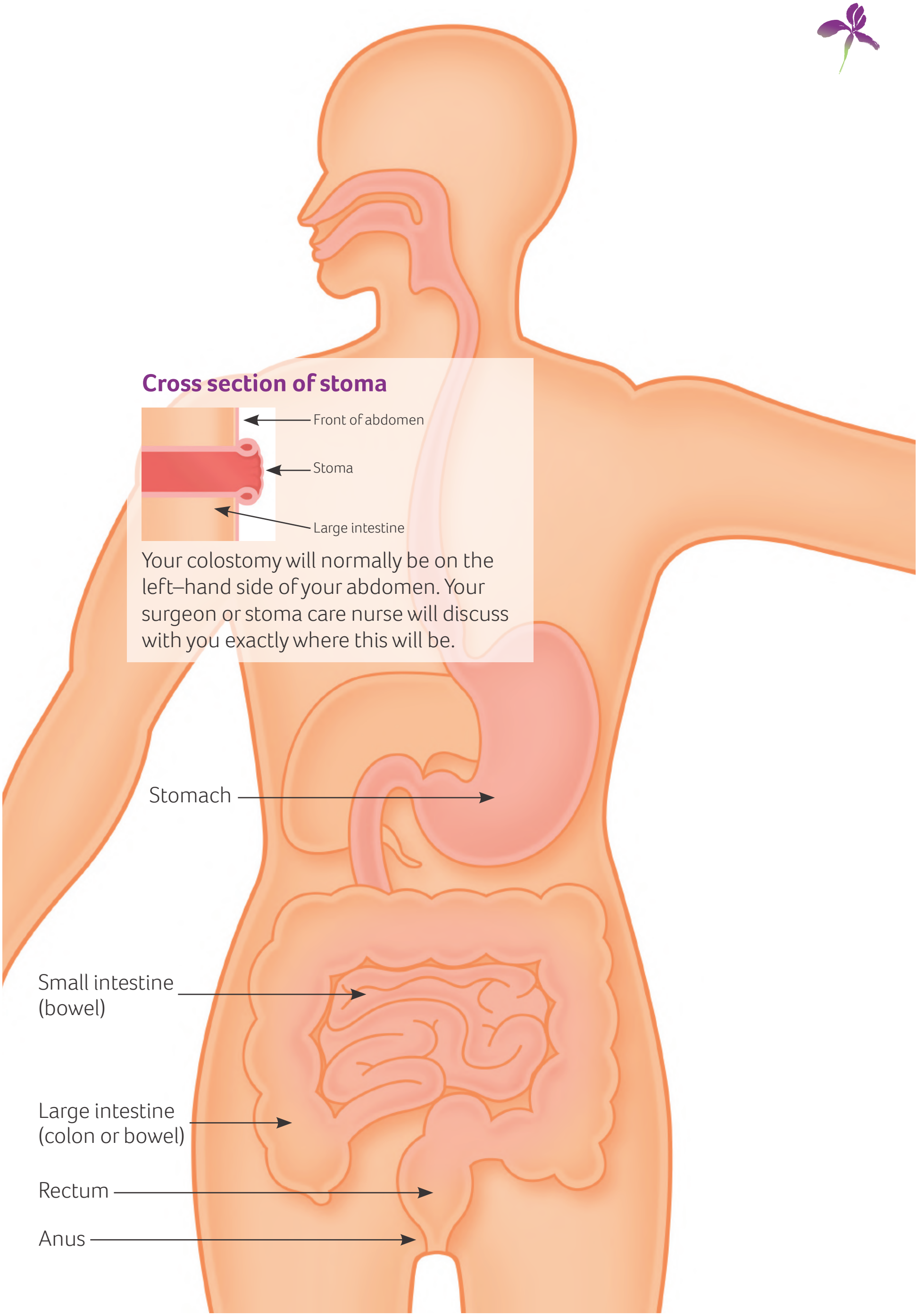
End colostomy



Loop colostomy



Cross section of stoma



Your colostomy will normally be on the left–hand side of your abdomen. Your surgeon or stoma care nurse will discuss with you exactly where this will be.

Will I always have a stoma?

Whether your stoma is permanent or temporary will depend on the reason for your operation. Your surgeon will tell you which you will be having. If s/he plans to join your bowel back together again, then you will need another operation at a later date. Either way, you will need to learn how to manage your stoma and you will go home wearing a stoma bag.

