



**Pain and Discomfort
in the Rectum
and Perineum
following
Stoma Surgery**

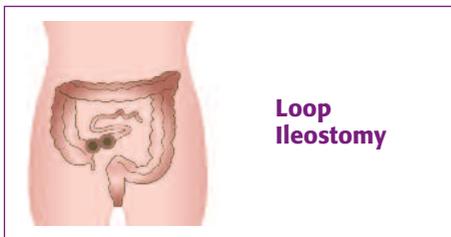
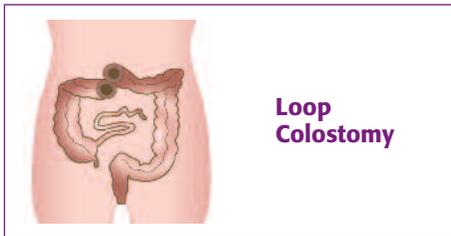
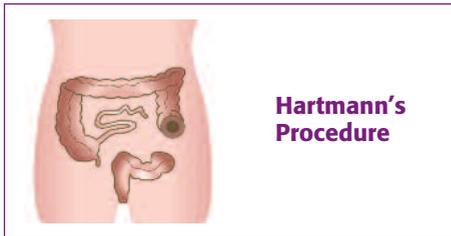
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The causes and treatment of pain in the rectal and perineal area are not always clear cut and will depend on whether your rectum is still intact or whether it was removed and your anus closed when your stoma was formed. If your rectum has been removed turn to page 4. If your rectum is still intact read on...

Pain or Discomfort following an operation to form a stoma without removing the rectum (Hartmann's procedure, loop stoma)



What causes the pain/discomfort?

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, and this may cause the sensation that you need to pass a motion.

The bowel produces a lubricant called mucus, which helps food pass smoothly through the system. Even when the rectum is redundant it still produces mucus, which can either be passed out through the anus or dry up into a ball and cause pain.

5% of the population (non-ostomates as well as ostomates) experience a condition called Proctalgia Fugax, a fleeting rectal pain due to uncontrolled muscle spasms in the pelvis, which occurs infrequently and lasts less than 20 minutes. The cause is not known.

After this type of operation you may still experience the feeling of rectal fullness and that you need to open your bowels in the normal way.

Coping strategies

Sitting on the toilet may provide some relief. If you gently bear down as if you were to have your bowels open this may expel any mucus. Doing this every day may help to reduce the build up of mucus.

What treatments are available?

If you are unable to pass the mucus naturally your stoma care nurse or GP may suggest using a mini-suppository or a micro-enema at regular intervals to prevent the build-up of mucus. How often you need to use them can vary between twice a week and once a month.

Some ostomates find haemorrhoid ointment may relieve rectal/anal discomfort. Consult your GP or Stoma care nurse to check whether this would be suitable for you.

Colostomates who still have their rectum intact share their experience of rectal pain.

Rebecca says: In 2005 I had surgery to alleviate increasingly serious episodes of diverticulitis and returned home with a colostomy. At my first two checkups, I complained to my colorectal consultant about rectal pain. Nothing was suggested. I found it increasingly uncomfortable and I could not sit on hard chairs.

Twenty-one months later when my GP examined me he felt something inside my rectum and I subsequently passed what looked like a wax candle. My consultant said that this was a build up of mucus and it does happen; some patients produce more mucus than others. If it is not passed, it gradually builds up and becomes solid in the rectal stump. He told me to ask my GP for suppositories and to use them regularly as required.

Now every time I realise there is a build up of mucus, I use a 2mg children's suppository that evening (The 4mg adult version is too uncomfortable and I have trouble keeping it in for long enough). This ensures the mucus is removed from the

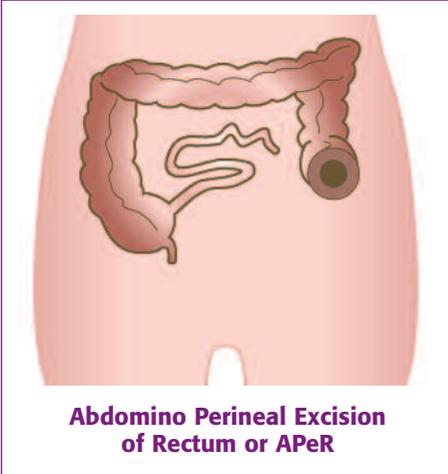
rectal stump preventing it from becoming solid. I still get a dull ache in my rectum but nothing like the pain I had before. I can tell when the mucus is building up because I get an 'urge' to go. I cannot pass this liquid mucus without using a suppository, no matter how hard I strain.

Jack says: I had a colostomy in December 2008. The surgeon said I might have trouble with the rectum about every fortnight. Not quite accurate. In fact I get a build up of mucus after about two months. It becomes periodically painful when there is pressure in the abdomen to discharge.

