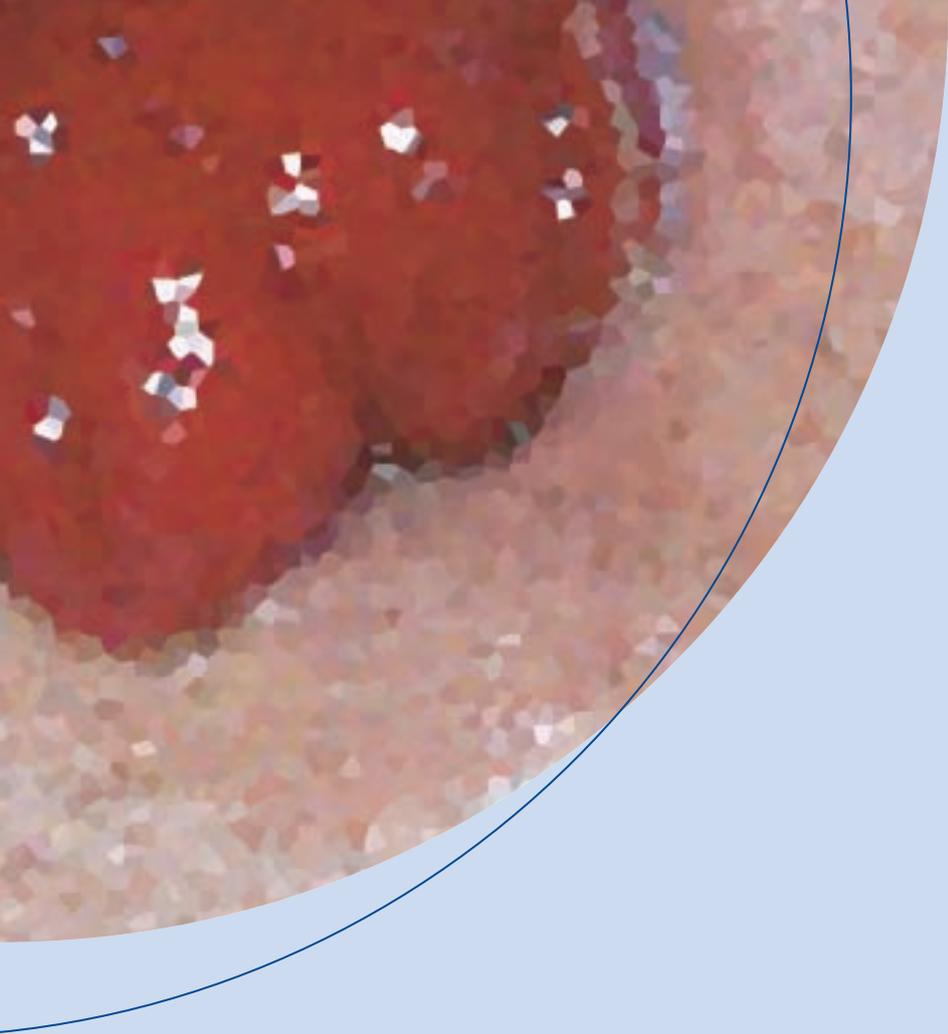




Urostomy

Background and Consequences



Foreword

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

Urostomy 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 the physiological and surgical procedures, the booklet discusses the practical, psychological and social issues that are important for people living with a urostomy.

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

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

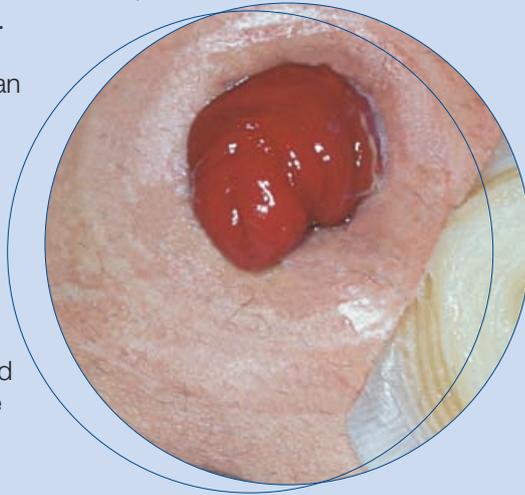
With many thanks to Berit Kisbye, an Enterostomal Therapist at Skejby Hospital, Denmark, and everyone who shared their knowledge and comments during the production of the DialogueEducation materials.

