



# Ileostomy

## Background and Consequences



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# Foreword

DialogueEducation is part of the DialogueProgramme, Coloplast's ongoing commitment to ostomy care. The DialogueProgramme aims to achieve new standards in ostomy care through the effective collaboration of Coloplast with stoma care nurses, health care professionals and people with a stoma.

**Ileostomy Background and Consequences** is an academic tool in the DialogueEducation package aimed at health care professionals involved in stoma care. In addition to an overview of physiological and surgical procedures, the booklet discusses the practical, psychological and social issues that are important for people living with an ileostomy.

The booklet is a dynamic document that is updated by Coloplast and we are happy to receive comments and will answer detailed questions.

**Ileostomy Background and Consequences** is also available on CD-ROM and is part of a series that includes **Colostomy Background and Consequences** and **Urostomy Background and Consequences**.

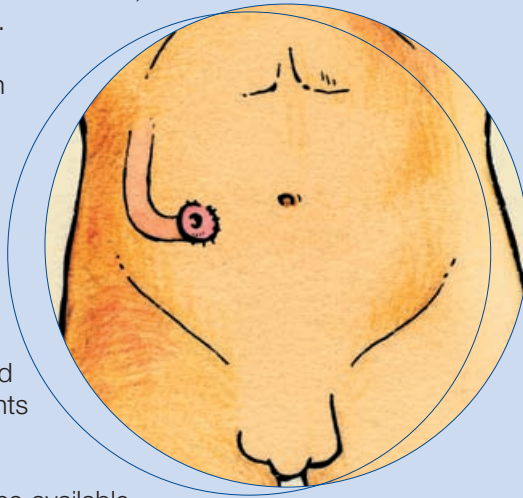
With many thanks to Annette Madum, a Stoma Care Nurse at Næstved County Hospital, Denmark, and everyone who shared their knowledge and comments during the production of the DialogueEducation materials.

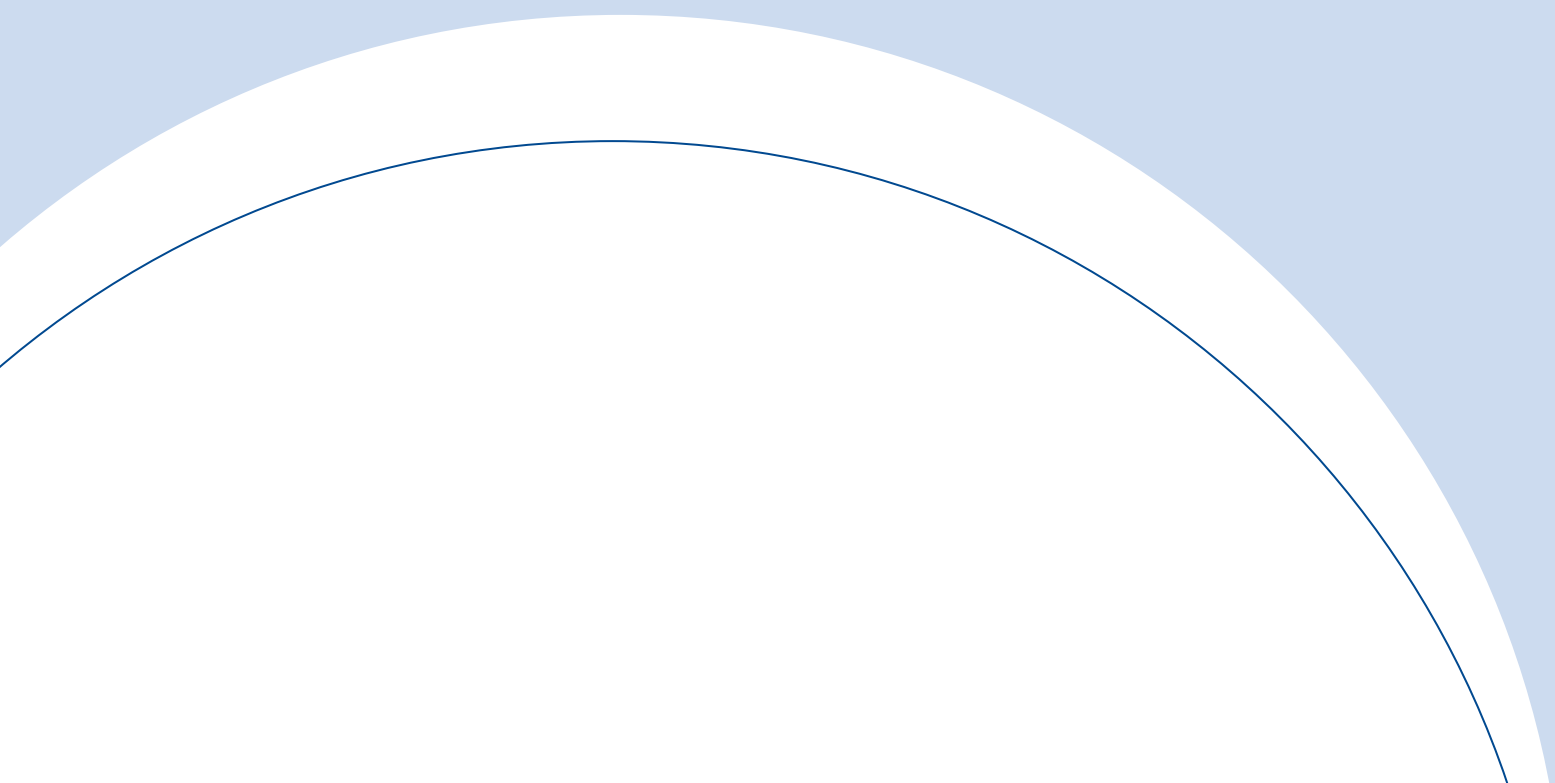
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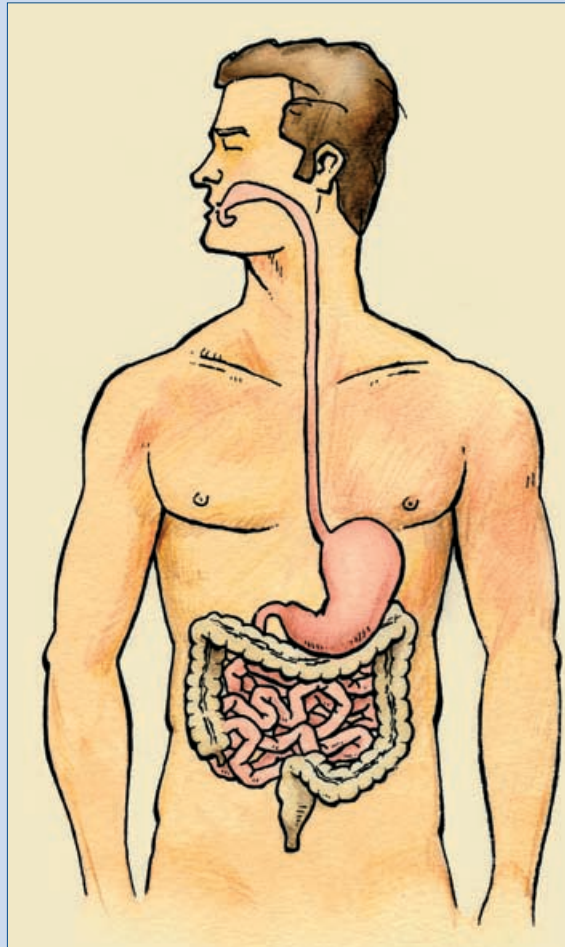


# 1. The digestive tract

The digestive tract stretches from the mouth to the anus and is around 9 metres long. It is divided into different sections, with each processing food in a specific way to prepare it for the next section of the intestine.

Food chewed in the mouth is swallowed and passes through the pharynx into the oesophagus. Contractions in the oesophagus gradually force food down into the stomach, where a mixture of saliva and stomach acids creates a semi-liquid mass to aid the digestive process. From the stomach the food mass continues to the small intestine.

The small intestine is 7–8 metres long and divided into three sections: the duodenum, jejunum and ileum. The key functions of the small intestine are digestion of food via enzymes and other secretions, and the absorption of nutrients. Bile and enzymes are secreted into the first 25–30 cm of the small intestine, known as the duodenum. The enzymes break down fats, carbohydrates and proteins, while bile emulsifies fat thus aiding digestion and absorption. From the duodenum, the food mass continues to the jejunum, which makes up  $\frac{2}{5}$  of the small intestine's total length and then on to the ileum ( $\frac{3}{5}$  of the length).



Nutrients are absorbed through the mucous membranes on the small intestinal wall. The mucous membrane of the small intestine has a very large surface of approximately 250 square metres due to millions of finger-like protrusions (villi) that cover the inner surface. This ensures maximum absorption of nutrients from food.

Contractions in the wall of the small intestine (called peristalsis) force the food mass into the large intestine (the colon), which makes up approximately the last 1.5 metres of the digestive tract. The main function of the colon is to absorb water and fluids from the food to form the faeces. This reduces the mass of the faeces, making it more solid and therefore easier to pass.

The newly formed faeces collect in the sigmoid colon. When this part of the colon is full, the food mass begins to sink into the rectum, which is approximately 12 cm long. Distension of the rectal wall triggers a natural urge to defecate, and when the sphincter is relaxed food mass exits the intestinal tract as faeces<sup>(1 chapter 11)</sup>.



# 2. Reasons for forming an ileostomy

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Various disorders of the small intestine, large intestine and rectum can make it necessary to perform an ileostomy. The number of temporary ileostomies performed is increasing.

### 2.1 Ulcerative colitis

Ulcerative colitis is the most common reason for performing an ileostomy<sup>(2, p. 3)</sup>. This illness is an infection-like condition in the wall of the colon that causes it to swell, thicken and redden, with cuts and sores on the inner side. As a result, the intestinal wall is unable to absorb as much water as normal, provoking peristaltic movements leading to diarrhoea containing blood and remnants of damaged mucous membranes. Substantial blood loss is seen in severe cases and the illness can be relatively debilitating. Ulcerative colitis is a chronic condition for which there is no known pharmacological cure, although therapies are available that may dramatically reduce the signs and symptoms. For most patients (approximately 80%) the illness is active for only short periods, with long symptom-free periods.

Ulcerative colitis begins in the rectum and can spread to the left side of the colon – and sometimes to the entire colon. An ileostomy is usually considered only if pharmacological treatment does not provide a satisfactory result. If the entire colon is not surgically removed, the illness will most likely flare up in the remaining part of the colon, leaving the patient at risk of having to undergo further surgery. Therefore, patients suffering from ulcerative colitis rarely undergo colostomy surgery. A pouch procedure or ileoanal anastomosis is an alternative to a permanent ileostomy (see ileoanal anastomosis, page 11).

Since ulcerative colitis affects only the large intestine, the condition can be cured surgically by removing the large intestine<sup>(2, p. 3)</sup> and the rectum or the mucous membrane of the rectum. The cause of ulcerative colitis is unknown.

### 2.2 Cancer

Ileostomies are rarely created due to cancer of the small intestine because the tumour can usually be successfully removed and the ends of the intestine rejoined (anastomosed). An ileostomy is more likely to be created due to cancer of the large intestine (colon or rectal cancer). People affected by colon cancer usually outnumber those affected by cancer of the small intestine by at least 50 to one.

The causes of colon cancer are not known, but there are certain congenital / genetic factors that increase risk, as well as lifestyle. If left untreated for several years, Crohn's disease, ulcerative colitis and celiac disease (gluten intolerance) are also linked to increased risk.

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When performing surgery for cancer on the left side of the large intestine (or rectal cancer) a temporary ileostomy is often created to give the anastomosis a chance to heal and reduce the likelihood of peritonitis due to leakage from the anastomosis. After radiation therapy to the abdominal area, the large and / or small intestine can become fragile, making it necessary to create an ileostomy to prevent peritonitis.

### **2.3 Crohn's disease**

Crohn's disease is also known as 'bowel tuberculosis' and was first described in 1932 by the American physician Burrill Crohn. It is an inflammatory condition of the intestinal wall causing swelling and the formation of ulcers, tears and fistulae. Eventually, scar tissue may be formed, which shrinks and causes narrowing of the intestine<sup>(6, p 5-11)</sup>.

Crohn's disease usually strikes adults aged 15–30 years of age, but may also occur in children and the elderly<sup>(7, p. 6)</sup>. It can affect any part of the intestinal tract and is sometimes found in several different places at the same time. In one third of cases, it is located in the large intestine and / or the rectum. The symptoms of Crohn's disease are persistent and include diarrhoea (sometimes bloody), abdominal pain, fatigue and weight loss. Children often show a delay in growth and development.

The cause of Crohn's disease has not yet been fully explained, however, much like arthritis it is thought to be an autoimmune disease (the person's own immune system attacks their body). The disease is not contagious and only hereditary to a small extent; the risk that an affected individual will pass the disease on to their child is less than 1:200<sup>(8, p.45;6 p 7-9)</sup>.

Crohn's disease is a chronic disease with no known cure. Like patients with arthritis, sufferers go through periods without symptoms and other periods where symptoms are severe. During symptomatic periods, patients can be treated with anti-inflammatory drugs to relieve the discomfort<sup>(6, pp. 4-11)</sup>.

