

Supporting and empowering
people living with a stoma



This is Colostomy UK

We support, we listen, we campaign, we educate and we influence.

There are over 200,000 people living with stomas in the UK. Colostomy UK is there for every single one of them.

ColostomyUK.org



Stoma helpline
0800 328 4257



Contact us

Write to:

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100 Berkshire Place
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Berkshire
RG41 5RD

Adminline:

Tel: 0118 939 1537

Stoma helpline:

0800 328 4257

E-mail:

For support and
general enquiries -
hello@ColostomyUK.org

For marketing, campaigns,
fundraising and trading -
getinvolved@ColostomyUK.org

Website:

www.ColostomyUK.org



Colostomy UK

Stoma surgery is a life-changing experience, and we are dedicated to helping and supporting the physical and mental well-being of all those who go through it.

Colostomy UK is a national charity that SUPPORTS, EMPOWERS and ADVOCATES for people living with any type of stoma and those who care for them.

We provide peer to peer support through our amazing volunteers, who have lived experience. We run a 24-hour stoma helpline, befriending support service, complementary support literature and advice booklets and a quarterly magazine.

We also run and deliver practical and educational awareness workshops and sessions, working with individuals and organisations. We advocate for the rights of people with hidden condition's, influencing policy and infrastructure change and often playing the role of a critical friend when incidents arise where people have felt discriminated.

We strive to make the World
#StomaAware.



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A Brief History

We have a proud history stretching back to 1963.

It all began when a surgical registrar in a London hospital approached one of his ex-patients and asked if she would visit his new patients on the wards. It quickly became clear that these visits encouraged recovery. She provided the reassurance that people needed and living proof that it was possible to lead an active life after stoma surgery.

Following a successful pilot across twenty nine hospitals, the Colostomy Welfare Group was established in 1967. As a charity we have never looked back. Five decades on and several name changes later, we are now Colostomy UK.

British Colostomy Association

"Dedicated to helping Colostomy People"



colostomy  **association**

Colostomy UK Today

In the pages ahead you can find out what a stoma is and why people who have stoma surgery sometimes need our support.

As you'll see, the support we offer today has grown far beyond visiting patients in hospital. If there's one thing we've learned in the past fifty-five years, it's that the type of support people want and when they want it varies according to everything from their age and gender to cultural background.

In recent years, Colostomy UK has also become active campaigning on behalf of people with stomas and running projects aimed at helping their physical and mental wellbeing after surgery. In this booklet we showcase our StomaAware campaign and our Active Ostomates campaign. If you are a bit puzzled by the names, all will be explained!

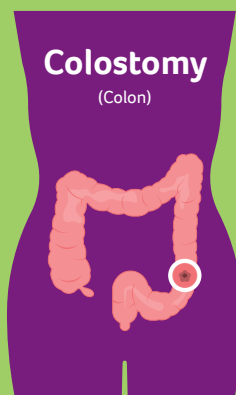
Last but not least, we talk about fundraising and why this is so important for a charity that receives no statutory aid.

What is a Stoma?

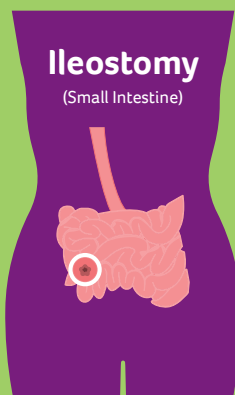
Stoma surgery involves the bowel and/or bladder being diverted through the abdomen so that bodily waste can be collected in a bag. 'Stoma' refers to the opening that the surgeon creates in the patient's tummy. People who have had stoma surgery are often referred to collectively as 'ostomates'.

As an ostomate's stoma bag is attached directly to their abdomen and under their clothes, their condition is 'hidden'.

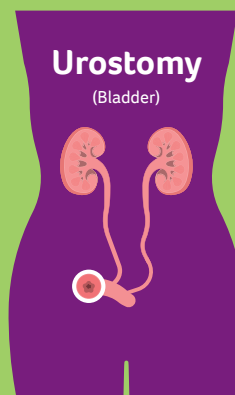
There are three main types of stoma: colostomy (colon), ileostomy (ileum), urostomy (bladder).



An opening from the colon (large intestine). Normally on the left side of the abdomen.



An opening from the small intestine (ileum). Normally on the right side of the abdomen.



An opening for the passage of urine. Normally on the right-hand side of the abdomen. Usually the bladder is removed but this depends on the operation.

Why do People Have Stoma Surgery

People of all ages and sexes have stoma surgery (including babies). This is because it is used in the treatment of many illnesses and conditions. These include: bowel cancer, inflammatory bowel disease (e.g. ulcerative colitis, Crohn's disease), diverticular disease, endometriosis, new-born malformations, incontinence, chronic constipation, trauma (which causes damage to the bowel or bladder). Some people's stomas are permanent, others are temporary and later reversed.

As you will probably appreciate from what you've read so far, stoma surgery changes the way a person's body functions. This brings with it physical and emotional needs. The new ostomate has to learn how to change their bag (which can be many times a day). They have to care for their stoma and deal with issues such as sore skin. It's also important to remember that stoma surgery is often just one part of a person's treatment. They may be facing the above challenges while still unwell and on medication, or undergoing other forms of treatment.

Over time the body heals, but it can often take longer for a person to come to terms with having a stoma. Many ostomates (collective name given to people living with a stoma) struggle with their body image, even though their condition is hidden.

The mental toll can be significant and in some cases lead to social isolation. Even a simple trip to the shops can be a problem for some, as they worry about things like having quick and easy access to public toilet facilities.

