



ConvaTec

Living

with a colostomy



Part one - before surgery
and during your hospital stay

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Introduction

This is the first booklet in a series of three produced by ConvaTec. We have written it with specialist stoma care nurses to provide you with useful information before and following your bowel operation, where you may have or have already had a stoma created.

If you are shortly to go into hospital or are currently in hospital waiting for bowel surgery, which could lead to a colostomy stoma (referred to as a colostomy), this booklet is for you. We try and explain what a colostomy is and why you need one, and hopefully answer some of the many questions you may have.

ConvaTec is one of the world's leaders in making and supplying stoma equipment. We have prepared this booklet for people living with a colostomy. Later in the booklet we will discuss how our bags (appliances) can help you to manage your colostomy and we outline some other services that we can provide to help you.

One thing to remember is that you are not alone. There are at least 1.7 million people in the world today living active, productive lives with a stoma. (See note 1 below.)

The booklet may help you to focus on the reasons why you are having the operation, for example, to reduce pain, or to improve your symptoms by removing the illness that is causing it, with the goal of improving your general health.

As you wait for surgery, it is perfectly normal to feel anxious. Although you may have discussed the procedure with your surgeon (and other health-care professionals) you may still have other questions. Knowing what to expect can help you feel prepared.



1: An overview of the ostomy market and ConvaTec's ostomy model. Global Business Intelligence Analysis 2009. December 2009. Data on file, ConvaTec.

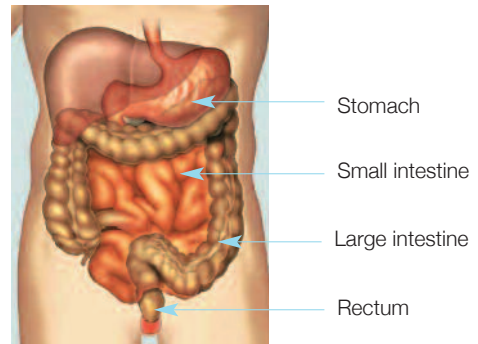
What is a colostomy?

A colostomy (or stoma) is when an opening is made on your tummy (abdomen). A piece of your large bowel (colon) is brought through this opening and stitched to your tummy to form a new exit for the waste product from your bowel. You wear a bag (also called an appliance or pouch) over your colostomy to collect waste from your bowel. All stomas are as individual as you are. They vary in size, shape, and where they are on your body.

The stoma may look like the image below. It sticks slightly out of your tummy (abdomen) and is red like the inside of your mouth. It has no nerve supply, so does not hurt when you touch it. However, you need to look after it carefully. You will be given help and advice so you can learn how to look after it.



A colostomy is created out of the end of the large bowel (colon) to get rid of the waste from your digestive system. To help explain further we will start with a description of the digestive system and how it works. The digestive system is basically a pipe, which takes food from your mouth to your bottom. As food travels through the stomach, small intestine and large intestine, it is broken down and nutrients we need are absorbed into the body. The left over waste products we don't need are passed through the rectum.



Where will my colostomy be placed?

The colostomy is usually placed on the left hand side of your tummy.



Reproduced with kind permission from St George's Healthcare NHS Trust, UK

Why do I need to have a colostomy?

The most common reason for a colostomy is as part of the treatment for bowel (colorectal) cancer. Part of the bowel (colon or rectum) where the cancer is, along with some bowel either side of the cancer, is removed during the operation. You may also need other treatment (such as radiotherapy or chemotherapy).

You may need a colostomy if you have severe diverticulitis. This is a condition where small pouches in the wall of the large bowel (colon) become inflamed and infected.

A colostomy may also be suggested as a treatment for inflammatory bowel disease (IBD) such as Crohn's disease.

Occasionally long-term bowel problems such as constipation, diarrhoea or incontinence may mean you need a colostomy.

You may need a colostomy in an emergency if you have had injury to your tummy, bottom or pelvis or because of a bowel obstruction.

Who will be involved in my care?

You will be seen before your surgery by the surgeon, nursing staff and usually a stoma care nurse. You may see your stoma care nurse at home, in your GP's surgery or hospital. In some cases, other therapists for example, dieticians and physiotherapists may also be involved.

