

Life with a Stoma

For some patients with inflammatory bowel disease (IBD), surgery may be the most effective treatment. This can be challenging to accept, but in most cases, patients experience an improved quality of life compared with severe or poorly controlled disease. The surgery may involve creation of a stoma as a way of diverting stool away from the operation site and allowing the area to heal temporarily, or as a longer-term or permanent, solution. It is important that you discuss any questions or concerns with your stomal therapy nurse and IBD team to ensure you are well-informed.

What is a stoma?

A stoma is a surgically made opening in the abdominal wall to attach the small or large bowel. Bowel output then drains into a specially designed disposable collection bag. The bag can be emptied easily throughout the day and removed and replaced with a fresh bag as needed. The stoma may be temporary or permanent, depending on the type of surgery you have. The stoma has no sensation and there is no way of controlling when the stool comes through the stoma. There are two types of bowel stomas:

Ileostomy: the last part of the small bowel (ileum) is connected to the abdominal wall. Stools are softer and looser than usual because there is little water absorption from the small bowel.

Colostomy: a part of the large intestine is connected to the abdominal wall. Stool can be semi-formed or fully formed depending on the location of the stoma along the intestine.

The stomal therapy nurse, stoma care and supplies

A stomal therapy nurse is an experienced nurse who specialises in the education and care of patients requiring a stoma and their carers. Your stomal therapy nurse will be available for ongoing care and education before and after your surgery.

You should continue to communicate with your stomal therapy nurse and IBD team about the health and function of your stoma and the skin surrounding it.

The stomal therapy nurse will arrange your stoma equipment for you initially and help with supplies ongoing. There are many different types of bags, all made up of an adhesive base plate which attaches to the skin and a bag that collects the waste. The most appropriate type for you depends on the type of stoma you have. There are many different products that can also be used for stoma care, such as support garments and belts and aids for adhesive removal and skin care.

Frequently asked questions (FAQs)

Having a stoma is a big step in your treatment for IBD. You may need to make some initial adjustments to your daily routine. In general, the aim is to continue to pursue a full life with respect to family, work, and social activities. Here are some answers to some FAQs.

How will a stoma change the way I look and feel?

You may understandably experience changes in your mood, self-esteem, and sense of body-image. A stoma bag, once your routine is established, should be discreet, manageable and there should be no odour other than when you change or empty the bag into the toilet. It is important that you discuss any concerns with your stomal therapy nurses. Counselling and assistance is a key part of your recovery. Help in navigating a return to a balanced life at work, home, and socially is available to you through your IBD team.

Can I still stay physically active with a stoma?

Initially, you will be able to do gentle exercise, but you should avoid any strenuous activity or heavy lifting for about 4 weeks after the surgery. Over time, you may be able to return to your normal level of activity through a gradual increase in core strength and fitness. Contact sports may be possible, as may water sports.

How will a stoma affect my sexual life?

It is completely natural to be worried about how a stoma may impact your sexual health, but with the right guidance, you and your partner should be able to adjust to this over time. If you are having difficulty with sexual function, please discuss this with the IBD team.

Effectiveness of the oral contraceptive pill may be affected by the type of surgery that you have, so please discuss this with your IBD team. You can also refer to the [Sexual Health and IBD information sheet](#) for further information.

What is the impact of a stoma on fertility and pregnancy?

It is still possible to become pregnant with a stoma. It is important your disease activity is well under control prior to conception. If you are planning on having a family, please inform your IBD team of this early so that they can work together to optimise your management and discuss the timing and type of surgery that may be needed.

Can I travel with a stoma?

Having a stoma does not prevent you from travelling. It is advisable to discuss your plans with your IBD team including your surgeon and stomal therapy nurse. They will help ensure you are well-equipped and prepared for any flights and locations you may visit and know how to care for your stoma while travelling. You should take ample supplies for the duration of the trip and consider splitting them between checked and carry-on luggage to reduce the risk of lost baggage. In general, it is advisable to hold off on air-travel until at least 6 weeks after formation of a stoma.

If you experience an episode of gastroenteritis whilst away, it is important to ensure that you are well-hydrated and have a plan that you have discussed with your IBD team should it be necessary to seek medical assistance. Being prepared for travel is essential and your IBD team will help you with this.

Will I have to buy my own stoma equipment and where can I source it?

Medicare will cover the costs of stoma equipment and appliances through the Stoma Appliance Scheme. Apart from a small yearly membership fee to a stoma association and postage of your monthly supplies, there are no out-of-pocket expenses. Your stoma therapy nurse will arrange this for you following your surgery. If you are not covered by Medicare, please speak to your stoma therapy nurse and IBD team about how funding can be obtained.

Will a stoma change the way I take medications?

There are many factors that influence how well a medication is absorbed in the gastrointestinal tract, including: the type of stoma you have, the amount and part of bowel removed, and the health of the remaining bowel. Most medication is absorbed at the start of the small bowel, but controlled release medication is often absorbed in the large bowel. Therefore, medication changes are more likely to be needed in patients with an ileostomy rather than a colostomy.

Your IBD team will work with you to review your medications and make any dose adjustments if needed. You may be asked to change medication dose or formulation, for example, from a tablet to a liquid or from a controlled release product to an immediate release product. Do not crush or manipulate your medications without discussing with your health professionals, as not all medications can be modified.

Please notify your team if you notice any undissolved medications in your stoma bag. This may indicate your medication is not having its full, desired effect.

Should I consider changing my diet with a stoma?

Most people with a stoma have an acceptable output and do not need to modify their diet. [The Australian Guide to Healthy Eating](#) is recommended. One of the roles of the large intestine is to reabsorb water, so ensuring good hydration by having plenty of fluid is important.

In certain situations, you may benefit from further consultation with a specialist dietitian. These include too much or too watery an output, or excessive gas. Many factors may influence your stoma output, including:

- the amount and type of fibre you consume;
- the liquids you drink;
- the way you eat and drink, including how well you chew food, the timing of meals, drinking with meals and what you actually consume.

You should avoid restricting large numbers of foods or whole food groups, as this may place you at risk of developing nutrient deficiencies. If you are experiencing loss of appetite or loss of weight, you should discuss this with your IBD team.

Where can I find more information on stomas?

Your stoma therapy nurse will guide you throughout all stages of having a stoma and provide you with information materials and resources. You can also refer to the Australian Association of Stomal Therapy Nurses (AASTN) website on <https://stomatherapy.au/patient-education-pamphlets-2/> for further information.

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