

Living with a Fistula

Introduction

A fistula is an abnormal channel or passageway connecting one internal organ to another, or to the outside surface of the body. Many fistulas (or fistulae) involve the bowel or intestine. So, a fistula might connect two parts of the bowel to each other, or the bowel to the vagina, bladder, or outside skin. You may develop a fistula like these if you have Inflammatory Bowel Disease (IBD), especially Crohn's Disease. About 1 in 3 people with Crohn's will probably develop a fistula at some time. Fistulas are much rarer in people with Ulcerative Colitis (UC).

This information sheet provides some general information about these fistulas and likely treatments. It also includes tips and suggestions which may help you if you are living with a fistula. These are based on the advice of health professionals and the experiences of NACC members with this condition.

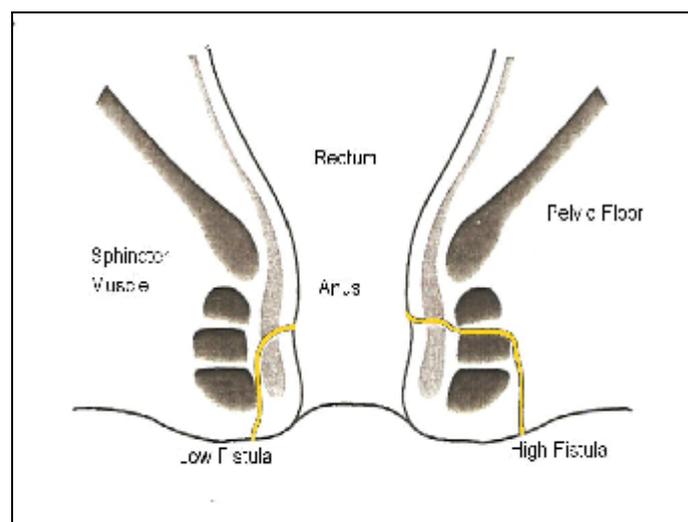
Are there different types of fistula?

There are quite a few different types of fistula. Those most commonly associated with Crohn's Disease are described below.

- Anal or 'perianal' fistulas: these connect the anal canal (back passage) to the surface of the skin near the anus.
- Bowel to bladder fistulas, also called enterovesical or colovesical fistulas.
- Bowel to vagina, or enterovaginal fistulas. If the fistula links the rectum to the vagina it is known as a rectovaginal fistula.
- Bowel to skin fistulas in areas other than near the anus, for example, on the abdomen. These are enterocutaneous fistulas and may occur following surgery, along the line of the incision.
- Fistulas linking different parts of the bowel or intestine together, bypassing a section in between. These are known as enteroenteric or enterocolic fistulas.

A simple fistula is one with only a single tract. Some fistulas have branches or several interlinking connections, and are referred to as complex fistulas.

Anal fistulas may be described as low or high. A low fistula is one that comes through to the skin below the sphincter muscles (the muscles surrounding the anus). A high fistula is one which runs through the muscle to the surface. The diagram below shows a high and a low simple anal fistula.



What causes a fistula?

Fistulas tend to occur with Crohn's Disease because the level of inflammation typical of Crohn's can spread through the whole thickness of the bowel wall. When this happens in the lower parts of the bowel it is particularly likely to cause small leaks and abscesses (collections of pus). As the abscess develops it may 'hollow out' a chamber or hole. This then becomes a passage or channel linking the bowel to another loop of bowel, another organ, or the outside skin. When the abscess bursts, the pus will drain away, but the passage or channel may remain as a fistula.

Fistulas are much rarer with Ulcerative Colitis because the inflammation in UC does not tend to spread through the full thickness of the bowel in the same way.

What are the symptoms of a fistula?

These will depend on where the fistula is.

If you have an internal fistula connecting one part of the bowel to another, food may be bypassing sections of your bowel, and you may develop diarrhoea and become malnourished. Sometimes, however an internal fistula may cause no symptoms at all, and will only be found using an X-ray or MRI scan. (See below)

With an anal fistula the symptoms often include:

- irritation of the skin around the anus
- a throbbing pain which may get worse when you have a bowel motion, cough, or sit in certain positions
- occasionally, a leak of faecal matter (waste matter from the bowel) through the fistula.

If you still have an abscess as well, you may also have a fever and feel generally unwell.

The main symptom of a rectovaginal fistula tends to be the passage of wind from the vagina, but some women find they are passing faecal matter as well. Sometimes a rectovaginal fistula can lead to a bladder infection with symptoms as described below.

Bowel to bladder fistula symptoms can include:

- leaking urine
- a frequent urge to pass urine
- passing air or faecal matter from the urethra during urination
- frequent urinary tract infections, which can cause a burning sensation when passing urine, and sometimes fever.

How are fistulas diagnosed?

Your doctor will ask about your symptoms and carry out a physical examination of the skin surface. Some fistulas are visible as tiny holes or raised red spots, which may be

leaking pus or faecal matter. The doctor may gently press on the skin around the fistula to see if there is such leakage. Internal fistulas will not be visible.

