INTRODUCTION

Some people with Inflammatory Bowel Disease (IBD) may develop a fistula. A fistula is an abnormal channel, tunnel or passageway connecting one internal organ to another, or to the outside surface of the body. Although a fistula (fistulas or fistulae, if plural) can develop in any part of the body, many involve the bowel or intestine. So, for example, a fistula might connect two parts of the bowel to each other, or the bowel to the vagina, bladder or skin.

It is estimated that around one in four people with Crohn’s Disease will develop a fistula at some time. Fistulas are much less common in Ulcerative Colitis (UC), and only occur in around one in 35 people. Although fistulas are associated with IBD, they can occur several years before the condition is diagnosed. While rarely life-threatening, fistulas can decrease people’s quality of life and often need combined medical and surgical treatment.

This information sheet provides some general information about fistulas and likely treatments. It also includes tips and suggestions which may help you if you are living with a fistula.

ARE THERE DIFFERENT TYPES OF FISTULA?

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

- Anal (also known as perianal fistulas) connect the anal canal (back passage) to the surface of the skin near the anus. These are the most common type of fistula, and usually appear following an abscess (a localised collection of pus caused by infection) around the back passage.
- Bowel to bladder fistulas (also called enterovesical or colovesical fistulas, depending on which section of the intestine is involved).
- Bowel to vagina fistulas (also called enterovaginal fistulas or rectovaginal fistulas if the fistula links the rectum to the vagina).
- Bowel to skin fistulas (also called enterocutaneous fistulas). These occur in areas other than the anus, most commonly on the abdomen. They often develop after surgery, along the line of the incision, but occasionally occur in people with Crohn’s Disease even when surgery has not been performed. Leakage of the bowel contents can damage the skin.
- Bowel to bowel fistulas (also called enteroenteric or enterocolic fistulas) linking different parts of the intestine together, bypassing a section in between.
WHAT ABOUT ANAL FISTULAS?

To understand the different types of anal fistulas and surgical treatments, it is helpful first to understand the structure of the anal sphincters (muscles). These are two cylinder (or doughnut) shaped muscles that help you control when you open your bowels by surrounding the anal canal:

- The internal anal sphincter is an involuntary smooth muscle (which you cannot mentally control) that keeps liquid and gas from escaping unexpectedly.
- The external anal sphincter, which wraps round the internal sphincter, is the muscle you voluntarily relax to pass wind, or can squeeze when you feel the urge to go to the toilet, but are not near one. See the diagram below.

There are several types of anal fistulas, with a variety of names depending on where they are and whether they involve the external or internal sphincters:
- Simple fistulas usually occur below the sphincter muscles and only have one passageway.
- Complex fistulas involve the sphincter muscles and may have several interlinking passageways. They can also be associated with abscesses or may connect with the bladder and vagina.

SIMPLE AND COMPLEX FISTULAS
WHAT CAUSES A FISTULA?

Fistulas tend to occur with Crohn’s Disease because the type of inflammation that is common in Crohn’s can spread through the whole thickness of the bowel wall. When this happens, it can cause small leaks and abscesses to form. As the abscess develops it may ‘hollow out’ a chamber or hole. This then can become a passage or channel linking the bowel to another loop of the bowel, another organ, or the outside skin. If the abscess bursts, the pus may drain away, but the passage or channel may remain as a fistula. Fistulas can occur anywhere in the bowel. The longer a person has Crohn’s Disease, the more likely they are to develop a fistula.

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

Although the causes are not fully understood, studies have suggested certain genes and gut bacteria may play a role in the development of fistulas and that fibroblasts (cells involved with healing) may not work as they should in people with Crohn’s Disease.

WHAT ARE THE SYMPTOMS OF A FISTULA?

The symptoms depend on where the fistula is located.

