

Sexuality for people who have a stoma



An information sheet for people with cancer, their families and friends.

This information sheet has been written to help people understand the effect a stoma may have on their sexuality.

The sheet contains suggestions on how to deal with the physical changes to the body, and the impact these may have on sexuality and sexual activity. It provides suggestions that may help with sexual difficulties experienced by some people as a result of their disease, its treatment, or because of stoma surgery.

Many people feel shocked and upset when they are told they have to have a stoma. They may worry the stoma will affect their ability to give or receive sexual pleasure or that the changes to their body will be unattractive. It is natural to have these concerns.

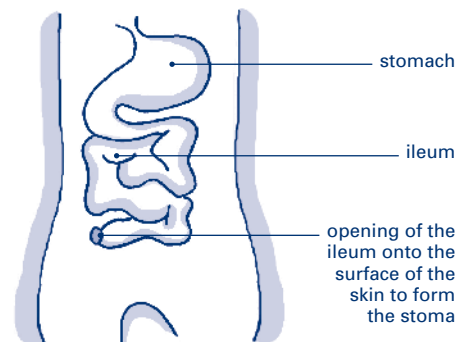
What is a stoma?

A stoma, which is sometimes called an ostomy, is formed when any portion of the small or large intestine is brought out onto the abdomen. The name given to a particular stoma depends on which piece of bowel is used, and the surgical procedure performed.

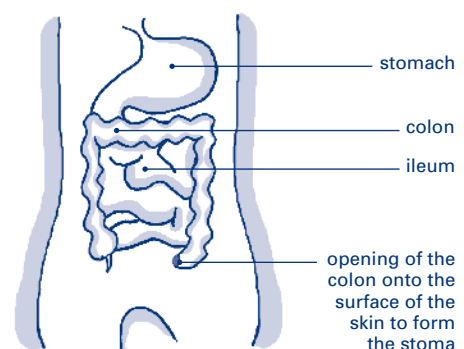
Stomas can be either temporary or permanent. When the stoma is temporary and later reversed, the rectum and anus should function normally. When the stoma is permanent the rectum may be removed and the anus closed. You may have a stoma that is round or oval, flat or pouting, as small as one centimetre or as large as 10 centimetres.

The most common stomas are:

Ileostomy: This is formed from the ileum, which can also be called the small intestine or small bowel; stool (output) will vary from a thick fluid to a consistency similar to toothpaste.



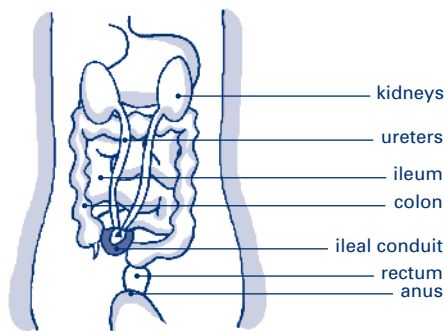
Colostomy: This is formed from the colon, sometimes called the large intestine or large bowel; stool (output) will vary from mushy to formed.



Ask your doctor or stomal therapy nurse to explain the surgery you had and what type of stoma you have. This helps ensure you are given the correct information when talking with other health professionals.



Ileal conduit: This is formed by isolating a small piece of ileum (small bowel) and implanting the tubes (ureters) from the kidneys into it. One end of the piece of small bowel is brought through the skin onto the abdomen as the stoma. Urine flows down the tubes from the kidneys, through the piece of bowel, into a watertight bag (appliance).



Stomal therapy nurse

A stomal therapy nurse is specially trained in the care of people who have stomas.

A stomal therapy nurse can help you by:

- providing support and information
- giving encouragement
- teaching you how to care for your stoma and how to adjust to living with a stoma.

If you are not happy with your appliance, if you have a problem with the stoma or surrounding skin, or think there may be something more suitable for you, see a stomal therapy nurse.

If you have a partner, encourage them to visit your surgeon and/or stomal therapy nurse with you to discuss the surgery and the stoma.

Stomal therapy nurses are available at most large hospitals and community centres.

Physical effects of surgery on sexuality

Like most people, you will probably feel vulnerable after surgery. You may find medications, hormones, chemotherapy and radiotherapy cause problems with your sex life or body image. It is important to talk to your doctor or stomal therapy nurse about these problems.

Creating a stoma usually involves the removal of part or all of one or more organs in the pelvic area, and this surgery may affect sexual function.

Effects on women

If the rectum is removed during surgery, the nerves controlling a woman's genital sensation may be damaged causing a different sensation in the vagina during intercourse. This is because part of the supporting structure has been removed. When the rectum is not there to cushion the vagina, women may find intercourse uncomfortable or painful. Patience, and trying different positions can help.

After surgery, women may find that their vagina lubricates less. There may also be some vaginal dryness and tenderness after radiotherapy. You may feel embarrassed or worried but there are several remedies for these problems. Try lubricants that are non-perfumed and water-soluble. Another simple solution might be a change of position during intercourse. If these do not work, discuss the problem with your doctor or stomal therapy nurse.

