SecuriCare®

Adjusting to life with a stoma

Putting you first

The SecuriCare award winning Home Delivery Service

- Stoma supplies are delivered direct to your door anywhere in the country, where and when you want – free of charge
- We can take care of organising your prescription and ensuring you receive your stoma care products cut to size. All it takes is one easy phone call to your own personal SecuriCare account manager
- Complimentary disposal bags are supplied with every order. Wipes are available on request
- We can provide you with any make of stoma product or accessory

How we work for you

With your prescriptions processed by your personal account manager your order is then printed out to the despatch department where it is picked and customised. Once your order is checked, it is packed and your personal driver will collect it from Head Office or the nearest depot and deliver to you the next day.

Freephone Orderline **0800 318 965**

Contents

Introduction

Adjusting to life with a stoma has been written to help you understand your feelings following stoma surgery. It also gives you guidance on how to come to terms with your new body image and how to feel comfortable with others.

Planning and rehearsing can help to build your confidence and speed up the process of adjusting to your new lifestyle.

The process of adjustment is not instant. It will happen over a period of time. For some people this could be a year but do not worry if it takes longer. We are all individuals and everyone adapts at their own pace.

This booklet should also be of interest to carers, spouses, partners, friends and close family members who want to understand more about how best to help you as you return to your normal routine.

Your feelings following stoma surgery

Feelings in hospital

How you feel immediately after stoma surgery will depend on the reason for your surgery. You may be relieved to no longer have diarrhoea, stomach ache or constipation. If you had a tumour you still may be worried about your illness but patients are often relieved the cancer has been removed.

To begin with you will probably feel strange and resent having a pouch on your abdomen, having to care for it and having to make adjustments to your lifestyle. You may also feel frightened or angry because you think the stoma looks unsightly and you feel less complete than before. This can lead to feelings of uncertainty about being intimate with your partner.

Stoma care nurses are familiar with these very natural feelings, so you should not be afraid to discuss these with them. Whilst the stoma might not feel 'quite your own' at this stage, and seem something that makes you different to others, skillful stoma care, guided by your stoma care nurse will soon help you be confident about your appearance.

Feelings at home

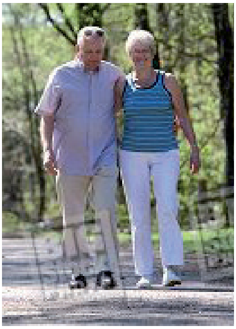
Some of the feelings described may not hit you until you leave hospital. Once you are at home you also have to deal with feelings about being with other people. Preparing for this while you are in hospital can help you adjust more quickly. Again your stoma care nurse can help you with your preparations, along with the advice in this booklet.

As time moves on you will become more confident and adapt to your new lifestyle. You can expect this period of adjustment to take up to a year. However everyone is different. For some it may take longer, for others less.

The first few weeks

Q ‘How long will it be before I get back to my usual self?’
A It varies from patient to patient, but it is likely to take around 6-8 weeks to get back to your usual level of activity and around 3 months before full recovery.

Q ‘I feel so tired – is this usual?’
A Yes, it is common to feel tired at first, but each week you will gradually improve.



Q ‘Should I rest or should I try to do some exercise?’
A You should do both!

- Plan a regular ‘rest time’ during the day – and let everyone know when it is so you will not be disturbed.
- Go out for one or two short walks every day as soon as possible and increase the distances gradually. Get friends or family to go with you, if you can, especially if you feel a bit wobbly.

Q ‘I’m having trouble sleeping’

A Changes in routine and restricted movement can cause sleeping difficulties and you may also be woken by discomfort caused by sudden movement. Taking a painkiller at bedtime may be helpful – ask your GP or Stoma Nurse for advice.

