

SecuriCare

BIG ENOUGH TO COPE – SMALL ENOUGH TO CARE



Adjusting to life
with a stoma

About the author

Bob Price first became interested in body image whilst caring for casualties from the Falklands conflict. During this time he came to realise a need to prepare patients mentally as well as physically for the outside world.

He designed measures for helping people recover from their ordeal, adapt to their new body image and to prepare for social interactions with others.

His work in burns and trauma settings was complemented by teaching duties he took up at the Royal Marsden Hospital, London. This centre of excellence in bowel surgery taught him a great deal more about stoma related body image needs, which he has subsequently used in workshops across Europe.



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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. Advice is given on how to plan what you say to others and there is a useful pull-out section where you can write down the information you wish to give them.

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.

Your feelings following stoma surgery

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.



Looking and feeling good

A confident appearance

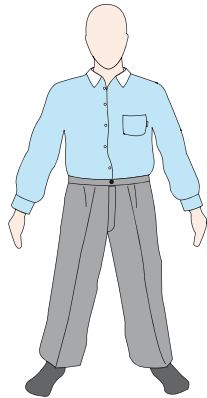
The way we appear to other people is affected by how we look and feel. Once you have mastered looking after your stoma in private you need to feel confident with it in public.

Choosing your clothes

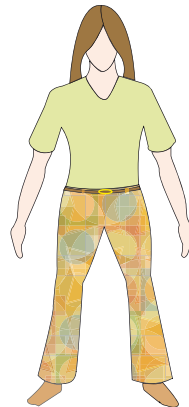
Wearing even a modern and well designed stoma pouch can sometimes change the outline of your appearance. Adapting your style of clothing can draw attention away from this part of your body. The following tips may help.

- ▶ 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.

Try pleated trousers which provide added room for movement.

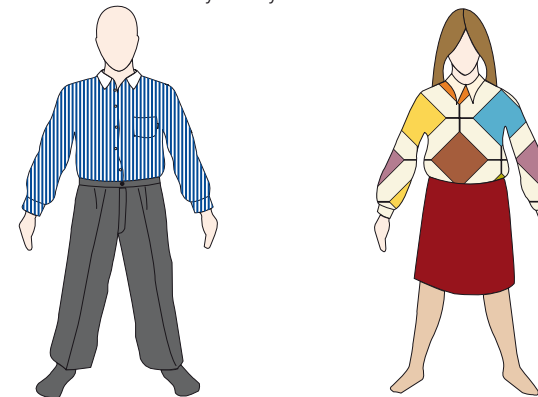


Very tight fitting trousers may restrict movement and cause discomfort.



Looking and feeling good

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.

Informing others

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.

Informing others

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 reactions 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 reactions 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.

Useful addresses and websites

Colostomy Association

Celia Waters – General Manager
15 Station Road, Reading
Berkshire RG1 1LG
Telephone: 0118 9391537
Freephone: 0800 3284257
E-mail: sue@bcass.org.uk

ia – the Ileostomy and Internal Pouch Support Group

Anne Demick – National Secretary
Pevehill 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.bcass.org.uk

www.cancerbacup.org.uk

www.clinimed.co.uk

www.bowelcanceruk.org.uk

www.the-ia.org.uk

www.macmillan.org.uk

www.nacc.org.uk

www.naspcs.co.uk

www.radar.org.uk

www.relate.org.uk

www.uagbi.org

- Colostomy Association
- CancerBACUP
- CliniMed Ltd
- Bowel Cancer UK
- **ia** – the Ileostomy and Internal Pouch Support Group
- Macmillan Cancer Relief
- National Association for Colitis and Crohn's Disease
- National Advisory Service to Parents of Children with a Stoma
- RADAR
- Relate National Marriage Guidance
- Urostomy Association

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