If the patient's symptoms are particularly severe and do not respond to treatment, surgery may be indicated. Immediate surgery may be required if the patient experiences a massive bleed, rupture of the intestine, fistulae, or if the condition results in formation of extensive scar tissue that prevents faeces from passing through the intestine. The surgery aims to remove the diseased part of the intestine, rejoin the two ends and restore normal function. However, in some cases, the placement of a stoma may be required<sup>(7, pp. 7-10)</sup>.

### **2.4 Trauma**

When the body sustains very severe injuries, such as a car accident or violent attack, serious damage to the intestine has been known to occur. If it cannot be repaired surgically, it may be necessary to perform an ileostomy.

### **2.5 Familial adenomatous polyposis**

Familial adenomatous polyposis (FAP) is an inherited disease resulting in the development of a large number of polyps in the large intestine. It is caused by a particular gene, and sufferers generally develop hundreds of polyps by the time they reach 15–20 years of age. The polyps are pre-cancerous and the large volume means that the sufferer will be expected to develop cancer by the time they reach 50 years of age, if not earlier.

The best treatment for this condition is the prophylactic removal of the colon to prevent cancer from developing. The general procedure is to remove the large intestine at about the age of 20 years. Around the age of 35, the rectum will typically be removed as well. An ileostomy is performed following the removal of the colon and rectum; alternatively, the patient may be a candidate for a reservoir operation or an ileorectal anastomosis (see reservoir and anastomosis, pages 10-11).

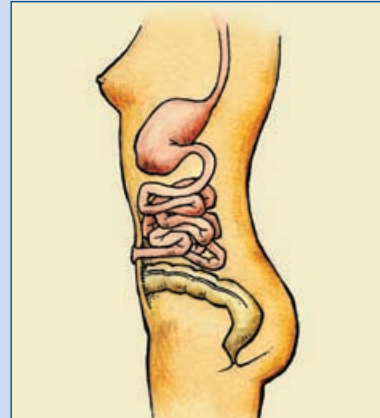


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As FAP is an autosomal dominant (only one gene required to produce the affect) hereditary disease, there is a 50% chance that an affected person's child will inherit the disease. Children who do not inherit the gene cannot pass it on to the next generation<sup>(10)</sup>.

## 2.6 Fistulae

A fistula is a spontaneously developed channel between two normally unconnected structures. People who develop fistulae in the intestine may require an ileostomy. Fistulae can occur in patients with Crohn's disease or in cancer patients suffering from the harmful effects of radiation. The ostomy can be temporary, giving the affected area a chance to heal.



## 2.7 Congenital defects

In very rare cases, congenital deformities like spinal hernia make creation of an ileostomy necessary. An ileostomy may also have to be performed in cases of necrotizing enterocolitis (NEC), an intestinal disease that affects one in 2,000–4,000 newborn babies and causes infection and damage to parts of the intestine. The ostomy is removed when the child is feeling better. The illness most frequently appears among premature babies and can be completely cured in most cases<sup>(11)</sup>.



### 3. History

Sometimes stomas spontaneously develop due to fistulae from a damaged or obstructed intestine. Monitoring of these stomas led surgeons to try copying nature's solution to obstruction<sup>(12)</sup>. In 1710 the French surgeon Littre described a method for placing a stoma, and in 1776 his countryman, the physician Pillore, performed the first surgery to place a stoma. Although the patient died from peritonitis 28 days later, the procedure was considered a great success. Similarly, 17 years later Duret performed a colostomy on an infant who died 3 weeks later. In 1819 an English physician Ping performed ostomy surgery on a 63-year-old woman. Attempts to cure her obstipation had been futile and it was later discovered that the cause of the obstipation was a cancerous tumour in the intestine.

In the past, living with a stoma could be difficult because no appliances were available to collect the stool or prevent the odour. When a well-known English businessman had a colostomy in 1824, developing a collecting system that the patient could manage personally was investigated for the first time. Several attempts were made to use tin containers and sponges that were meant to hold the stool and allow intestinal gasses to escape.

In 1839 the Frenchman J. Amussant described a method for placing a stoma in the groin. Although this practice is no longer used, Amussant is considered the originator of the surgical technique used today. In the years that followed great strides were made, making more complicated surgery possible. In 1846 the anaesthetics ether and chloroform were introduced, and in 1857 Louis Pasteur's microbiological discoveries enhanced understanding of the connection between surgery and peritonitis. In 1867 Lord Lister introduced sterile techniques using antiseptics, and in 1928 penicillin was introduced, which greatly increased the success of stoma surgery<sup>(13)</sup>.

Although creating a collecting system for patients who had undergone stoma surgery was first investigated in 1824, production of ostomy appliances did not occur until the 1930s and 40s. Some early appliances were made of glass, and in the 1950's the first rubber bags appeared. The rubber bags were attached to the skin using an adhesive and a belt, and had to be cleaned regularly with soap and water because they were reused. Many people developed allergies to the rubber after long-term use<sup>(14, pp. 4-5)</sup>, however, some people still use this type of ostomy bag.

The Danish nurse Elise Sørensen, whose sister had colostomy surgery, believed that it ought to be possible to improve the stoma care appliances in use at the time. In 1954 Sørensen suggested the idea of a disposable stoma bag made of plastic. She presented the idea to Aage Louis-Hansen, the owner of the Danish plastic packaging firm Dansk Plastik Emballage.



*Elise Sørensen*

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Although he was not initially interested his wife was a trained nurse and managed to persuade him to start manufacturing colostomy bags. This was in 1957 and marked the establishment of Coloplast<sup>(14, pp.4-5)</sup>.

The American physician, Rupert Turnbull from the Cleveland Clinic in Ohio was the first to realise that people with a stoma needed specialised care. In 1958 he trained one of his patients, Norma Gill, to be a stoma care nurse and in 1961 he established the first ostomy training program. In England the first training programme for ostomy therapy was established in 1972 at St. Bartholomew's Hospital, London, and Scandinavia followed suit in 1980 with the first school founded at Sahlgrenska Sjukhuset in Gothenburg, Sweden. Similar schools exist in Germany, Norway, the Netherlands, Italy, Australia, Africa, and the Far East.

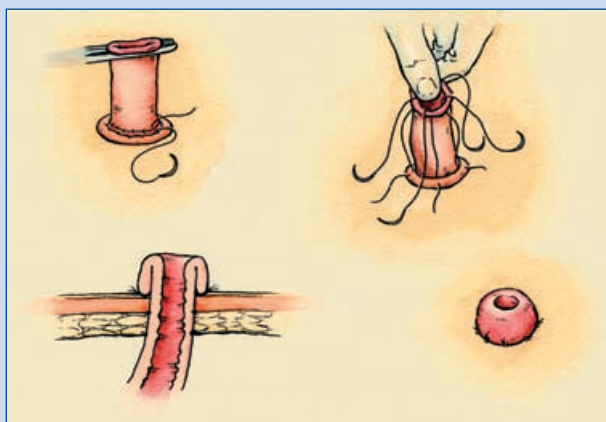
## 4. Types of stomas and surgical procedures

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There are several types of ileostomies. They can be located at different places in the 7–8 metre-long small intestine, and can either be single- or double-barrelled. Approximately 26% of people with a stoma have an ileostomy (about 62% have a colostomy, and about 12% have a urostomy). An ileostomy can be located on either side of the body, but is usually placed on the right side for anatomical reasons. There are also different types of intestinal surgery that lead to temporary stomas or do not require stomas at all. These are described at the end of this chapter for completeness.

### 4.1 Single-barrelled ileostomy

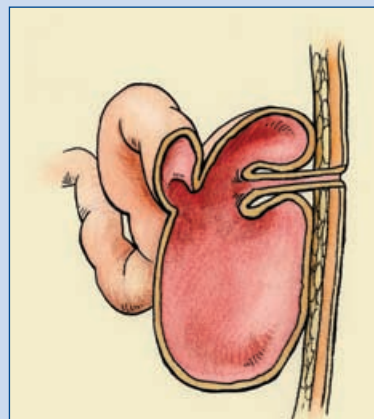
Most ileostomies are single-barrelled, i.e. the intestine opens into a single stoma. The intestine is resected slightly above the diseased area, and the healthy part of the intestine is guided through a hole in the skin, rolled back, and sutured to the skin.



The traditional single-barrelled ileostomy is performed in accordance with the British surgeon Bryan Brooke's original procedure, with a height of approximately 2.5 cm. The distal portion of the intestine leading to the rectum is either removed, or closed and left inside the abdomen. In people who have had the rectum closed and left inside, the closed section of the bowel remains vital still producing mucous secretions which are emptied through the anus, sometimes in quantities large enough to stimulate the need to defaecate<sup>(15, p. 8; 16, p. 156)</sup>.

### 4.2 Continent stoma

The continent stoma, or Kock's reservoir, was introduced by Professor Nils Kock in the 1960s. An internal reservoir is constructed using about 0.5 metres of the small intestine, and is connected to the outside through a stoma. The stoma is level with the skin and the person does not have to wear a bag because the reservoir is emptied via catheterisation a few times daily or as needed. The catheter is thicker than those used for urine and is constructed differently. When not being emptied, the stoma is usually covered with a minicap.

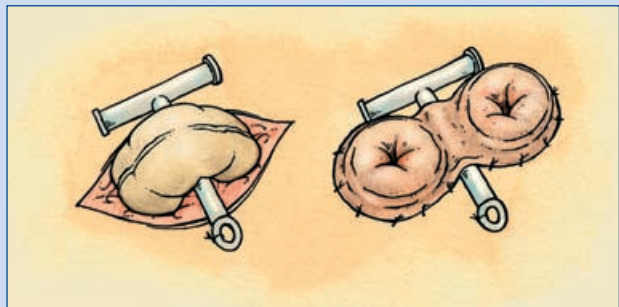


This type of ostomy surgery is best suited for people with ulcerative colitis or familial polyposis, and the person must be psychologically capable of regularly emptying the reservoir with the catheter.

People who have significant psychological difficulty in accepting a traditional ileostomy and using stoma appliances may benefit from this procedure. A study showed that 98% of people with a traditional stoma felt uncomfortable or hindered as a result of the stoma, but only 24% felt the same way after receiving a continent stoma instead. A Kock's reservoir is not recommended for people with Crohn's disease because the disease can spread to the reservoir. It is also not recommended for people who are extremely overweight, or those with a hernia at the ostomy site; these conditions can cause problems when inserting the catheter into the reservoir<sup>(16, 17 and 18, p. 89)</sup>.

### 4.3 Loop ileostomy

A loop ileostomy is often an option to provide relief for people who have had an anastomosis (see below) close to the anus, or in order to resume intestinal function by bypassing severe constipation and/or intestinal blockage. Severe constipation and blockage are particularly uncomfortable, causing sufferers to experience painful cramping and vomiting.



The most common way of constructing a loop ileostomy is to lift the intestine above skin level and hold it in place using a stoma rod. An incision is made on the exposed loop of intestine, and the bowel is then rolled down and sewn to the skin. In this way, a loop ileostomy actually consists of two stomas that are connected to one another (double-barrelled stoma). Faeces are expelled from only one of the stomas, which is connected to the upper, functional part of the intestine leading from the mouth.

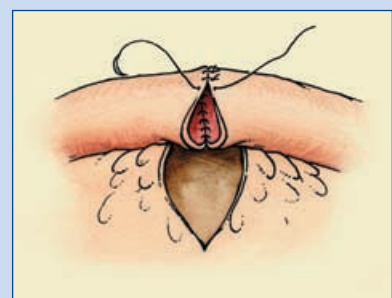
The stoma rod is removed 7–10 days after surgery. It is easier for people to learn to attach stoma appliances once the rod has been removed.

### 4.4 Surgical methods that do not result in a stoma

There are several different types of surgical procedure that do not result in a stoma. For completeness these are briefly described below.

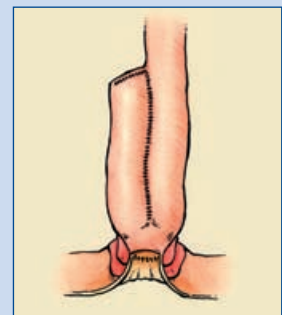
#### 4.4.1 Anastomoses

An anastomosis is the joining together of the two intestinal ends that remain after a diseased section has been removed. Often a temporary loop ileostomy is formed in conjunction with an anastomosis in the rectum to give it time to heal.



#### 4.4.2. Pouches

There are several types of pouch surgical procedures. This surgery is used if the large intestine and the rectum have been partially or entirely removed, and involves creating a reservoir in the last part of the small intestine. The reservoir is then connected to the anus, allowing the patient to retain control of the stool<sup>(26)</sup>. Often a temporary loop ileostomy is placed in conjunction with pouch surgery to give the anastomoses time to heal. This surgical procedure is primarily used on people with polyposis or ulcerative colitis.