Wound healing

All wounds progress through several stages and you may notice these changes over the coming weeks:

- Unusual sensations, such as tingling, numbness or itching
- A slight hard lumpy feeling as the new tissue forms
- Slight pulling around the stitches as the wound heals

Don’t pull off any scabs, these are the body’s ‘natural dressings’ to protect the new tissue underneath; they will fall off when ready without help.

Seek help if...

- the amount of pain in your wound increases
- the amount of redness and/or swelling increases
- there is any discharge from your wound.

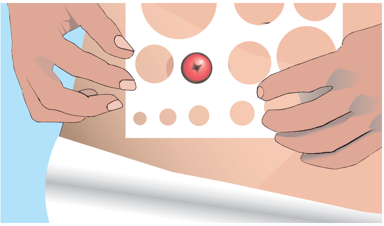
These symptoms might suggest a wound infection.

Hygiene and caring for your stoma

At first, looking after your stoma may seem to take up a great deal of time, but rest assured that this quickly gets better and you will soon get into a routine.

Q ‘My stoma looks quite large and seems to have stitches in’

A Your stoma will gradually settle down during the first 6- 8 weeks and may reduce in size. Check it weekly with a measuring guide to make sure the hole in your pouch is a snug fit. Your stoma nurse can show you how to do this.



There may be small stitches visible around the edge of your stoma; these usually dissolve of their own accord within 2-3 weeks, but tell your stoma nurse if they are causing you discomfort.

Q ‘Is it OK to take a bath or shower?’

A Yes, this is safe from 2-3 days after your operation, unless advised otherwise. You can bathe or shower with your stoma pouch on or off, whichever you prefer. It is possible that your stoma may work whilst you are bathing, but rest assured that water won’t seep into your bowel as it is a “one–way system”.

If you keep your pouch in place while you are bathing and do not intend changing it afterwards, protect the charcoal filter on the pouch with a filter cover (the sticky patches normally supplied by the manufacturer in your box of pouches).

There is no evidence to suggest that using salt aids healing. It is a good idea to avoid using soap or bath oils on the skin surrounding the stoma, to prevent irritation in this sensitive area.

Safety first

A non-slip mat will reduce the risk of slipping in the bath or shower. If necessary, your local social services may be able to help with fitting handles to hold on to. It is reassuring to have someone else in the house when you first take a bath or shower, even if actual help is not needed.

Stoma output

Q Is my stoma output normal?
A The output depends on which type of stoma you have – Ileostomy, Colostomy or Urostomy.

Ileostomy

If you have an ileostomy, you may find the output becomes very watery. Should this persist, or if you need to empty your pouch very frequently, you may need tablets to thicken the output, and/or special thickening agents to put in the pouch. You should always ask for advice from your Stoma Nurse or doctor first.

If the watery output is accompanied by abdominal pain, nausea or vomiting you should seek medical advice straight away.

Colostomy

If you have a colostomy and you have been prescribed painkillers these may cause constipation. It is important to make a habit of drinking plenty of fluids and gradually introducing fruit, vegetables and other high fibre foods into your diet. If constipation persists it may be helpful to take a mild laxative. If you are in any doubt ask your Stoma Nurse.

Urostomy

If you have a urostomy it is usual to expect mucus (jelly/slime) in your pouch as your stoma is made from a piece of bowel. The amount should decrease over time but may be helped by taking Vitamin C or a daily glass of cranberry juice (Warning – if you take Warfarin you should not drink cranberry juice). You may experience either diarrhoea or constipation in the first few weeks after your operation; if so, speak to your GP.

Eating and drinking

Q ‘I feel very bloated when I eat – is this normal?’
A You may find your appetite is small and that you get a bloated feeling or indigestion after meals. It may take several weeks before your appetite returns, especially if you have been unwell for a time before. Try eating small meals at regular intervals until your appetite returns. These symptoms usually resolve themselves as you become more active. Soups and milky drinks are nourishing if you can’t face a meal.