Where will my stoma be?

When you have a colostomy, your stoma is normally situated on the left-hand side of your abdomen. It also needs to be positioned in a place that isn't lost in folds of skin when you sit down or stand up.

Before your operation, the stoma care nurse will usually mark where the stoma should be formed as a guide to the surgeon. It will be in a position where you can see it so that you can easily change your stoma bag. Sometimes, it is not possible to put the stoma in the exact position marked by your nurse.

If you need a stoma in an emergency, it may not be possible to decide on a position beforehand.

How do I care for my stoma?

You will need to wear a stoma bag to collect your bowel motion. There are a wide variety of stoma bags to choose from and also different methods for managing them. Your stoma care nurse will discuss these with you. The stoma bag sticks to your abdomen and you will need to change it regularly. Your stoma care nurse will explain how to look after your stoma and how to change your bag.

Most stoma bags are about the size of this page. They are designed to be worn under normal clothes. Many have air filters to absorb smells and allow wind to gradually escape. Stoma bags are usually covered in a soft material, which helps to make them comfortable to wear.

When you have a bath or a shower you can either leave your stoma bag on or take it off. It’s up to you. Water cannot get into either the bag or your stoma.

Will it smell?

It will smell, but only when you are emptying or changing your bag. Remember, everyone produces smells when they go to the toilet. There should be no smell at other times, because stoma bags are odour–proof. That said, some ostomates remain concerned about smell. As a consequence many stoma care manufacturers produce odour neutralisers which can be put inside the bag for extra confidence. If, however, you notice a smell outside of the normal bag changing routine, then it is usually an indication of a poorly fitting bag. If this happens to you then contact your stoma care nurse who will be able to help.

Leaving hospital

When you leave hospital you will be given some stoma bags. Your stoma care nurse will explain how to obtain prescriptions for further supplies. You can give your prescription to your specialist supplier or local chemist. You can choose where you get your bags from and which make of stoma bag you want to use. You need to feel as comfortable as possible when you're wearing the bags, so it is important to choose the ones that suit you best.

Prescription charges

If you live in England, are under the age of 60 and have a permanent stoma you will need to apply for a prescription exemption certificate. You do this by completing form **FP92A** (obtained from your GP Surgery) and returning it to your doctor. Once you have this certificate your prescriptions will be free of charge.

You will not be entitled to free prescriptions if you have a temporary stoma and live in England. If you think you will have to pay for three or more prescriptions in three months, or 13 or more items in 12 months, you may find it cheaper to buy a prescription prepayment certificate (PPC). If you have been told that your stoma may be temporary, please discuss this with your surgeon, stoma care nurse or GP.

Prescriptions in Scotland, Wales and Northern Ireland are free of charge.

Using stoma bags

Changing a bag

Your stoma care nurse will show you how to change your bag while you are in hospital. Further details on changing a bag are available in our *Living with a stoma booklet.*

Disposing of used bags

There are a number of options:

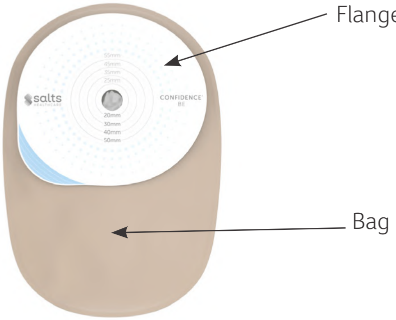
- Empty the used bag and seal it inside a disposal bag (provided free by suppliers) and discard with your normal household waste.
- If it is not practical/acceptable to empty the used bag, contact the environmental department at the local council to enquire if they operate a domestic clinical waste collection service.
- Bags with liners that contain the waste and can be flushed down the toilet are now available.
- Some ostomates keep a bin designed for nappy disposal in the bathroom. These systems seal each used bag individually within a polythene film and control odour until the bin can be emptied.

