

Patient Information

acknowledgements

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Why do I need a Stoma?



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This booklet has been produced with the help of stoma care specialists, ostomy organisations and ostomists to help you through your first questions when you learn that you need a stoma formed.

How do you feel?

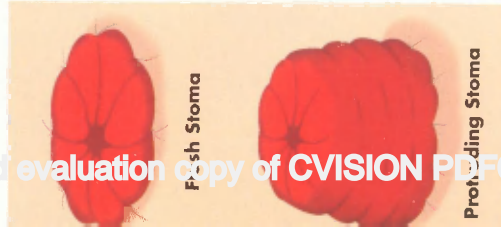
There are many reasons why you might require stoma surgery and the way you feel about this depends on why it is being done.

It can be shocking and upsetting news to learn that you need to have a stoma formed. Even though a stoma may save your life or give you a manageable option to the pain and discomfort you already experience, it may still leave you asking "Why do I need a stoma?"

Living a stoma may mean making adjustments to your lifestyle and you may be worried about your appearance, how to control the stoma pouches (bags) and asking other people about your surgery.

Are there other people with stomas?

In the UK there are an estimated 80,000 ostomists (colostomists, ileostomists and urostomists) who have already had an operation to form a stoma.



Why do I need a stoma?

There are many reasons for forming a stoma, but it is always done to improve your current situation. Sometimes it is a life saving procedure or perhaps it is because the formation of a stoma outweighs the pain and discomfort already experienced.

Understanding why you are having a stoma formed can help you prepare for your surgery. Your specialist care team (GP, Surgeon, stoma care nurse) understand your anxiety and are there to answer any physical or emotional questions you might have.



Who is going to help me through this?

You may have a close friend or relative who you can talk to about the operation who can offer you support during this often stressful time. Alternatively, you might decide it is better to talk to someone who has actually been through the operation and your stoma care nurse or specialist organisations such as the British Colostomy Association (BCA), the Urostomy Association (UA) and the Urostomy and Internal Pouch Support Group) and the Urostomy Association (UA) can put you in touch with someone. There may also be a local support group that your stoma care nurse can put you in touch with or stoma groups on the internet.

In general, any of your questions are best dealt with by your stoma care nurse who is a specialist in the field of stoma care. S(he) will have had similar questions or queries before and will be able to offer you an opportunity for counselling, advice and information to help you understand, adjust and cope with your stoma.



What should I include in the discussions?

You can be helpful to include your partner or another family member in all or some of the discussions that you have with the stoma care nurse, so that they can understand and support you in your recovery. Please don't be afraid to ask.

What questions should I be asking?

Although your stoma care nurse will cover any questions you might have, you might not remember to ask all the questions you want to such as:

- Where will my stoma be sited (height, position, size)?
- Will my stoma be permanent or temporary?
- What will my stoma be like (size, colour, how often it works, output)?
- What does a pouch (bag) look like? (size, types, colours, style, security, changing)
- Where do you obtain a supply of pouches?
- How much do they cost?
- How long will I be in Hospital?
- Will I have to change my diet? (food, alcohol)
- How will it affect my sex life?

Can I go back to work, socialise and travel?

Will my stoma be visible under my clothing?

Where can I get help and support?

Will I need any special care when I go home from hospital?

It is a good idea to write down any questions you think of before seeing your stoma care nurse.

What about my change in appearance?

It is important to recognise that it takes time to feel comfortable with your new appearance.

Because we expect our bodies to age (grey hair, wrinkles), we learn to slowly accept and adapt to these changes. A stoma, however, is an unexpected body change and is often performed relatively quickly.

It is natural that you might be anxious about the reactions and concerns of other people, but with the help of your stoma care nurse, friends and family, you can start to feel in control again.

Choosing the right clothes will help you to manage your appearance - and therefore make you feel more confident.

Your stoma care nurse may be able to help you learn to adapt and help you find workable solutions. Ask for more information on this subject.