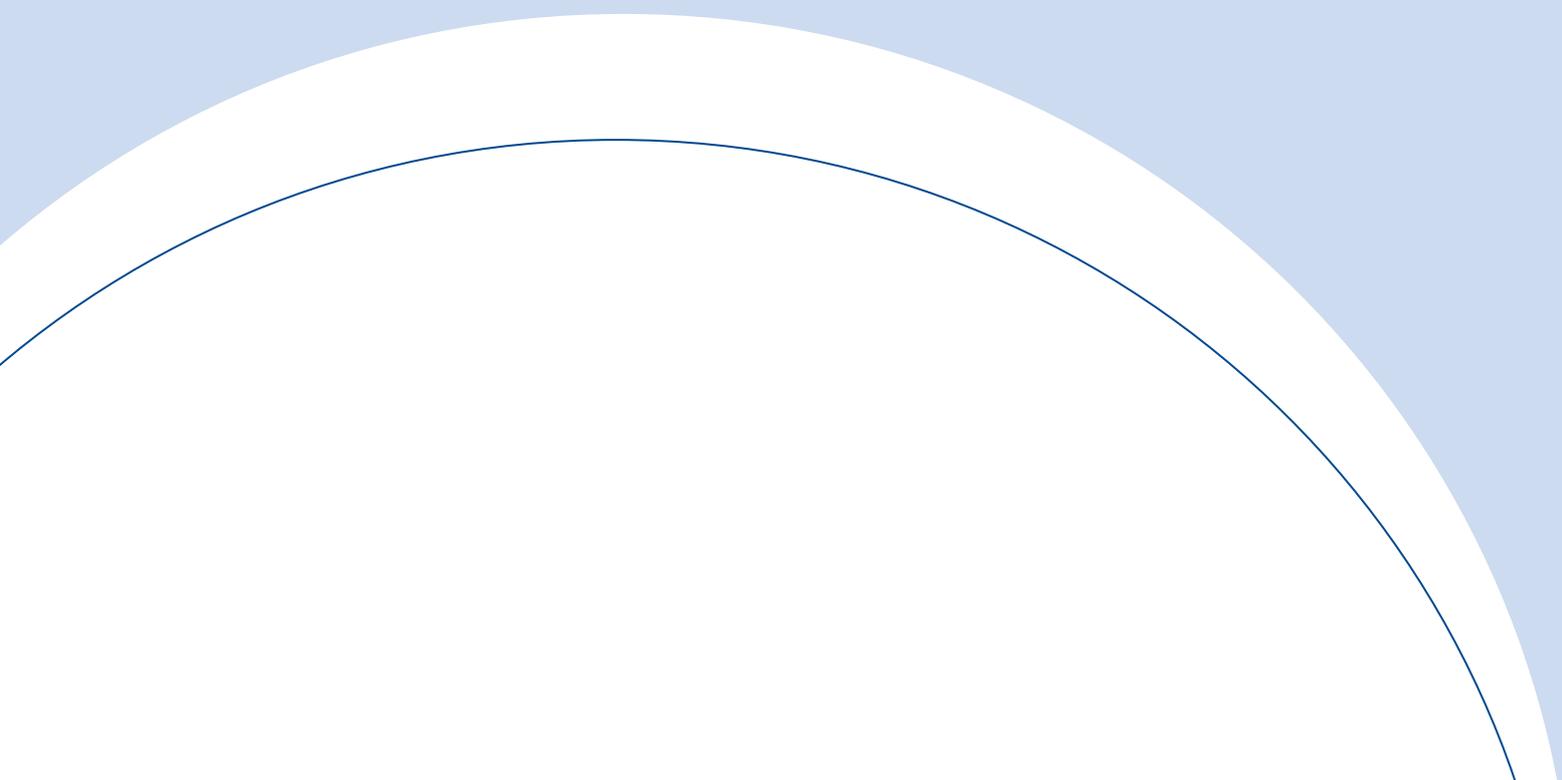
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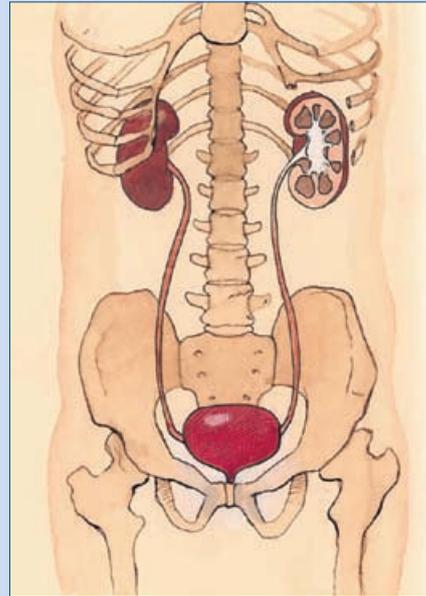


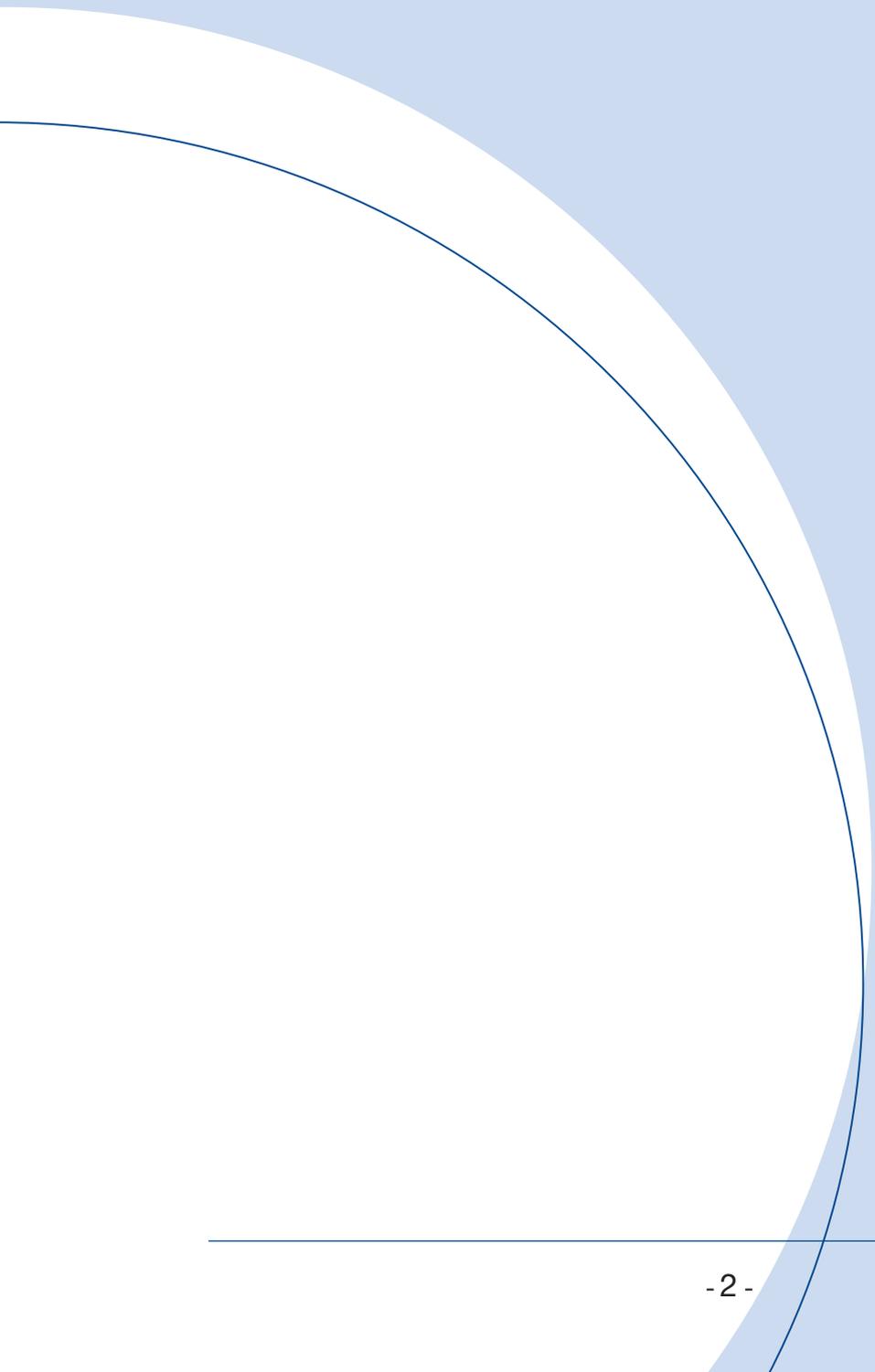
1. Excretion of urine

The kidneys are located just within the bottom of the ribcage on either side of the spine. The main function of the kidneys is to excrete waste products produced by the biochemical processes that occur in the body. The kidneys are continually flushed with blood, which they filter to remove salts and other chemical substances for excretion. These salts and chemicals, along with water, are excreted from the body as urine.

