Supporting patients with a colostomy

The Colostomy Association is a national charity that provides support, reassurance and practical advice to anyone in the UK who has, or is about to have, a colostomy. We are here to help and support patients, their families and carers. Our helpline is manned 24 hours a day by volunteers who all have a stoma. Our wide range of leaflets, quarterly magazine Tidings and closed Facebook group offer information and support to anyone affected by life-changing stoma surgery.

At the Colostomy Association we believe that everyone with a colostomy should be able to live a full and active life. Our team of volunteers are at the core of everything we do. Coming from right across the UK, they bring the human touch to what can be an immensely emotional and isolating time for patients. Our volunteers are able to demonstrate to patients that life can go on as normal after surgery; nobody can even tell they have a stoma, they can wear normal clothes, have a social life, progress successfully with their career, try new sports, and go about their daily lives.

‘Our trained helpline operators man our 24-hour helpline every day of the year and are able to deal with a wide range of enquiries on lifestyle topics.’

As all of our volunteers have a stoma, they have first-hand experience of how patients feel following their life-changing surgery. They are also carefully vetted, Disclosure and Barring Service (DBS) checked, and fully trained. The latter includes a special induction course with input from qualified stoma care nurses and regular refresher sessions each year.

Our dedicated team of volunteers attend local open days providing leaflets, information and invaluable face-to-face assistance. Some lead support groups while others undertake hospital and home visits, offering hope and inspiration to people at their most vulnerable time. They also give talks to healthcare professionals and lay audiences providing an insight into the patients’ perspective of living with a stoma.

SUPPORTING CHILDREN

Callers to our Junior Ostomy Support Helpline (JOSH) are able to speak with parents of children with bowel or bladder dysfunctions at a time that’s convenient to them. Our JOSH volunteers can help parents and carers through a difficult time in their lives, having ‘been there’ themselves.

Topics range from when or how to tell school friends, how to cope with life can go on as normal after surgery; nobody can even tell they have a stoma, they can wear normal clothes, have a social life, progress successfully with their career, try new sports, and go about their daily lives.

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I’ve been using Colostomy Association volunteers as part of my practice for many years, to inform and support patients undergoing life-changing stoma-forming surgery. I feel my patients benefit greatly from being able to meet with somebody who knows how they feel and this is corroborated by patient feedback. This personal approach through hospital visits has made a huge difference to my patients, helping them to adapt and return to a full lifestyle. I would recommend approaching the Colostomy Association when you need someone to talk to a patient, no matter what the topic.

Julie Rust, clinical nurse specialist stoma/colorectal, Royal Stoke University Hospital and University Hospitals of North Midlands NHS Trust

Clare Matthews, marketing officer, Colostomy Association

Viewpoints
sleepovers away from home, or even bullying at school. Our JOSH parents also direct callers to charities who can offer other types of support.

HELPLINE

Our trained helpline operators man our 24-hour helpline every day of the year and are able to deal with a wide range of enquiries on lifestyle topics. Whether it be preoperation anxiety or postoperative questions about diet, there will always be a Colostomy Association volunteer available to offer help.

Also, where we can, a patient is matched to a particular volunteer by gender, age, reason for surgery, topic of concern, or geographical location. We can even match patients who have had emergency surgery to volunteers who have gone through the shock of waking up with a stoma.

The Colostomy Association and its volunteers do not offer medical advice.

‘We help patients with queries around lifestyle issues and offer emotional and practical support.’

When patients raise concerns over medical matters like rectal discharge, granulomas and blood from a stoma, they are always referred to their stoma care nurse or GP. We help patients with queries around lifestyle issues and offer emotional and practical support.

It is so hard for a patient, lying in a hospital bed with a bag-covered ‘alien’ sitting unmounted on their abdominal wall. They are surrounded by well-meaning healthcare professionals telling them how they will get used to it, but few have personal experience of what life with a stoma really means.

To see a fit, well-dressed visitor, who has been there, done that and has the bag (not the T-shirt) to prove it, is often the one single intervention in a person’s hospital stay that creates a new-found belief that people do get back to normal life. I have no doubt that the recovery of many of my patients has been greatly enhanced by Colostomy Association volunteers.

When visiting a patient, it is gratifying to see the difference in that person’s perspective of life with a stoma. They often come into hospital terrified about the operation, or they wake up after emergency surgery not knowing what has hit them.

To receive a visit from myself — looking ‘normal’, leading life to the full and answering practical questions about travel etc — has a positive impact on them and they are very grateful for my visit.

Moira, a Colostomy Association volunteer who has been visiting people in hospital since 2007.