

STOMA SURVIVAL GUIDE

YOUR GUIDE THROUGH THE
FIRST THREE MONTHS

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INTRODUCTION

Many people have stoma surgery each year. In fact an average of 13000 people in Britain have a stoma formed each year. So you are not alone. This stoma may be temporary, to allow your surgery to heal, or permanent, usually when part of the bowel or the bladder has been removed. Of course there are lots of reasons for having this type of operation, and your surgeon and stoma care nurse, (S.C.N.) will have explained it in detail to you and your family. This booklet is designed to help answer your questions and give you the information you need to regain control of your life in the first few months after the operation. We will discuss your feelings at having the surgery, give you ideas of how you can best help yourself, and guide you to finding the best person to help when you need others advice.

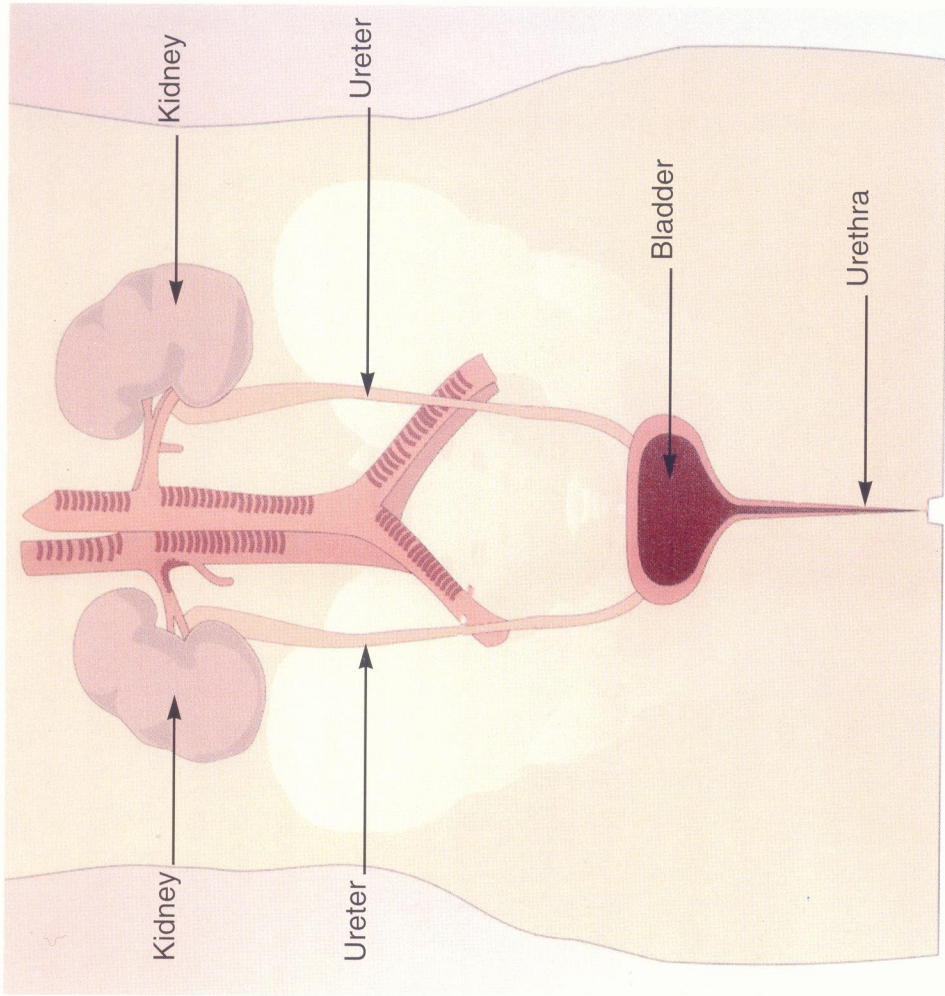
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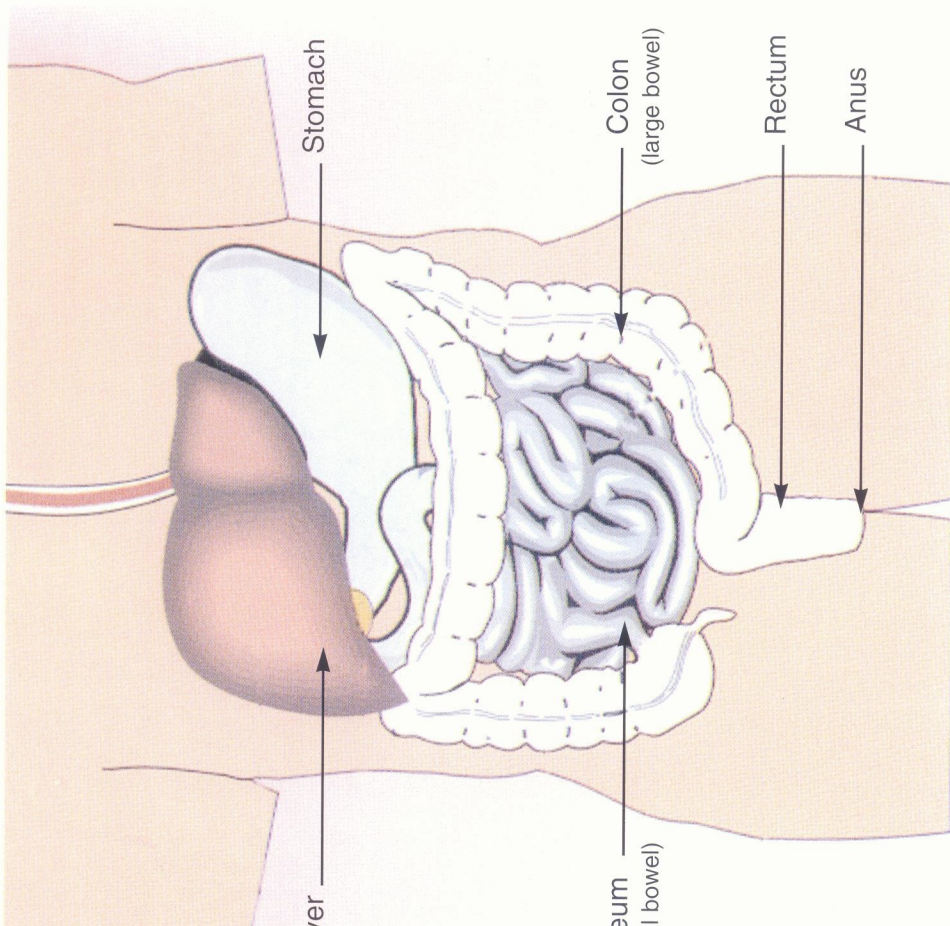
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THE BLADDER