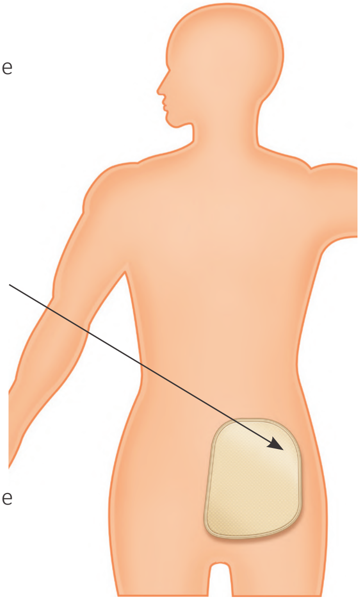
Types of bags

There are many different stoma bags. They are made by a number of different stoma care companies. Your stoma care nurse will help you decide which one is best for you.

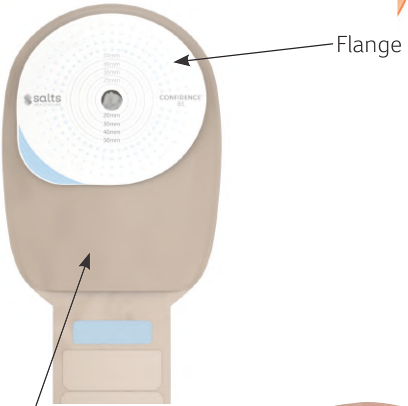
- **One–piece system** where the adhesive flange is attached to the bag and after use the complete bag is removed and replaced with a new one.
- **Two–piece system** which consists of an adhesive base–plate that is fitted snugly round the stoma and a bag that either sticks or clips onto the base–plate. The bags can be changed quickly, without removing the base–plate, thus avoiding disturbing the skin.
- **Closed bags.** These are mainly used for coping with formed motions. They are usually changed two or three times a day. Closed bags with a special liner that can be flushed down the toilet are also available.
- **Drainable bags.** These are mainly used for coping with liquid motions. They can be worn for two or three days as they can be emptied through an outlet at the bottom and then resealed afterwards (using an integral Velcro seal or a clip).
- **Mini–bags and stoma caps.** These have a limited capacity and are designed for wearing for a short time, when the stoma is likely to be less active.

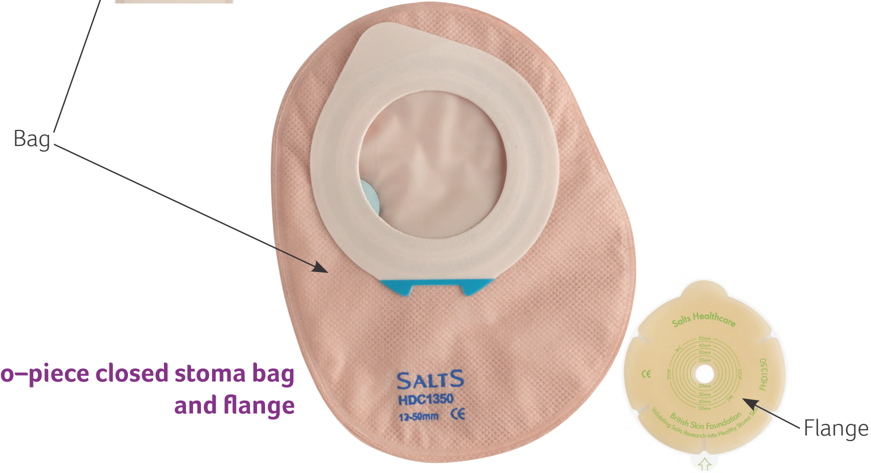
One–piece closed stoma bag





One–piece drainable stoma bag





Two–piece closed stoma bag and flange

Bag and flange pictures used by kind permission of Salts Healthcare

What can I eat?

You should try to eat regular, well–balanced meals. This can include all your favourite foods. Remember to chew your food properly to help your digestive system.

You may find that certain foods produce more wind from your stoma than others. If this bothers you, simply cut down on these foods. Many people find that keeping a food diary is helpful to begin with. You will soon find a balance of food that is right for you.

It is important that you drink plenty of fluids, especially water. Alcohol is fine in moderation, but beer and lager can produce wind and cause the output from your stoma to become more liquid.

If you feel you are underweight or overweight, please discuss this with your stoma care nurse.

Getting the balance right with your diet is as important for you as it is for the rest of the population. Following your surgery, and if you have been ill, it is even more important that you eat well to allow for a full recovery.