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If the colon and rectum are removed, e.g. due to ulcerative colitis or familial polyposis, patients were previously advised to undergo either a traditional ileostomy or continent ileostomy. In 1978, however, Parks and Nicholls described an entirely new surgical method in which a reservoir was constructed from the small intestine and connected to the anus. The surgery normally consists of three steps:

1. The colon and rectum are removed and a temporary ileostomy is established; the person is then allowed to recover for several months
2. A reservoir is constructed from the lower part of the small intestine, which is then connected to the anal sphincter around the rectum. A loop ileostomy is placed to allow the reservoir to heal
3. After a few months the loop ileostomy is reversed and faeces can pass through the reservoir

A person who undergoes this procedure can control their bowel movement with the anal sphincter. Once the reservoir is functioning normally, bowel movements will be more frequent – about six times daily. There is some debate as to whether pregnant women who have had a pouch operation should be advised to have a caesarean section in order to protect the reservoir. There are several types of pouch operations, such as the J-pouch. The pouch operation is not suitable for people with Crohn's disease, because this illness can inflame the reservoir<sup>(16, 19)</sup>.

#### **4.4.3. Ileoanal anastomosis**

This surgery involves removal of the colon. However, approximately 15 cm of the rectum and the anal sphincter are saved, and the rectum is joined to the small intestine. This surgery is offered to people who exceed the age limit for receiving surgery to construct a J-pouch. People who undergo this surgery must have a normally functioning sphincter and the rectum must be free of ulcerative colitis or only minimally affected. A renewed outbreak of the illness in the rectum is regularly seen and can lead to further surgery to remove the remaining rectum and place a permanent ileostomy. People who undergo ileoanal anastomosis will have more frequent bowel movements than those who receive a J-pouch.

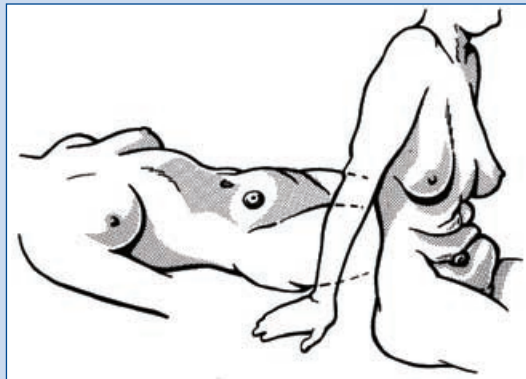




# 5. Siting of the stoma

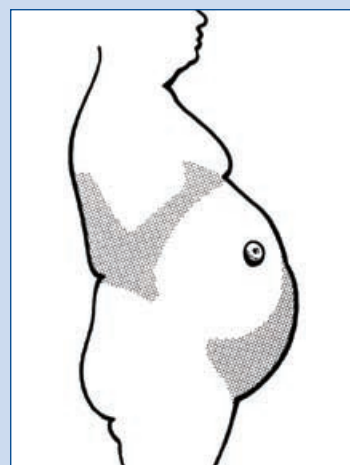
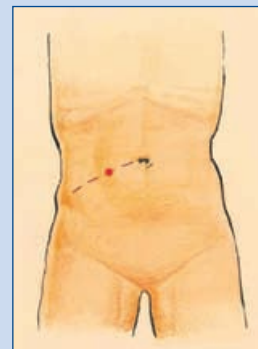
How people adjust to life with a stoma depends to a great extent on how easily they can manage the stoma appliances and avoid leakage. It is therefore very important that the stoma is sited in the most suitable place on the abdomen. The stoma should be adapted to the person – and not the other way around. Among other things, this means that the stoma must be sited where the person will find it easiest to care for; i.e. the person must be able to see the stoma and be able to reach it to change appliances.

Two days before surgery, the site for the stoma has to be marked. This is especially important if the patient is very thin, since the abdomen may change shape when the intestines are evacuated before surgery. The marking is done jointly by the nurse, surgeon and patient. The patient will need to lie down, stand, sit, crouch, bend forwards and sideways so that all factors can be taken into consideration. Ideally, the patient should wear a water-filled bag under clothing.



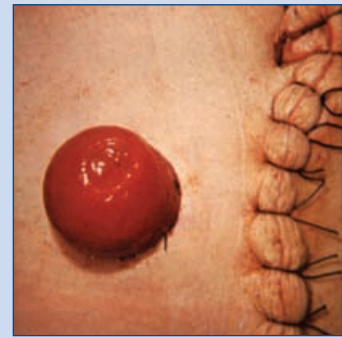
When determining the site for the stoma, the following must be taken into account:

- Physiological factors: The aim is for the stoma to be positioned so that it transects the rectus abdominalis muscle. This will provide muscle fibre to keep the intestine in place and might help to prevent it from prolapsing and forming a sliding hernia (see p.24)
- The patient's body contours: It is crucial that the adhesive can adhere to a smooth surface. This means that the stoma should not be sited in immediate proximity to natural body contours and skin creases. The distance to the navel must be sufficient to ensure that the adhesive does not cover the navel. In women with large, heavy breasts, the stoma should not be sited where the breasts will cover it. In obese patients, the stoma is often sited on the upper part of the abdomen to ensure that the patient can see the stoma. In patients who have lost weight in the period preceding the operation (commonly seen in cancer patients) it must be taken into consideration that the patient will typically regain weight after surgery, so the stoma should not be sited too low. The stoma should not be formed near old hernias, as these may increase the risk of complications
- Visual factors: The patient may have individual cosmetic preferences, which should be taken into account as far as possible
- Any disability: If the patient has a physical disability requiring the use of disability aids, stoma-site marking should be done while the patient is using the aid, e.g. wheelchair users should be marked while they are seated in the wheelchair. The stoma should be sited anywhere on the abdomen that will make it easy to see and manage. If the patient already has a colostomy or urostomy, the ileostomy must not be

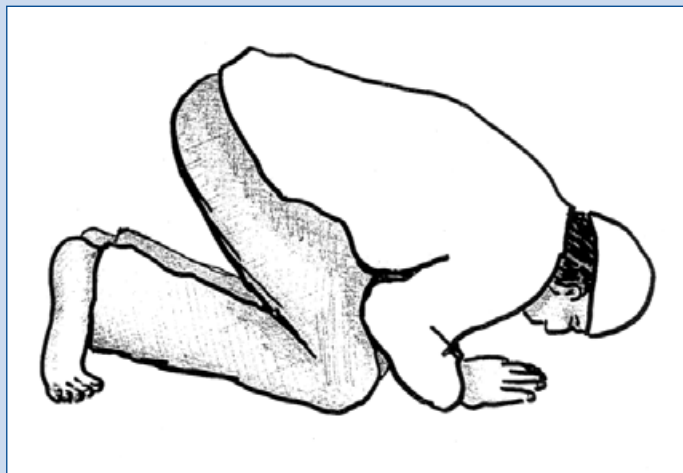


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positioned along the same vertical line as the existing stoma, as this will make it impossible to use a supporting belt for one or more of the ostomies without disturbing the others



- The operative scar: The distance to the operative scar (and old scars) must be sufficient to allow the baseplate to be attached without the scar getting in the way. If the stoma is sited too close to the operative scar itself, the skin around the stoma (peristomal skin) will be uneven and the adhesive will not adhere properly to the skin. This increases the risk of leakage under the baseplate. Any leakage is generally regarded as being a serious inconvenience
- Occupational factors: Working posture and the actual work duties can influence stoma siting
- Leisure activities: Certain leisure activities and other special activities can have an influence on where the stoma should be sited
- Ability to see the stoma
- Clothing: The stoma must be sited so as not to get in the way of the type of clothing usually worn by the patient. In the majority of cases this will mean that it needs to be sited below the waistline where it would otherwise be exposed to friction from the waistband/belt. In people from certain cultures who wear leggings or saris for example, where most of the garment is concentrated around the waist, the stoma should ideally be sited away from this area
- Cultural background: Muslims pray about five times a day. This is done kneeling with the trunk bent forward. For Muslims it will therefore often be more appropriate to position the stoma above the navel in order to avoid leakage<sup>(51, pp.36&39; 13, part 2, pp.7-11)</sup>



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# 6. Use of ileostomy appliances

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## 6.1 Drainable appliances

Once a person is stable following ileostomy surgery, the volume of faeces for most will be between 750 and 1,000 ml per day. A drainage bag is used to collect the stool expelled from the stoma. Bags with an outlet (drainable bags) can be emptied as required, while bags with no outlet (closed bags) must be disposed of when full. Most people who have had an ileostomy use drainable bags and empty them 5–8 times per day<sup>(2,14)</sup>.

## 6.2 1-piece and 2-piece systems

The ileostomy bag is attached to the skin surrounding the stoma via an adhesive, which is either integral to the bag (1-piece system) or supplied separately for attachment to the bag via a special coupling system (2-piece system).

### Advantages of the 1-piece system:

- Less bulky and more discreet than a 2-piece appliance
- More flexible, moulds to creases in the skin – an advantage especially if the stoma is close to the navel, operative scar or crest of the hip bone
- Fast and easy to replace
- The skin surrounding the stoma can be cleaned at every change
- Can be changed without the need to apply firm pressure to the abdomen



### Drawbacks:

- The skin suffers because the adhesive has to be removed at every change
- The appliance may be difficult to place because the bag may block the view of the stoma
- Changing the appliance can be a challenge for beginners

### Advantages of the 2-piece system:

- Gentle on the skin because the adhesive does not have to be removed every time the bag is changed
- Easier to change the bag frequently, e.g. in the event of odour
- The bag can be turned so that it is more comfortable when lying down, sitting or standing
- The stoma is visible when the adhesive is applied
- Easy to attach correctly because of the rigidity of the baseplate – an advantage if the wearer has shaky hands



- The ideal solution if the need for frequent inspection or treatment of the stoma is required

**Drawbacks:**

- The bag may be difficult to attach to the coupling of the baseplate
- Pressing the bag into place may be painful – e.g. for those who have only recently had the operation
- The system is bulkier
- The system may seem rigid because of the coupling

Choice of a 1-piece or 2-piece product is up to the individual and some people alternate between the two types depending on the situation.

**6.3 Minicap**

The minicap is a very small volume bag that helps to ensure the absorption of moisture, small amounts of faeces, and intestinal gas at times when no bag is in place. It is rarely used by people who have had an ileostomy due to its low volume capacity.



**6.4 Changing the appliance**

Skin problems around the stoma can be caused by failing to follow guidelines for adjusting the adhesive, which exposes the skin to faeces, and by failing to clean the stoma and peristomal area properly. The adhesive must be removed as soon as there are any signs that it is starting to erode and there is a risk of leakage. It should also be removed if the wearer feels that the adhesive is beginning to detach or experiences itching under the adhesive. Itching is often an indication that faeces or moisture has eroded the adhesive and has come into contact with the skin.



An ileostomy is most active just after meals, and is least active after a night of sleep without eating and drinking. Therefore, it is recommended that the adhesive be changed in the morning, before having anything to drink or eat and before smoking, as production of stool at this time is at its lowest. If there is only one bathroom in the home, this may require some coordination with other members of the household. Alternatively, the adhesive can be changed about 3 hours after having something to eat or drink.

Some people also have certain times when they regularly change the appliance such as before showering or before going to bed.

Changing the appliance typically requires:

- Adhesive sized to fit the stoma (standard size or cut to fit).  
Within the first 4–8 weeks of the operation the stoma will gradually shrink in size. It is very important that the hole in the adhesive is always exactly the right size to match that of the stoma at skin level. If the hole is too small it can irritate the stoma, and if too large, faeces will be able to leak under the baseplate and come into contact with the skin. Stoma appliances are often supplied with a ‘stoma guide’ to measure the stoma; a cutting guide is printed on the release liner protecting the adhesive
- Drainable stoma appliance
- Lukewarm tap water



- Cotton wool or soft gauze to clean the stoma and peristomal area
- Towel
- Small disposal bag that can ideally be tucked inside the waistband so it is to hand and can serve as an apron
- Any other useful accessories

The procedure is as follows:

- Empty the bag
- Keep the skin around the stoma stretched with one hand, carefully peel off the adhesive from top to bottom using the other hand. To help protect the skin, some counter pressure needs to be applied to the skin while peeling (like pulling a piece of tape off a sheet of paper). The adhesive should then be placed in the disposal bag
- Wash the stoma and surrounding skin with lukewarm tap water and cotton-wool or gauze pads. Any residue from the adhesive that does not come away with a gentle wipe should be left alone, rather than rubbed off, which may irritate the skin. This residue will come off when the next adhesive is removed. If there is no tap-water to hand a mild cleanser – for effective removal of both faeces and adhesive residue – can be used instead. Soap is not recommended, but if it is used, it should be unperfumed and have a low pH. It should be completely rinsed off before fresh adhesive is applied (most easily done in the shower). Any soap residue remaining under the adhesive can irritate the skin, making it vulnerable to infection. Users are strongly advised not to use methylated spirit or other solvents as they remove the natural oils in the skin making it prone to bacterial infection
- Any moisture on the skin around the stoma should be dabbed off and the stoma allowed to air-dry
- The stoma and the peristomal skin should be observed for any problems (see the following section on problems, page 19) – ideally using a hand mirror or a wall-mounted mirror at the same height as the stoma. The peristomal skin should look like the skin on the rest of the body – healthy with no discolouration or signs of irritation
- The new adhesive may be warmed to body temperature (e.g. between the hands or using a hair dryer) to make it as flexible as possible and ensure maximum adhesion
- Apply the adhesive from below and upwards to avoid any wrinkling. The slightest wrinkle might allow the faeces to seep out under the adhesive and result in skin damage and leakage
- Run a finger all the way around the stoma to ensure that the adhesive seals against the stoma
- Smooth the adhesive down, from the stoma out to the edge, using the hand to apply heat for about 1 minute
- When applying a 1-piece system the adhesive must be smoothed down by running a finger around the stoma both from the outside of the plastic film and between the back of the bag and the welding of the adhesive
- When using a 2-piece system attach the bag to the baseplate and ensure that it is firmly attached



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Problems and complications arising from use of ileostomy appliances and accessories are described in Section 7.1.