Your specialist stoma care nurse

The stoma care nurse (sometimes called an enterostomal therapist) is responsible for helping you to learn to cope with your colostomy and will guide you in choosing and getting the supplies that you will need and all other aspects of caring for your stoma. They are specialists and will be able to talk to you in more detail about the operation and answer any questions you may have.

When you meet your stoma care nurse for the first time, they will find out as much as possible about your lifestyle and needs and take this into account when recommending the best place for your colostomy. However, the final positioning of the colostomy is up to the surgeon who is carrying out your operation.

Discussion at this stage will probably focus on where your colostomy may be placed (sited) and whether your colostomy will be temporary or permanent. This is a good opportunity to ask questions and raise concerns and worries because your understanding and involvement at this stage may help you to cope later.

If you would like to meet someone who has had a stoma, your stoma care nurse will be able to organise this for you.



What questions should I ask?

When we are in stressful situations we often forget all the things we would like to ask. It can help to prepare a list of questions to ask your health-care professional.

Here are a few suggestions.

- ▶ Where will my colostomy be (position, size)?
- ▶ What will my colostomy look like (size, colour)?
- ▶ How does the colostomy work, how often and how much will it release?
- ▶ Will people be able to see my colostomy under my clothes?
- ▶ What does a bag look like (size, type, colour, style)?
- ▶ How do I change the bag?
- ▶ Will the bag leak?
- ▶ Where do I get supplies?
- ▶ How much do they cost?
- ▶ Will I have to change my diet (food and alcohol)?
- ▶ When can I go back to work?
- ▶ Will I be able to go out with family and friends?
- ▶ How will it affect my sex life?
- ▶ Will I be able to travel?
- ▶ Where can I get help and support?
- ▶ Will I need any special care when I get home from the hospital?
- ▶ Will my medical insurance cover the procedure?
- ▶ Will I be able to go on holiday?



How will I feel when I first wake up?

Many people are worried about having a general anaesthetic, and how they will feel afterwards.

When you wake up you may be in an intensive-care unit (ICU) or high-dependency unit (HDU) for a day or two after your operation. This is so that your doctor and nurses can keep a close eye on you. When you first wake up, you may have a heart monitor connected to you.

Once you have recovered a little from the anaesthetic, the nurses and physiotherapists will help you to move around as soon as possible. Even when you are still in bed, they will help you to do deep breathing and leg exercises to support your recovery.

To start with you are likely to have a drip (intravenous infusion) in your arm to give you fluids until you are eating and drinking. You may also have some different tubes in place.

This can be a bit frightening but it helps to know what they are all for.

You may have the following.

- ▶ One or more thin tubes called 'wound drains' into the operation area to drain away any blood and tissue fluid that collects.
- ▶ A tube down your nose into your stomach (nasogastric tube) to drain fluid and stop you feeling sick.
- ▶ A tube going into your back (epidural) to give painkillers into the space around your spinal cord, or drip which delivers pain relief directly into a vein (either of these are very effective.)
- ▶ A catheter into your water-works (bladder) to drain urine away.
- ▶ A bag over your new stoma.

The stoma will be swollen just after your operation but will get smaller as it heals. It may take up to eight weeks after your operation for it to get smaller. It may also take a few days for your colostomy to start working (producing waste matter) while your body recovers from the operation. At first the nursing staff will manage this for you and gradually teach you how to care for your stoma on your own.

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How long will I be in hospital for?

The nursing staff will get you up out of bed - usually the day after your operation - and help you to start walking soon after this. Generally, people are up and about and can move on their own three to four days after their operation.

The length of time you are in hospital will depend on you (how fit you are and so on), but it can be anything up to 14 days.

While you are in hospital your stoma care nurse and ward nursing staff will teach you how to use and change your bag (pouch or appliance) and help you choose a bag that is appropriate for you. Your stoma care nurse will also advise you about getting further supplies.

It is normal for many people who have just had a colostomy to feel out of control when their stoma begins working and it can take time to adjust to this as the stoma settles down. In time it may develop a pattern or work in a more predictable way as some people's bowels do. Over time you will find out what is normal for you. It is likely you will not be able to control your wind (flatus). Modern bags have a filter which will release the wind without smell.