- **Anal fistulas:** The first sign can be a tender swelling or lump in the area round the anus, followed by pain and irritation which gets worse when you sit down, move around, have a bowel movement or cough. Drainage of pus, stool, or blood can occur from the fistula opening.

- **Bladder fistulas:** Symptoms include passing of air, pus or faeces in the urine, and more rarely leakage of urine from the back passage. You may also experience a frequent urge to pass urine and urinary infections.

- **Vaginal fistulas:** Symptoms include pain (ranging from mild to severe depending on the size and location of the fistula), and passing wind, faeces or pus through the vagina. Pain during sexual intercourse can also occur.

- **Bowel to skin fistulas (enterocutaneous):** Symptoms include leakage of bowel contents through the skin, which can lead to dehydration, diarrhoea, malnutrition and electrolyte abnormalities (including changes in levels of sodium, potassium, calcium and magnesium).

- **Bowel to bowel fistulas (enteroenteric or enterocolic):** Symptoms depend upon the extent of bowel affected and location of the two ends of the fistula. Where only a short segment of bowel is bypassed by the fistula, people may have no symptoms, but when a large segment is involved, people can experience diarrhoea, problems absorbing nutrients, and dehydration.
HOW ARE FISTULAS DIAGNOSED?

The way fistulas are diagnosed depends on the type of fistula you have. Your IBD team will aim to identify:
- the location of the fistula opening,
- the route that the fistula takes,
- the number of different channels involved,
- whether the fistula passes through the sphincter muscles (see section What about anal fistulas?)
- whether infection is also present.

For anal fistulas: First, your doctor will carry out a physical examination of the skin around the anus, as fistulas can be visible as tiny holes or raised red spots. The doctor may press on the skin around the fistula to see if there is leakage of pus or faecal matter. For some fistulas, an examination under anaesthesia (EUA) may be needed. This uses a specially designed probe to trace the route of the fistula. As well as finding out whether the fistula crosses the sphincter muscles, the procedure allows any abscesses to be drained or setons to be put in place (see What treatments are available for fistulas?). Your doctor may use various techniques to help locate the fistula. These can include:
- pelvic MRI for imaging fistulas (using magnetic fields and radio waves),
- endoanal ultrasound (using high frequency ultrasound),
- fistulography (where fistulas are injected with X-ray contrast materials), less commonly performed now.

For other types of fistulas: MRI, ultrasound, CT scans and fistulography are also used to map the route of other types of fistula (vaginal, bowel to skin, bowel to bowel, and bowel to bladder fistulas). For vaginal fistulas, a blue dye test can be used where the doctor inserts a tampon into the vagina and blue dye into the rectum. If the tampon stains blue this shows that a connection is present. With bowel to bladder fistulas, doctors can use a cystoscope (a long thin telescope with a camera) to view inside the bladder and urethra (tube carrying urine from the bladder); or may carry out the ‘poppy seed test’. Here, the person takes poppy seeds (which remain undigested in the bowel) with yoghurt, and if the seeds appear in the urine this shows that there is a bowel to bladder connection.

WHAT TREATMENTS ARE AVAILABLE FOR FISTULAS?

Fistulas may be managed medically or surgically, or by a combination of treatments. Your exact treatment will vary according to the type of fistula and the type of treatment you are already having for your IBD. Your medical and surgical IBD team should explain the choices for treatment. Do ask for extra information if anything is unclear. Continuing your usual IBD medication can often 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 fistula, as steroids can increase the chance of developing an infection or abscess and the need for surgery.

Anal fistulas

- Medical treatment
  The aim of treating anal fistulas is to achieve a balance between healing the fistula and keeping faecal continence (ability to hold faeces in).
Antibiotics: Antibiotics, such as metronidazole and ciprofloxacin, may help reduce discharge and make your fistula feel more comfortable. But antibiotics rarely lead to complete and lasting healing. Fistulas generally take six to eight weeks to respond to antibiotics, with treatment often continued for some months.