### **6.5 Disposal of used appliances and accessories**

Used adhesives and bags must not be flushed down the lavatory and should be treated like any other household waste<sup>(13, part 3, p.19)</sup>.

# 7. Problems

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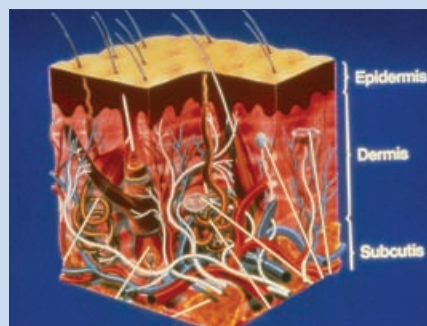
In order to guarantee that the ileostomy appliance remains firmly in place and leak-proof, it is vital to ensure that the skin underneath is smooth and healthy. However, both the stoma and the appliance itself can cause problems for the wearer.

## 7.1 Appliance-related problems

Stoma complications are usually due to the shape and position of the stoma itself; the appliance is less likely to be at fault. However, appliance problems do occur from time to time.

### 7.1.1 Skin

Perspiration and natural skin oils normally create a film that protects the skin by keeping it moist, oily and slightly acidic. The slight acidity (pH 5–6) inhibits the



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growth of fungal organisms and bacteria, with the important exception of the beneficial 'skin flora'. These organisms cover the entire skin surface and prevent the growth of other, harmful bacteria and fungi. The natural skin flora is shed along with dead skin cells<sup>(20, p.19)</sup>.

The skin's thickness, elasticity, moisture and blood flow varies from person to person and, among other things, is determined by age, race, disease and medical treatment. It is essential that the skin around the stoma is kept healthy and intact so that it can withstand exposure to the adhesive, leakage under the adhesive and regular cleaning of the peristomal skin. With age, the rate of turnover of the outer layer of the skin (the epidermis) slows significantly. For people aged over 60 years, the rate of epidermal replenishment is 64% slower than that for people aged 18–29. The dermis layer (directly under the epidermis) is 20% less thick, reducing the strength of the skin. The number of small blood vessels (capillaries) in the deeper layers of the skin is also reduced, and sweat production diminishes<sup>(20, p.8)</sup>.

### 7.1.2. Maceration

Maceration is a process that erodes the skin. If the person perspires heavily or faeces seep under the adhesive, the underlying skin can become macerated. Maceration damages the skin's natural barrier properties and leads to microbial production of ammonia (a waste product resulting from bacterial digestion of amino acids), which alters the skin's pH from slightly acidic to alkaline. This change compromises the skin's defences against harmful bacteria and fungal organisms and the risk of infection is increased. As maceration develops, the skin becomes paler and whitens because of the higher moisture content.



Adhesives that cover the peristomal skin must be able to cope with the moisture produced by the skin. The majority of modern stoma adhesives contain hydrocolloids, which absorb moisture and prevent maceration. For those using an older type of adhesive without hydrocolloids, any maceration problem can be solved by switching to a hydrocolloid adhesive<sup>(20, pp.10+17)</sup>. Switching from an old occlusive adhesive to a hydrocolloid adhesive should be done with support from a stoma care professional, as peristomal skin disorders are likely to occur for a period until the peristomal skin adapts to the new adhesive.

A protective film can be used as a preventive measure, for example by people with very sensitive skin and during convalescence when the adhesive is changed frequently.

For further information on treatment of the skin please see "Your guide to healthy skin" (Coloplast).

### 7.1.3 Leakage

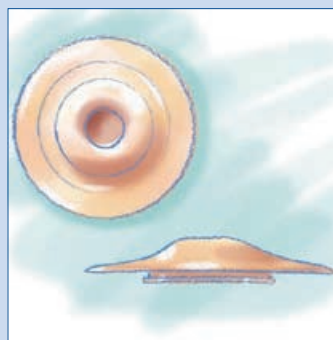
There is always a risk that adhesive will fail and leakage will occur. The risk of leakage is dependent on the type of adhesive used, how physically active the wearer is, and on the skin surrounding the stoma. If the stoma is sited on a skin crease, at skin level or below skin level, or if the patient has gained a great deal of weight after the operation so that a crevice is created around the stoma, it can be difficult for the adhesive to adhere properly. As a result, the skin may be exposed to faeces that leaks beneath the baseplate.

Depending on the composition of the faeces and the length of exposure, the skin will be affected to a greater or lesser extent. As described in the section on the digestive tract (p. 1), a number of digestive enzymes are released in the stomach and in the first section of the small intestine. These acidic enzymes along with a high water content mean that the faeces can be very damaging to the skin in the event of leakage. The enzyme content is lower in the final section of the small intestine.





Leakage under the adhesive is distressing for people with a stoma. Once leakage occurs, the adhesive will have to be changed to maintain healthy skin. However, if this happens too frequently, the skin will be subjected to increased surface stripping as the adhesive is peeled off (see section on stripping below). Leakage can be prevented using a special stoma paste to smooth out any uneven skin surfaces before the baseplate is applied. If paste is used for smoothing/levelling out irregularities, it is recommended to build it up in layers, allowing each layer to dry for about 30 seconds before applying the next layer for best results. The paste also absorbs moisture from the skin so that maceration is prevented<sup>(20, p.73)</sup>. Stoma paste is available in both a tube and as strips.



A convex adhesive can also be used, i.e. an adhesive that is not flat but has a slight indentation towards the stoma that provides extra support around the stoma. Another solution is to wear a belt, which can be used alone or in combination with the other two solutions.



It is important to be aware that a deep convex adhesive can leave pressure marks, and in some cases, sores. The paste supplied in a tube contains alcohol that can irritate the skin.

#### 7.1.4 Stripping

When an adhesive is removed, the outer layer of the skin is also removed. When this layer is removed at a faster rate than it can be regenerated (i.e. as a result of frequent adhesive changes), the skin is stressed – a process known as stripping. Stripping often produces redness, bleeding and infection, which can be exacerbated by maceration. Stripping is most easily prevented by changing the adhesive less frequently. This is achieved by providing an optimum skin surface for adhesion, and by switching from a 1-piece to a 2-piece appliance that allows the bag to be changed without removal of the adhesive. Stripping may also be reduced by switching to an adhesive that does not stick quite so firmly to the skin. Irritated skin can be painted with gentian violet (methylrosaniline chloride), which is an antifungal that reduces the risk of infection. A protective film can also be used, as it promotes healing, disinfects and dries out the skin<sup>(20, p.12)</sup>. Many people who use zinc oxide adhesives (occlusive) can develop shiny skin around their stoma.

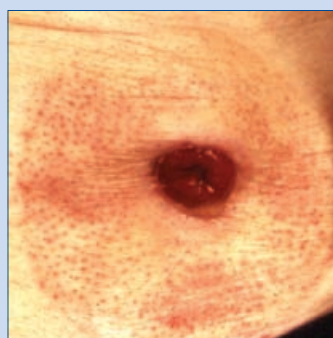


#### 7.1.5 Friction

In some cases the outer edge of the adhesive will rub against the skin causing it to become irritated and red, and develop sore areas (marginal lesions). The same can happen if the stoma belt chafes against the skin, or if skin creases rub against each other. Depending on the cause, this problem can be solved by switching to a different size of adhesive, a different appliance (e.g. by not wearing a stoma belt) or by using a protective baseplate or paste<sup>(20, pp.12+17)</sup>.

#### 7.1.6 Folliculitis

Folliculitis is an infection of the hair follicles (small sacs that anchor body hair). When an adhesive is removed it will pull the hairs under the adhesive, dislodging them slightly from the follicles. When the hairs are released from the adhesive they retract, but will draw bacteria back into the follicles. Any hairs pulled completely out of the follicles will leave an opening for bacteria to enter. These bacteria, usually staphylococcal strains, can cause folliculitis<sup>(13, part 4, p.6)</sup>, which can be prevented by carefully removing the hairs around the stoma before applying the adhesive. The hairs can be trimmed or shaved off. It is best



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to trim them away, as shaving risks stripping the skin. An electric shaver may also be used. Whatever method is used, the stoma should be protected by a piece of gauze while the hair is removed<sup>(23)</sup>. If folliculitis is already present, it can be treated with gentian violet and a gentler adhesive can be used until the skin is back to normal.

#### **7.1.7 Contact dermatitis**

Contact dermatitis is an inflammation of the outer layers of the skin. Contact dermatitis under the adhesive is usually due to leakage of faeces under the adhesive, or the use of irritating substances while caring for the stoma (irritant contact dermatitis). These include soap, solvents, skin cream, impermeable skin barriers or cleaning agents for removing adhesive residue. It is therefore important to use only lukewarm tap water for cleansing the stoma and the skin around the stoma. Contact dermatitis can also be caused by the constituents of the adhesive itself (allergic contact dermatitis). In such cases the solution may be to switch to a different type of adhesive. However, it can be difficult to determine whether the condition is caused by an irritant or an allergy.



For acute treatment of contact dermatitis a mild cortisone (steroidal) cream may be used (which must be prescribed). Only a thin layer should be used as the effect of the cortisone is enhanced when covered by the adhesive or baseplate<sup>(20, p.45)</sup>. For example, a 0.1% cream will typically have the effect of a 0.2% cream if the skin is covered. In addition, the skin should be protected until it is back to normal by using a 2-piece appliance or protective film.

#### **7.1.8 Allergic contact dermatitis**

Allergic contact dermatitis is hypersensitive to a specific molecule to which the skin is repeatedly exposed. Generally speaking, allergic reactions to adhesives are becoming rarer since the raw ingredients are designed to be hypoallergenic. Exceptions to this include microporous adhesive tape, which increasingly causes allergic reactions.



Allergic contact dermatitis looks like an infection of the outer skin layers. The symptoms include redness and itching, and tiny fluid-filled blisters appear after 10–14 days. Subsequently, the skin may begin to peel<sup>(20, p.7)</sup>. The only treatment is to stop using the product causing the allergy. This type of allergy will persist for the rest of the person's life, which means that even if the sufferer takes a break from using the product, the allergy will usually reappear as soon as the skin is re-exposed. If an allergic reaction occurs the first time a certain product is used, the allergy must have developed earlier<sup>(20, p.13)</sup>. The cause of the allergy can be determined by carrying out a patch test in which the individual constituents of a product are applied to the skin in minute doses (usually on the back) and the reactions are monitored. The quickest way of resolving the allergic reaction is treatment with a steroidal water-based solution (which must be prescribed). The adhesive should be removed and a thin layer of the solution can be painted on. With controlled treatment using a steroidal solution, there is no risk of the skin becoming thin and vulnerable<sup>(20, p.14)</sup>.

#### **7.1.9 Warts**

If the adhesive is not completely sealed against the skin, faeces will be able to seep under the baseplate. Exposure of the skin around the stoma to faeces may cause tiny 'bumps' called pseudovaricose warts to develop. These bumps are not real (virus-specific) warts, but they make the skin uneven and it becomes difficult to obtain proper contact between the adhesive and the skin. However, as cleaning regimens and the quality of adhesives have improved, pseudovaricose warts have become rare and are most often seen on people with a urostomy.



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The warts are removed with silver nitrate, or gentian violet in a 0.5–2% solution, and can be prevented by ensuring that the adhesive is firmly sealed around the stoma<sup>(24, p.43)</sup>.

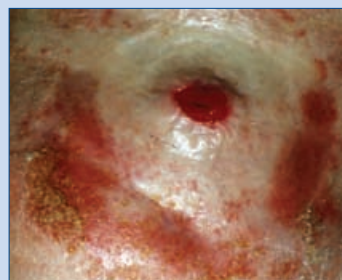
### 7.1.10 Granulomata

Granulomata are patchy formations of scar tissue (granulation tissue). Granulomata present no risk, and typically occur on the mucous membrane of the bowel as a result of small scratches. They may also occur in the transition between mucous membrane and skin as a result of a poorly fitted adhesive. Granulomata can be treated with silver nitrate and by ensuring that the adhesive is properly fitted<sup>(24, p.43)</sup>.



