

STOMA SURVIVAL GUIDE

YOUR GUIDE THROUGH THE
FIRST THREE MONTHS

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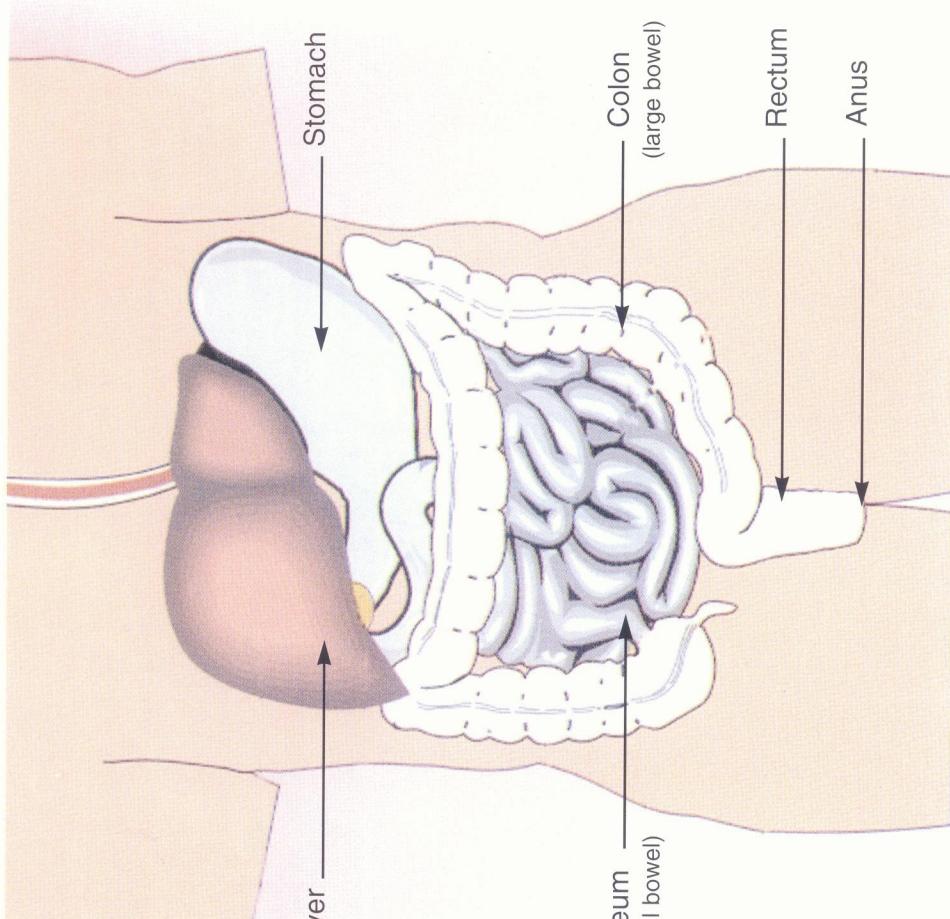
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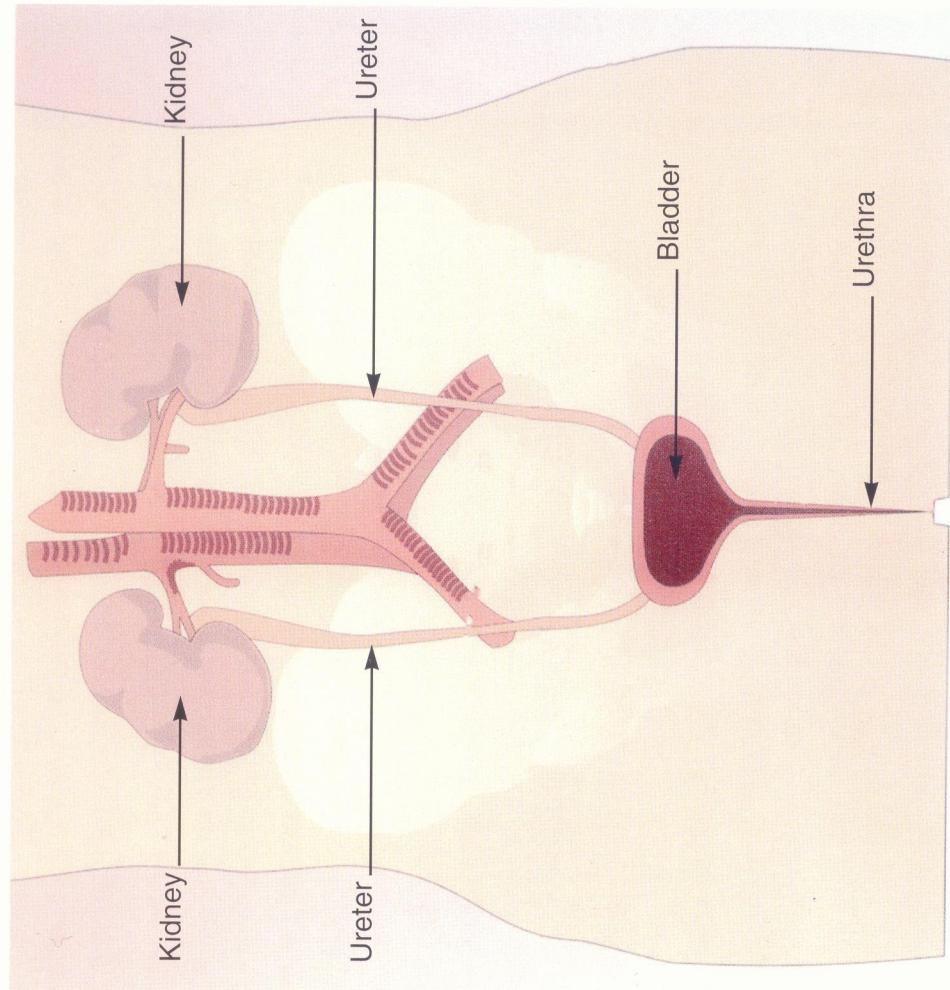
INTRODUCTION