Azathioprine: Azathioprine (and the less frequently used mercaptopurine) are immunomodulatory drugs that have been shown to help fistulas close, although not in everyone. If this works you may continue with treatment for some time (often a number of years) to keep the fistula closed. Since azathioprine is slow acting (it can take three to six months before people notice benefits) antibiotics are sometimes used as an initial treatment before azathioprine takes effect. Studies show combining azathioprine with antibiotics is more effective than either treatment alone.

Biologic or anti-TNF drugs: If antibiotics and azathioprine do not seem to be helping, you might be prescribed one of the biologic (or anti-TNF) drugs. Studies show infliximab, adalimumab, and certolizumab help fistulas to heal. You are likely to be on these treatments for at least a year. NICE (National Institute of Health and Care Excellence) recommends biologic treatments for Crohn’s Disease patients with severe fistulas.

Other drugs: Other drugs sometimes used to treat anal fistulas include ciclosporin, tacrolimus, methotrexate and thalidomide. See our individual drug treatment information sheets for more details on these drugs.

• Surgery

Up to one third of people with Crohn’s Disease who have anal fistulas will require surgery at some stage. Studies suggest that the combination of medical and surgical treatment produces the highest rates of healing. The goal of surgery is to heal fistulas while avoiding damage to the anal sphincter muscles, which could affect continence. The type of treatment advised will depend on the location of your fistula and the amount of anal sphincter muscle involved. Any abscess that is present will also need to be drained.

There are many different types of procedures, including:

Setons: Loose setons are soft surgical threads which the surgeon passes through the opening in the skin, along the fistula track and out through the anus, where it is tied to form a loop with protruding ends. The seton acts as a ‘wick’ to drain away pus or infected tissue. It can be removed if the fistula is healing, or kept in place for extended periods if improvement has not occurred. Studies show that adding loose setons to infliximab treatment improves outcomes for people with anal fistulas. People report a loose seton feels like having a ‘rubber band’ hanging out of the anus, and that after a few days they no longer notice it is there. See a diagram of a loose seton on the next page.

A cutting seton is an alternative, where the thread is gradually tightened over a period of months, allowing the seton to slowly move through the sphincter muscle and fistula, causing scar tissue to form and thereby close the fistula. Although healing with a cutting seton occurs in four out of five people, there can be high rates of incontinence, so the procedure is rarely used now.
Fistulotomy: Also known as ‘laying open’. Fistulotomy involves cutting open the length of the fistula from the internal opening to the external opening, much like cutting open a cardboard tube along its length and flattening it out. The procedure provides excellent healing (although this can be slow), but some risk of incontinence after surgery. It is therefore only suitable for simple fistulas that either do not cross the sphincter muscle at all or only pass through a small amount of muscle.

Mucosal advancement flap procedure: Here, after the fistula track has been cleaned (leaving sphincter muscles intact), the inside lining of the rectum is lifted and pulled down inside the anal canal to cover the internal opening of the fistula. The procedure is used for complex fistulas involving the sphincter muscles where cutting the fistula track open carries a high risk of incontinence.

LIFT (Ligation of intersphincteric fistula tract): Developed as a procedure to avoid cutting the sphincter muscle, this operation involves the surgeon gaining access to the space between the internal and external anal sphincter muscles (intersphincteric space) through a small incision at the entrance to the anal canal. Once the fistula tunnel crossing this space has been identified, it is cut in two and both ends are stitched closed, preventing faeces getting into the fistula.

Video-assisted anal fistula treatment (VAAFT): Using a telescope, the technique allows direct visualisation of the fistula track from inside. After cleaning, the fistula can be cauterized (sealed) with an electric current to close the track. Stitches and fibrin glue can also be used. This is a new technique which may help surgeons find extra passages, running off the main fistula, which also need treatment if the fistula is to heal.