### 7.1.11 Fungal infection

Fungi thrive in moist, warm, alkaline environments such as those found around a stoma when the hole in the adhesive is too large. A fungal infection around a stoma will present as intense redness, oozing and puffiness. Fungal infection is rarely seen as the primary cause of skin disorders in people who have had an ileostomy, but can occur if the skin's natural defences are weakened by another skin disorder. Poor general health or treatment with antibiotics, adrenocortical hormone or chemotherapy can also promote fungal infections<sup>(13, part</sup>



<sup>14, p.7)</sup>. Fungal infections can be painted with gentian violet (methylrosaniline chloride) or an anti-fungal solution (e.g. a miconazole nitrate-based solution). Care must be taken to ensure that the adhesive is sealed around the stoma. Unlike miconazole, an over-the-counter preparation, gentian violet may only be available on prescription or on special order from hospital pharmacies (this varies from country to country).

If fungus is observed and diagnosed on the peristomal skin and stoma, it is also likely to be found in skin folds elsewhere on the body, such as under the breasts and in the groin area.

## 7.2 Problems involving the stoma

### 7.2.1 Odour

Odour, or the fear of odour from the stoma bag will be a familiar concern to the majority of people who have had an ileostomy. Most stoma bags are made from materials that prevent any odour from escaping, and most have a filter that removes odours from intestinal gas. However, the filter can become blocked with faeces which may lead to odour if the bag is not changed often enough. If a drainable bag is used and the wearer neglects to wipe the outlet of the bag thoroughly after emptying odour can easily be produced.

### 7.2.2 Retraction

If the patient gains a lot of weight, or there is a constriction of the intestine or its blood vessels, the stoma may retract below skin level. This can also happen if the section of bowel used in constructing the stoma was not long enough, or when the stoma rod is removed after formation of a loop stoma. The stoma will then sit in a crevice, which makes it very difficult for the appliance to adhere properly to the skin, and causes leakage. In many cases, problems with retraction can be solved by using paste, a belt or a convex adhesive



(p. 21). In some cases, however, the patient may need to undergo corrective surgery. If obesity is the cause of the retraction, a weight loss programme or liposuction may be the answer<sup>(13, part 4, p.12)</sup>.

### 7.2.3 Separation

Mucocutaneous separation is the detachment of the stoma from the peristomal skin in the first few days after surgery. It can be partial or affect the entire circumference of the stoma. A

number of factors can cause separation, including infection, abdominal swelling or malnutrition, poor wound healing, choice of suture and suture method. Separation may also occur if the hole made during surgery, through which the intestine is everted, is too large. Separation in the deeper muscular layer can also cause the stoma to separate from the skin. Partial separation will usually heal from the bottom up within a couple of weeks if the wound is correctly dressed. If complete separation occurs, a new stoma may have to be formed.

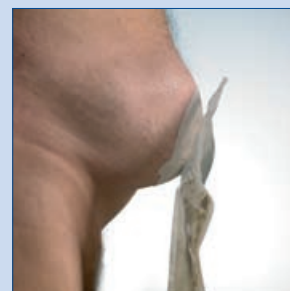
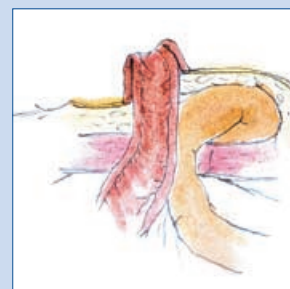
There is no consensus on how to treat separation. Some clinicians suggest cutting the adhesive to fit the wound, which is then left open to drain into the stoma bag. Others treat with alginate wound dressings and fit the baseplate to cover the separation. In both cases it is important to protect the wound edges and the surrounding skin. If the stoma is retracted, a convex adhesive may help the stoma to protrude but should be used carefully to avoid damaging the peristomal skin.

#### 7.2.4 Bleeding

Since the exterior of a stoma was formerly the interior of a section of the intestine (see digestive tract, page 1), the stoma retains the same properties as the intestinal mucous membrane. This is why people have no sensation in the stoma. It also means that the stoma has a great many blood vessels that lie just beneath the sensitive surface and are not protected by the body. When cleansing the stoma it is therefore very easy to accidentally graze the mucous membrane. Although this may make the stoma bleed, it is generally no cause for concern and will soon stop of its own accord. Slight bleeds from the stoma do not require treatment, but it is advisable to use gentle products when cleansing the stoma and to avoid chafing from the edges of the adhesive<sup>(13, part 4, p.10)</sup>. If bleeding is due to a larger lesion of the mucous membrane of the stoma, it will need to be stopped using compression, and the next adhesive must be applied so as to protect the lesion as much as possible. Any bleeding from inside the stoma should be investigated by a physician<sup>(24, p.44)</sup>.

#### 7.2.5 Sliding hernia

A weakness in the muscle fibre surrounding the stoma can give rise to a sliding hernia. A sliding hernia is produced when part of the section of intestine used to create the stoma is pushed through the muscle fibre and gets trapped between the abdominal muscles and the skin. This is usually seen in the shape of a bulge around the stoma. As its name suggests, a sliding hernia slides back and forth and is therefore most prominent when the person is standing. Heavy lifting and similar effort can also cause a sliding hernia<sup>(13, part 5, p.11)</sup>. Some people experience pain from a sliding hernia, and it may be unsightly<sup>(13, part 4, p.13)</sup>. Moreover, the bulge makes it difficult for the adhesive to seal properly. A sliding hernia can often be kept in place using a custom-made belt or trousers, but in severe cases surgery may have to be considered.



#### 7.2.6 Stoma prolapse

In very rare cases, the section of intestine used to create the ileostomy may turn almost inside out and slide forwards. This is known as a prolapse. The prolapse may either slide back and forth or be permanent. Although rarely a health risk, this condition can be quite troublesome. A stoma that has prolapsed will tend to become thickened (oedematous) and hence increase the risk of the adhesive cutting into the side of the stoma. The prolapse can also become trapped (incarcerated) in the abdominal wall, cutting off the blood supply to the stoma (ischaemia) and resulting in death of the tissue (necrosis). In this situation the patient will require surgery to free the prolapsed section of intestine<sup>(13, part 4, p.14)</sup>.



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Apart from the physical problems of a prolapsed stoma, there are also purely cosmetic concerns. The section of intestine that protrudes from the body can be surprisingly long and seem alarming. Some women especially find it difficult to come to terms with a prolapsed stoma, which may look similar to a penis.

Corrective surgery should be weighed up against the degree of discomfort involved and the risk that the stoma will prolapse again after corrective surgery.

### 7.2.7 Stenosis

Stenosis is a constriction of the stoma outlet. Several things can cause this constriction:

- If the mucous membrane dies (becomes necrotic), subsequent healing will cause the tissue to contract around the stoma and constrict it
- Constriction may occur as a separation heals
- Fluid build-up (oedema) in the mucous membrane of the stoma can constrict the outlet
- If the hole in the abdominal wall is too small, or if the stoma becomes trapped in the abdominal wall, this will also constrict the stoma
- A hard, fibrous ring may form around the stoma at the point where it was sutured to the skin. The fibrous ring can also constrict the stoma

If the constriction is only moderate, it may be possible to dilate the opening with a well-lubricated finger. If an obstruction is indicated, surgery will be required<sup>(13, part 4, p.13)</sup>.

### 7.2.8 Fistulae

A fistula is a spontaneously developed channel between two normally unconnected structures. If the adhesive chafes against the stoma, a pressure sore may develop, which in rare cases may slowly develop into a fistula (an additional opening from the skin to the stoma). This will cause faeces to seep out of the body adjacent to the stoma. This causes major problems sealing the adhesive and in maintaining healthy skin. Once the pressure from the adhesive is removed, the fistula will soon close by itself<sup>(13, part 4, p.15)</sup>. Formation of a fistula is rare in people who have had an ileostomy and is most often seen in those suffering from Crohn's disease or the harmful effects of radiation.

### 7.2.9 Oedema

Oedema of the stoma describes a condition in which fluid builds up in the mucosal tissue making the stoma large, swollen, pink and slightly transparent. Oedema is caused by fluid leaching out of the blood and into the surrounding tissue. It can arise if blood cannot return from the stoma due to the stoma becoming trapped in the abdominal wall. Prolapse, infection and low albumen content of the blood can also cause oedema of the stoma. If the oedema is due to low albumen content in the blood, a high-protein dietary supplement may be taken. If the oedema is due to stenosis, a surgeon will need to determine whether the person should undergo surgery for the condition<sup>(13, part 4, p.10)</sup>.



### 7.2.10 Ischaemia

Ischaemia means inadequate blood supply. The stoma may become ischaemic if its blood supply is reduced. This may occur if the hole in the skin created for the stoma is too tight, if the intestine becomes trapped between the layers of the abdominal wall, or if the section of intestine used to create the stoma becomes overstretched and constricts the blood supply. The visible signs of ischaemia are that the stoma becomes bluish and oedematous. If the condition persists for a long enough period of time, the stoma will be partially or entirely necrotised. In many cases the blood supply will re-establish itself, but an ischaemic stoma must always be kept under close observation, e.g. by carefully introducing a test tube into the stoma and assessing the extent of the ischaemia by shining a light into the tube. If the stoma is necrotised entirely, a new stoma will need to be constructed immediately<sup>(13, part 4, p.10)</sup>.



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## 8. Living with an ileostomy

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### 8.1 Clothing

People with an ileostomy can dress as they did before surgery but it is important that the clothing does not prevent the stool from flowing unobstructed into the bag. Tight waistbands should be avoided since they can press against the bag and cause it to leak or may even prevent the stool from leaving the stoma<sup>(13, part 5, p. 7)</sup>. It may be more practical to wear braces instead of a belt. However some men prefer to wear braces only when wearing a suit jacket or other item of clothing on top.



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People with a stoma sometimes feel that the bag is visible through their clothing, although this is usually not the case. This perception is often a result of the person's heightened awareness of the bag and the fact that they view it from above where it may seem more prominent. Trousers with pleats in the waistband hide the stoma bag better than trousers with a flat front. The bag is less visible if it is worn inside the underpants, which should ideally be of an elastic material like Lycra. If wearing bathing trunks, a swimsuit, or bikini it may be advantageous to use a small bag, which takes up as little space as possible. However, people with an ileostomy may find that a small bag fills quickly and becomes more visible as a result. The bag must therefore be emptied more frequently which may not be so easy on the beach.

There are companies that have designed clothes and particularly underwear for people with a stoma.

See also the section on stoma-site marking on p. 13.

## 8.2 Sport and leisure

There are few physical limitations to participating in leisure activities after having an ileostomy. As soon as the person recovers from surgery, they can return to most of the activities they enjoyed before, such as sports and gardening. However, they should be encouraged to consult their physician or stoma care nurse first. If necessary, the stoma can be protected with a special protective accessory known as a StomaGARD, which is a special rigid cap worn over the stoma. Cycling, ball games, golf and similar sports usually do not cause problems, but high-impact contact sports like boxing should be avoided for practical reasons<sup>(2, p. 5)</sup>. Weight-lifting should also be avoided since it may increase the risk of developing a sliding hernia (see hernia, page 24). For those engaging in more strenuous sports where they work up a sweat, the adhesive will be challenged<sup>(13, part 15, p. 12)</sup>. Therefore it is a good idea to change the adhesive before participating in sport to make sure it stays firmly in place.



The biggest challenge facing people who want to participate in sports is psychological. Past experience with leakage, or the fear of the bag leaking, unfortunately causes some people to avoid any sports activity.

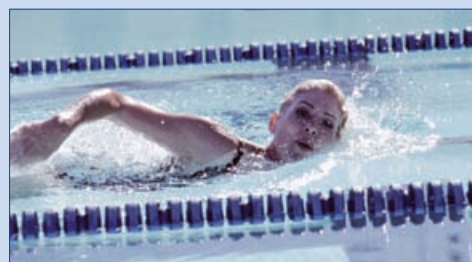
When participating in team sports, it is rare to be able to shower in private. For many people with an ileostomy, undressing in front of others and having the stoma visible is hard to cope with. Instead, some will choose to wait until they get home to shower. This may be noticed by team mates and lead to prying questions, which in turn may further limit willingness to participate<sup>(26, p. 86)</sup>.

## 8.3 Swimming, showers and baths

### Swimming

People with an ileostomy should not be deterred from going swimming. After swimming, it is important to dry off the skin around the stoma very carefully before attaching new adhesive.

The adhesive can withstand getting wet while the person is swimming, and the best way to camouflage the bag is for women to wear a patterned swimsuit (not a bikini) and for men to wear





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boxer shorts. After swimming, the appliance should be dried carefully to avoid any skin irritation due to moisture.

### ***Showers and baths***

A bath can be taken with or without the bag. Soap and water will not harm the stoma or be forced into the stoma. In public places a bag must be worn at all times for hygiene reasons.

When taking a bath, bath oils and lotions should be avoided as they may make it difficult for the adhesive to stick to the skin.

### ***Hot tubs and Jacuzzis***

People with an ileostomy may only use hot tubs at public pools on the condition that the adhesive and bag are firmly in place.

## **8.4 Sauna and sunbathing**

The stoma will not be harmed by spending time in a sauna<sup>(13, sec. 5, p. 7)</sup>. In public saunas a bag must always be worn.

When sunbathing there is a risk of the stoma being burnt through the appliance if not covered.