BOWEL



CHAPTER 1

YOUR STOMA

The stoma should look a bright red colour, it has the same texture and appearance as the skin inside your mouth, and will always remain like this. Often people think that the stoma will be painful when they start to work with it, because of how it looks, making you feel frightened to touch it, but the stoma feels numb to the touch.

When you saw the stoma at first it would have been quite swollen, and it may even have got larger a couple of days after the operation. It is common for the stoma to change shape usually getting smaller as the days go by. You should measure the stoma at least once a week at the beginning, as it may continue to change shape and size once you go home from hospital. This may mean that the first appliance order you are given may have to be changed. Before your S.C.N. stops seeing you at home she will usually check the size and adjust the order if necessary, but you should be aware that it may continue to change as time goes on. It usually gets slightly smaller but, it can get bigger if you put on weight!

Looking after the skin around the stoma is very important, we usually advise not to use soaps or lotions on the surrounding skin as this can interfere with adhesion of appliances in some cases. At first you may want to empty or change the bag more often than is necessary. Nobody likes to think that there is matter in the bag they are wearing, but remember that these bags are very well tested by the manufacturers, so that they are completely odour proof. In the early days you might imagine that you can smell the stoma, but this passes as you get more used to having a stoma. Be assured that no-one else can smell anything from the bag when it is on you. If there is a smell from the bag change it and discuss with your stoma care nurse.

YOUR STOMA IS A

Please read only the sections which apply to you.

PERMANENT COLOSTOMY

This type of stoma can be permanent or temporary.

PERMANENT COLOSTOMY

The rectum and anus (back passage) is removed in this operation. This type of stoma will produce a formed bowel motion. The appliance will usually need to be changed one to three times a day. In the beginning the stoma can appear to have settled into a pattern and be quite solid, then at other times it will be more loose and even seem overactive. It doesn't matter what you eat when this happens. Over a period of time following the operation you will learn the foods that you can and cannot eat. (See later section on diet).

The stoma does eventually settle down into a pattern of working, provided you eat regular healthy meals. People with a colostomy find that they can eat almost everything. You should try various types of appliances to find what suits you best. Some people choose to irrigate their bowel as an alternative to wearing a bag, your S.C.N. can tell you more about this and if it is a suitable form of management for you.

