

Body Image

- after stoma surgery



Introduction

Stoma surgery is a major operation. When your operation is over, one of your body functions will be different, and there will also be a change in how your body looks. This pamphlet discusses some of the things that can happen to your body following stoma surgery, as well as some of the emotions you may experience as a result of the changes to your body image.

We hope this phamplet can help you face the challenges of resuming your daily life.

Author

Michael Kelly Professor, London School of Hygiene and Tropical Medicine.

Professor Kelly is a medical sociologist with special research interests in coronary heart disease prevention, chronic illness, disability, exercise and health and community involvement in health promotion.

Michael Kelly has had a stoma for many years.

Editor

Vigdis Hannestad, RN, CETN, Dansac Global Clinical

Contents:

1.	Your body and your mind p.4
2.	Feelings about your body p.7
3.	Changes to the human body p.8
	 Loss of function Loss of control Damage to your body Pain and disorientation The responses of others The stoma as a barrier Sex Relationships Emotional responses to bodily changes
4.	Conclusion
5	References n 30

Your Body and your Mind

Your mind is an extraordinary thing. It has the ability to think about things, to picture them and to imagine them as different from how they really are. This is a basic human characteristic. Through work we change things. We use our body to provide food and shelter and to obtain all the other necessities and luxuries of life. Because our bodies are linked so closely to our survival as humans, we form very strong mental attachments to our bodies. We also have strong attachments with the mental picture of our bodies, as well as what we think our bodies can do, and should be able to do.

These feelings and understandings are called body image.

"In retrospect, the first days after the operation seem unreal"





Feelings about your Body

We all have a mental picture of our own body. This picture involves more than just size and shape. It includes the whole emotional and physical experience of the body, and stretches across the range of pleasures and pains of being human. The delights of eating, drinking, sex, laughter, sleep and intoxication, the distress of exhaustion, anxiety and pain, childbirth, the overwhelming feelings of being in love or in mourning, are all bodily experiences. Work and tool use are also physical experiences. In different ways, these experiences and activities are accompanied by physical sensations - churning stomach, tears, sighs, taste, smell and so on. It is this physical experience, that is so familiar to us, that will be focused on in this pamphlet.

Changes to the human body

It is important for you to know that your emotional reactions (feelings) after stoma surgery can be very intense. This is because the operation makes fundamental changes to your body. Changes that are both sudden and significant. There can be several reasons for the very strong feelings you may experience after surgery.



"Be open. It helps you get on with life."

Loss of function

Your body and its functions distinguish you as a member of the human family. You feel a part of the culture of the human family because you are more or less in control of these functions. For a time, losing control of a function like going to the toilet can make you feel different, that the loss of a function somehow seems to separate you from your regular social patterns or contacts.

"It was difficult to see the light at the end of the tunnel, but my partner's care and understanding saw me through."





Loss of control

Controlling your body is something you have learned to do. When you were born and during the early years of your life, you had little or no control over your body functions. During childhood you learned to gain control over your toilet functions, an essential part of being an adult human.

However, with an ileostomy or colostomy you cannot control your bowel function without a pouch. Similary, with a urostomy you cannot control your urine function without a urostomy pouch. You have to learn these functions all over again. Losing control can seem like loss of adult status. This is a very direct change in your body, and you may become acutely aware of your limited ability to control the new way your body works.

"I don't need sympathy or stupid remarks.
I need pats on the back and small personal victories."

Damage to your Body

Bowel or bladder surgery is a major invasion of your body. Having your bowel or bladder, or part of it removed, is a critical turning point. The same is true of your need to wear a pouch to collect your bowel or urine output. Up to now, you have been accustomed to using the toilet appropriately and privately. Stoma surgery changes the natural location of your bowel or bladder function as well as your privacy in using the toilet. In the early stages after surgery, this may make you feel that you are different to everybody else.



EXPERIENCE

"I asked for a stoma."

It is difficult to describe the pain and feelings one experiences during an illness. However, after I had been ill for more than a year, I began to panic. I was unable to do anything, and didn't feel like doing anything because of the pain. At the same time, I was afraid of losing my job because I was absent from work so often.

So, I asked to have a stoma, just to be able to get on with my life. I haven't regretted it for a minute.

Anne, 50 years, Colostomy

Pain and disorientation

Bowel surgery is major and causes tissue damage. While modern pain medication helps a great deal, you will still experience discomfort after your operation. Your discomfort and fatigue will make the changes in your body tangible and real. In addition to this, painkillers sometimes make you feel temporarily disoriented and disconnected from the world around you – as if you are separated from the normal social and physical world.

Shock and surprise

As the days go by, you will automatically begin getting involved in the world around you again. At that point, you will probably begin focusing on your stoma, what it looks like, what it feels like and so on. At this time, the stoma will still be swollen from the operation. It will be very red, and it will have irregular discharge that is likely to be quite smelly. At this point, it is natural for you to feel that you have changed physically. However, the swelling will recede considerably, the redness will fade, and your stoma output will become manageable.



