Living with a urostomy

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If you have a radical cystectomy, the surgeon will create an artificial opening to your urinary system (urostomy).

It's natural to feel upset if you have a urostomy as it is a significant change. The stoma bag (appliance) needs to be emptied and changed regularly.

Learning to look after the urostomy may take time and patience. However after you learn how to take care of it, you will find that people who have a urostomy live a normal life.

Positioning the stoma

Before your operation the surgeon and/or stomal therapy nurse will plan the position of your stoma. The stoma is usually formed on the abdomen, to the right of the belly button (navel). The medical team must take into account any wrinkles, scars or bones near the stoma, as placing it in the incorrect place may cause leakage later on.

For the first few days after your operation the nurse will look after your stoma for you and make sure the bag is emptied and changed as often as necessary.

At first your stoma will be slightly swollen – it may be several weeks before it settles down to its normal size. The stoma may also produce mucus (a thick white substance). As time passes the amount of mucus produced will lessen but it won't disappear completely.

The nurse will show you how to clean your stoma and change the bags. It may be helpful for a close relative or friend to join you at this time in case you ever need help at home. There are several types of appliances available and the nurse will help you to choose one that suits you best.

The first couple of times you are changing your bag you should allow yourself plenty of time and privacy so that you can work at your own pace without interruptions.

Adapting to the urostomy

It's natural to worry about how the urostomy will affect your lifestyle including your relationships and appearance. You may be worried about rejection, continuing to have sex with your partner or starting a new relationship. Many people find that once they talk about their fears their minds are set at ease.

Some people with cancer have the support of a partner while others do not. If you meet a new partner during or after treatment, it can be difficult to talk about your experiences particularly if your sexuality has been impacted. You may find that a new partner is understanding and supportive.
Although you may feel self conscious due to the urostomy most modern appliances are designed to be flat and unnoticeable under clothing. Whether or not your appliance is noticeable through your clothes will depend on its size and location. The style of clothing you wear is also important but most people with a stoma find that they can wear fitted clothing without advertising that they are wearing a bag. It's unlikely that anyone will notice unless you tell them.

**Stomal therapy nurses**

Stomal therapy nurses have specialist training in helping people with stomas.

Nurses can:

- answer your questions about the surgery
- help you adjust to having a stoma and regain confidence
- give you (and any carers) information about looking after the stoma
- assist you with fitting and using urostomy bags
- provide ongoing care and support after you leave the hospital.

Stomal therapy nurses work in many hospitals.

Your surgeon, GP, Cancer Council Helpline 13 11 20 or an ostomy association can help you find a stomal therapy nurse.

**Getting help**

Before you leave hospital the nurse will make sure you have a supply of urostomy bags. You can join an ostomy association for support, free bags and related products. Visit the Australian Council of Stoma Associations website on [www.australianstoma.com.au](http://www.australianstoma.com.au).

When you are at home you will be able to contact your stomal therapy nurse for advice. Your doctor may also be able to arrange for a district nurse to visit you when you first leave hospital to sort out any problems you may have with your urostomy.

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