## **8.5 Transport and travel**

An ileostomy rarely causes major problems during travel. However, there are certain issues to be aware of<sup>(27, p. 24)</sup>.

Immediately after surgery it is not advisable to drive a car; people should wait until they are fully recovered. The stoma and the incision must be able to withstand an emergency stop, and the driver must be able to twist their body when reversing. Furthermore, the stoma must not affect the driver's ability to concentrate on driving.

In case of delays or being caught in a traffic jam it is a good idea to keep an extra appliance in the glove compartment so it is always possible to change it. However, in very hot weather, stoma products should not be left in the car, as the heat may damage the adhesives.

People with an ileostomy who travel by car either as the driver or passenger must wear a seatbelt like everyone else. Although the seatbelt can sometimes irritate the stoma, a person with a stoma is not exempt from laws governing seatbelt use unless they have a medical certificate stating otherwise. Shops that sell equipment for cars also offer special equipment for seatbelts that will ease pressure on the stoma.

Leakage is always uncomfortable, but will cause added distress if it occurs while travelling on a bus or plane where space and toilet facilities are limited, and where it is difficult not to attract attention. People with a stoma should always remember to change the adhesive earlier than normally planned so that it remains firmly in place<sup>(13, part 5, p. 7)</sup>. It is also important to bring waste disposal bags so that the stoma waste can be disposed of discreetly. On long journeys where it is difficult to dispose of used bags, it may be a good idea to use a drainable bag that is larger than usual.

When travelling in hot climates, the wearer will perspire more heavily, causing the adhesive to lose some of its strength and require more frequent changing. It is also common to bathe more frequently while in a hot climate, both in swimming pools and open water, and although water does not damage the stoma or adhesive, wear time may be shortened. Therefore, it is important to pack plenty of appliances when going on this type of holiday. A good guide is to take twice the quantity that would normally be used. If further supplies are needed, similar products may be purchased in most countries. Before leaving home, it is a good idea for people with a stoma to check precisely where stoma products can be purchased to avoid wasting time during the stay.

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In hot climates, heat and sweat will also make the bag more likely to stick to the skin if it does not have a soft backing. It is a good idea to bring a covering bag made of fabric to prevent the bag from sticking. In climates with high humidity, the supply of adhesives should be protected by sealing them in a plastic bag. They should also be protected from direct sunlight and strong heat<sup>(14, p. 10-11)</sup>. It may also be useful to pack products for cleansing and protecting the skin around the stoma in case it is affected by the heat and change in humidity. People with an ileostomy are generally advised to drink 2–3 litres of fluid per day, and in a hot climate it is important to drink a minimum of 3 litres because of the increase in fluid loss due to perspiration. As people with an ileostomy are at a greater risk of dehydration and developing an electrolyte imbalance if they get diarrhoea, it is recommended that they pack some soluble electrolyte powder when travelling.

For people who are anxious about travelling or have had their surgery recently, it may be a good idea to make a note of the address of a stoma care nurse or patient association at the destination to make sure professional guidance is always available. Patient associations (p. 41) can often provide information about contacts in foreign destinations. It is also advisable to recommend that people with a stoma take the telephone number of their own physician when travelling. A medical identification bracelet or necklace may be worn so that the person's medical history can be obtained in case of an emergency.

When travelling by plane there is always a risk that checked luggage will reach the destination late or will not arrive at all. It is therefore important to pack extra appliances and other accessories in hand luggage. Holes in the adhesives should be cut and fitted at home, since airlines no longer permit even the smallest pair of scissors in hand luggage. Most airlines do permit stoma products in hand luggage even if they exceed weight requirements. However, this has to be arranged prior to the journey, preferably when making the reservation<sup>(23)</sup>. If travelling by plane it is a good idea to ask for an aisle seat for easy and quick access to the toilet.

To avoid problems when entering and departing other countries, it is advisable to carry a travel certificate from a stoma care nurse that provides information about the surgery and the appliances carried in the hand luggage. The certificate should be in several languages and should clearly state the importance of the appliances that must be carried by the traveller at all times and that a stoma care professional must be in attendance if there is a need for observation of the stoma. Some companies also offer people with a stoma a 'No Waiting Card', which states in several languages that the bearer of the card has an ileostomy and in an emergency should not be denied access to lavatories that are not otherwise intended for public use.

It is advisable to ensure that travel insurance does not exclude pre-existing health-related conditions, otherwise any issues that may occur with the stoma while travelling will not be covered.

If there is any doubt about the quality of the drinking water when travelling, bottled water should be purchased for cleansing the stoma to prevent a gastrointestinal infection.

## **8.6 Returning to work**

People with an ileostomy who are still professionally active can most often return to work following surgery. The speed at which someone can return to work after surgery varies from person to person and depends on the type of job, surgical procedure, and possibly on the aftercare. People who have had ileostomy surgery should wait at least 8 weeks before attempting physically demanding tasks, such as heavy lifting, vacuum cleaning and gardening. The body will usually protest if the person is doing too much. Sick leave of 2–4 months after the operation is typical.

Any work involving heavy lifting can be harmful to a person with a stoma because there is a risk that the strain will cause a sliding hernia (see hernia, page 24). Such work may have to be replaced with less physically demanding tasks or by using a precautionary hernia belt.

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The nature of a person's work may influence which type of appliance is most suitable to wear. For example a delivery van driver might choose a large bag that does not need to be emptied too often, and a belt as a precaution against lifting packages that might scrape against the stomach.

To be able to function optimally in the workplace, it is very important to have somewhere to empty the bag or reservoir, change the appliance and dispose of waste. In most cases having an ileostomy causes no work-related problems, and very few people have to inform their colleagues that they have a stoma.

If asked about health conditions when applying for a job, people with a stoma should state that they have had an ileostomy procedure to avoid any subsequent problems arising from sick leave.

### **8.7 Financial aspects**

Coverage of expenditure on stoma appliances and accessories (e.g. bags and adhesives) varies greatly from country to country. In the UK, this expense is covered by the NHS.

Some ileostomy patients experience a reduction in income as a result of their disease and surgery. Some of these occur because of the need to change occupation or retire.

If a stoma patient's private toilet and bathing conditions are insufficient for nursing the stoma, in some countries it is possible to apply for financial support to renovate the facilities<sup>(28, p. 6)</sup>.

### **8.8 Diet and fluid intake**

In the past, people who had just undergone an ileostomy procedure were given only chipped ice until the intestine was functioning again (the first time the bowel passed gas). The person was then given a liquid diet until the first stool exited the stoma. At this time, the person could slowly return to eating normally again, starting with small portions.

New research, however, shows that the sooner the person eats real food after surgery, the sooner the intestines will return to normal functioning<sup>(29)</sup>. Sometimes a gastric tube is inserted into the stomach during surgery, so the patient can take in liquid foods immediately after. This encourages the intestine to return to functioning quickly, allowing the person to regain the energy to get out of bed and get back on a normal diet.

There will often be loss of appetite during the first 4–6 weeks after an ileostomy procedure. It may therefore be necessary to supplement the diet with high protein and energy drinks. In general, people who have had an ileostomy can eat and drink whatever they want unless the surgeon or stoma care nurse advises otherwise.

Immediately after surgery, people with an ileostomy tend to lose a significant amount of fluid via the stoma – normally between 750 and 1,300 ml per day. Physicians recommend that people with an ileostomy should drink at least 2 litres of water per day (or 35 ml per kg of body weight), as well as enough liquid to make up for that which is lost through waste. The small intestine will gradually become accustomed to absorbing more liquid 3–12 weeks after surgery, meaning that less liquid is lost through waste. This adaptation is known as 'colonisation', as it is normally the large intestine (the colon) that absorbs liquids. People with an ileostomy lose 2–3 times more water and salt through waste than normal. Reduced fluid intake or loss of liquids and salt can cause headache, nausea and cramping. People with an ileostomy should therefore add some salt to foods and possibly drink soda water<sup>(30, p. 14, p. 41, 2, p. 6, 32, p. 105)</sup>. If the patient suffers from diarrhoea, salt loss will be greater than normal, at approximately 7 g per litre of waste. It is therefore very important for these individuals to increase their salt intake<sup>(21, p. 16)</sup>.



It is important that food is chewed thoroughly before swallowing because stoma blockage is sometimes the result of indigestible and insufficiently chewed food remains. In such cases, the ileostomy stops functioning and causes bloating and stomach pain. In the most severe cases, this can cause intestinal blockage or volvulus. The patient should therefore drink liquids, exercise and carefully examine the stoma. It may also be necessary to evacuate the intestine with water through the stoma. If this does not help, the patient will have to be hospitalised. The stoma normally begins to function again after a couple of hours<sup>(21, p. 16, 17)</sup>.

Those with a continent stoma should avoid foods that are difficult to chew or digest, as it can be difficult for them to pass through the catheter used to empty the reservoir (see page 9). Examples of such foods include cabbage, corn and nuts<sup>(16, p. 163)</sup>.

Some foods are beneficial for people with an ileostomy, while others should be avoided. A single unpleasant experience with a given food should not mean avoiding it altogether. Food should only be excluded after repeated bad experiences<sup>(31, p. 41)</sup>. Using a different method to prepare certain foods will make them more tolerable. For example, vegetables containing sulphur like cabbage can be cooked, and the first batch of boiling water disposed of before cooking is continued. Although this procedure will reduce the food's nutritional value, it will also reduce unpleasant odours.

Below is a list of foods that typically influence the digestive system<sup>(21, p. 17; 33, 2 pp. 6-7; 34, p. 9; 35)</sup>:

<b>Less solid stool</b>	<b>More solid stool</b>	<b>Increased volume of stool</b>
<ul style="list-style-type: none"> <li>• Pears</li> <li>• Cherries</li> <li>• Plums</li> <li>• Raw vegetables</li> <li>• Fresh and preserved fruit</li> <li>• Prunes and raisins</li> <li>• Figs</li> <li>• Orange juice</li> <li>• Large quantities of sugar and sweetened products</li> <li>• Sorbitol</li> <li>• Alcohol</li> <li>• Spices</li> <li>• Fatty and fried foods</li> <li>• Chocolate</li> </ul>	<ul style="list-style-type: none"> <li>• White bread</li> <li>• Grains</li> <li>• Potatoes (preferably mashed)</li> <li>• Pasta</li> <li>• Rice</li> <li>• Carrot purée</li> <li>• Ripe bananas</li> <li>• Grated apples</li> <li>• Plain yogurt</li> <li>• Blueberry juice</li> <li>• Salted crackers</li> </ul>	<ul style="list-style-type: none"> <li>• Raw vegetables</li> <li>• Spices</li> <li>• Prunes</li> <li>• Breakfast products with bran</li> <li>• Leafy green vegetables</li> <li>• Milk</li> <li>• Fresh fruit/fruit juice</li> <li>• Figs</li> <li>• Alcohol</li> <li>• Chocolate</li> </ul>

If the patient experiences overly liquid stool, medicines that solidify faeces may be useful but must be used only after consulting with a stoma care professional.

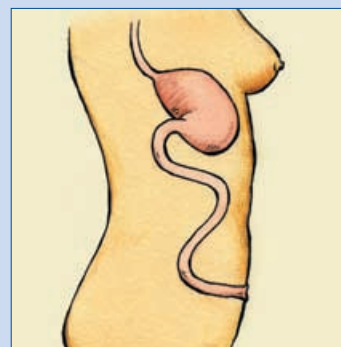
If more than 25 cm of the lower portion of the small intestine has been removed, vitamin B 12 and gallic acids cannot be absorbed. The body has a reserve of vitamin B 12 that can last up to 6 months. Therefore, if the section of the small intestine that absorbs vitamin B 12 from food is removed during surgery, symptoms of B 12 deficiency will appear only after about 6 months. B 12 can be administered by injection.