Your doctor may use a specially designed probe to trace the route of a fistula, or inject a dye visible to x rays. An MRI scanner may be used to provide information about complex perianal or internal fistulas. If the fistula is particularly difficult to find because, for example it is hidden by the folds of the bowel, the examination may be done under an anaesthetic.

Sometimes a barium meal and follow through test, (where you will be asked to drink a white liquid to give a clearer X-ray of the digestive tract) or a CT scan will be used to help diagnose an internal fistula. (For further information on these tests see our booklet, *Investigations for IBD*.)

What treatments are available for a fistula?

Fistulas may be managed medically or surgically, or by a combination of treatments. Continuing to take your usual IBD medication may help as active disease tends to make fistulas worse. However, you may find that your doctor recommends avoiding steroids if you are diagnosed with a perianal fistula, as these can increase the chance of developing an infection or abscess.

With anal fistulas, antibiotics such as metronidazole and ciprofloxacin may help reduce the discharge and make the fistula less uncomfortable. You may also be started on an immunosuppressive drug such as azathioprine, mercaptopurine or methotrexate to try and close the fistula. If this works you may be kept on this treatment for some time, perhaps a year or more, to keep the fistula closed.

If these drugs do not seem to be helping, you may be prescribed one of the newer biologic (or anti-TNF) drugs. Of these, infliximab is known to be effective in encouraging some types of fistula to close. As an alternative you may be offered adalimumab. Again, you may be on this

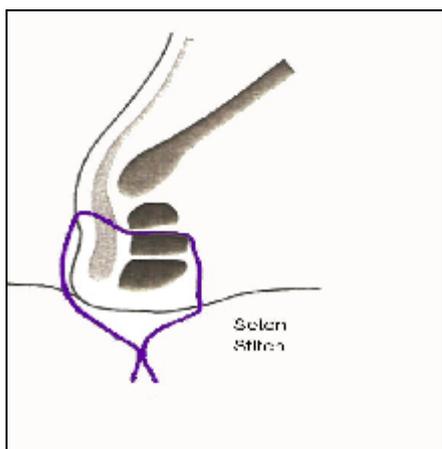
treatment for at least a year. (See our booklet, *Drugs Used in IBD*, or our individual drug treatment information sheets for more details on these drugs.)

Whichever drugs you are on, your doctor or IBD team should be carefully monitoring your treatment and its affect on your fistula. They will also watch out for any possible side effects. Do let them know if you develop an infection, abscess, or any other symptoms that concern you, especially while on immunosuppressant or anti-TNF drugs.

Surgical treatment may also be recommended, often in combination with drug therapy. The type of operation suggested will depend on the location and severity of the fistula. With complex fistulas, the surgery may be carried out in stages, spread over a period of weeks or months.

With a simple low anal fistula the most common operation is a fistulotomy. In this, the infected tract is cut open (or 'laid open') so that the fistula heals from the bowel end towards the skin surface. How long this healing takes varies from individual to individual. It can take a few weeks, but may take much longer.

With complex or high fistulas which involve the anal sphincter muscle there can be a risk of incontinence if the fistula is laid open. So, the surgeon may put in a 'seton stitch'. This is a soft plastic thread which is passed through the fistula and out through the anus. It is then tied to form a loop with protruding ends. The diagram below shows a seton stitch in place.



The most common type of seton is a loose seton. This acts as a 'wick' and helps to drain away remaining pus or infected tissue. This should allow the fistula track to heal gradually around the seton, which can be removed later.

Other treatment options for anal fistulas may include trying to close the fistula with fibrin glue or a collagen (biological) plug. Sometimes the internal opening of an anal fistula can be closed up using a section of the lining of the rectum.

However, none of these ways of closing the fistula is guaranteed to be successful, and multiple or repeat operations may be needed. Complete closure can sometimes be difficult to achieve for fistulas in people with active Crohn's Disease, and some people continue to have problems with fistulas even when their disease is in remission.

Occasionally, people with perianal fistulas are left with a residual channel from a fistula that is no longer painful but may still leak, and so needs ongoing care to prevent infection.

Your medical and surgical IBD team should talk through your treatment options with you. If you have a fistula which involves the bladder or vagina, it can be helpful to speak to a specialist from the Urology or Gynaecology departments as well. Ask your consultant to arrange this.

Medical treatment, for example with infliximab or adalimumab, is sometimes successful with rectovaginal and bowel to bladder fistulas. However, surgical treatments are also often recommended. A seton stitch may be put in to drain the fistula. A flap of tissue is then used to repair the part of the bladder or vagina wall where the fistula comes through, and the section of bowel where the fistula starts is surgically removed. Sometimes a temporary colostomy or ileostomy may be necessary. (These are surgical operations where a loop of intestine is connected to a stoma, or opening, in the surface of the abdomen so that waste can be collected in an external

bag. See our information sheet on *Surgery for Crohn's Disease* for more details.)

How can I manage my fistula on a day to day basis?