Your doctor will advise you about how soon you will be able to get back to doing everyday things such as work, driving, shopping, gardening or playing sport. Everyone is individual; so give yourself time to fully recover.

When you leave hospital, the hospital will send a letter to your GP outlining your treatment. Also, if necessary, they will arrange a visit from a district nurse for you. The stoma care nurse will also arrange to see you either at home or in the clinic to make sure you are confident about caring for your stoma effectively.

The hospital will send you an outpatient appointment. This will be a check-up following your surgery and is a good time to discuss any concerns you may have after your operation.

How do I choose an appropriate colostomy bag (appliance)?

While you are in hospital you may be shown two types of colostomy bags.

- ▶ One-piece appliance, for example ConvaTec's Esteem® range.
- ▶ Two-piece appliance, for example ConvaTec's Natura® range.

When using the imitation stoma coach in this pack, your stoma care nurse will show you these bags so you can have a look at them to see how they may feel.



How soon will I get back to 'normal'?

The time it takes to get better after surgery varies but usually you should notice improvements after about six to 12 weeks. During the first six to eight weeks at home you should avoid driving and any strenuous tasks or activity – even housework will have to wait for a while!

What will the new 'normal' be like?

During the first few months after surgery it is important to recognise that you and your family will be undergoing a major period of change. Having a colostomy means you must adapt to a new 'normal' way of life.

Up to the first eight weeks after your operation your colostomy will shrink in size. Your stoma care nurse will help you to make sure your bag fits correctly to prevent common problems for example, sore skin. This will also make sure that you feel confident wearing your bag so you can get on with your normal life.

Living with a colostomy will take some adjustment. You may find yourself struggling because of your new self-image or because you find it difficult to cope.

If you do remember the following.

- ▶ **Be patient** - don't be too hard on yourself. Some days will be better than others, and in time you will feel like yourself again.
- ▶ **Keep talking** - talk about your feelings with a loved one or carer. You may find that talking makes you feel better.
- ▶ **Try to stay active**, and get back to your usual routines or take up a hobby. Maybe, in time, get involved with a group. You can find contact details of the Colostomy Association at the back of this booklet.

If the difficulties don't get better, contact your GP or stoma care nurse who may be able to offer you specific advice or suggestions.

Being active and setting yourself small and achievable goals can help you feel in control and as if you are making progress. Learning to relax can also help with this.

Learn how to relax

When we feel stressed or anxious, we can experience bodily symptoms and discomfort that add to our feelings of stress. We have included some hints and tips for you to practise and hopefully find useful throughout this period.

While relaxing with a good book or watching TV can be a distraction, learning to physically relax the body to get rid of tension has many benefits. It can relieve the build-up of tension and help us feel that we can cope better. The more we physically relax, the more we can mentally relax.

Get yourself comfortable

- ▶ Find a quiet spot where you won't be disturbed by interruptions or too much noise.
- ▶ Make sure you will be warm, are not hungry or have just eaten.
- ▶ Whether you are lying or sitting, use pillows and cushions to support your body, and loosen any tight clothing.
- ▶ Try to feel passive. In other words try not to force the relaxation to come – allow it to grow and develop.
- ▶ Your mind will inevitably wander, just keep bringing it back to the task of relaxation and tell yourself this is normal and OK.

- ▶ Make a commitment to practise. It is a skill that you may need to learn (or re-learn) so give yourself a chance to make it work.



Getting started

Learn the instructions and exercises before you start. Concentrate on the breathing and the exercises because they work together to give you the best result.

Breathing

- 1 Take three deep breaths in, making sure you breathe in through your nose and out through your mouth.
- 2 Try a counting exercise like this one.

“Breathe in 2....3 and out 2....3....4...., and in 2....3.... and out 2....3....4....”

- 3 Then just try and keep your breathing slow, making sure you raise your rib cage when you breathe in (diaphragmatic breathing).