It’s important to drink plenty of fluids

This will help your body function properly. Aim to drink 8-10 large mugs of fluid per day e.g. water, squash, tea, coffee or milk.

Q ‘Can I have a glass of wine or beer?’
A A small amount of alcohol can improve your appetite and is not usually harmful (but check first with your doctor if you are taking any medicines).

Q ‘Are there any foods I should avoid?’
A Some foods can cause flatulence. If you think an item has upset you, try it again after a few weeks. In time you will be able to enjoy your food as before. More detailed advice about the foods which may affect your stoma can be found in ‘Nutritional Advice’, another booklet in this series. If you are in any doubt about the right sort of food to eat, ask your Stoma Nurse.

Q ‘Should I carry on with my usual medicines?’
A Check with the hospital or your GP about the suitability of any medicines you regularly take. Some medicines such as ‘slow-release’ tablets, or others such as the contraceptive pill, may be affected by changes in absorption in the bowel.

For further information see ‘Nutritional Advice’, another booklet in this series. For your copy please call the SecuriCare Careline.

A confident appearance

The way we appear to other people is affected by how we look and feel. Once you have mastered looking after your stoma in private you need to feel confident with it in public.

Choosing your clothes

Wearing even a modern and well designed stoma pouch can sometimes change the outline of your appearance. Adapting your style of clothing can draw attention away from this part of your body. The following tips may help.

- Avoid wearing belts or cummerbunds which are very tight around your abdomen.
- Avoid wearing very tight or hipster trousers. Try pleated trousers which provide added room for movement.
- Wear clothes which distract gaze away from your abdomen eg. bright or patterned tops together with plain coloured trousers or skirts.

Dropped waistline garments, skirts and trousers without waist bands, low slung belts, long jackets and tops and long skirts create the illusion of lowering your waist.

Pushing your belt lower down your waist can create the impression that your waist is narrower than it really is! Matching colours are also good with vertical necklines.

Wear clothes which distract gaze away from your abdomen.

Odour control

Most stoma pouches are now designed with odour filters, so odour should not be apparent apart from when you are emptying or changing your pouch. Special deodorants, such as CliniMed Limone® Deodorant Spray, are available on prescription. If you have not had time to get a special deodorant spray for your stoma pouches you can use your own favourite deodorant, perfume or after-shave but be careful not to overdo it.

Preparing for accidents

Accidents are rare with modern pouches but to minimise problems do make sure you have mastered the use of your stoma products. Compile an 'emergency kit' of stoma products that can be carried discreetly in a coat pocket or handbag.

Just in case an accident does occur in public it is worth planning what you will say and how you will excuse yourself from company. However strange it may feel, ask your partner or a friend to listen to your plans. Rehearsing will make it easier to remain calm and to feel good about yourself afterwards.

Carry supplies with you

Once you are out and about, it's a good idea to carry a small travel bag with you containing spare pouch, wipes etc. If you are worried about odour when changing your pouch (which shouldn't be any greater than odour from a normal bowel movement) you can obtain a special deodorant spray on prescription. For a sample of deodorant spray, please call the SecuriCare Careline.

Travel bags are available free of charge to users of the SecuriCare Home Delivery Service.

Your supplies

Storage Avoid storing pouches near a heat source, such as a radiator, direct sunlight or in a steamy bathroom as these can affect the adhesives and quality of the products.

Obtaining your supplies Your stoma nurse will have arranged for a supply of appliances to be delivered to your home. Future supplies can be delivered in the same way, ready cut to size for you. Many people with stomas are exempt from prescription charges – check with your Stoma Nurse or GP for more details.

SecuriCare order line **0800 318 965.** You can also order your supplies by visiting our website at **www.securicaremedical.co.uk**

Getting active

Q ‘When can I get back to the gym and swimming pool?’
A Wait until after your first outpatients appointment (usually about 6 weeks after discharge) before starting formal exercise again. But remember it normally takes about 3 months for the abdominal muscles to heal completely. Check with your Stoma Nurse or GP if you are unsure. Additionally it’s a good idea to ask for advice following abdominal surgery as to which gym equipment you should use. Speak to a qualified gym instructor for guidance.