If your fistula is healing following an operation the hospital staff will show you how your dressings should be done at home. Once you are home, a district nurse may visit to do the dressing for you, but you may soon find that you can manage it by yourself.

Usually, you will get regular specialist check ups with your hospital IBD team to make sure the fistula is healing properly. They, especially the IBD nurse if you have one, should also be able to help with practical advice and suggestions. Your GP or the practice nurse at your GP's surgery may also be a good source of information about day to day care of a fistula.

Do talk to your nurse or doctor about the different types of dressings that are available, many of which you will be able to get on prescription. Make sure you are clear about the best way to keep your fistula clean and avoid infection, and if and when you should use a barrier cream.

You may also find some of the following suggestions helpful.

- With a perianal fistula, when washing the skin around your fistula, use warm water, and soft cotton wool or a disposable cloth, rather than flannels or sponges. Dry the area carefully: using a hair dryer on a low setting can be a good way of doing this.
- Avoid using anything with a strong perfume, such as scented soap or talc, as these may irritate the skin. Some people have found that even when a fistula has healed, it is better to continue to use soaps specially formulated for sensitive skin around the scar area.
- Your doctor will probably prescribe a suitable barrier cream. If not try something simple like Sudocrem or a small amount of Metanium Cream. Avoid

using other sorts of creams or lotions unless they have been recommended by your doctor or nurse.

- Put together a kit to help you manage your fistula when at work or away from home. This might contain, for example:
 - a small hand mirror
 - disposable wipes and gauze swabs
 - barrier cream
 - clean dressings
 - scissors
 - small pads such as incontinence pads
 - nappy sacks or small plastic bags for easy disposal of used dressings
 - hand sanitiser or anti-bacterial handwash
 - odour neutralising spray.
- Some people have found dressings made from absorbent lint softer and more comfortable than those made with gauze. 500 gram roles of lint should be available on prescription and pieces of this can then be cut to size. Try micropore tape (available from chemists) to fix these in place.
- Pads, as well as helping to keep the fistula area clean, can often make sitting slightly more comfortable. You might like to try using a soft cushion as well. There are several types of cushion on the market specially designed to relieve pressure when sitting. These include ring cushions such as those made by Dunlopillo and a range of portable cushions from Tempur (obtainable online, or ask at your chemist's). Some people have found a small pillow in a cushion cover is just as effective and portable.
- If you have an anal fistula which makes sitting particularly painful, try lying on your side on a sofa or bed. Regular warm baths can also relieve fistula pain and discomfort.
- If you have returned to work and feel you need better access to toilet facilities to help you manage your fistula, you may find our information sheet, *Employment and IBD*, which covers a range of workplace related issues, useful.

What other help can I get?

Fistula symptoms can come as quite a shock even to people who have got used to the idea of having IBD. You may feel quite distressed about what is happening, and reluctant to talk about it even to people you normally confide in.

The fact that some fistulas can take months or even years to heal, often requiring several courses of treatment, or, may in some cases still leave residual problems, can also be difficult to deal with.

It is not unusual for people in such situations to feel frustrated and depressed, as well as embarrassed by their symptoms. It may help to bear in mind, however, that your condition is not that uncommon. Although your symptoms may have come as a shock to you, your GP is used to discussing all sorts of bodily functions, and your IBD team will be very familiar with the problems caused by fistulas. Specialist nurses in particular are usually very aware of how upsetting a fistula can be. If you can talk through your concerns you may find that they have helpful suggestions for coping with even the most embarrassing situations.

If you would like to speak to a professional counsellor, check whether your GP has a counselling service. There may also be a counsellor attached to your IBD team or hospital. (See our information sheet: *How can counselling help you?*)

At Crohn's and Colitis UK we have a confidential supportive listening service, NACC-in-Contact, which is staffed by trained volunteers with experience of IBD. The staff on the general Crohn's and Colitis Information line are trained to answer queries on any aspect of IBD.

You may also find that living with a fistula becomes easier once you have come to terms with the care a fistula requires, and the need to accept that treatment may take some time.

The Crohn's and Colitis Information Line: 0845 130 2233, open Monday to Friday 10am – 1pm There is an answerphone service outside these hours.

The NACC-in-Contact Support Line: 0845 130 3344, open Monday to Friday 1pm – 3.30pm and 6.30pm-9pm (excluding Bank Holidays). This is a supportive listening service staffed by trained volunteers with personal experience of IBD.

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We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. References or details of the research on which this publication is based can be obtained from Crohn's and Colitis UK at the address below. Please send your comments to Helen Terry at Crohn's and Colitis UK, 4 Beaumont House, St Albans, Herts AL1 5HH, or email h.terry@crohnanndcolitis.org.uk.

Crohn's and Colitis UK is the working name for the National Association for Colitis and Crohn's Disease (NACC). NACC is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom.

Membership costs £12 a year. New members who are on lower incomes due to their health or employment circumstances may join at a lower rate. Additional donations to help our work are always welcomed.