The urine passes from the kidneys through ducts called ureters to the bladder where it collects. Urine is produced mainly during waking hours and once the bladder contains 200–250 ml, most people will have the urge to empty it, although most can wait without any problems. However, when the bladder contains 500 ml, the urge to urinate becomes urgent.

The base of the bladder has an opening that is normally closed by a circular muscle (sphincter). When this 'valve' is opened, the urine passes out through the urethra^(1, Ch.14).





2. Reasons for forming a urostomy

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The normal route by which urine is transported away from the kidneys can be destroyed by disease or by other dysfunctions in the body, and in such cases it may be necessary to find a way of bypassing the normal urinary organs.

2.1 Cancer

Cancer of the bladder is the most common reason for removal of the bladder. Bladder cancer is typically seen in people over the age of 50, and is 2–3 times more frequent in men than in women. With the increase in average life expectancy, the incidence of bladder cancer has also increased. Each year, around 17 in 100,000 people worldwide develop the disease.

In Europe and the USA, smoking is one of the main causes of bladder cancer. Smoking doubles the risk of developing bladder cancer because chemical agents in tobacco smoke are concentrated in the urine, affecting the mucous membrane of the bladder. In 47% of men and 37% of women (this figure is rising for women) who die of bladder cancer, smoking is the cause^(4, p.17).



Certain industrial chemical agents are also suspected of causing bladder cancer. Studies indicate that people who live in industrial areas or who work closely with dyes, leather, rubber and textiles (e.g. those who work in the printing industry), are at higher risk^(4, p.17).

In West Asia and North Africa a specific type of larva that lives in contaminated fresh water penetrates the skin to produce bilharzia (schistosomiasis) and can be caught when bathing in infected water. Bilharzia can be an indirect cause of bladder cancer^(8, p.37). Bladder cancer cannot be cured by radiation treatment, and must always be treated surgically.

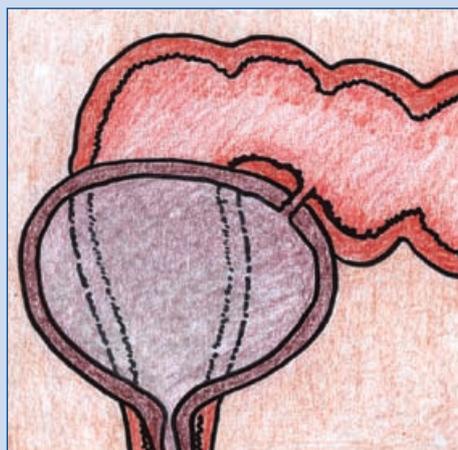
The first sign of bladder cancer is usually blood in the urine. Although blood in the urine can also be a symptom of a bladder infection, it is rare in men and requires immediate medical attention. Bladder cancer may also produce symptoms such as frequent urination, stinging when passing water and continence problems. In advanced disease fatigue, weight loss, pain and swollen legs are common^(3, p.3).

While surgical procedures for bladder cancer are improving all the time, some patients are referred for radiation treatment. In mild cases, it may be possible to remove just the tumour, while in more severe cases (approx. 25%), the entire bladder may have to be removed^(13, p.5; 17, p.1694).

In some cases, ovarian, cervical or rectal cancer may result in removal of the bladder^(8, p.13).

2.2 Radiation injury

Primary surgical treatment for cancer of the bladder, is often supplemented by radiation therapy. A side effect of radiation therapy is the formation of unwanted connections (fistulae) between the bladder and bowel or the bladder and vagina due to tissue break down. These connections allow urine to seep out into the bowel or vagina, providing direct access for bacteria into the bladder and causing infection and great discomfort to the patient.



Radiation therapy can also cause what is known as a contracted bladder. In severe cases the person has an incessant urge to urinate, leaving them in constant discomfort.

In such instances, the decision will often be made to relieve the condition by diverting urine away from the bladder by creating a stoma. However, as radiation techniques are continuing to improve, surrounding organs are less likely to suffer injury. In the case of a contracted bladder, the bladder is rarely removed because there is no disease^(19, part 1, p.14).

2.3 Congenital birth defects

When the foetus is approximately 25 days old, nerve pathways that ultimately develop into the brain and spine are created. If the nerve pathways are malformed (Spina Bifida), the child will typically have a bladder dysfunction, making it difficult to fully empty the bladder. In some cases urine may flow back to the kidneys. Some of these children will be given a urostomy – usually of the Mitrofanoff type – in order to avoid kidney damage and urinary incontinence^(8, pp.45-46).

One in 30,000 to 50,000 children (twice as many boys as girls)^(8, p.44) are born with a malformed bladder, which lies exposed on the outside of the abdomen (bladder exstrophy). The bladder is very small, the urethra is not entirely closed, and sphincter function is absent. Urine drips constantly from the bladder and may also return to the kidneys. A surgical procedure can be performed to move the bladder to the pelvic region, but the bladder will rarely be leakproof. These children will often need a urostomy^(19, part 1, p.14).

2.4 Urinary incontinence

The causes of urinary incontinence (inability to control the bladder) are numerous:

- Senile dementia may mean that the person is unaware of the need to urinate, and the bladder therefore 'overflows'
- Recurrent urinary tract infections may irritate the mucous membranes of the bladder to the extent that the bladder empties itself

- Chronic urinary tract infection, a slack pelvic floor, prolonged catheterisation, and catheterisation during surgery may cause tissue damage resulting in incontinence
- Oestrogen deficiency during menopause may cause the mucous membrane of the urethra to shrink, inhibiting bladder function
- Long-term catheterisation in men and gynaecological radiation therapy may weaken the sphincter and muscles of the pelvic floor causing the bladder to leak
- Spinal disease may mean that the patient is unable to retain urine in the bladder resulting in incontinence.