Q ‘Will I be able to do the housework and other household chores?’

A Discomfort in the wound will prevent you from attempting too much at first and will act as a warning, particularly with movements that involve bending and stretching (e.g. reaching high and low shelves), lifting heavy weights, and pushing or pulling, (e.g. vacuuming). Standing up for long periods can be tiring.

If help with chores is available for the first few weeks after discharge it is very useful. After 4-6 weeks you should be beginning to feel fit enough to resume most household chores, but avoid strenuous activity, eg mowing the lawn, for 3 months or so.

Q ‘Why can’t I do any carrying or lifting?’
A For about 3 months after surgery, avoid carrying shopping or lifting anything heavier than a kettle of water as this could result in a hernia.

Q ‘When can I drive again?’
A Usually around about 6-8 weeks after surgery, but this will vary according to the type of operation you have had. Ask for specific advice but do remember that your movement and strength must be up to coping with an emergency stop as well as normal driving. It is also a good idea to check with your insurance company.

Q ‘When should I go back to work?’
A This depends on the type of surgery you have had and the sort of work you do. It is better to feel completely well before you return as many people feel tired and find concentration difficult to start with. More advice can be given by hospital staff or your GP.

The need to share

Sharing your new circumstances with others will help you return to a successful social life after surgery. A stoma does not mean that you have to withdraw from society. On the contrary, learning to adapt and helping others to understand how you feel can make you seem more impressive than ever.

The need to plan

Planning what to say about your stoma gives you control over what you tell others. Answering questions without deciding what you want people to know, can lead to incomplete answers or uncomfortable situations. Rehearsing your planned discussion with a loved one and/or a stoma care nurse can help give you a moral boost for being so organised.

Planning and rehearsing will help you to explain clearly and confidently and so put others at ease. People are then more likely to respond and support you in the way you would like.

Remember, even if you think you would intuitively know what to say to others, this may be clouded by the rush of events associated with being in hospital and then recovering from your operation.

How to plan

First make a list of all the people you regularly meet both at home and at work and then decide on the level of information you wish to give to each. The following are suggested guidelines.

Simple level:

You may simply say that surgery was successful and that the problem has been sorted out. Details of your health will not be mentioned. This is usually sufficient for work colleagues.

Detailed level:

You may say that you have had a stoma that needs looking after carefully. Information will be kept practical and may refer to your diet and exercise, the need for health check-ups and similar. This can work well for close work colleagues and friends or family members.

Intimate level:

You not only talk about the practicalities of your stoma care but also your feelings associated with this. For instance, you might discuss feelings about sexual relationships or fears about a pouch failing in some way. This information is kept for those closest to you.

The reaction of others

Types of response

You may find some people who find it easy to cope with difficult subjects are very supportive while others may want to help, but are unsure about how to react. Here are some possible reactions you may come across.

Avoiding:

People do not avoid you, but they will avoid discussing your surgery and will look you less in the eye. This is because they do not know what to say and/or they are afraid they might embarrass you.

Focusing:

People want to know so much they seem to be intruding, but they usually mean well. They think that discussing 'out in the open' will help you cope.

Cocooning:

Some relatives, and especially partners, may try and protect you from dealing with others, i.e. 'wrap you up in cotton wool'. Whilst some form of protection can be helpful when you first leave hospital, in the long term it will isolate you.

Promoting:

Other relatives or friends may decide to inform a wider audience for you so that you don't have to explain matters 'over and over again'. This can be helpful but only if done with your approval.

The reaction of others

Coping with response

If you are unhappy with the reactions of someone then you might want to help them respond in a more helpful way. The kind of approach you take will depend on the person, your relationship with them and therefore the amount of information you need to discuss with them. It can be a good idea to approach a difficult subject slowly over time, especially if you are dealing with the reaction of your spouse or partner.