In general, at least 100–150 cm of properly functioning small intestine must remain intact following ileostomy surgery. If not, the person can develop short bowel syndrome, which is an insufficient absorption of nutrients caused by the inadequate amount of small intestine left, and

<b>Create unpleasant odour</b>	<b>Mask unpleasant odour</b>
<ul style="list-style-type: none"> <li>• Asparagus</li> <li>• Baked beans</li> <li>• Broccoli</li> <li>• Cabbage</li> <li>• Cod-liver oil</li> <li>• Eggs</li> <li>• Fish</li> <li>• Garlic</li> <li>• Onion</li> <li>• Peanut butter</li> <li>• Certain vitamins</li> <li>• Strong cheeses</li> <li>• Certain medicines</li> </ul>	<ul style="list-style-type: none"> <li>• Buttermilk</li> <li>• Cranberry juice</li> <li>• Orange juice</li> <li>• Tomato Juice</li> <li>• Parsley</li> <li>• Plain yogurt</li> <li>• Peppermint tea</li> <li>• Peppermint oil in water</li> </ul>

<b>Create gas</b>	<b>Leads to stomach pain and potential blockage</b>	<b>Prevent constipation</b>
<ul style="list-style-type: none"> <li>• Cabbage</li> <li>• Broccoli</li> <li>• Spinach</li> <li>• Mushrooms</li> <li>• Onion</li> <li>• Radishes</li> <li>• Ripe legume plants</li> <li>• Sorbitol</li> <li>• Carbonated drinks</li> <li>• Beans</li> <li>• Soya</li> <li>• Cucumber</li> <li>• Chewing gum</li> <li>• Milk</li> <li>• Nuts</li> <li>• Pineapple</li> <li>• Popcorn</li> <li>• Seeds</li> <li>• Beer</li> </ul>	<ul style="list-style-type: none"> <li>• Fruit rinds</li> <li>• Grapes</li> <li>• Pineapple</li> <li>• Vegetable peels (asparagus, leeks)</li> <li>• Mushrooms</li> <li>• Carrots (raw and boiled)</li> <li>• Nuts</li> <li>• Almonds</li> <li>• Popcorn</li> <li>• Dates</li> <li>• Figs</li> <li>• Coconut</li> </ul>	<ul style="list-style-type: none"> <li>• Water</li> <li>• Hot coffee</li> <li>• Figs</li> <li>• Prunes</li> <li>• Fresh and boiled fruit</li> <li>• Boiled vegetables</li> <li>• Fruit juice</li> <li>• Hot drinks</li> </ul>

the reduced transit time in the shortened small intestine. Short bowel syndrome is treated with a lifelong special diet, vitamins, and mineral supplements, in addition to medication that reduces the speed at which food passes through the intestine. Some people with short bowel syndrome spend a great deal of time trying to obtain sufficient nourishment, and in more difficult cases intravenous feeding (parenteral nutrition) may be required. A small intestine transplant may be considered in severe cases – particularly if there is a risk of significant intestinal failure<sup>(36, 37, 38)</sup>. However, this procedure is still in the experimental phase and is rarely performed.

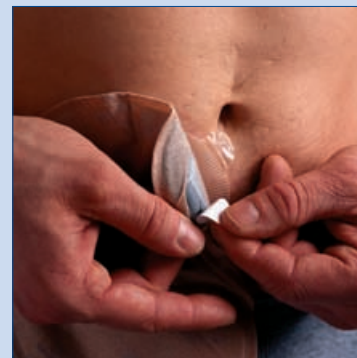


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## 8.9 Gas in the intestine

Approximately 70% of the gas in the intestine is taken in while talking and chewing. The other 30% is formed when digesting food (see section on diet and fluid intake, page 31). By carefully choosing what and when to eat, and by chewing the food thoroughly with the mouth closed it is possible to limit gas in the intestine to some extent. However, gas cannot be avoided completely<sup>(21, p.17,15, p. 24)</sup>. Usually, a person controls when to expel gas from the intestine by contracting and relaxing the anal sphincter. After an ileostomy, however, people can no longer control the expulsion of gas and instead, the gas escapes from the stoma bag spontaneously at regular intervals. For newly operated people in particular, this uncontrolled rumble may be distressing.

Most ileostomy bags are equipped with a filter that allows gas to escape and removes unpleasant odours. The filter will function as long as it is dry, so it should be kept from becoming wet when bathing. Thin faeces can also cause the filter to become blocked. If gas accumulates in the bag, there is risk that it will escape by creating an opening in the adhesive plate and thus create a leak (see section on leakage, page 20). If a drainable bag is used, the gas can be let out through the outlet if the bag suddenly becomes filled with air. If a 2-piece appliance is used, the coupling may be opened slightly to allow the gas to escape. Although some people with a stoma loosen the adhesive from the skin to let gas escape from the bag, this is not recommended because adhesion deteriorates and the risk of leakage increases.



For more information, see the section on odour, page 23.

## 8.10 Medication

The vast majority of oral medications are absorbed in the small intestine. After an ileostomy, medication in the form of a tablet or coated pill can end up in the stoma bag without having any beneficial effect on the patient. Some vitamins and antibiotics can cause unpleasant odours or thin faeces, so individuals should consult a doctor or chemist before taking a new medicine<sup>(15, p. 25)</sup>.

## 8.11 Psychological factors

As mentioned earlier, the location of an ileostomy is far from being purely a physiological procedure with practical aspects. The person's cultural practices and traditions, social life, self-image, religion and sexuality are affected by the surgery. The effect of the stoma on an individual depends on the person's age, the reason for the stoma procedure, their lifestyle and the person's ability to cope with the situation.

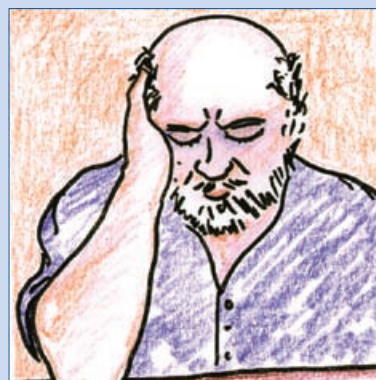
### ***Punishment***

In some cultures/religions a disease, and hence the formation of a stoma, is considered a punishment, and visible evidence that a person has done something wrong in their life. For these people it is relatively more difficult to regain self-confidence following ileostomy surgery<sup>(13, part 5, p. 14)</sup>.

### ***Loss of control***

A large part of growing up and becoming an independent individual is achieving control and autonomy. By the age of 2–4 years, most children have learned to control their bowels and are aware that contact with faeces is unhygienic. This control over the stool is suddenly lost after having an ileostomy and it is not uncommon for people to feel that they have been reduced to the 'nappy stage' along with the attendant shame. In a survey of 20 people who underwent a stoma, one of the participants described the major change as no longer being aware that a bowel movement is imminent and described the stoma as an illness in itself<sup>(39)</sup>.

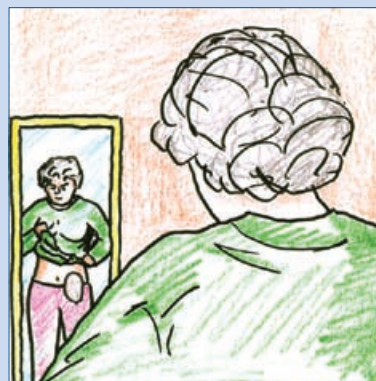
Fear of the appliance leaking and of odours escaping from the bag affect everyday life and influence relationships with other people (including sexual relationships). Taboos in society only intensify these feelings. The individual's ability to cope with this situation depends to a great extent on their personal resilience and the attitude of the immediate family. Generally people with a stoma begin to feel more confident and comfortable once they have had some positive experiences of life with a stoma<sup>(13, part 2, p. 2)</sup>.



### **Change of body image**

Constant bombardment by advertisements and the media telling us how to make our bodies more attractive contribute to the huge significance society places on physical appearance. Our sense of identity is often tied up in the way we look. After having an ileostomy, the body's appearance is radically altered, and in many cases the body image is negatively affected. The stoma may cause the body to appear asymmetrical, the incision and subsequent scar, and the bag on the abdomen can make people feel unattractive<sup>(13, part 2, p. 2)</sup>. A survey among 66 people who had a urostomy showed that women tended to be more concerned with the aesthetic change to the body than men<sup>(27, p. 29)</sup>.

Another survey asked 15 people who underwent an ileostomy to draw their bodies prior to discharge from hospital, 3 months after discharge, and then 6 months after discharge<sup>(41)</sup>. In drawings made immediately before discharge, the body image was typically naked without arms, legs, and faces, and with a large uncovered stoma. Drawings made 3 months after surgery were more complete with body parts and all stomas were covered with a bag. Six months after surgery, the drawings were complete – some even had detailed facial features and clothing. It is important that people with a stoma put ideas of the familiar symmetrical body aside, come to terms with the loss and learn to embrace life once more. Again, personal resilience (both intellectual and social) are critical in determining how well the individual copes with the situation<sup>(13 part 3, p. 18)</sup>.



### **Changes in sexual ability**

As discussed in the section on sexuality on page 36, the ability to perform sexually can be affected by an ileostomy, particularly in men. For both men and women it is important to accept that their situation has changed, and that there are sexual aids available that can help.

### **Facing the future**

Following ileostomy surgery, some people react with depression, weariness and a sense of pointlessness<sup>(42, p. 23)</sup>. An interview-based survey of 34 stoma patients revealed that 20% still had difficulty coming to terms with their situation a year after surgery. The fear that the disease that led to the stoma will return may never disappear completely, but after a while the fear will no longer dominate the person's life. Some people even experience a fuller and richer life after surgery because it has reminded them that they cannot live forever, and they learn to distinguish between the important and unimportant things in life<sup>(43, p. 16)</sup>.

## **8.12 Social perspectives**

In the UK, a person who has undergone ileostomy surgery is often referred to as an 'ileostomist'. This term is misleading. By analogy to words like optimist and pessimist, it suggests a particular identity and way of life, which is inaccurate. Like everyone else, people who have had an ileostomy have far more interesting qualities than the fact that they have

undergone stoma surgery. The surgery rarely has an effect on what they can do afterwards. To avoid stigmatisation, more neutral language like 'person with a stoma' should be used.



Deciding who to tell about the stoma is an individual decision – some people are open by nature, while others are more reserved. Being open about a stoma can be difficult because bodily functions are normally considered to be private. However, most people who have had an ileostomy will face social situations where it is appropriate to be more open, such as with sexual partners, during sporting activities, or sometimes with work colleagues. Odour, the fear of odour, and the changed body shape may cause some to avoid physical contact with others.

With children, talking openly about what has happened to mummy's, daddy's or a grandparent's body rarely presents any problems. When information is given candidly, most children have no trouble accepting it. On the other hand, a lack of openness and secrecy around children may cause them to imagine the situation to be far worse than is actually the case<sup>(13, part 5, p. 2-4)</sup>.

### **8.13 Sexuality**

Sexuality is an important part of life for both young and older people and this does not change because of stoma surgery. However, fatigue after surgery, psychological problems due to the stoma, practical issues with the stoma, and purely physiological factors can affect the person's sexuality. For the majority, the libido remains the same and it is important to remember that a sex life is more than sexual intercourse, and a new approach to sexual activities can be very beneficial.

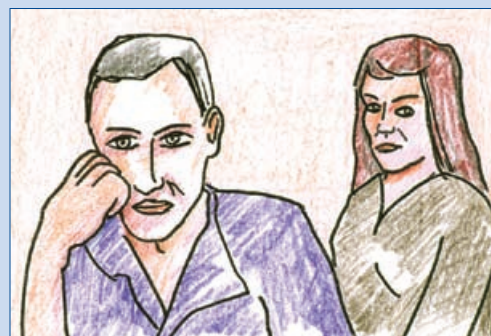
In a survey among people who had an ileostomy, 30–40% believed that their stoma made it physically or emotionally more difficult to have intercourse<sup>(44)</sup>. Another survey found that 80% felt that their sex life had been disrupted by the stoma<sup>(44)</sup>.

#### **8.13.1 Fatigue**

Having stoma surgery is physically and emotionally draining. Most people will need time to recover after surgery before they have the energy to resume their sex life. Attempts at intercourse too soon after surgery may fail, leading to feelings of inadequacy<sup>(13, part 5, p. 3)</sup>.

#### **8.13.2 Psychological aspects**

People who have had an ileostomy will be affected in varying degrees and lengths of time by grief, fear of mortality, depression, and altered body image, all of which will affect their sex drive<sup>(13, part 14, p. 21)</sup>. How people feel about their body is closely linked to how sexually attractive they feel, and how secure they feel during intimacy. Many consider that the visible waste along with the risk of odours escaping from the bag make them less attractive, and they worry how their sexual partner will react to the stoma and the bag on their stomach. This is a particular issue if the person does not have a regular partner. Experience shows that it is usually a good idea to talk about the ileostomy early in a new relationship, and that most partners tend to be curious rather than put off.



It is very important for people who have had an ileostomy to develop a relaxed attitude to themselves and their stoma. Some people have achieved this by looking at their body in a full-length mirror and by talking about the stoma with their partner<sup>(13, part 5, p. 3)</sup>.



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### 8.13.3 Practical aspects

Although the stoma will not be damaged by intercourse, the bag can get in the way, and can be seen, felt and heard. In addition there is always a risk of detaching. If the bag is left on during sex, it is a good idea to change it beforehand. The bag can be made more discreet by using a special cover made of a matching fabric, or a piece of clothing that will camouflage the bag, such as a T-shirt, girdle or a scarf worn around the waist<sup>(13, part 5, p. 4)</sup>.

A penis may not be inserted into the ostomy as this will damage the sensitive tissue and place the anastomosis at risk.

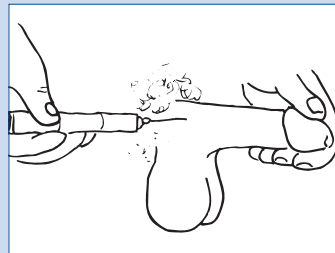
### 8.13.4 Male sexuality

Sexual activity can be resumed as soon as the man has recovered from surgery, but in many cases the surgery will have physiological effects that will influence the ability to perform sexually.

Nerve pathways that regulate erection and ejaculation are close to the rectum. If the rectum is removed during surgery there is a risk of damaging these nerves, resulting in problems with erection and ejaculation into the bladder. However, the ability to achieve orgasm is not affected. A 1990 survey among men who had had their rectum removed showed that 39% had erectile dysfunction after surgery. Fortunately the prevalence of surgically related erectile dysfunction is declining, as surgical techniques improve and fewer rectums are removed.