Attempts will always be made to treat incontinence with pelvic floor exercises, medication or other therapy, ensuring that the affected individual becomes aware of the urge to urinate and that the bladder is emptied effectively. In rare cases, it may be necessary to perform a urostomy if these remedies do not work^(9, p.65).

2.5 Neurogenic disorders

The bladder is usually emptied every 3–4 hours. Precisely when the bladder needs to be emptied is controlled by a complex set of nerves. Conditions such as multiple sclerosis, however, affect the nerves in such a way that control of urination is lost. If medication and / or catheterisation do not adequately solve the problem, it may be necessary to form a urostomy. Typically, this will be of the Mitrofanoff type (p. 11)^(6; 19. part 1, p.14).

2.6 Spinal cord injuries

An injury to the spinal cord caused by a road accident or similar trauma will often paralyse the bladder's voiding reflex for days or even years. Urine will accumulate in the bladder and flow back to the kidneys. Consequently, until the 1970s, kidney failure and urinary tract complications were among the primary causes of death in people with spinal cord injuries. It is therefore vital that people with such injuries have their bladder drained with the aid of a catheter^(5, pp.5168-5170).



However, many people with spinal cord injuries are wheelchair-bound, and have to be moved to and from their wheelchair, bed and toilet every time their bladder needs to be drained by catheter. This is a source of great discomfort for the 40-70% of people with spinal cord injuries^(7, p.20), who already suffer from chronic pain due to the injury itself, or because their hands and shoulders are strained from using a wheelchair. In such cases, the decision may be made (albeit rarely) to relieve the patient by creating a urostomy of the Mitrofanoff type (p.11)^(7, pp.10-11; 5, pp.5168-5170).

2.7 Trauma

When the body sustains very severe injuries such as a car accident or a fall from a great height, there have been instances of bladders bursting if they were distended. If the bladder cannot be repaired surgically, it may be necessary to perform a urostomy.

2.8 After-effects of torture

It is not uncommon for people who have been subjected to torture by electrocution to suffer from a paralysed bladder. These people may become incontinent, and may require a urostomy.

3. History

Over time, humans have been increasingly exposed to factors that can cause cancer, including bladder cancer. At the same time, the survival rate in patients with urinary tract complications due to other diseases (or a congenital birth defect) has increased. As a result, the need for an artificial means of eliminating urine from the body (urinary diversion) has also increased.

As early as in 1851, Simon undertook the first attempts to divert urine via the bowels. In 1887 Harrison tried a technique whereby urine was diverted out to the skin, such as we know it today. Then in 1889 Pawlik tested a method that connected the ureters to the vagina^(14, p.4; 33, p.5).

However, the first established surgical procedure for urinary diversion was not performed until 1911, by Coffey^(30, p.10). This involved stitching the ureters (the ducts that transport urine from the kidneys) to the terminal rectum. Urine was then voided from the body along with faeces. Depending on the strength of the patient's anal sphincter control, the patient could retain urine to some extent. The benefit of this procedure was that it was relatively uncomplicated, and provided a discreet solution for the patient. This technique was used for decades, but had a number of drawbacks (p.14).



In 1950 Mitrofanoff invented a method for diverting urine away from the bowel and out to the skin surface, where the urine was collected in a rubber bag (p.11). The rubber bag was large and cumbersome and had to be attached to the skin using adhesive and a belt. As the bag was intended for long-term use, it had to be cleaned regularly with soap and water, and many people developed allergies to the rubber used to make the bag^(14, pp.4-5). However, this type of stoma bag (as opposed to the modern bag) is still used by a small number of people.

In 1952, Brian Brooke, a British surgeon, invented a new procedure for suturing the bowel to the skin, and in 1954, the American surgeon Eugene Bricker constructed the first urostomy in which a section of the small bowel was used for bladder reconstruction and then stitched to the skin (p.11). The principle behind the Bricker bladder had actually been conceived by Seiffert, a German surgeon, as early as in 1935, but at that time no collection system had been invented to make the procedure viable^(33, p.6). However, by the 1950s this situation had changed and the surgical procedure became a great success.

The next great advance in urostomy surgery was made in 1972 when Nils G. Kock, a Swedish surgeon, constructed the first continent urostomy that was drained with a catheter (p.10).

Many other surgeons have developed variants of the procedures for urinary diversion described above (p.11-14).

Despite many years of efforts to develop surgical procedures for diverting urine away from the bladder, there was no real move to address the care of people with a stoma until 1934. Until then, specially designed collection systems were non-existent, and people were left to find their own way of staying dry and odour-free. In 1944 the Koenig-Rutzen rubber bag (previous page) was launched, heralding a new era in care for people with a stoma^(33, p.7).



Elise Sørensen

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. Although he was not initially interested his wife was a trained nurse and managed to persuade him to start manufacturing colostomy bags in 1957^(14, pp.4-5).

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As described above, certain types of surgical procedures for urinary diversion make exclusive use of the patient's existing anatomy, and do not require the creation of a stoma. However, this document deals primarily with procedures that lead to the formation of a stoma. Approximately 12% of all people with a stoma have a urostomy (62% have a colostomy and 26% have an ileostomy)⁽³⁵⁾. Urostomies fall into two categories – continent and non-continent stomas, both of which have advantages and disadvantages.

Choice of surgical procedure

As a rule, procedures that preserve the bladder are preferred, since other types of procedures often lead to kidney disorders after 20–30 years. The type of urinary diversion undertaken in each case, however, depends on many contributing factors:

- Nature of the disorder
- How far the cancer had spread at diagnosis
- Age
- General state of health (heart and lung disease, etc.)
- Person's wishes
- Person's circumstances (social, occupational, etc.)
- Person's ability to deal with his/her own situation

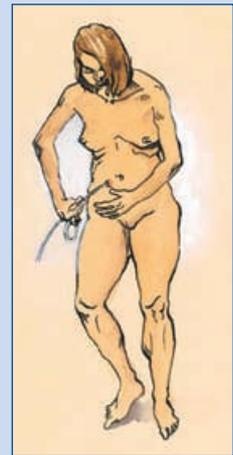
The various types of procedure will, to a greater or lesser extent, entail changes in the patient's way of life. The sections below describe the different types of procedure^(11, p.46; 13, p.9; 15; 23, part 1, pp.16-17).

4.1 Continent stomas

It is possible to surgically reconstruct the bladder by creating what is known as a 'reservoir' or an 'internal pouch'. The reservoir is made either by using the bladder itself or sections of bowel for reconstruction. It will need to be drained regularly using a catheter.