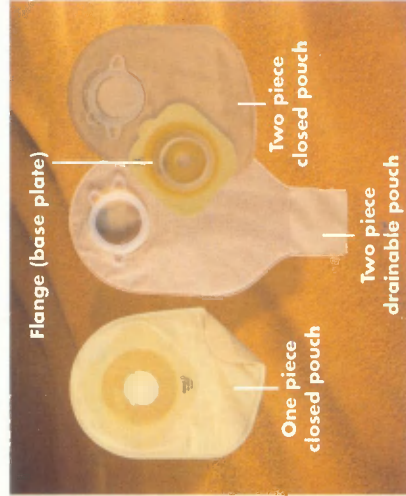
How will I feel after the operation?

There are various emotions which you might experience when trying to come to terms with your new situation and it is helpful to understand that this is normal in the recovery process.

Depending on the reason for your surgery, you might sometimes feel related that you are going to have more freedom and will be able to do things that you couldn't do before your surgery eg not having to constantly run to the loo.

You may have expected this surgery and know that it will improve your quality of life, but you might not like it all of the time. So don't be hard on yourself if that is the case.

You might even feel anger that you have been put into this situation or you might feel resigned and occasionally depressed because you can't see how you are going to cope. You may be one of those people who have not had a day's illness in your life and this has struck like a bolt out of the blue, so it's not surprising that your emotions might be in turmoil. These are normal feelings, this is when talking to someone you know and trust can help.



Most people, despite knowing that the operation is in their best interests, still have confused and constantly changing emotions and take time to accept their situation. Try to discuss your thoughts and any fears that you might have. You are not alone in this experience and other people have expressed similar thoughts. It will help your stoma care nurse to help you gain confidence and a sense of control if you can share your thoughts with her. The nurse is experienced and is used to helping people in this situation.

How do I tell other people about my stoma?

It might be best to plan in advance what you want to say to whom before being confronted by questions you find difficult to answer. Although you can never fully anticipate people's reactions, having a planned response will help you stay in control of the situation.

You might want to tell them simply that the operation has gone well and your problems have now been sorted out. Or you might want to explain that you now have a stoma and what this means to you, so they have some sort of understanding.

Your stoma care nurse can help you to take charge by planning and rehearsing your response to questions, and discuss who needs to know and what level of information you will give them.

How long will it take for me to get back some normality in my life?

It depends on why you have had your surgery and how fit and well you were before the operation to discover how long you will take to fully recover physically. You should not set yourself unrealistic goals as you have undergone major surgery and your body will take time to recover.

It is not unusual to take a little longer to recover psychologically, as it takes time to adapt to your new situation and regain your confidence and control. Once you have mastered the practicalities of stoma care and have begun to gain confidence, you will find that your life will slowly start to fall back into place. You will need to gain confidence with each new situation in turn until you have the confidence to deal with most eventualities.

Where can I find out more information?

Your stoma care nurse will be able to offer you lots of advice and information. In addition, various ostomy associations and information from the internet, all offer an excellent source of information. A list of how to contact them is supplied in the Dansac's Ostomy Directory. Dansac also offers a series of booklets on stoma care - order them from your Stoma Care Nurse.

Useful Addresses

The British Colostomy Association (BCA)

15 Station Road
Reading
Berkshire
RG1 1LG
Helpline: 0800 328 4257
Tel: 0118 939 1537
Fax: 0118 956 9095
E-Mail: sue@bcass.org.uk
Web Page: www.bcass.org.uk

International Ileostomy and Internal Pouch Support Group

National Office
PO Box 132
Scunthorpe
North Lincs
DN15 9YW
Freephone: 0800 018 4724
Tel: 01724 720150
Fax: 01724 721601
E-Mail: ia@ileostomypouch.demon.co.uk
Web Page: www.ileostomypouch.demon.co.uk

The Urostomy Association (UA)

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Buckland
Beaumont Park
Danbury
Essex
CM3 4DE
Tel: 01245 224294
Fax: 01245 227569
E-Mail: ua@centraloffice.fsnet.co.uk
Web Page: www.uagbi.org