At this stage I sit on the loo and put pressure on my sphincter muscles. With luck I might get a string of mucus hanging from the rectum so that I can give it a pull by hand. Then I clean up and fix a cotton soft "facial wipe" over the rectum. It then discharges mucus for several days. I treat it by regular washing and using a haemorrhoids treatment prescribed by my GP. As a result the pain subsides quickly.

Christine says: I had a colostomy formed after abdominal surgery for cancer in 2005 and subsequently had pain in my rectum. I produce quite a lot of mucus and the pain eases after evacuation but sometimes no mucus is passed even when it feels as though there is some in the rectum. I have not had a large hard lump, it is mostly very liquid. The strange thing is that I am most uncomfortable when I go to bed but it usually settles down after 15-20 minutes. There are times in the day when I am not aware of it at all and it really is nothing compared to having bowel cancer. I have been irrigating, for around six months, and now find that during that procedure I produce more mucus which easily evacuates.

Pain following an operation to form a stoma during which the rectum was removed (APER: Abdomino Perineal Excision of Rectum)



As your rectum and anus (back passage) have been removed there will be a wound and stitches in the perineum (the area between the anus and scrotum or vagina) and for a while it may be uncomfortable to sit down for long periods. The time it takes for the wound to heal will vary from person to person – the scar may appear healed on the outside but the tissues beneath may not be.

You may also still get the sensation that you need to pass a bowel motion. As it occurs even though your rectum has been removed this is sometimes called Phantom Rectum Syndrome.

For the majority of ostomates the pain will gradually diminish and disappear but for some it will persist after the healing process is complete or return at a later date. If this happens it is advisable to consult your GP, surgeon or stoma care nurse to check there is no underlying problem e.g. a perineal hernia (where the

pelvic contents bulge out through a weakness in the perineal wound), an abscess or a recurrence of the original disease.

For a small number of ostomates the pain may be severe. They describe the pain as sharp, shooting, stabbing, searing, burning, throbbing or like “sitting on a stone”, “a red hot poker” or “toothache in the bottom”. In some cases it comes in waves. It can be constant or intermittent.

What may cause the pain?

The feeling of needing to “open your bowels” may be because the nerve supply is still intact even though the rectum has been removed.

Scar Tissue

The surgical scar can become hard and thickened, especially if the wound was slow to heal or the tissues were damaged by radiotherapy. The bowel or other organs within the pelvis pressing down on this scar tissue may result in a feeling of fullness where the rectum used to be.

Nerve Damage (Neuropathic pain)

It has been suggested that the pain may be the result of damage to the nerves during:

- the operation;
- radiotherapy treatment;
- chemotherapy treatment; or
- an infection.

Coping strategies

Some ostomates have found that sitting on the toilet and going through in their mind the process of having their bowels open can relieve the feeling of wanting to pass a motion.

For more severe or persistent pain or discomfort the following may help:

- Sitting on an ice pack or soaking in a warm bath.
- Massaging scar tissue with a moisturising cream to make it more supple.
- Tilting the pelvis to reduce the pressure on the perineum. To do this:
 - a) Kneel down, then lean forward, resting your forearms on the floor and your head on your hands.
 - b) Lie on your back and place a pillow under your bottom
- Medication: check with your doctor or pharmacist about suitable pain killers; some have the side effect of constipation, which may lead to added problems with your stoma. Long term use of pain killers can result in a build up of tolerance so that higher dosages are needed to have the same effect.
- Exercises:
 - a) To stretch hard and inflexible scar tissue gradually lift one leg, or crouch down, until you reach the point where it hurts
 - b) Pelvic floor exercises
 - c) Yoga, Tai Chi or Pilates
- Hypnotherapy, relaxation techniques, acupuncture or reflexology.

N.B. Before beginning an exercise programme or complementary therapy it is important to consult your GP, surgeon or stoma care nurse to ensure that it is appropriate for you. It is important to

check that any private practitioners are trained and registered with a recognised professional organisation.

What treatments are available?

For chronic, severe pain your surgeon or GP may be able to refer you to a specialist pain clinic where the following treatments may be suggested.

Medication

Some drugs originally developed to treat other conditions e.g. Gabapentin (an anticonvulsant) and Amitriptyline (an antidepressant) have been found to be effective in reducing neuropathic (nerve) pain. However, they do not work in all cases and can have side effects.

Nerve Blocks

Pudendal nerve block: an injection of anaesthetic or slow release steroid near the site of the nerve, carried out under CT scanner guidance.