There are three main surgical procedures for the construction of continent urinary diversions. Kock's reservoir was the first to be introduced, followed by the Indiana pouch and finally by the Mitrofanoff reservoir. The last two procedures are less complicated than a Kock's reservoir and generally present fewer problems with catheterisation and leakage.

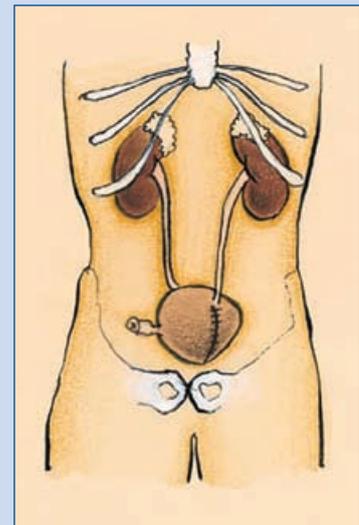
In rare cases the reservoir itself may leak. This results in urine seeping into the abdominal cavity, causes acute pain and requires corrective surgery. Similarly, if the valve between the reservoir and the stoma itself leaks, the patient will need a further procedure^(13, p.10).



4.1.1 Kock's reservoir

This surgical procedure results in a very discreet stoma. The stoma does not protrude and resembles a navel. When not being drained, the stoma is covered by a small piece of adhesive tape, and the patient does not have to wear a bag. For practical reasons, most right-handed patients prefer to have the stoma positioned on the right side of the abdomen. In spite of its obvious advantages, this procedure is used less and less because the metal clips used in the operation can slip, or give rise to stones (mineral concretion).

A Kock's reservoir is constructed from a 70–80 cm section of the small bowel (large bowel can also be used). The middle 44 cm or so is cut lengthwise and stitched together crosswise to produce the reservoir itself. The remaining ends of the section of bowel on either side of the reservoir are then folded and clipped together to create a valve at both ends. One of the valves is connected to the ureters to allow the urine to flow from the kidneys down into the reservoir – but not in the opposite direction. The other valve is sutured to the skin and prevents urine from flowing out of the reservoir so that it can only be emptied by catheterisation^(19, part 1, p.16).



This procedure is relatively complicated and may lead to a number of complications. After surgery most people will require a relatively long recovery period, yet they must be both physically and mentally capable of draining the reservoir round the clock even if they are tired. This procedure is therefore most commonly offered to young and middle-aged people⁽¹⁵⁾.

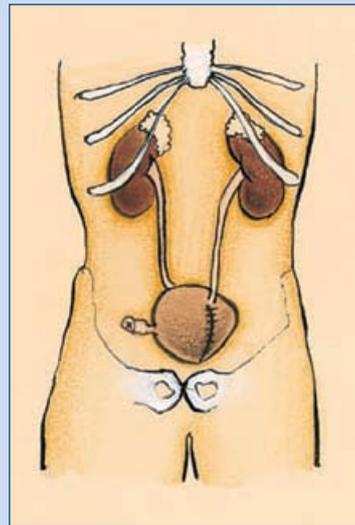
Constructing a Kock's reservoir is a relatively major procedure, and it takes quite a long time to start functioning properly. The person is usually hospitalised for 3–4 weeks after surgery, for the first 4 weeks or so, a permanent catheter is installed in the reservoir^(19, part 1, p.17).

Immediately after the operation, the reservoir can hold no more than a few millilitres of urine, and has to be gradually stretched to increase its capacity. This is started approximately 14 days after surgery by shutting off the permanent catheter with a clip to allow the urine distend the reservoir slightly. After an hour the reservoir is emptied and the catheter shut off again. This procedure is repeated for a week, after which the interval between emptying is extended to 2 hours. After a further week the catheter is removed and the reservoir is drained using a disposable catheter every 3 hours. During the night, however, the patient need only drain the reservoir once, as output is less during the night. The interval between emptying is increased very gradually, so that after 6 months the reservoir will only need to be drained five times a day⁽¹⁵⁾.

The reservoir can be emptied with the patient lying down, sitting or standing, but it is very important that it is drained fully every time in order to avoid infections (see Urinary tract infections, page 26). Initially the area around the stoma will be quite tender and sensitive, but after around 6 weeks, drainage can be achieved with light manual pressure against the reservoir.

4.1.2 Indiana pouch

This procedure involves using the section of the bowel where the ileum (end of the small intestine) turns into the colon (large intestine) as this section features a valve that normally prevents faeces moving from the colon back to the ileum. The colonic section is dissected and stitched together to form a reservoir, while the ileal section is diverted to the navel or the right-hand side of the abdomen. The valve is used to prevent urine from flowing out of the pouch. The pouch is usually leak-proof and is drained using a catheter as in a Kock's reservoir. Clips are not used in this procedure, and it is therefore being used more often in cases where a Kock's reservoir might previously have been performed.



The emptying frequency and volume of mucous shreds (see page 26) are equivalent to those in a Kock's reservoir. Patients are hospitalised for around 2 weeks after the operation and discharged with a catheter. Around 1–2 weeks later, patients are readmitted for training in emptying using a catheter (self-catheterisation). However, catheterisation and leakage from the stoma may present problems^(19, part 1, p.17).

4.1.3 Mitrofanoff reservoir

This surgical procedure was invented by Paul Mitrofanoff in 1950 and is performed in people with a deformed or missing urethra, vagina or penis (usually children). The procedure is also performed in people with some types of paralysis (e.g. following trauma or as a consequence of disease), and for women who find standard catheterisation difficult because of obesity or immobility.^(5, p.5170; 19, part 1, p.14; 15)

The procedure consists of stitching one end of the appendix to the bladder and stitching the other end to the navel or the skin of the abdomen. Since it leaves the bladder intact, this procedure has great advantages in that urine rarely returns to the kidneys. However, in practice, this procedure can only be performed on a relatively small number of patients, as it requires the bladder to be intact. The procedure is nonetheless performed in some cases by using a section of the large intestine in place of the bladder.

The bladder is emptied using a catheter every 4 hours or so, depending on urine output^(19, part 1, p.18).

4.2 Non-continent stoma types

With a non-continent type of urostomy (i.e. those that leak fluid continuously) the person has to attach a bag to the abdomen for collecting urine.