TEMPORARY END COLOSTOMY

You may still have the sensation to pass something from your rectum. This is very common and quite normal. It may be due to the build up of mucous and/or old blood from the operation. It is quite safe to go to the toilet to allow this to pass, although you should not strain. If you have difficulty passing this please seek advice from your doctor or S.C.N. The reversal of the operation will usually involve opening up your scar again to join the two ends of the bowel together.

PRACTICAL ADVICE

APPLIANCES

There are lots of different types of appliances available which your S.C.N. will explain to you. Immediately after the operation you will have been using a clear drainable bag. As you learn how to manage the stoma you will be shown opaque bags which most people choose to use at home. Being able to manage these bags helps to build your confidence, and they are more pleasant to work with.

TYPES

ONE PIECE - means that the bag and base plate are bonded together.

TWO PIECE - the bag and base plate are separate, and attach to each other by a locking system. The base plate stays on for longer, allowing you to change the bag each day without disturbing the skin.

CLOSED BAG - the bag is completely sealed, and has a built-in filter, which allows wind but not odour out of the bag. This is used by colostomists.

DRAINABLE BAG

The bottom of the bag is open, allowing the bag to be emptied regularly. It is sealed using a clip. There are various types which your S.C.N. will show you. This type of bag can be worn for more than a day.

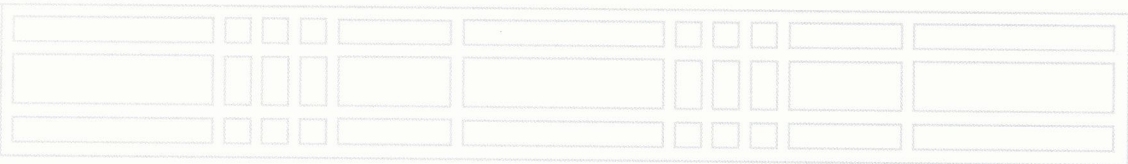
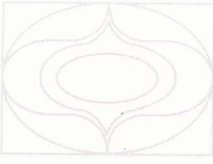
UROSTOMY BAG

This type of bag is used by people who have a Urostomy or ileal conduit. The bag has a tap at the bottom to allow drainage. This tap can also connect to a larger drainage bag at night to allow a good nights sleep. In the morning this bag should be emptied into the toilet and rinsed out for re-use. This bag can be re-used several times. If this bag becomes discoloured or smells it should be discarded.

SAMPLES

You can obtain samples of stoma appliances to try out. Your S.C.N. can give you the freephone numbers of the manufacturers. When you call these lines, tell them what kind of stoma you have and they will send you samples. If you try various bags, keep a written note of the ones you like and those you don't.

If you choose to use any new appliance, just give your S.C.N. a phonecall if you require the ordering information.



CHANGING YOUR APPLIANCE

You will need....

- New appliance
- Swabs or wipes
- Warm water
- Disposal bags
- Air freshener
- Clips (for drainable bags)
- Paste / creams / skin wipes

How to change your Appliance

- Gather all the equipment together.
- Remove the used bag.
- Wash and dry around the stoma.
- Fit your new appliance (use a mirror if needed).
- Empty contents of the used bag down the toilet.
- Put your used bag in newspaper or disposal bag.
- Dispose of your used appliance in your outdoor rubbish bin.

N.B. If you use any accessories apply them as you have been shown by your stoma nurse.

CHAPTER 2

LIVING WITH YOUR STOMA

CONVALESCENCE

When you go home at first you may feel easily tired and should take a rest each afternoon. Try to avoid staying up all day as this can over tire you, with the result that you cannot sleep at night. When you do start to exercise again it is advisable to start gently, for example walking daily or swimming are good. If you do not exercise, but would like to start housework again, then start with the lighter tasks and take frequent rests. Your S.C.N. or G.P. can give you more advice.

DRIVING

You should not drive until you feel comfortable performing an emergency stop without hurting your abdominal muscles or wound. This can take up to 8 weeks. If you are concerned about this please consult your doctor. The first time you drive it may be advisable to take another insured driver with you to take over if you feel unable to continue, or start by driving short distances

CLOTHES

Immediately after you go home you may feel more comfortable in loose fitting clothes because your abdomen will still be swollen following the operation, and you will still be feeling a bit sore. This settles gradually over the first couple of months, and you will then be able to start wearing the type of clothes you want. You may feel a little self-conscious about the bag when you have your clothes on the first few times you go out.