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.

BOWEL



THE BLADDER



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.

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 mucus 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.

TEMPORARY LOOP CROSTOMY

You may still have the sensation to pass something from your rectum. This is very common and quite normal. It may be due to build-up of mucus and old blood from the operation, or you may have some overflow of bowel motion from the stoma in to your rectum. This is possible because the bowel has not been fully disconnected. Your S.C.N. can explain this in more detail. The reversal of this operation will not usually involve opening up your scar, and is a much smaller operation than the first one.

QUESTIONS AND NOTES

ILEOSTOMY

This type of stoma can be temporary or permanent.

PERMANENT ILEOSTOMY

The rectum and anus (back passage) will usually have been removed in this operation.

This type of stoma usually protrudes a little from the skin and produces a soft to fluid output. The consistency of the motion can change over the course of each day. This is quite normal and is related to what and how much you are eating. You will need to empty the appliance an average of five times a day, and change the bag every two to three days. If the output from the bag increases drastically for more than twenty four hours you should see your doctor or S.C.N. immediately, as there is a risk of you becoming dehydrated. In very hot weather or if you are exercising vigorously you must be aware that you should replace lost salt and fluid from excessive sweating.

TEMPORARY LOOP ILEOSTOMY

This type of stoma is usually done to allow the operation on your bowel to heal. The stoma will usually be reversed (put back into your abdomen) three to six months after the first operation. Occasionally this can be left for longer. Your surgeon will give you more details about this. This stoma has two openings on it although they are not easy to see. The 'spout' of the stoma is where the bowel motion comes from and the other opening which is flat on the skin surface is still connected to the rest of your bowel. You may still have the sensation to pass something from your rectum. This is very common and quite normal. It may be due to build-up of mucus and old blood

from the operation, or you may have some overflow of bowel motion from the stoma into the rectum. This is possible because the bowel has not been fully disconnected. You should be able to have control of this. Your S.C.N. can explain this in more detail.

UR^OSTOMY

UR^OSTOMY / ILEAL CONDUIT

This is usually a permanent stoma, and can be performed for several reasons. This type of stoma is formed to drain urine from the kidneys. When the stoma is just formed it will have one or two thin tubes hanging into the stoma bag, these are positioned in theatre and are there to help the operation heal inside. They will usually fall out into your stoma bag within 10 - 14 days after the operation. The output from this stoma is continuous and the bag should be drained an average of 5 times each day. Your bladder may be removed in this type of surgery; your surgeon will discuss this with you in detail

WOUND CARE

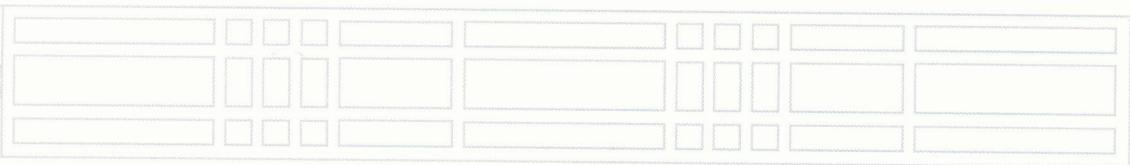
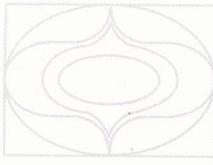
During the first months after your operation it is important that you take care of your abdominal wound, if you have one. The District Nurse may visit if the wound takes longer to heal. Your physiotherapist will have shown you how to protect the muscles around the wound when you cough. They are weakened by the surgery and need time to heal. It is essential that you do not put strain on these muscles from vacuuming, lifting heavy bags, moving furniture or ironing for example. Seek advice from your own hospital as to how long you should wait before resuming these activities. If your rectum has been removed you will have a wound at your bottom. This will be checked by your district nurse at home, and your consultant will check this at your first clinic appointment.