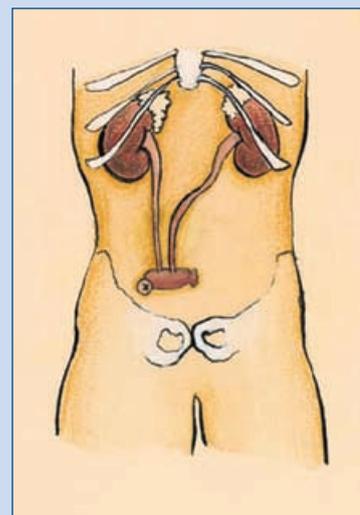
4.2.1 Bricker bladder

Despite the name, a Bricker bladder is not actually a bladder but a diversion.

This procedure involves using a section of the bowel as an outlet duct. The ureters are detached from the bladder and stitched to a 20–25 cm section taken from the small or large intestine. One end of the section is sewn up, while the other end is passed out to the abdominal skin, where the inside of the section is then folded back like a rollneck collar and sutured to the skin. The section of intestine is too small to act as a reservoir, and there is no muscle (see Coffey's Procedure on p.14) or valve (see Kock's reservoir on p.10) to retain urine. This means that urine will flow out as fast as it is produced in the kidneys. Because of this, the patient will need to wear a bag constantly to collect urine from the stoma. At night, the bag can be connected to a larger collection bag (night drainage bag) by a long tube to avoid the need to interrupt sleep to empty the bag (p.20). In the majority of cases, a Bricker bladder will start working immediately after the operation, the urine will flow through urostomic stents, passing through the ileal conduit to the outside surface of the abdomen protecting the anastomoses. In some cases a temporary nephrostomy catheter will be installed until the Bricker bladder is fully

functioning^(8, chapter 4.2.3). The ideal height of the stoma is 2 cm in order to make the bag easy to attach, so that urine does not seep under the adhesive, causing it to fall off. Anatomically, the ureters are positioned in such a way that there are fewer complications if the Bricker bladder is sited on the right-hand side, which is usually also the most convenient for right-handed patients^(11, p.45).

Construction of a Bricker bladder is not as complicated as constructing a Kock's reservoir, and post-operative procedures are also less of a strain on the individual. This type of procedure is usually performed on elderly people and people who are physically debilitated by cardiovascular disease, chronic conditions, or obesity, and on people who are not capable of, or in a situation not allowing regular emptying of the reservoir using a catheter^(11, p.46). The Bricker bladder procedure is the most common form of urostomy surgery in Europe and is considered the "Gold standard"^(8, p.21). Subsequent sections in this document refer primarily to people with a Bricker bladder.



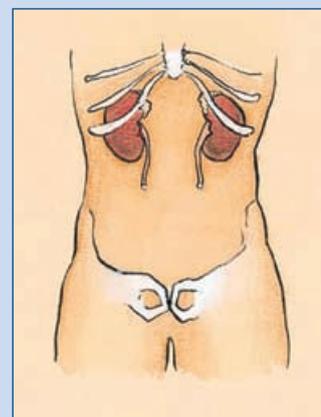
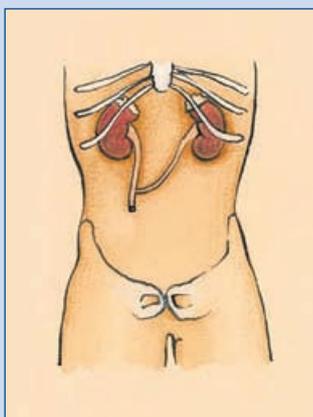
The structure of the Bricker bladder means that urine can return to the kidneys, which poses a risk of infection, and ultimately may damage kidney tissue.

4.2.2 Ureterocutaneostomy

This procedure is relatively rare and is most often used solely to provide relief for severely ill or dying patients^(15; 19, part 1, p.16).

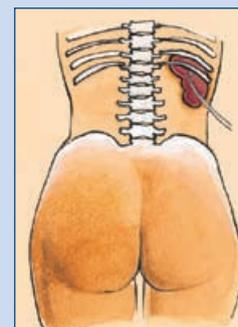
The procedure consists of leading the ureters from the kidneys to exit through the abdominal skin. In some cases, only one ureter will be diverted in this way. If both ureters are diverted, they may exit on each side of the abdomen or on the same side^(8, p.29).

It may be difficult to fit surgical appliances to a ureterocutaneous nephrostomy, and skin problems are relatively common. Accumulation of pus (purulence) in the renal pelvis, infections and formation of kidney stones are also common. In order to reach to the abdominal skin, the ureters will have to be stretched, so constriction may sometimes occur. In about 20% of cases the exit to the skin will also become constricted. During surgery, catheters are placed in the kidneys, and in some cases these will be left in permanently to avoid constriction.



4.2.3 Nephrostomy

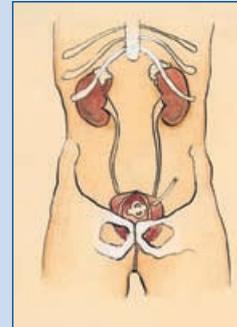
A nephrostomy is an opening in which a catheter is introduced directly into the kidneys from the back (as opposed to the abdomen) to allow urine to drain out. The surgery is relatively quick and easy to perform and is used primarily as a temporary procedure to empty the kidney when a stone has blocked the urinary tract and must be surgically removed. It may also be used as a temporary measure until a recently formed Bricker bladder begins to work properly, and can also be used palliatively in dying patients.



People who have had a nephrostomy are hospitalised fairly often because the catheter must be replaced at least every 3 months, and because nephrostomies are relatively vulnerable to complications. The most common are infections, the formation of kidney stones and problems due to incorrect positioning of the catheter^(8, p.23).

4.2.4 Cystostomy

The construction of a cystostomy involves stitching the bladder to the abdominal wall. A hole is then made through the skin so that the bladder can be drained using a catheter. This procedure is typically performed in children with a malformed bladder (e.g. bladder exstrophy) as a temporary solution until they are older. Children with a cystostomy have to wear incontinence pads until they are more fully developed and can have a bladder reconstruction and possibly a Mitrofanoff procedure.

