

www.ColostomyUK.org



## Colostomy UK

We are Colostomy UK. Here if you have questions, need support or just want to talk to someone who lives with a stoma.

Your voice on the bigger issues: advocates for your rights and campaigning to raise awareness of what matters to you; running projects to empower you; building communities to support you.

### Contact us

#### Write to:

Colostomy UK 100 Berkshire Place Winnersh Wokingham Berkshire RG41 5RD

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Tel: 0118 939 1537

Stoma helpline: 0800

328 4257

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Once recovered from stoma surgery, some ostomates experience pain and/or discomfort in the rectal or perineal area. The causes, treatment and location varies according to the type of surgery that was performed and whether or not the rectum was removed.

This booklet takes each of the main types of stoma surgery in turn and talks about the pain and/or discomfort known to accompany it. Consideration is then given to coping strategies and available treatment.

What follows is intended for general guidance and information only. If you are experiencing any pain or discomfort then it is important that you seek advice from a healthcare professional, such as your stoma care nurse, GP or consultant.



# Stoma surgery where the rectum is left intact (Hartmann's procedure, loop stoma)



Hartmann's Procedure

Ostomates that have the above surgery can experience pain and/or discomfort in the rectum. This often manifests itself as a feeling of rectal fullness and the need to open your bowels.



Loop Colostomy



Loop Ileostomy

#### Causes

Muscles in the bowel wall propel food and waste through the digestive system by a process called peristalsis. Even though waste now passes out of the body through a stoma, muscles and nerves in the rectum still function as before, which can cause the sensation of needing to pass a motion.

The bowel produces a lubricant called mucus, which helps food pass through the system. Even though the

rectum is now redundant it still produces mucus, which can either be passed through the anus or dry up into a ball which is then often difficult to pass and causes pain.

#### Coping strategies and treatment options

Sitting on the toilet can provide some relief. Gently bearing down as if you were opening your bowels may help to expel mucus. Doing this everyday can reduce the build—up of mucus too.

If you are unable to pass mucus naturally then your stoma care nurse or GP may suggest using a mini–suppository or micro–enema at regular intervals. This can vary from twice a week to once a month.

Some ostomates find that haemorrhoid ointment relieves pain and discomfort. You should consult your stoma care nurse or GP to check whether this treatment is suitable for you.





# Stoma surgery where the rectum is removed



Abdominoperineal excision of rectum or APeR

Some stoma surgery necessitates the removal of the rectum and anus (back passage). After this type of surgery there is a wound and stitches in the perineum (the area between the anus and the scrotum or vagina) and, until this has healed, it can be

uncomfortable to sit for long periods. Healing time varies from person to person and, even when the scar appears healed on the outside, the tissues beneath may not be. Occasionally this wound can break down and you may need a special type of dressing to aid healing.

For most ostomates both the pain and the sensation of needing to pass a bowel motion gradually diminish and, over time, disappear. For some, however, it persists after the healing process is complete or returns at a later date. If this happens then you should consult your stoma care nurse, GP or consultant, as it is important to check that there is no underlying problem such as a perineal hernia (where the pelvic contents bulge out through a weakness in the perineum), an abscess or a recurrence of the original disease.

For a small number of ostomates the pain can be severe. The adjectives they use to describe it include: sharp, shooting, stabbing, burning or throbbing. It can be constant or intermittent. In some cases the pain comes in waves.

#### **Causes**

The causes of pain are not always clear. They can include scar tissue, where the surgical scar becomes hard and thickened. This is more likely to occur if the wound was slow to heal or the tissues were damaged by radiotherapy. The bowel or other organs in the pelvis pressing down on this scar can lead to a feeling of fullness where the rectum used to be. Another cause of pain is nerve damage (neuropathic pain). It is possible for nerve damage to be sustained during surgery, from radiotherapy and chemotherapy treatments and from an infection.

#### Coping strategies and treatment options

Sitting on the toilet and going through in your mind the process of opening their bowels can help to relieve the feeling of wanting to pass a motion. For more persistent pain or discomfort ostomates report that the following can help:

- Sitting on an ice pack or soaking in a warm bath.
- Massaging the scar tissue with a moisturising cream.
- Tilting the pelvis to reduce the pressure on the perineum. This can be achieved in two ways:
  - Kneel down, then lean forward, resting your forearms on the floor and your head on your hands.
  - Lie on your back and place a pillow under your bottom.
- Over the counter pain killers can help, but you **should not** use these without first speaking to your stoma care nurse or GP. This is because some can cause constipation, which might lead to problems with your stoma.
- Exercise (call or visit our website for a copy of our booklet: *Active ostomates*: *Sport and fitness after stoma surgery*).

Although the above may help, if the pain you are experiencing is severe and/or persistent then you should consult your stoma care nurse, GP or consultant.



# Support from Colostomy UK

We hope you found this booklet useful. Unfortunately, even after medical intervention some ostomates find that the pain persists. This can be very disheartening. If you find yourself in this situation then you may find it useful to speak to one of our volunteers who has had the same experience. Just call or e—mail us to arrange this. Attending a pain management programme is another option worth exploring (speak to your stoma care nurse or GP). Further help can be found by attending a local support group, joining our closed Facebook support group or by visiting the websites detailed below, which have lots of useful information and advice.

British Pain Society: www.britishpainsociety.org
Pain Relief Foundation: www.painrelieffoundation.org.uk

#### We provide:

- A stoma helpline: 0800 328 4257.
- Support literature and factsheets about all aspects of Living with a stoma.
- Tidings, a quarterly magazine full of the latest news, articles by stoma care professionals, product information and real–life stories from other ostomates.
- A closed Facebook group for supporting each other and exchanging hints and tips.
- A website that provides practical information, details of open days and a directory of organisations, support groups, products and services.

No one should face stoma surgery alone



Make sure they don't - donate now

To donate **£5**, text **ColUK001** to **70970**To donate **£10**, text **ColUK001** to **70191** 

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**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

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