Other treatments for anal fistulas include trying to close the fistula with fibrin glue, a bioprosthetic plug (using materials such as Gore-Tex®), a collagen paste, stem cells, or sealing the fistula tract with a laser probe.
**Bladder and vaginal fistulas**

If you have a fistula which involves the bladder or vagina, it can be helpful to be assessed by a specialist from the Urology or Gynaecology departments, as well as your IBD team. Ask your consultant to arrange this.

For bowel to bladder fistulas, treatment can involve:
- resting the bowel. Parenteral nutrition (a liquid food mixture given into the bloodstream through a needle in the vein),
- antibiotics,
- steroids,
- immunosuppressant drugs.

Surgery for bowel to bladder fistulas generally aims to remove the affected bowel, join up the healthy bowel, and to close the hole in bladder wall. This may be carried out in stages rather than in a single operation.

A recent study showed that many people undergoing surgery for bowel to bladder fistulas maintained remission for over eight years.

For vaginal fistulas, medical therapy is aimed at treatment of the underlying active IBD (rather than the fistula itself) with antibiotics, immunosuppressants and infliximab. One study showed that infliximab has limited effectiveness at closing vaginal fistulas.

Surgical options for vaginal fistulas include:
- drainage of abscesses with a loose seton,
- vaginal advancement flaps (where a flap of healthy tissue is folded over the fistula opening),
- a modified ‘Martius Graft’, using the fat pad inside the labia majora (outer vaginal lip) to close the fistula.

**Bowel to bowel and bowel to skin fistulas**

Some bowel to bowel and bowel to skin fistulas may not need any treatment because they get better by themselves.

For bowel to bowel and bowel to skin fistulas, biologics, such as infliximab, may help to heal the fistula or improve symptoms.

If surgery is needed for bowel to bowel fistulas, the diseased bowel is removed, and the fistula opening in the non-diseased bowel is sutured (stitched). For bowel to skin fistulas, the fistula may close of its own accord. However, if the fistula remains open for longer than two months, spontaneous closure is considered unlikely and surgery may then be considered.

If the fistula opens onto your skin, there may be a discharge that needs to be collected. A drainage bag can be positioned over the area where the fistula opens. Your skin will need to be protected from the irritant effects of the gastrointestinal contents (which can damage the skin). Surgical treatment for bowel to skin fistulas can be difficult, and may be affected by factors such as the position of the fistula and the severity of disease.

The aim of surgery, which is carried out in a number of specialist centres, is to remove the affected bowel, join up the healthy bowel, and close the fistula opening on the abdominal wall. Sometimes people with bowel to skin fistulas may need to be hospitalised for long periods.

Some people with bowel to skin fistulas require nutritional support if they are not absorbing adequate nutrients from their food or are losing nutrients through the opening in the skin. This may be in the form of enteral nutrition (a special liquid only diet with all the necessary nutrients), or by intravenous nutrition (given into a vein). For more information on enteral nutrition, see our booklet: Food and IBD.
LIVING WITH A FISTULA

For bowel to skin fistulas, your body fluid levels and electrolytes (including levels of sodium, potassium, calcium, and magnesium) in the blood will need to be monitored regularly and corrected to replace any losses.

WHAT IF THESE TREATMENTS DO NOT WORK?

Unfortunately, none of these ways of closing fistulas is guaranteed to be successful, and multiple or repeat operations may be needed. Complete healing can be difficult to achieve for fistulas in people with active Crohn’s Disease, and sometimes fistulas that have closed may recur. Some people continue to have problems with fistulas even when their Crohn’s Disease is in remission. Occasionally, people with fistulas are left with a residual channel from a fistula that is not painful but may still leak, and need ongoing care. In a very small number of people with anal fistulas for whom neither medical therapy nor surgery has worked, an operation to remove the rectum may be recommended to allow the fistula to heal. The intestine is brought to the surface of the abdomen as a stoma so that waste can be collected in an external bag. See our information sheet: Surgery for Crohn’s Disease for more details.