Effects on men

Sometimes pelvic surgery can interfere with the nerve and blood supply to the genitals. Men who have had their rectum, bladder or prostate removed may experience difficulty in having erections. Discuss possible solutions with your doctor or stomal therapy nurse.

Effects on gay men

Removal of the rectum may be a particular problem if you are gay. Intercourse via the stoma can cause damage and can allow the transmission of sexually transmitted diseases.

Practical hints

You may like to try some of the following suggestions:

- Ensure the appliance fits correctly and feels comfortable.
- Empty or change the appliance before having sex.
- Cover your appliance with a ready-made cover or make one if you don't like the feel of plastic on your skin. Choose soft material such as cotton or satin.
- Wear a mini-slip, nightgown, nightshirt, boxer shorts or crutchless underwear during sex if you feel uncomfortable. Many people are happy wearing nothing.
- Experiment with positions that keep your partner's weight off the stoma, or place a small pillow over the stoma so your partner is lying on the pillow rather than on the appliance. You can lie on top or underneath your partner – you will not hurt the stoma.
- Let your partner look at and feel your stoma or appliance if they want to. You can do this in the shower. Don't force them, but let it happen naturally. If they feel uncomfortable, don't take this as rejection. Give your partner time to adjust to the stoma.
- Share your thoughts. You and your partner may be afraid of hurting your stoma or worried that the appliance will become dislodged during sex.
- Maintain physical closeness. Continue to sleep in the same bed and show affection in other ways such as touching, caressing and kissing.

Stomas often cause more embarrassment and distress to the person with a stoma than to their partner. Take time to be with those you love, share your concerns with them and accept their reassurance.

- Wear the same clothes and swimwear as before surgery. Some people like to wear a wetsuit for swimming. If you prefer, underwear and swimwear can be custom made.
- Be patient. It may be several weeks or months before you and your partner feel entirely comfortable with a stoma. Acceptance may be gradual rather than immediate and will happen at different times for different people.
- Keep your sense of humour and try to laugh when things go wrong. Embarrassing moments happen during sex with or without a stoma.
- Seek help if you are having trouble coping. Your stomal therapy nurse may be able to help, or will refer you to an appropriate counselling service.

Pregnancy

Having a stoma doesn't prevent you from becoming pregnant and having a healthy delivery. You will experience all the usual symptoms of pregnancy such as morning sickness and backache. The stoma may swell and protrude more than usual mid-pregnancy but tends to return to its previous size after the baby is born.

If you want to have a baby, discuss this with your surgeon, gastroenterologist and stomal therapy nurse. You will probably be advised to wait one or two years after surgery before becoming pregnant.

Contraception

The effect of the contraceptive pill may change depending on the surgery and type of stoma you have.

Discuss with your doctor or stomal therapy nurse what contraception is suitable for you.

Seeking support and information

Stomal therapy nurses are available at all major hospitals and community health centres.

For information on support groups and patient to patient counselling networks such as The Cancer Council's Connect program, call the Cancer Council Helpline.

Ileostomy Association of NSW
Block E, Ozanam Village
West Street, Lewisham
Tel: (02) 9568 2799

Colostomy Association of NSW Inc.
Units 5-7, 29 Bridge Street, Stanmore
Tel: (02) 9565 4315

For more information on the effects cancer can have on sexuality read The Cancer Council's free booklets *Sexuality for Women with Cancer* or *Sexuality for Men with Cancer*.

The Cancer Council Helpline

The Cancer Council Helpline is a service of The Cancer Council NSW. It is a telephone information and support service for people affected by cancer. It is a confidential service where you can talk about your concerns and needs with specialist cancer health professionals. They can send you written information and put you in touch with appropriate services in your own area.

You can call the Cancer Council Helpline on 13 11 20, Monday to Friday, 9am to 5pm, for the cost of a local call. The tele-typewriter (TTY) number for deaf or hearing-impaired people is (02) 9334 1865.

As well as English, the Helpline is offered in the following languages:

Cantonese and Mandarin	1300 300 935
Greek	1300 301 449
Italian	1300 301 431
Arabic	1300 301 625

To access the Cancer Council Helpline in languages not on this list, call the Translating and Interpreting Service on 13 14 50.

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The Cancer Council New South Wales

The Cancer Council is the leading cancer charity in New South Wales. It plays a unique and important role in the fight against cancer through undertaking high-quality research, advocating on cancer issues, providing information and services to the public and patients, and raising funds for cancer programs.

This information sheet is funded through the generosity of the people of New South Wales. To make a donation to help defeat cancer, visit The Cancer Council's website at www.cancercouncil.com.au or phone 1300 780 113.

Before commencing any health treatment, always consult your doctor. This information sheet is intended as a general introduction to the topic and should not be seen as a substitute for your own doctor's or health professional's advice. All care is taken to ensure that the information contained here is accurate at the time of publication.

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