Possible approaches are:

Confronting

This tack may be taken if you are very upset by somebody's response, but you could upset them if they have not realised the distress they have been causing you.

Go gently. Start by asking them to describe how they think they have been responding and then pick up on any positive points and thank them for their support. You can then begin to describe the problems their reaction has caused you.

Empathising

You may think it strange to ask a friend or relative about their feelings about your stoma but it shows that you care. Listening and asking careful questions can help them 'open up' and start talking about what you hoped they always would.

If you are unsuccessful in changing someone's response consider asking the stoma care nurse or other specialist to talk to the person. Maybe giving them a booklet to read like this one will help them to understand your wishes better and view your situation from a wider angle.

Personal relations

Q 'When should I resume sexual relations?'
A There are no specific guidelines about when you can resume your usual sexual relationships – be guided by your own feelings. As a guide, by the time you are ready to go to work this can be resumed, although some people feel ready earlier.

Q 'I'm worried about how my body looks'
A If you feel unsure, try experimenting with attractive underclothing. Specially designed underwear is also available on prescription – ask your Stoma Care Nurse for more information or advice or visit the fashion pages on our website.

Q 'Am I likely to be impotent?'
A You will have been advised if this is a possibility. A few operations do have unavoidable side effects which may cause impotence but there have been many advances in treatments for this – sometimes as simple as taking a tablet – so seek advice as soon as possible.

Continuing support

Your Stoma Nurse will continue to provide support after you are discharged from hospital. She may see you once or twice at home and then at the local stoma clinic. Sometimes a district nurse may be arranged if you have a particular need, such as a wound dressing.

If you require advice, or develop a problem with your stoma, you can phone the Stoma Nurse directly on weekdays during their normal office hours. If an urgent problem occurs outside these hours contact your district nurse or doctor's surgery.

The SecuriCare Careline is also available to answer your queries from 9.00am-5.00pm Monday to Friday. Outside these hours there is an answerphone service.

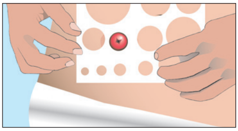
NHS Direct offers emergency advice 24 hours a day on **0845 46 47**

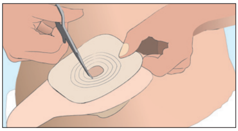
Trouble-shooting guide

The following tips may help you solve some of the common problems which can occur. If things don't improve within a few days, contact your Stoma Nurse for further advice.

Leakage

The most common cause of leakage is that the hole/aperture in your pouch is the wrong size. It should fit snugly around the base of your stoma. Check your stoma size using a measuring guide and cut your pouch to fit. If in doubt ask your Stoma Nurse to check this for you.





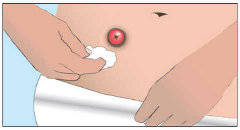
Make sure you are drying your skin carefully and avoid using powder or cream on the skin around the stoma. Use of a formulated skin barrier wipe may be recommended. Take time to fit your pouch carefully, pressing the flange down firmly.

Pancaking (colostomy or ileostomy)

Sometimes the faeces collects at the top of your pouch instead of dropping down to the bottom; this is known as pancaking. It may seep under the flange causing a leak.

Pancaking occurs when there is little or no air in your pouch causing the inside of the pouch to stick together. Try covering the filter with the special filter covers supplied with your pouches. Alternatively, try putting a baby little oil into your pouch.

Sore skin



Often occurs if the hole/aperture in your pouch is too large. Check your stoma size using a measuring guide and cut your pouch to fit snugly around your stoma, making sure that the area of sore skin is covered by the flange. If in doubt ask your Stoma Nurse to check this for you. A skin barrier wipe* will protect the skin around the stoma.

'I still feel as though I want to pass a motion'...