HOW CAN I MANAGE MY FISTULA ON A DAY-TO-DAY BASIS?

If treatment of your fistula includes an operation, the hospital staff will show you how your dressings should be done. Once at home, a district nurse may visit to do the dressing for you. Depending on the type of fistula, you may soon find that you can manage the dressing yourself.

It is likely you will have regular specialist reviews to check that the fistula is healing properly. Make sure you are clear about the best way to keep your fistula clean and how to avoid infections, and if you should use a barrier cream to protect the surrounding skin. The team (especially the IBD nurse) will be able to help with practical advice and suggestions. Your GP and the GP practice nurse may also be a good source of information about day-to-day care of your fistula.

Ask your nurse or doctor about the different types of dressing that are available, many of which you can get on prescription. People with a permanent fistula, requiring continuous surgical dressings, can be issued with a Medical Exemption Certificate to get free NHS prescriptions. Talk to your IBD team or GP to find out whether you are eligible.

You may also find some of the following suggestions helpful:

- With a perianal fistula, when washing the skin around your fistula, only use warm water and soft cotton wool or a disposable cloth, rather than flannels or sponges. Dry the area carefully – pat it dry rather than rubbing vigorously. Using a hair dryer on a low setting may be a good way to dry the area.

- Regular warm baths can also relieve fistula pain and discomfort. Make sure to cleanse the bath tub after each use to avoid the risk of infection. Portable bidets (known also as sitz baths) can help to keep the area clean. These can be obtained online or from pharmacies.

- Do not use soap or put salt or perfumed products in the water as this can irritate the wound. Talc may also 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.

I found using fragrance-free toilet wipes and using a hairdryer on a very low heat to gently dry my bottom, helped me to prevent getting an infection in the anal fistula I had.

Lucy, age 45
diagnosed with Crohn’s Disease in 2013

The sitz bath was the easiest, least painful and most effective way for cleaning myself after a toilet motion.

William, age 61
diagnosed with Crohn’s Disease in 1996
• Your doctor will probably prescribe a suitable barrier cream to protect the skin around the area. Avoid using creams or lotions unless they have been recommended by your doctor or nurse.

• If you have an anal or vaginal fistula, do not use tampons or pessaries without checking first with your IBD team. Following surgery for vaginal fistulas women should avoid sexual intercourse until their surgical team has checked healing.

• If you have any discharge from your fistula, it can help to wear a pad or panty liner, which has the additional advantage of making sitting more comfortable.

• Try to avoid becoming constipated, as this may mean you have to strain when using the toilet, which could cause complications or pain. To avoid dehydration drink plenty of fluids to keep stools soft, since softer motions are easier to pass (see our Dehydration information sheet for further details). Ask your doctor whether a stool softener (such as lactulose or macrogol) might help and get advice from a dietitian about which diet would be best for you. High fibre foods, such as fresh fruit and vegetables, normally recommended to help constipation, can make symptoms worse for some people with IBD.

• After recent surgery it can help to take a dose of oral pain killers about half an hour before you open your bowels or have your dressing changed to reduce discomfort. It is probably better to avoid ibuprofen, diflofenac, and aspirin since these are non-steroidal anti-inflammatory drugs (NSAIDs) and studies suggest they may trigger an IBD flare-up. Paracetamol may be a safer option. If you have concerns talk to your GP. If you experience difficulty urinating after surgery, it can help to urinate while you are in the bath or shower.

• Cushions or pillows may help to relieve the pressure when sitting. There are several types of cushions on the market, such as ring cushions and those made of memory foam (designed to relieve discomfort and pain). These can be obtained online or from pharmacies. If you have an anal fistula which makes sitting particularly painful, try lying on your side on a sofa or bed.

• It may help to wear loose-fitting clothing and cotton underwear.

• 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 Employment and IBD information sheets useful. See our website in Help and Support from Crohn’s and Colitis UK for further details.