This is a normal reaction, and it should get easier as you get back to your usual lifestyle. You will probably have discussed any clothes preferences you may have with your stoma care nurse before the operation.

However if the operation has been done as an emergency, or the stoma was not marked before the operation, then you may need to adjust your waistline slightly.

In some cases men may find wearing braces is more comfortable than a belt. You can still wear a girdle if you want to. Ask your S.C.N. for advice. You can be fitted for a girdle which will be made-to-measure.

You should be able to wear tight fitting clothes and swimwear. Ask your S.C.N. to advise you about the best mini pouch for you.

FOOD AND DRINK

While you are recovering from your operation you may find that your appetite is quite poor. This is not at all unusual, and that your taste buds make food taste strange. Some people cannot eat or drink things that they have always enjoyed. Don't worry, both your appetite and your taste buds will return to normal. However, be prepared for this to take up to a month. During that first month or so if you feel like this, it is advisable to maintain a good fluid intake and eat smaller meals more often.

Introduce new fruits and vegetables one at a time, to see the effect they have. Try fruit without the skins to begin with. If a food upsets you, don't try it again for a month or so. If it still upsets you but you want to be able to eat it, then you should try preparing it in a different way. For example, raw onions may give you wind, however fried or boiled onions in a casserole or soup, may not.

You should be able to get back to enjoying most, if not all of the foods you enjoyed before the operation. Some people, may even be able to take foods that they have had to deny themselves for several years!

Just a note - Ileostomists are advised not to eat too many nuts as they occasionally clog together and may cause a blockage of the bowel. This would cause severe pain and your stoma could stop working.

Colostomists - A good rule of thumb is that foods that made your motion loose or caused wind before the operation will do the same afterwards.

CHAPTER 3 PRESCRIPTIONS

If your stoma is temporary you will have to pay for your prescription. It may be advisable to buy a prepaid prescription card depending on how long you will have your stoma. If the stoma is permanent, you will need to fill out a prescription payment exemption form (obtainable from your stoma care nurse, chemist or surgery) as you will be entitled to free prescriptions.

Before you leave the hospital the stoma care nurses will give you at least a weeks supply of stoma products. They will give you specific advice about obtaining further supplies at home, as each Nurse's practice may be slightly different regarding this.

Once your GP has a note of what is required, you can get a repeat prescription when required.

Order new supplies when you start your last box, this way you will never run short. If you have difficulty getting your supplies, inform your S.C.N. You can get your supplies from the local chemist, from delivery services or direct from the manufacturing companies.

CONTACTS AND SUPPORT AT HOME

There are many people who can offer you different types of support. The Stoma Care Nurse will continue to support you after discharge, either by coming to visit you at home, or asking you to visit her clinic.

The district nurse may also be visiting to assist in wound care and give you support, although you will probably be able to do all your stoma care independently before you are discharged from hospital. However some people do need extra help to manage the stoma, particularly if they have other physical problems.

The social worker may be involved if you need advice about finances and benefits. You can ask the ward staff to arrange a visit from the hospital social worker.

Of course there are many other people who can help when you get home, your G.P., homehelps, meals on wheels etc, but probably the most important people to help you can be your family and friends.

There are S.C.N.'s in most big hospitals. If you do not know where your local S.C.N. is based you can ask your G.P. or the local hospital which should be able to put you in touch with her. If you need advice in a hurry you can refer yourself to the nurse direct, without seeing your doctor first. Most S.C.N.'s hold clinics where you can be seen relatively quickly. This is particularly helpful if you are having problems with the stoma, surrounding skin, appliances or need advice about any aspect of living with a stoma.

There are also self-help groups in most areas, either run by the local S.C.N. or the local branch of the national self-help groups, where you can speak to someone who has had the same surgery as yourself, or just attend meetings to chat to others in similar circumstances

UI ADDRESSES

Colostomy Association

Executive; Mr Howard Jones, CBE.
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g,
ire. RG1 1LG.
734) 391537

Macmillan Cancer Relief

Chief Executive Mr N. Young
Anchor House,
15-19 Britten Street,
London SW3 3TY.
Tel: (0171) 351 7811

Colostomy & Internal Pouch Support Group

al Secretary Mr David Eades
nurse House.
s 23, Mansfield,
NG18 4TT
623) 28099

Bacup

Cancer Information Service,
3 Bath Place,
Rivington Street,
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Tel: (0171) 696 9000

Colostomy Association

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ont Road, Danbury,
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National Association for Crohns & Colitis Disease

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Colostomy Advisory Service for Children with Stomas

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560) 22024

Radar

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