Progressive muscle relaxation

- ▶ Start by breathing gently and evenly, using the counting to help you. Close your eyes if you would like to.
- ▶ Then, thinking about the top of your head to the tips of your toes do a quick body scan to make sure you are as comfortable as you can be. Shift yourself around to make that happen.
- ▶ Think about the muscles in your body starting with your hands. Just clench your right hand tightly. Squeeze it into a fist, increasing the tension, feel the tension, hold it.....then let go.
- ▶ Keep breathing and keep relaxing and let all the tension go. When you feel you have let go of all the tension, just let go a little bit more.
- ▶ Now try this with your left hand, then both hands together.
- ▶ Now focus on each of the muscle groups listed in the box. Create the tension, hold it and feel it - then release the tension.
- ▶ Breathe evenly and smoothly between each muscle group before you move on to the next.

Arms - Stretch out your arms and hands then let them hang loosely and limply.

Shoulders and neck – Shrug your shoulders up towards your ears, pressing them back into the chair or bed, then let go.

Back – Arch your back, hold, then let go.

Face – Tense your forehead by frowning, scrunch up your face as tightly as you can by shutting your eyes.

Stomach – Tense these muscles gently at first by pulling them up and in, as if preparing for a blow.

Legs – Point your feet up towards your face, or point the toes away from you.

Feet – Pull your toes back.

Repeat the body scan and then repeat the exercises for any areas that still feel tense.

Allow yourself some time at the end to relax by breathing gently. Then open your eyes and allow yourself some time to get used to your surroundings again before you get up and continue as normal. If you are not used to this kind of exercise it may feel strange to begin with but it will be beneficial to you so why not give it a try!

Will there be other help available?

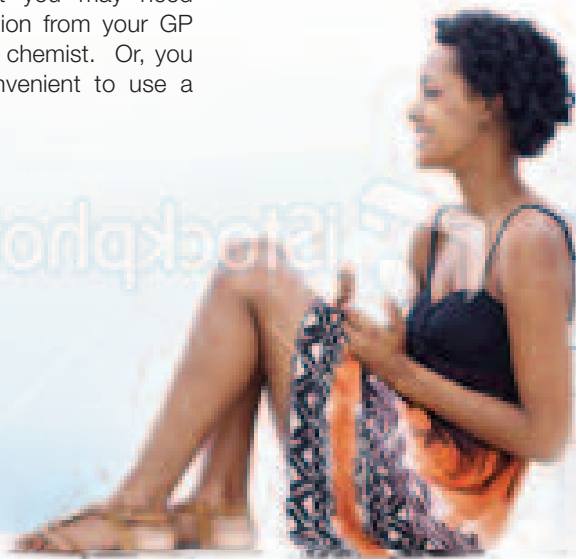
As you learn to live day-to-day with a colostomy, there is a great deal of help and support available. Generally, you can contact your stoma care nurse if you need specialist advice on managing your stoma. You can also contact the Colostomy Association (details are at the end of this booklet).

We are also committed to providing help and support for everybody who has a stoma. You can contact us through our help line. You can find contact details at the end of this booklet.

You can get supplies of appliances and other equipment that you may need by getting a prescription from your GP and visiting your local chemist. Or, you may find it more convenient to use a home-delivery service.

Amcare™ offer a home-delivery service and will arrange to deliver supplies free of charge. They have a network of care centres, each with a team of dedicated staff. They have regular delivery couriers to make sure you get your supplies as promptly and discreetly as possible, with as little hassle as possible.

They also offer a free advice service and a free cutting service. You can find contact details for Amcare™ on the back cover of this booklet.





More information

Please remember that this book is part one of a series produced by ConvaTec covering the different phases of life with a colostomy. Ask your stoma care nurse for part 2 which will give you more information about the first few weeks at home.

Or, please fill in and return the card included in this pack and ask someone to post it for you or call the Freephone number given. We will automatically send you parts 2 and 3 to your home.

ConvaTec free customer helpline
0800 834 822

Acknowledgements

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**If you would like more information,
you can get it from the following
organisation.**

The Colostomy Association

2 London Court, East Street
Reading RG1 4QL

Phone: 0118 939 1537

Website: www.colostomyassociation.org.uk

Further contact details

Amcare™

Home-delivery service

Freephone: **0800 88 50 50**

ConvaTec

Free customer helpline

0800 834 822

or visit: www.convatec.co.uk



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