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I have a stoma and peri-anal drains due to fistulas. These drains produce liquid, so I make sure I always carry lots of useful things to help with this, including swabs and wipes. I find this little bag of ‘stuff’ keeps me calm, knowing I have it with me.

Gillian, age 39 diagnosed with Crohn’s Disease in 2002

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WHAT SHOULD I GET TOGETHER IN A KIT TO HELP ME MANAGE MY FISTULA MORE EASILY?

A kit to help you manage your fistula might contain:
• a small hand mirror,
• disposable wipes and swabs,
• barrier cream,
• clean dressings,
• micropore tape,
• scissors,
• small pads such as incontinence pads,
• nappy sacks or small plastic bags for easy disposal of used dressings
• clean underwear,
• hand sanitiser or anti-bacterial handwash,
• odour neutralising spray.

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WHEN SHOULD I SEEK MEDICAL HELP?

For people with abscesses there is a small risk of developing sepsis. Sepsis (also known as blood poisoning or septicemia) is a potentially life-threatening condition that can occur in people with infections. Sepsis is uncommon in people with simple fistulas, but can occur in more complex cases or where there is a large collection of pus (an abscess) that fails to discharge. With sepsis, chemicals released into the blood stream to fight infection can occasionally trigger inflammatory responses throughout the body that lead to organ failure. If not recognised and treated quickly, sepsis can be fatal. If sepsis is detected early and treated promptly, full recovery is normally achieved. Warning signs of sepsis include:

- a high temperature (fever) greater than 38.33 degrees Centigrade (101 degrees Fahrenheit), chills and shivering, or a low body temperature,
- mottled or discoloured skin,
- if you have passed no urine in a day,
- fast heart beat or fast breathing,
- sudden changes in your mental state or slurred speech.

WHAT OTHER HELP CAN I GET?

Developing a fistula can be quite a shock even to people who are used to living with IBD. You may feel distressed about what is happening, and reluctant to talk about it, even to people you normally confide in. However, fistulas are not uncommon and IBD specialist nurses, in particular, are usually very aware of how upsetting a fistula can be. If you can talk about your concerns, you may find that your specialist nurse has helpful suggestions for managing day-to-day life with your fistula.

It can be difficult to deal with the fact that some fistulas take a long time to heal, may require several courses of treatment and might still leave residual problems. Fistulas can also have a psychological impact that disturbs people’s body image and self esteem. The presence of a fistula can affect your feelings about sex and intimacy, and may make it harder to take part in sport and swimming. It is not unusual for people in such situations to feel frustrated and depressed, as well as embarrassed by their symptoms. Sometimes a professional counsellor can help with these sorts of feelings. There may be one attached to your GP’s practice or your IBD team. (See our information sheet: Counselling for IBD.) You may find it helpful to see if there are online support groups for people with fistulas.

Taking action in this way can help you to feel more in control and to cope better with the difficulties of living with a fistula. It may also help to remember that having a fistula is not uncommon and that fistulas also occur in people without IBD. For most people, living with a fistula becomes much more manageable once they are used to the care their condition requires.
I have found the information from Crohn’s and Colitis UK really useful in terms of the practical tips to help manage the symptoms of Crohn’s Disease and the peri-anal fistulas I have.

Gillian, age 39
diagnosed with Crohn’s Disease in 2002
LIVING WITH A FISTULA

Crohn’s and Colitis UK publications are research based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject and are not intended to replace specific advice from your own doctor or any other professional. Crohn’s and Colitis UK does not endorse or recommend any products mentioned.

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We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at publications@crohnsandcolitis.org.uk. You can also write to us at Crohn’s and Colitis UK, 45 Grosvenor Road, St Albans, AL1 3AW or contact us through the Information Line: 0300 222 5700.

ABOUT CROHN’S & COLITIS UK

We are a national charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 28,000 members and 50 local groups throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

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