Stoma surgery can be life-saving, but it is also life-changing. Whatever a person's need, Colostomy UK is there, supporting them as they recover and get their lives back on track.



Our Support

You will recall that we started in 1967 with hospital visiting. Since then we have expanded considerably the range and type of support we provide, to make us as accessible as possible to all patient groups.

However, one thing that hasn't changed and never will, is the emphasis we put on giving ostomates peer-to-peer experienced-based help and advice. In simple terms this means patients helping patients. We achieve this through our nationwide network of trained and DBS-checked volunteers. All of them have or have had a stoma. They play a central role in the delivery of many of our support services:

We provide:

- **24-hour free Stoma helpline:**
0800 328 4257.
- **Telephone Befriending service.**
- **A private Facebook group** where ostomates, their families, friends and, where appropriate, carers, can support one another and exchange hints and tips.
- **A comprehensive range of literature.**
Research shows that access to quality information is vital for patient recovery. Our literature is also handed out in hospitals to new patients by stoma care nurses.
- **Tidings a quarterly support magazine**, whose articles by health care professionals, and real lives stories from people with stomas address both the physical and mental challenges ostomates face. Tidings won a British Medical Association patient information award in 2018.
- **A website packed with campaigning and fundraising news**, practical information, details of open days and a directory of organisations and support groups for people with stomas.
- **Run and deliver national care workshops** to educate individuals, support groups, care homes, agency staff and reablement teams about everything from stoma management, to a guide to different stoma problems, common concerns, support from Stoma Care Nurses, and psychological issues connected with having a stoma.

Campaigning



#StomaAware

Our StomaAware campaign aims to tackle the stigma of having a stoma. This stigma is often borne out of ignorance and leads to ostomates facing discrimination and prejudice, simply because their condition is hidden and their needs are poorly understood. For example, public places that lack accessible toilets can become 'no go' areas for ostomates. Our belief is that the more society understands, the easier it will become for people with stomas to lead fulfilling lives, hence the name 'StomaAware'.

We do lots of things to make the world more StomaAware. We work with businesses, shopping centres, tourist attractions, sporting and entertaining venues and aviation, helping them to ensure that their facilities meet the needs of people with stomas. We also deliver training to their customer-facing staff, so that they can deal with ostomates in a considerate and understanding manner. This can be important when, for example, an ostomate goes through airport security and needs to be searched.

We do all we can to raise awareness through the media and we make it our mission to ensure that references and portrayals of stoma surgery and life as an ostomate are accurate, empathetic and representative.



Our campaigning includes collaborating with other stoma charities, our industry partners, influential individuals who have stomas, policy makers and members of parliament.

Projects to Empower

Our **Active Ostomates** campaign has been running for nearly six years and just keeps growing! It's central aim is to empower people to return to sports, hobbies and other interests after their stoma surgery. It's also about giving them the confidence to take on fresh challenges as they start to feel better.

A key part of the project is the provision of different activities which, in order to reduce barriers to participation, we provide free.

These include everything from swimming and archery to Mindfulness & Meditation, art, Zumba classes, Yoga, Pilates and 'pop to the 80s' dance sessions.

Some activities are delivered face-to-face via support groups, others are delivered online.

Rugby League Team

We also have our own Rugby League Team! Team Colostomy UK is Comprised of ostomates and their friends and families. The team play exhibition and competitive matches and are a great way to show ostomates that having a stoma need not be a barrier to achieving anything – even contact sports are possible.

They are also a great help to our StomaAware campaign!



Fundraising & Getting Involved

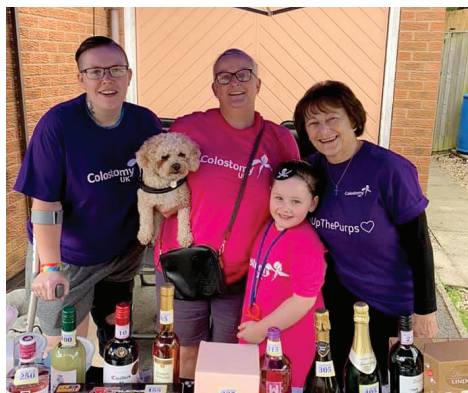
Can you help support over 200,000 people in the UK living with a stoma, by supporting the work we do?

Stoma surgery saves lives and for those who are unwell, can significantly improve the quality of their life. It is also a life changing experience and for some it can be hard to adjust. Reaching out to our charity and talking to people with lived experience at the right time could make all the difference to someone's quality of life and well-being.

Our support services mentioned in this booklet are volunteer-led. However, we have paid employees that manage, train and support our volunteers to be able to do the vital peer to peer support that's needed. We also need funds to enable us to do the campaigning work through our advocacy work.

Colostomy UK is an independent charity, financed solely from donations and fundraising activities. We do not receive statutory aid, so every penny we raise is vitally important to us.

For an easy way to support us by donating, scan this QR code.



You can support us in a number of ways:

- Charity of the year partnership
- Raise your awareness of life with a stoma to better support your employees and or customers through our Stoma Aware training
- Allocate time for your employees to support us
- Fundraise for us
- Become a volunteer by sharing your experience and knowledge to add value to our charity.
- Make a donation
- Sponsor our Rugby Team



Colostomy UK's flagship magazine *Tidings*, is hailed by ostomates and healthcare professionals alike for the support and information that it provides readers with on a quarterly basis.

Visit our website or call us to sign up for your free copy.

How to contact us

Write to: Colostomy UK, 100 Berkshire Place, Winnersh, Wokingham, Berkshire, RG41 5RD

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