"Be comfortable. Nobody will notice."

"I felt everybody were staring during shopping"



The response of others

You will naturally wonder how others will respond to your new stoma. All new ostomates do! Because you may feel shocked and surprised by your stoma, it is easy to think that others will feel the same way. One of the crucial skills you use your body for is interaction with others. Interaction with others involves the ways in which you move and present your body. You use your body both to give and receive messages from others. Your body language is crucial to how you read other peoples signals, and return signals to them.



The stoma as a barrier

Sometimes, new ostomates feel that their stoma is a significant barrier to interacting with others. There are several reasons for this. Immediately after surgery, most of your contacts will involve your stoma. During this time there will also be some odour. This is not usually a major problem, but it is often easy to worry about what others will think. In most cases, no one can see your pouch under your clothes. However, your new pouch will feel bulky and awkward, and you may feel that others can see and recognize the bump under your clothes. In fact, very few people will ever notice the slight bump, and even fewer will recognize what it is. However, it is a real physical presence that you cannot disguise completely and therefore some people living with a stoma can find this a real worry.



EXPERIENCE

"Is your bottom turned all the way round?"

Kids have a way of being very straightforward. When I finally showed my granddaughter my stoma (after dozens of requests), I suddenly realized I had nothing to hide. She didn't see anything particularly remarkable about my stoma, but was more interested in how my body functions now.

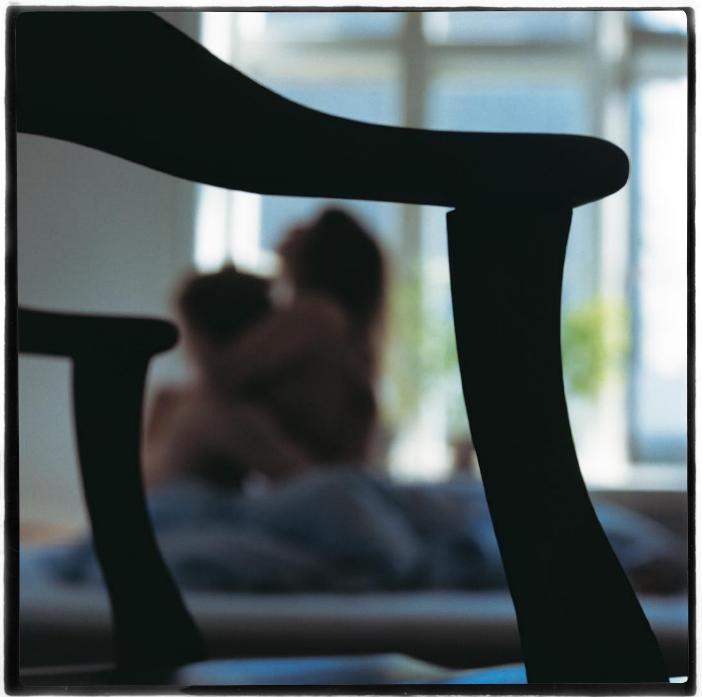
After listening thoughtfully to my answer she asked, 'Is your bottom turned all the way round then, Gran? The good thing about the episode was that it gave me a new understanding of my own body and the excellent job the surgeon had done. Today, many years after surgery, I have no problem seeing myself in full figure in a mirror, and I allow others to see me too."

Lilljan, 52 years, Colostom

Sex

You might have some worries about sex, as well. If you should have any physical problems as a result of your surgery, you can get advice and help to overcome them. You may worry that your pouch will make you sexually unattractive, or worry about telling potential new sexual partners about your stoma. But remember that sexual attractiveness is linked to all sorts of things like personality, conversation and sense of humour, for example.

New ostomates can find this difficult to believe and to handle. However, others have had the same experience and you can obtain a great deal of help to handle this issue successfully by talking to your doctor or Stoma Care nurse.



Relationships

Having a stoma, does not make you any different when it comes to human relationships. Many ostomates continue their relationships with others in exactly the same way they did before their surgery, either with long-term partners, or in more varied relationships. It is important to remember that relationships are not determined by the shape and size of your body. However, you may need time to work through the worries and anxieties you have after your operation.





EXPERIENCE

"I can't live without it."

Everything taken into consideration, it's a relief. It's been easy enough to accept my stoma mentally, although it's one thing to live with a disobedient spout on your stomach, and something else to make it behave. It insists on performing at the most impossible times. Actually, it's a bit like training a puppy, it needs attention but also consistency. If you aren't careful, it will take over. So, at the moment, I'm concentrating on controlling it by eating at the strategically ideal times. This is working better and better

Lene, 29 years, Ileostom



Emotional responses to bodily changes

Our daily lives are limited in many ways by the physical world around us. However, the limits placed upon us by our social world are even more important. Our social world is made up of our intimate and regular social contacts, as well as our more casual acquaintances. Our sense of body is also developed in these contacts, and it is these contacts that can make you feel anxious about the changes in your body after surgery.