QUESTIONS AND NOTES

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QUESTIONS AND NOTES

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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.

CHAPTER 2

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.

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

PSYCHOLOGICAL ADJUSTMENTS

It is important that you talk to someone you feel comfortable with, to help you cope. If you don't find the right person to begin with, don't give up. There are lots of people to help, and remember, you're worth it!

Depending on the reasons for your operation you may feel that you are on an emotional rollercoaster, being weepy sometimes for no apparent reason. This is often more noticeable in the first weeks after the operation. Having a stoma makes your body look and work differently, and there will be times when you find this difficult to cope with. You may find yourself feeling quite angry about having the stoma, and thinking that you will never live a 'normal' life. It seems that during these first weeks all you can think about is having the stoma, and you find yourself thinking 'Is this how it will always be?' But through time you will be less conscious of the bag and if it is filling up. Indeed you can reach a stage when you can forget about having it there. As you are reading this, you may be thinking 'never', **but it will happen.**

Feelings of disgust at dealing with the stoma output are also common. Most people are not used to having such close contact with their bodily functions, and so it can take quite a time to adjust to. Talk to your S.C.N. or another ostomist who will understand how you feel and may have useful ideas on how to combat problems with odour, disposal of used appliances, mess and so on.

There is usually a satisfactory answer to such problems. All of these thoughts and feelings you are experiencing now, do become more manageable.

If you have a partner, they may also feel upset and emotional about all that is happening to you both. Sometimes your partner can be more upset than you are, and might also need some support. The S.C.N. can arrange to speak to your partner either while you are in hospital or when you get home.

If you have had emotional problems in the past, you may find yourself struggling to cope with your emotions now, please don't try to do it alone, talk to your G.P. or S.C.N.

QUESTIONS AND NOTES

SEXUALITY Anxiety concerning your partner's response to you with your stoma is normal. It will take you both time to adjust to the changes. You must also remember that you have had major surgery, which takes you time to recover from. So physically you may not be able to relax and enjoy an intimate relationship for a period of time. This will vary according to how long you were ill before surgery, the extent of the surgery itself, and the need for other treatments after the operation.

Diminished libido can lead to anxiety for both partners, so it is vital that you talk to each other, so that there are no misunderstandings. A lot of support can be gained from your loved ones. If the presence of the bag is a problem to you, discuss this with your stoma care nurse who can suggest various options, one of which may help you. You must be prepared to discuss the details of your problem with her so that she can help you. Her advice can take several forms. She may advise a practical solution, such as changing sexual position, or using lubrication if dryness or discomfort is the problem. There are also several other specialists she is able to refer you to if she feels that you would benefit from their advice. You can also refer yourself to clinics such as the psychosexual counsellor at the local family planning clinic, the address for your local clinic is in the phone book. There are also psychosexual counselling specialists within the ileostomy and internal pouch group. Their address and phone number is in the "useful contacts" section.

If you have a partner of the same sex, you can discuss any anxieties with your stoma care nurse who may recommend you contact the dedicated helpline at the Ileostomy Association and internal pouch group. You can also refer yourself direct to these agencies.

If you don't have a partner at present, but are concerned about how to introduce having a stoma to a future partner, you should discuss this with your S.C.N. or a fellow member of your support group. This can be a worrying time, and while we cannot give you specific advice in this booklet, your S.C.N. is always available to discuss this in more detail.

QUESTIONS AND NOTES

CONTRACEPTION, PREGNANCY AND CHILDBIRTH

WORK

You should ask your stoma care nurse about contraception following surgery. For those with stomas and internal pouches this may need to be changed from oral contraceptives, as you may no longer be able to absorb the full dosage of medication.

It is usually advisable to wait for about a year after your operation to have a family, this gives you time to heal after the surgery, and allows you to recover psychologically from the operation.

You may want more information about having a baby, ask your S.C.N. Many women have had successful, uncomplicated pregnancies after their surgery. Indeed in many cases they have had several children following stoma formation.

You should be able to resume your previous work unless there is a specific reason. Talk this through with your S.C.N. Think through how you will change or empty your bag in your toilets at work. Run through how you will do it. What you will need, how much time it will take? There may be a specific toilet that would be best to use, for example it may be larger, have a hook on the door, a sanitary bin, shelf, window, or it may not be used often, which initially may cause you less anxiety, as you will not feel that you need to rush.