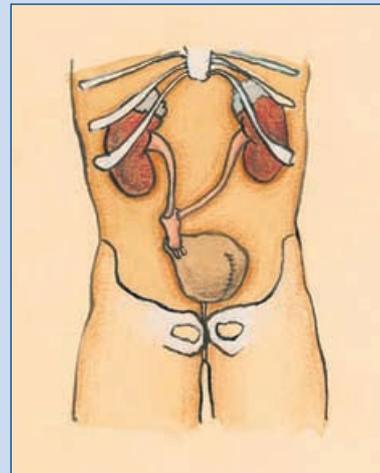


4.3 Surgical procedures that do not result in a stoma

There are several types of procedure for creating a urinary diversion in which the existing anatomy is used for the passage of urine and no stoma is created. For completeness, these surgical procedures are described in the following sections.

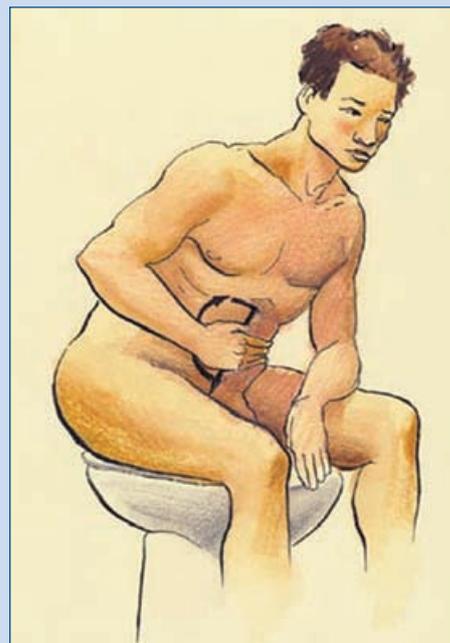
4.3.1 Permanent internal urinary diversion

A Permanent internal urinary diversion is one of several types of procedure, referred to as orthotopic bladder replacement. 'Orthotopic' means using one of the body's organs for a different function than usual. The procedure involves the construction of a replacement bladder from 60–70 cm of the small intestine. The replacement bladder is attached to the ureters in such a way that urine cannot flow back to the kidneys. The replacement bladder is also attached to the urethra so that urine may be passed in the normal way. The procedure is complex^(8, p.25), and is performed principally on men because the urethra in women is relatively short once the bladder has been removed. Patients with urological nerve damage, poor muscle tone in the bladder or in whom cancer has spread to the urethra are not suitable for this procedure⁽¹⁵⁾.



The reservoir is drained of urine every 3–4 hours or so by slight straining, however, some may need to learn to self-catheterise to drain the reservoir fully (approximately 30%)^(11, p.46). At the same time it is very important to exercise the pelvic floor regularly in order to avoid incontinence. Some use a uridom, vaginal diaphragm or incontinence pads because of inability to control urine flow⁽¹⁵⁾. Since the reservoir is created out of a section of the small bowel, it will continue its peristalsis (squeezing movements) and at night, when the person is relaxed, peristalsis will squeeze urine out while the person is sleeping. This is why 40–50%^(22, p.7) of those who have had the operation use a uridom or incontinence pad at night^(30, p.11). Alternatively, the person can choose to get up and empty the reservoir a couple of times during the night^(11, pp.45-46).

This procedure is regarded as highly promising because there is no stoma and because male erectile function is preserved in many cases (p. 37)⁽¹⁵⁾.



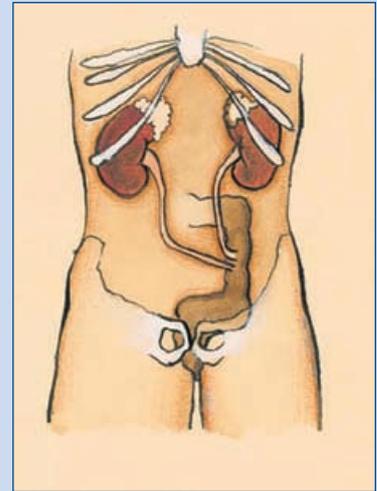
Another type of orthotopic bladder replacement is the Hautmann Neobladder. In this procedure, clips are not used in constructing the reservoir.

Some people with a urostomy, especially those who had their stoma formed some years ago, are now being offered orthotopic surgery, meaning that the urostomy is removed^(36, section 5).

4.3.2 Ureterocolostomy/Coffey's Procedure

This procedure consists of removing the bladder and stitching the ureters to the terminal section of the large intestine. The urine is then passed from the body together with the faeces. The resulting continence will then depend on the capacity of the anal sphincter to retain urine. However, incontinence is relatively common^(7, 11).

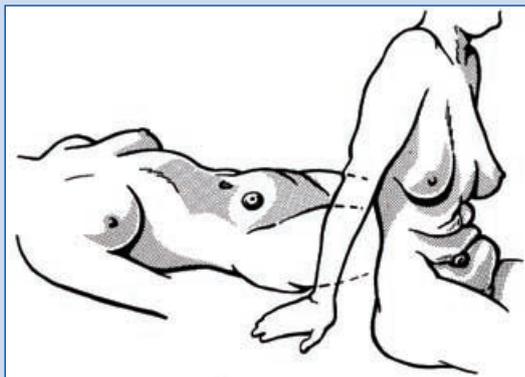
This procedure is rarely used, as bacteria from the large bowel can migrate to the kidneys causing infection. The diversion also increases the risk of developing cancer of the large intestine by 40–100%^(8, p.27).



5. Siting of the stoma

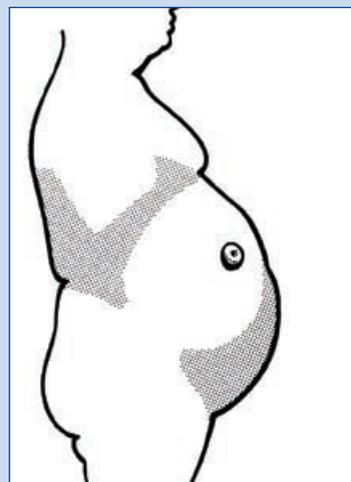
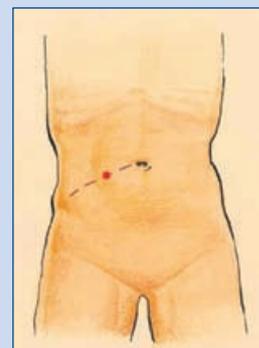
How people adjust to life with a stoma depends to a great extent on how easily they can manage the ostomy appliances and how easily they can avoid leakage. It is therefore very important that the stoma is sited in the most suitable place on the abdomen. The stoma should be adapted to the patient – and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

Before surgery, the site of the stoma has to be marked. It is important to be careful if the patient is very thin, as the shape of the abdomen may change when the intestines are evacuated before the 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 the clothes.