The Eat Well Plate

Fruit and vegetables – choose a wide variety

Bread, other cereals and potatoes – eat all types, choose high fibre whenever you can

Meat, fish and alternatives – choose lower fat alternatives whenever you can

Milk and dairy foods – choose lower fat alternatives whenever you can

Fatty and sugary foods – try not to eat these too often and, when you do, have small amounts

Source: Department of Health in association with the Welsh Government, the Scottish Government and the Food Standards Agency in Northern Ireland. Crown Copyright 2007.

How can I make sure I get my 5–a–day?

Many patients with stomas find getting their recommended 5–a–day difficult, due to the high fibre content of fruit and vegetables. If you have this problem, then the tips below may help you to increase your fruit and vegetable intake whilst avoiding undesirable side effects:

- Try peeling your fruit and vegetables to reduce the fibre content.
- Try fruit smoothies such as blended strawberry and banana with a little milk or yogurt.
- Cook your vegetables well and try steaming which helps vegetables to retain their water soluble vitamins.
- Choose fruit which is soft and ripe: nectarines, peaches, melons and mangoes, for example, are well tolerated by most people.
- Try vegetable juice for a nutritious vitamin boost.
- Root vegetables such as carrots, swedes, squash and parsnips are usually well tolerated and are delicious roasted, mashed or made into soups.
- Vegetable soups which have been blended and sieved are a low fibre option for people with stomas.

If you feel that you cannot eat as many fruit and vegetables as you need, it is worth speaking to a health care professional about taking a good quality vitamin and mineral supplement.

Are there any foods ostomates should avoid?

We are all different. Some ostomates can eat anything, while others have found by experience it is best to avoid certain foods.

If you suspect a food causes you problems, try it at least three times, separated by an interval of a couple of weeks, before eliminating it altogether. Keeping a food and symptom diary and looking for a trend can sometimes help to identify a food which may be causing a problem.

Are there any things I should or shouldn’t do?

The important thing is to be guided by your body.

Do:

- Give yourself time to get over your operation.
- Take plenty of rest and let your body recover.
- Try to take short walks, but remember not to go too far as you have to be able to get home again.

Don’t:

- Lift anything heavier than a kettle for about eight to 12 weeks following your stoma surgery and, even then, don’t overdo it (times can vary depending on your operation).
- Attempt abdominal exercises (e.g. sit-ups) for about eight to 12 weeks following your surgery.
- Drive until at least six weeks after your surgery and then only when you feel confident enough to do so. (You should also check with your motor insurer as policy conditions can vary).

Will my stoma change my life?

In some ways it will. You've just had a major operation. Your body has been altered and it may take a while to get used to how you look. Likewise, you have to get used to caring for your stoma and changing your stoma bags. However, that's as far as it should go. With some adjustment, the rest of your life does not need to change. In the early days you might find it useful to talk to someone who has a stoma. Call us if you would like to arrange this, alternatively speak to your stoma care nurse.

You might also find our booklet Living with a stoma: Information for ostomates and their carers useful. You can download this free from our website, or give us a call and we will send you a copy.

Can I go back to work?

Yes, but you will need time and rest so listen to your body. Everyone is different when it comes to how long it will take to get back to work. It also depends on the type of work that you do and the operation you have had. You should discuss this with your stoma care nurse, surgeon or GP.

Can I go on holiday?

Yes you can. A stoma doesn't stop you from travelling, either at home or abroad. But give yourself time, start with a short trip and see how it goes. If in doubt, ask for advice. We produce a useful booklet on travelling and your stoma care nurse should be able to advise you too. Remember, that if you are travelling abroad you will need insurance cover for any medical conditions that you have. Insurance companies call these 'pre-existing conditions'. Above all, enjoy your holiday.

Hobbies and sports

Keeping fit and having interests is good for everyone and having a stoma shouldn’t prevent you from doing most things. Special small stoma bags are available for when you are swimming or playing sport. Your stoma care nurse can give you details.

Our booklet ***Active Ostomates: Sport and Fitness after stoma surgery*** provides more in–depth information and also contains a range of safe and simple exercises you can do to get you back on track. To receive a copy just give us a call or visit our website and download it straight away.

Will it affect my sex life?

Most people with a stoma can enjoy a healthy sex life.

Some ostomates feel more comfortable wearing attractive underwear, use a cummerbund to conceal/ support the bag or use a bag cover.

Mini–bags and stoma caps are also available

If the rectum is removed during stoma surgery:

- Some women may experience a different sensation, pain or dryness in the vagina during intercourse. This can be helped by using a lubricant.
- Some men may experience difficulty in getting an erection. This can be successfully treated in 90% of cases.