Unfortunately, for some ostomates the pain persists even after trying all the above suggestions. This can be very disheartening and you may begin to think that no one believes the pain is real. If you find yourself in this situation it may help to attend one of the following:

- A pain management programme. Although not a cure for the pain they can help to improve your ability to manage the pain, increase your level of physical activity and return to your usual activities.
- A support group for ostomates or chronic pain sufferers where it may help to share your experiences and concerns with someone else who also suffers similar pain.
- An Expert Patients Programme: courses run by tutors who have persistent health conditions themselves.

Colostomates share their experience of Pain following an operation during which their rectum was removed

Anne says: When I first had a colostomy I experienced a variety of rectal pain. It didn't devastate me or overwhelm with its intensity or remain for long periods of time, but it did exist. When it arrived (or when I recognised its postoperative existence as other discomforts cleared up) it did so with the sharpest of red-hot pokers thrust up the area where I previously housed a rectum.

My initial concern was how this new pain seemed related to the tumour spasms of my pre-op days. My stoma nurse allayed my fears. I didn't realise how common this after effect was until a discussion with other ostomates at a support group. A problem shared with others "who've been there" is comforting, if not curing.

With my red hot pokers there was never any rhyme or reason and no warning. When it happened I'd walk and walk. It didn't cure it but I was doing something and I felt it helped. Then there was a steady throb from the area at the base of the spine. This often felt like a growing mass, but it wasn't. There was nothing there. However, as time went by and life with a bag settled down, so too did the pain. It happened less often. One day I realised it was all in the past. Perhaps it is all part of the healing process and time really does and has healed.

Catherine says: I have suffered rectal pain since operation for colon cancer in 2008. My anus was sewn up when I had the colostomy but I've had the urge to bear down ever since. I have had

numerous scans and the doctors have found out my womb has fallen backwards leaning on to my small bowel.

Jason says: I had my stoma in 1996 due to solitary rectal ulcer syndrome. The operation was a Hartmann's procedure. Then in 2001 I had a proctectomy to remove my rectum. Due to an infection in the rectal wound/cavity, my pain problems started almost immediately.

The nerve damage pain is best described as neuralgia in my butt: a sharp, stabbing pain that can be a quick stab and vanish or come in waves for hours. I was sent to pain management specialists, who recommended a painkiller regime consisting of neuropathic and opiate-based painkillers and also spinal freezes.

Every few months I also get the urge to go to the toilet, even though the rectum has gone. It's best described as there being a golf ball stuck in the cavity that I need to expel, but cannot. It lasts about an hour or two, and repeats for a few days, then vanishes for a few months. Sometimes sitting on the toilet helps ease this, although I'm sure it's in the mind and not a physical solution to the problem.

Tony says: I had surgery for cancer ten years ago, but it wasn't until three years ago that the pain started. It feels like a red hot poker where my rectum used to be and it only eases off when I lie down at night. I have had a CT and an MRI scan which have confirmed that the cancer has not returned.

My consultant thinks the pain may be the result of nerve damage due to the radiotherapy I had prior to surgery, or maybe scar tissue.

I have been to the pain clinic and have tried various medication and pain patches. I cope by pacing myself and sitting and resting if the pain gets too bad.

Jim says: I was diagnosed with bowel cancer in late December of 2007 which resulted in me undergoing an Abdominoperineal Resection (APR) in early February 2008. Following my operation the wound on my tummy was painless and healed very quickly, whereas the wound in my back side refused to heal, needed new dressings at least once a day, and was extremely painful.

It was eighteen months before the wound healed, gradually becoming less painful as it did so. I can't say that I am now completely pain free but on a scale of one to ten I would describe it as only one and more of a dull ache than a pain and I no longer take painkillers.

Paul says: Having a perineal resection is quite a life changing event! One day you have an anal passage which operates as a waste disposal unit, the next it is no longer there but the body seems to think that everything is normal! For me rectal pain started to become something I endured every day. I really felt that my buttocks were clamping onto a brick most of the time; remember the nerve endings have been cut and not joined up so there is this numb area between the two sides. I suppose I could describe the sensation as the feeling of coming back after a visit to the dentist at the halfway stage.

There are also the times when one's body has the urge to want to pass wind or evacuate the bowel, yet there is actually nothing there, and this promotes

a sort of pain, like when one is really bursting for the loo. These sensations pass with time, or you just get used to it. I had my resection just over ten years ago, and whilst I still have the 'brick clamping' feelings I have got used to the 'supposed' rectal pain. I still have some numbness in the crease and doubt that feeling will ever return. I live with it and enjoy life to the full!

This booklet is intended for general information and guidance only. If you have pain or discomfort in your rectum or perineum it is important to seek advice from a healthcare professional such as your stoma care nurse, GP or surgeon.

Sources of further information:

- **British Pain Society**
www.britishpainsociety.org
Booklet: Understanding and managing pain
- **Pain Relief Foundation**
www.painreliefoundation.org.uk

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