

Living with a Stoma

Your Crohn's and Colitis Ireland
Mini Guide

Understanding Stomas & IBD

Inflammatory Bowel Disease (IBD) is a term used to describe chronic conditions that cause inflammation in the digestive tract. The two main types of IBD are Crohn's disease and Ulcerative Colitis: Crohn's disease can affect any part of the gastrointestinal tract from mouth to anus while Ulcerative Colitis primarily affects the colon and rectum.

A stoma is a surgically created opening from the gastrointestinal or urinary tract that allows waste to exit the body into an ostomy bag. The term 'stoma' originates from the Greek word meaning 'opening'. Stomas are often necessary when bowel damage or inflammation is severe. They can be life-saving and significantly improve quality of life by restoring independence and reducing symptoms. Stomas may be temporary or permanent depending on the underlying condition and surgical approach. They are commonly used in the treatment of IBD, cancer, and other bowel disorders.

Appearance of a Stoma: A stoma looks like a small, pink or red piece of bowel protruding from the abdomen. It is warm and moist, similar to the inside of the mouth. Since it has no nerve endings, it does not feel pain. After surgery, the stoma may be swollen but this typically reduces over approx. 6-8 weeks. It begins functioning within a few days, passing waste into the ostomy bag.

Types, Locations, and Care

Types of Stomas

- Ileostomy: created from the ileum (end of the small intestine)
- Colostomy: created from the colon (large intestine)
- Urostomy: created from the urinary tract to divert urine.

Stoma Care Essentials: Stoma care is guided by specialist nurses who provide equipment and training. Essential items include adhesive remover spray, seals including adhesive pastes, and ostomy bags.

Ileostomy bags need to be emptied more frequently due to looser output, while colostomy bags can be emptied less frequently daily. Urostomy bags collect urine and require regular emptying.

Proper skin care around the stoma is crucial to prevent irritation and ensure a good seal. Leakage can cause skin damage, so finding the right fit is important. Stoma bags are designed to be secure, discreet, and odour-proof. Confidence in managing your stoma grows with practice and support from your care team.

Diet, Hydration, and Lifestyle

Dietary Considerations

Ileostomy: digestion is quicker; avoid high-fibre foods like nuts, seeds, skins, and raw vegetables to prevent blockages.

Colostomy: avoid constipation and foods that cause bloating such as eggs, beans, and certain vegetables. - Urostomy: generally no dietary restrictions, but hydration is important.

Eating and Drinking Habits

- Eat slowly and chew food thoroughly.
- Avoid rushing meals and consuming large volumes of food and drink together.
- Stay hydrated and monitor how different foods affect your output.
- Establish regular eating routines and consult with a dietitian if needed.

Hydration Tips

- Ensure regular consumption of fluids daily.
- Use oral rehydration solutions if recommended by your healthcare provider.
- Avoid over consumption of caffeine and alcohol which can lead to dehydration.
- Monitor urine output and colour as indicators of hydration status.

Living, Travelling, and Support

Daily Life: Recovery from stoma surgery allows individuals to return to daily routines. With adjustments, people can participate in swimming, running, yoga, and other activities. Support garments and gradual reintroduction to physical activity are recommended. Confidence builds over time with experience and support.

Travel Considerations: Travelling with a stoma is safe and manageable. Preparation is key!

- Carry a travel certificate explaining your medical condition and supplies for airport security.
- Use the Hidden Disabilities Sunflower Ireland lanyard, available from the CCI shop, to discreetly indicate that you may need additional support.
- Pack extra supplies including ostomy bags, remover spray, and seals.
- Avoid dehydration and sunburn.
- Be cautious with unfamiliar foods to prevent stomach upset or diarrhoea.
- Choose accommodations with accessible facilities and plan your itinerary with comfort in mind.

Support and Contacts: Coloplast nurses and other stoma product care nurses offer personalised support based on your product brand. Hospital stoma nurses can be contacted even years after your initial surgery for ongoing advice. Here at CCI, we also provide online stoma support groups - visit Events at crohnscolitis.ie for details. You can also contact CCI via our email info@crohnscolitis.ie, or phone 01-1234567.