Various methods can be used to help a man who has had an ileostomy during which the nerves controlling erection and ejaculation were damaged, to have conventional sexual intercourse, even if he has erectile dysfunction.

- The most common method is to receive instruction on self-injecting a prostaglandin preparation into the erectile tissue of the penis (intracavernosal injection). The drug works by causing the smooth muscle around the erectile tissue to relax so the blood can flow in. The large volume of blood in the erectile tissue will exert sufficient pressure against the veins to prevent blood from flowing back. The pressure in the erectile tissue will rise approximately tenfold, producing an erection. A side effect of this method is that the erection may last a long time (several hours), and may be painful if the foreskin is too tight, because the blood flow cannot be controlled. Additionally, 5–10% of men develop excessive connective tissue within the erectile tissue, which in extreme cases can damage the erectile structures.



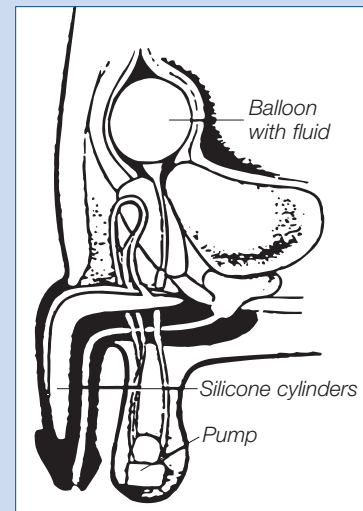
Needles used for intracavernosal injection are the same type used by people with diabetes to inject insulin. The first injection must be administered by a physician, and thorough training is required before the man can self inject. The prostaglandin is first dissolved in a solvent and then drawn up into the syringe. The injection site must be cleaned thoroughly (alternating between the right and left sides of the penis is recommended). The penis is stretched out along the thigh, and the injection administered in a single, steady action. Once the drug is injected, the needle is withdrawn and pressure must be applied to the injection site for about 30 seconds to prevent bleeding. Some men experience a burning sensation during injection, which is harmless. This technique can be used no more than once per day, and no more than three times per week<sup>(46; 13, part 4, p. 18)</sup>.

- Prostaglandin preparations are also available as a small pellet that is inserted into the urethra with a special applicator. This achieves the same effect as intracavernous injection, but requires more manual dexterity. Erection is achieved in 5–10 minutes. Side effects in the form of a slight itching and stinging can be experienced by a female partner.
- Nitroglycerine patches, which are usually placed on the chest of people with angina to dilate the blood vessels of the heart, can be applied to the penis to increase blood flow and produce an erection. The patches are available on prescription only.

- If the nerve pathways are intact, the drug Viagra may be a solution. Viagra acts by relaxing the blood vessels, facilitating the blood flow to the penis in response to sexual stimulation. A pill takes effect within 30–60 minutes. Viagra is available only on prescription<sup>(47)</sup>.

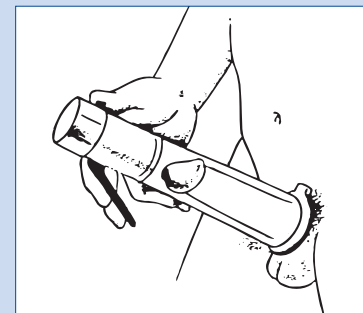
- If the nerve pathways between the lower part of the spinal cord and the genitals are intact, it may be possible to achieve a reflex reaction by stimulating the penis and scrotum directly – with a vibrator if necessary.

- Erectile dysfunction can also be improved by surgically implanting two silicone cylinders into the penis. The cylinders are connected to a small balloon containing fluid in the abdominal cavity, and to a pump in the scrotum. Using the scrotal pump, fluid from the balloon is pumped into the silicone cylinders, which function like erectile tissue. This procedure allows the man to decide how rigid the penis should be<sup>(13, part 4, p. 18)</sup>.



- A flexible plastic rod can also be implanted into the erectile tissue. This method results in more permanent length and rigidity than the method described above<sup>(13, part 4, p. 19)</sup>.

- More simple aids include constriction rings (bands) and vacuum pumps. The constriction ring is a latex band that is placed around the base of the penis. The ring has to be tight enough to constrict the veins through which blood would flow along the erectile tissue. The blood that flows into the penis cannot flow back, causing the penis to enlarge and become erect. A constriction ring can be used for up to 30 minutes without causing any harm. If the effect of the ring alone is not enough, the effect can be enhanced using a vacuum pump that draws blood into the penis. When the penis is erect the pump is removed, and the ring is placed around the base to prevent the blood from flowing back. The use of a constriction ring and vacuum pump only cause erection of the penis in front of the ring (i.e. in the penile shaft), not in the erectile tissue that extends deeper into the body. During a normal erection, the erectile tissue becomes rigid along its entire length<sup>(13, part 4, p. 19)</sup>.



An ileostomy does not always result in erectile dysfunction, and in cases where the nerves are only slightly damaged, the damage can often be rectified within a year.

In some cases the erectile dysfunction is psychological (performance anxiety), caused by an emotional reaction to the changes to the body caused by the ileostomy<sup>(13, part 5, p. 4)</sup>.

Men who want to have children in the future may wish to consider banking their sperm before having stoma surgery.

### 8.13.5 Female sexuality

Sexual activity can be resumed as soon as the woman feels well enough after surgery, but in some cases surgery has a major impact on sexuality.

Nerve pathways that regulate the lubrication of the vagina and the flow of blood to the clitoris are located close to the rectum. If the rectum is removed during ileostomy surgery there is a risk of damaging these nerve pathways leading to insufficient lubrication and reduced clitoral sensitivity. This can be solved by moistening the vagina with a lubricant or saliva, and by learning to stimulate other sensitive areas to produce an orgasm<sup>(13)</sup>.

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When the rectum is removed, a vacuum is created that may cause the uterus to move backwards. Sometimes it may be necessary to remove some of the vagina along with the rectum resulting in a narrowing of the vagina. The resulting change in shape, flexibility and positioning of the vagina can cause pain during intercourse. A study has shown that the proportion of women experiencing pain during intercourse rose from 15–38% after the rectum had been removed. Different sexual positions or an expansion of the vagina by a gynaecologist may be the solution to such problems<sup>(13)</sup>.

### **8.14 Pregnancy**

Women with an ileostomy who have also had their rectum removed often find that the vagina and uterus are positioned differently after surgery. This may reduce the chance of becoming pregnant. There may also be some tissue growth or blockage of the ovarian canals, particularly in women with ulcerative colitis. However there is a good chance of becoming pregnant using in vitro fertilisation, and the risk of miscarriage is no greater than it is for women without an ostomy<sup>(48; 26, p. 84; 13, sec. 2)</sup>.



Having an ileostomy does not prevent a woman from carrying a pregnancy to term or having a normal delivery. In fact, experience indicates that it may be easier for women with an ileostomy to give birth<sup>(21, p. 6)</sup>. In addition to regular obstetric examinations, women who have an ileostomy should also see a physician with enterostomal expertise<sup>(13, part 5, p. 4)</sup>. As the belly grows, the stoma will typically grow and change shape and the bag may be increasingly difficult to change because it will be located on the underside of the belly. Many women in the later stages of pregnancy use a mirror when changing the bag. Approximately 10% of pregnant women experience prolapse of the stoma in the third trimester, but few require surgical intervention. When the abdominal wall is stretched the hole through which the stoma protrudes may be widened. Because of the increased pressure caused by the child's growth, 3% of women develop an ostomy hernia during pregnancy. There is a 50% chance of the hernia disappearing after the child is born. If not, surgery must be performed after delivery. Delivery usually proceeds normally<sup>(48; 2, p. 6)</sup>.

If colon cancer is suspected to have spread to the urethra, cervix, ovaries or vagina, these may also be removed. This means that these women will be unable to conceive normally. It is possible to remove the eggs prior to surgery for subsequent use in artificial insemination and a surrogate. However, this happens very rarely<sup>(13, part 5, p. 4)</sup>.

### **8.15 Homosexuals with a stoma**

Many homosexuals are concerned about prejudice that others may have against them. As a result, many do not inform stoma care nurses about their sexual orientation. This limits the nurse's ability to provide the patient with advice about intimacy and sexuality. The stoma care nurse's knowledge of and attitude towards homosexuality will affect the advice offered to the individual patient. An organisation has existed since 1982 in the US, whose goal is to identify unique lifestyle situations for this group of stoma patients and to help stoma care nurses to be able to offer better care and guidance<sup>(49)</sup>.

### **8.16 Children and adolescents with an ileostomy**

In the first two years of life, children are often preoccupied with exploring their own bodies and are very receptive. Therefore, parents of a young child with a stoma must not react negatively to the stoma but instead must be positive and accepting. This will help the child accept the stoma and adjust. The ostomy bag can be an interesting discovery for a child 0–2 years old because of the shape and sound. It may be a good idea to use a 1-piece bag for children of this age and to dress the child in a romper suit to prevent access to the bag.

Children aged 2–6 typically try to be more independent and autonomous. They tend to become interested in their genitals and may begin to masturbate. Having a stoma at this age may be perceived as a punishment. The child may experience feelings of shame and have castration anxieties related to the surgery. Stoma dolls can help children express their emotions, and again it is crucial that parents accept the situation and do not become overly protective of the child. Overprotection can lead to passive behaviour and an inability to develop self-confidence.



Children with a stoma do not have to attend a special school or avoid participating in sports activities. However, the school and the child's teachers should be informed. Depending on the child's age, practical help during the day might be necessary and parents should keep in touch with the school nurse.

Children who are able to change the appliances or empty their bags themselves need access to private facilities at school as well as a place to store spare appliances and a set of clean clothes in case of leakage. Some children prefer to change clothes in private when taking physical education classes.

Teenagers may have more difficulty accepting the stoma and how it affects their body appearance than younger children. They have been used to controlling their own personal hygiene and will suddenly be faced with an unfamiliar situation that they may not be able to handle. Patient associations can often put teenagers in contact with other young people in the same situation<sup>(50; 43 sec. 12)</sup>.

### **8.17 Religious aspects**

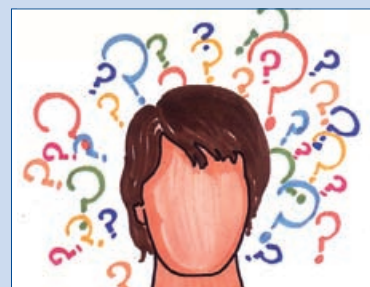
For some very religious people having a stoma is visible evidence that the person has 'sinned' earlier in life and is now being punished. This will naturally influence how that person copes psychologically and socially following ileostomy surgery.

Jews often observe the Sabbath (day of rest) from sunset on Friday until sunset on Saturday. According to Jewish law sick people do not have to follow the rules of the Sabbath, however orthodox Jews often try to avoid touching the stoma while observing the Sabbath. This may occasionally cause problems.

Muslims pray five times a day. It is very important to observe strict personal hygiene during prayer, and therefore a ritual cleansing process is required before prayer. This means that ileostomy patients must change the bag prior to each prayer. A 2-piece system is most convenient, otherwise the skin may be damaged by frequent removal of the adhesive. Praying is done while kneeling with the forehead touching the floor. This position puts a great deal of strain on the adhesive and may cause leakage. The use of a belt may help prevent leakage. It is also important for the stoma to be sited being least obstructive during prayer – see section on siting of the stoma, page 13<sup>(13, part 4, p. 14)</sup>. Orthodox Muslims consider the right hand to be the 'clean hand', and this hand is not used for cleaning after going to the bathroom. These people may have difficulty changing the ostomy bag.

### **8.18 Support groups**

A good deal of information about having an ileostomy is available, but inevitably there are unanswered practical, psychological and social questions. Because relatively few people have had an ileostomy and knowledge of stomas in general is limited in the general public, it is not always easy to get questions answered. In addition, having a stoma is a very private and intimate matter that many people choose not to



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discuss openly. Thus it is important for people with a stoma to have support from both professionals and from others in the same situation.

The following is a list of support organisations in selected countries.

***List of patient associations:***

Denmark	<a href="http://www.COPA.dk">www.COPA.dk</a>
Sweden	<a href="http://www.ilco.nu">www.ilco.nu</a>
Norway	<a href="http://www.kreft.no">www.kreft.no</a> (patient association, NORILCO)
Italy	<a href="http://www.mastectomia.it/stomia/associazioni.htm">www.mastectomia.it/stomia/associazioni.htm</a>
Spain	<a href="http://www.estomaterapia.com">www.estomaterapia.com</a>
France	<a href="http://www.fsf.asso.fr">www.fsf.asso.fr</a>
Germany	<a href="http://www.ilco.de">www.ilco.de</a>
Holland	<a href="http://www.stomavereniging.nl">www.stomavereniging.nl</a>
UK	<a href="http://www.bcass.org.uk">www.bcass.org.uk</a>
USA	<a href="http://www.uoa.org">www.uoa.org</a>
Japan	<a href="http://www.joa-net.org">www.joa-net.org</a>



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