If you have a colostomy or ileostomy but your rectum (back passage) has not been removed, you may still feel the urge to open your bowels as usual. This is common and quite normal. If the sensation is particularly strong, sit on the toilet and don't strain. You may pass mucus (jelly/slime), which is normal bowel secretion. Try to keep the skin around your anus clean and dry to prevent soreness.

Rectal discomfort or pain

This can occur in some patients when their rectum has been removed, and is sometimes referred to as 'phantom rectum'. Whilst pain or discomfort usually resolves spontaneously when the wound has healed, this may take as long as 6 months. If it continues you should mention it at your hospital clinic visit.

You may experience a discharge from the rectal wound as it heals; if concerned ask your community nurse or Stoma Nurse to check this.

Skin barrier wipes are available by calling the SecuriCare Careline

Useful addresses and websites

Colostomy Association
Head Office: 2 London Court
East Street, Reading RG1 4QL
24 hour helpline:
0800 587 6744 or 0800 328 4257
Email: cass@colostomyassociation.org.uk

***ia* – the Ileostomy and Internal Pouch Support Group**
Anne Demick – National Secretary
Peverill House, 1-5 Mill Road, Ballyclare, Co.
Antrim BT39 9DR
Freephone: 0800 0184724

Urostomy Association
Mrs Hazel Pixley – National Secretary
Central Office
18 Foxglove Avenue, Uttoxeter, Staffordshire
ST14 8UN
Telephone: 0870 7707931

NASPCS
(National Advisory Service to Parents of Children with a Stoma)
Mr. John Malcolm
51 Anderson Drive, Darvel, Ayrshire KA17 0DE
Telephone: 01560 322024

CancerBACUP
3 Bath Place, Rivington Street, London EC2 3JR
Telephone: 020 7696 9003
Cancer Information Service
Freephone: 0808 800 1234

National Association for Colitis and Crohn's Disease
4 Beaumont House, Sutton Road, St Albans,
Herts. AL1 5HH
Telephone: 0845 130 2233

Relate National Marriage Guidance
Harbert Gray College, Little Church Street, Rugby
CV21 3AP
Telephone: 01788 573241

Royal Association for Disability and Rehabilitation (RADAR)
12 City Forum, 250 City Road, London EC1V 8AF
Telephone: 020 7250 3222

Bowel Cancer UK
(Information on Bowel Cancer)
7 Rickett Street, London SW6 1RU
Telephone: 020 7381 9711

Websites

www.colostomyassociation.org.uk – Colostomy Association
www.cancerbacup.org.uk – CancerBACUP
www.clinimed.co.uk – CliniMed Ltd
www.bowelcanceruk.org.uk – Bowel Cancer UK
www.the-ia.org.uk – ***ia*** – the Ileostomy and Internal Pouch Support Group
www.macmillan.org.uk – Macmillan Cancer Relief
www.nacc.org.uk – National Association for Colitis and Crohn's Disease
www.naspcs.co.uk – National Advisory Service to Parents of Children with a Stoma
www.radar.org.uk – RADAR
www.relate.org.uk – Relate National Marriage Guidance
www.uagbi.org – Urostomy Association

What SecuriCare can do for you

Free home delivery

Prescription collection service

Phone lines are open from 8.00am - 5.30pm

Order online via internet and email

Customisation service

Our own delivery drivers (most areas)

Freephone Careline for advice

Stoma Care Nurses/nurse advisors (certain areas)

Samples from any manufacturer

Holiday delivery in the UK

Travel certificates & No Waiting card

Complimentary information booklets

SecuriCare (Medical) Ltd, Compass House,Knaves Beech Way
Loudwater, High Wycombe, Bucks HP10 9QY

Freephone Careline
0800 585 125

Email: info@securicaremedical.co.uk
www.securicaremedical.co.uk

Opening Hours: Monday to Friday 08.00 - 17.30*

* Answerphone service available outside normal working hours

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