Plan who you will tell, and how much you want them to know, remember no-one except your employer need know unless you want to tell them. You may want to go back to work part-time to start with, most employers are happy to help if they can.

Have more than one idea ready when you see them. For example, work mornings or afternoons only, work Monday, Wednesday, and Friday only, and so on.

However most people are able to resume their previous employment within 3 months depending on their surgery and work.

Before you start back at work you may want to use the route you would usually take. If it's a long journey, are there toilets you can use to empty the bag if necessary?

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.

HOLIDAYS

Once you feel well enough, you may consider a holiday. It is advisable not to be too adventurous the first time. Perhaps going away for the weekend, or back to a favourite place where you feel relaxed. Self catering is also a good idea the first time as you can have a lazy day around the apartment or caravan when you want, and have total privacy to change and empty the bag. The main thing is to build your confidence, so that the next holiday is less daunting. There is lots of information available on holidays at home and abroad. Get all the booklets from your S.C.N. and the self-help groups.

The Main things to remember :-

- Check that you have adequate insurance, which covers pre-existing illness. Ask your travel agent for more advice.
 - Ensure you have adequate toilet facilities within your accommodation.
 - Plan your best opportunity to empty or change your appliance.
 - For longer Breaks send appliances in advance to your destination or have them delivered to you while you are there.
 - Take a couple of drainable bags in case you have diarrhoea.
 - Mini pouches are available for swimming and sun bathing. Most standard pouches have a mini version that will suit you.
 - Split supplies between hand luggage and your case.
- ### EATING AND DRINKING ABROAD
- Avoid alcohol and fizzy drinks on the plane and drink plenty of water.
 - To avoid over production of wind eat yoghurt daily and avoid yeasty foods.
 - If the local water should not be drunk, avoid salads and ice in drinks.
 - If you have an ileostomy or diarrhoea drink plenty of water and ensure that you take adequate salt in your diet while in a hot climate.

FOREIGN LANGUAGES

Information is available from the I.A. in foreign languages. Some appliance companies can give you a card written in several languages, which will explain why you need supplies.

QUESTIONS AND NOTES

CHAPTER 3

PRESCRITIONS

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

QUESTIONS AND NOTES

to yourself. Volunteer visitors are available either through your stoma care nurse or these associations. Many people find it very useful to talk to someone else who has experienced the trauma of having a stoma operation first-hand.

Help and advice is also available through other organisations such as N.A.C.C. and BACUP. The addresses for these organisations are listed later.

Ongoing support is available, so please use these services if you feel you would like to help in any aspect of life with your stoma. It is often only once you are over the operation and any further treatment, that you may be informed that the stoma is going to be there for longer than you initially thought, possibly for the rest of your life. This may cause you to feel anxious about the future: Dealing with new situations, meeting new people, deciding who you should tell and how to tell them. Often just talking it through with someone who has already experienced these difficulties can be of great value.

If, however, you feel that you are not coming to terms with one specific aspect of your new life with your stoma, then speaking to your S.C.N. may be your best course of action. If you don't find the right person to help you at your first attempt, don't give up.

Remember, seeking help with a problem is not admitting defeat, it is making a positive move towards improving your situation. There are lots of people who want to help, and remember, you're worth it!

QUESTIONS AND NOTES

QUESTIONS AND NOTES



USEFUL NUMBERS

My Stoma Care Nurse is _____ Tel: _____

My District Nurse is _____ Tel: _____

My Consultant Surgeon is _____ Tel: _____

My GP is _____ Tel: _____

WE ADDRESSES

Colostomy Association

Executive: Mr Howard Jones, CBE.
10 Union Road.

9g
Mansfield
shire, RG1 1LG.

Tel: (01734) 391537

Stomach & Internal Pouch Support Group

al Secretary Mr David Eades
nurst House.

23, Mansfield,
NG18 4TT

Tel: (0123) 28099

Stomach Association

al Secretary Mrs Angela Cook
and",

ont Road, Danbury,
CM3 4DE

Tel: (01245) 224294

Stomach Advisory Service for Children with Stomas

Mr John Malcolm,
erson Drive,
iew Park,
KA17 0DE

Tel: (01560) 22024

Macmillan Cancer Relief

Chief Executive Mr N. Young
Anchor House,

15-19 Britten Street,
London SW3 3TY.

Tel: (0171) 351 7811

Bacup

Cancer Information Service,
3 Bath Place,

Rivington Street,
London EC2A 3JR.

Tel: (0171) 696 9000

National Association for Crohns & Colitis Disease

98a London Road,
St Albans,

Herts, AL1 1NX

Tel: (01727) 44196 (answerphone)

Radar

Unit 12,
City Forum,
250 City Road,

London EC1V 8AF.
Tel: (0171) 250 3222