In your social world, there are people who know all about your illness, operation and recovery. There are others who are not familiar with the details, but who will note that they did not see you for a while at work or at the club, etc. Some will be nosy, others will be genuinely interested. Either way, it will be necessary for you to meet these well-wishers. This can cause you some anxiety about your new body.

"What a pity there are so many taboos about something people know so little about."

The best way of reducing your anxiety is to prepare in advance, to rehearse possible questions and potential answers. You do not need to be completely open with everyone. Choose how much you want to tell, and to whom. The people closest to you probably know most of the details anyway, so it is usually best to be straightforward with them. With the others, you decide.

It is very important to recognize that these worries can cause you to react strongly. It is not unusual to feel weepy and sad, or even a bit depressed. You should see this as a normal and appropriate response to what has happened. It is always better to get these feelings out into the open. Once you have exposed your feelings, you can begin the process of looking to the future.



Conclusion

After surgery, you will be able to resume the activities you normally enjoy. The only real exceptions are hard physical contact sports like rugby or boxing. You will gradually resume your full social life, and you can look forward to sexual activity and eating a normal and varied diet.

During the first few weeks, your emotional and physical responses can be very intense, and getting through this period can be difficult. But it is possible to cope with this. Your body will be different after your surgery, and it will function differently. Getting through the first few weeks and months following surgery can be tough.

Your concerns and worries about body image are real, and you may experience them for the reasons outlined in this pamphlet.

It helps to express feelings and emotions and to acknowledge the hurt, anger and sadness you feel. You may feel like you have a mountain to climb, but life on the other side can be very good indeed.

References

Douglas, M. (1966) Purity and Danger: An Analysis of Concepts of Pollution and Taboo, London: Routlege & Keegan Paul.

Kelly, M. (1992) 'Self, Identity and Radical Surgery Sociology of Health and Illness 14: 390 – 415

Kelly, M. (1992) Colitis, London: Routledge.

Kelly, M. (2001) 'Disability and Community: A Sociological Approach, in

G. L.Albrecht, K.D. Seelman and M. Bury (eds)

Handbook of Disability Studies, London: Sage, 396-411.

Schilder, F. (1950) The Image and Appearance of the Human Body: Studies in the Constructive Energies of the Psyche, New York: International Universities Press.

"As a dentist I've seen things that were a lot worse than a plastic pouch on someone's stomach."

Suggested reading:

Cohen, Amira md Zierstein, Riva (1995):

"Drawing your body image" in World Council of Enterostomal Therapists journal Vol. 15, No.3.

Dansac A/S, (2002): What about sexuality?

Gloecker, Mary Reid (1984):

Perceptions of sexual attractiveness following ostomy surgery. Research in Nursing and health, 7, 87-92

Gearing, Y (1990): Am I an allright person. Inforum, page 12

Jones, Howard (1985):

Colostomy care, Maintaining an active life. Nursing times 13-19, No.:81(7), 36-38

Kelly, M (1987):

"Adjusting to ileostomy" in Nursing times August 19, Vol. 83, No33

Kelly, M (1992):

"A thirst for practical knowledge" in Professional Nurse, March, Vol. 7:530-56

Kelly, M (1985):

"Loss and grief reactions as responses to surgery" in Journal of Advanced Nursing, 10, 517-525

Kelly, M (1987):

"Managing radical surgery: notes from the patient's viewpoint" in Gut, 28, s.81-87.

Kelly, M (1993): "Open discussion can lead to acceptance" in Professional Nurse, 9:101-110, November

Kuula, Vicki (1990):

[&]quot;Stoma Care. Eye of the beholder" in Nursing Times November 28, Vol. 86. No. 48.

Suggested reading:

Majola SG, Ntombela BB and Zungu BM (1995):

A study of attitudes of colostomy patients towards a stoma. Curationis Vol.18, No.:1

Mullen B, Kerry A (1980/1992):

"The Ostomy Book" revised edition, Bull publishing Company, Paolo Alto California (1992)

Radley, A (1994): "Making sense of illness". Sage

Schilder, F (1950):

The Image and Appearance of the Human Body: Studies in the Constructive Energies of the Psyche, New York: International Universities Press.

Trunne,l Eric P (1996): Mindfullness and people with stomas. Journal of Wound, Ostomy and Incontinence Nursing, Vol. 23, No.:1,38-45

Wade, Barbara (1989): "A stoma is for LIFE", Scutari Press 1989, England

Dedicated to Stoma Care

Dansac is continually developing new solutions based on the wishes and requirements of ostomates and nurses. To encourage dialogue and break down taboos, new information is being compiled for patients and their families in collaboration with stoma professionals around the world.