Should you experience any such problems do not be embarrassed to discuss them with your surgeon or stoma care nurse. Colostomy UK has a number of male and female volunteers who are willing to talk in confidence about any concerns.

See our factsheets for further information.

Pregnancy and contraception

Many women have normal, successful pregnancies after stoma surgery.

Before your operation it is important to consider fertility issues, particularly if other treatments are part of your medical plan. Oral contraceptives may not be fully effective after your surgery, so you may need to consider another type of contraception. We recommend that you discuss this with your stoma care nurse or GP.

Risk and benefits

Your consultant will outline in detail the risks associated with your operation. These will also be included in your 'consent to operation' form. Your consultant will also explain the potential benefits of having surgery.

What should I do if I have a problem?

If you have any problems or concerns, always talk to your stoma care nurse or GP. The sooner they are aware of any problem, the sooner they can help sort it out.

Changes to your stoma

If you notice any changes in the shape, colour or working of your stoma, talk to your stoma care nurse or GP.

Leaks and accidents

Your stoma bag may leak occasionally. However, your stoma bag should not leak regularly, and you should speak to your stoma care nurse or GP if this happens.

If your stoma shrinks

Check the size of your stoma regularly because it may shrink and you may have to change the hole size on your stoma bag.

Sore skin

Your skin could become sore for many different reasons. If this happens, your stoma care nurse will be able to recommend the right treatment for you.

Bleeding

Don't panic if the outside of your stoma bleeds. This is fine and shows it is working normally. If there is a lot of blood, or if the blood comes from inside the stoma, you must contact your stoma care nurse or GP.

Hernias

If you notice a small bulge around your stoma, you may have a hernia and so you should contact your stoma care nurse or GP.

Abdominal pains

Some discomfort is normal after an operation. This will gradually disappear and ordinary painkillers will help. However, if you have prolonged or severe pain you should contact your stoma care nurse or GP.

Changes in how your stoma works

Remember the consistency of your bowel motion can vary and you can still become constipated or have diarrhoea. However, you should talk to your stoma care nurse or GP if you have any long–term problems.

Who can I ask for advice?

There is a lot of information available. It is possible that much of this will not be relevant to you. The following will be able to provide practical help and advice.

- **Your surgeon**
- **Your stoma care nurse**
- **Your GP**
- **Your community nurse**
- **Colostomy UK**

Some people find it helpful to meet other people with stomas who are now enjoying a full and active life. This is something that you can arrange through your stoma care nurse or by calling us. We will be pleased to help.

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:

- Our free Stoma helpline: **0800 328 4257.**
- Information booklets, leaflets and factsheets about all aspects of *living with a stoma.*
- *Tidings,* a quarterly magazine full of the latest news, articles by stoma care 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 (all ostomates), so if you still have any concerns or questions please get in touch and we can arrange for one of them to contact you.

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Useful Information

Main Contacts:

Consultant/Surgeon: **Tel No:**

Hospital/Outpatients: **Tel No:**

Stoma Care Nurse:

Stoma Care Department/Hospital/Community:

Tel No:

GP/Practice:

Tel No:

Name of Pharmacist: **Tel No:**

Colostomy UK: **Stoma helpline: 0800 328 4257** **Adminline: 0118 939 1537**

Medical Helplines:

NHS Direct (England)	**www.111.nhs.uk**	**Tel: 111**
NHS Direct (Scotland)	**www.nhs24.scot**	**Tel: 111**
NHS Direct (Wales)	**111.wales.nhs.uk**	**Tel: 111**

List of your stoma care supplies:

Supplier/Company:	Product name:	Ref No:	Product Type:

Stoma support charities in the UK

Colostomy UK

IA®

The ileostomy & internal pouch

Support Group

Listen • Inform • Support

UROSTOMY ASSOCIATION

three organisations :

one aim : you :

www.stomasupport.org

This booklet is intended for general information and guidance only. **Colostomy UK** would like to take this opportunity to thank:

Dr Iain Murray – Consultant Gastroenterologist (Royal Hospital Cornwall)

for his assistance in the production of this booklet.

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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Berkshire, RG41 5RD

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Stoma helpline: 0800 328 4257

E-mail: hello@ColostomyUK.org
Website: www.ColostomyUK.org

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