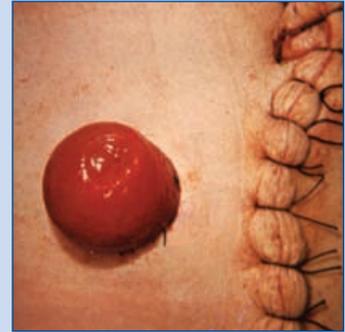
When determining the site for the stoma, the following must be taken into account:

- Physiological factors: The aim is for the stoma to be positioned so that it transects the muscle known as 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. 28)
- The patient's body contours: It is crucial that the adhesive can be sealed against 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 sufficiently large to ensure that the adhesive does not cover the navel. In women with large, heavy breasts, the stoma should not be sited so that the breasts will cover it. In obese patients, the stoma is often sited in 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). Consideration should be taken that 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 it may increase the risk of further 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 ileostomy, the urostomy must not be



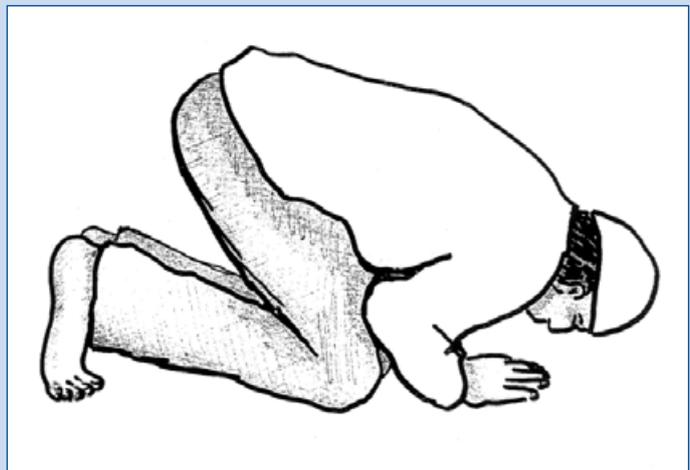
positioned along the same vertical line as the existing ostomy, as this will make it impossible to use a supporting belt for one or more of the ostomies without disturbing the others

- 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 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^(11, pp.36&39; 19, part 2, pp.7-11).

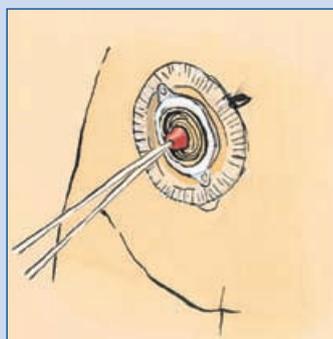


6. Use of urostomy appliances

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6.1 Postoperative use

For the first few days after the operation, the stoma must be kept under observation to ensure that it is functioning properly. During the first 10 days or so after urostomy surgery, it is important to relieve the section of bowel used to construct the stoma, so that it can heal properly^(19, part 3, p.3). Consequently, a catheter (stent) will be placed inside each kidney. The catheters will extend from the kidneys out through the stoma and down into the bag. About 4–5 days after the operation, the catheters will typically be cut off so that they protrude just 4–5 cm from the stoma. This will make it easier for the patient to start learning to change the bag and baseplate.



Bags used post-operatively need to meet some key requirements, they:

- Should be made of a transparent material so the stoma can easily be inspected
- Should be easy to connect and disconnect from the night drainage bag, which will be connected most of the time
- Should be able to hold both the catheters. A non-return valve is not always necessary since the bag is connected to the night drainage bag most of the time. The valve may even be bothersome because the catheters have to be led through the valve whenever it is changed⁽²⁰⁾.

6.2 1-piece and 2-piece systems

People with a continent stoma usually require only a small adhesive tape.

People with non-continent stomas, however, need to attach a bag that can be emptied as required. The bag is attached to the skin surrounding the stoma via a baseplate, 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 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

Manufacturers produce both 1-piece and 2-piece systems for people with a urostomy, and has a range of different adhesives with different couplings and dimensions. Urostomy bags also come in various sizes and with various drainage outlets. Approximately 90% of people with a urostomy use the maxi size. The most commonly used bags are transparent or opaque.

6.3 Changing the appliance

In many cases, skin problems occur around the stoma because the guidelines for adapting the adhesive to fit properly are not followed^(33, p.21). This exposes the skin to alkaline urine^(34, p.110). 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 urine has eroded the adhesive and has come into contact with the skin.

Changing the adhesive is easiest in the morning and before the user has had anything to drink, since urine production 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 the user last had something to drink, since urine output will be reduced. It is a good idea to cough a few times before changing the adhesive, because much of the urine inside the stoma will then empty into the bag.

There is always a risk that urine will suddenly flow out of the stoma and wet the surrounding skin. This means that the user only has a short space of time in which to change the adhesive, so it is important that the person has everything they need within easy reach before removing the adhesive.



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 always is 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, urine will be able to leak under the baseplate and come into contact with the skin. It is often a good idea to use a template for cutting the hole so that it fits exactly. Ostomy appliances are often supplied with a 'stoma guide' to measure the stoma, a cutting guide is printed on the release liner protecting the adhesive
- Bag (with outlet closed)
- Lukewarm tap water
- Gauze (or soft paper towel) for wiping off mucous shreds from the stoma (p.28) and cotton wool or soft gauze for cleansing the stoma
- 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
- Wipe off any mucous shreds from the stoma
- 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 it 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 urine 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. If urine starts dripping from the stoma, a bit of cotton-wool can be placed on the opening to absorb the urine. Gauze pads can also be wrapped around the stoma, or the stoma can be dabbed with cold water to make the opening contract and block off any urine. Another solution is to line a small medicine cup with gauze and then place it over the stoma while preparing to apply the new adhesive. Lying down can restrict the amount of urine from the stoma
- The stoma and the peristomal skin should be observed for any problems (see the following section on problems) – 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 can also be heated 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 urine 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
- Attach the pouch to the baseplate (2-piece system) and ensure that it is firmly attached



Problems and complications arising from use of urostomy appliances and accessories are described in Section 7.1, p.22.

6.4 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^(19, part 3, p.19).

A questionnaire survey of 369 persons with a urostomy in the Netherlands indicated that 80% of respondents considered it a problem to dispose of used bags when away from home⁽³²⁾.

6.5 Night time

Most people with a non-continent stoma produce so much urine that they have to empty the bag one or more times during the night. Since interrupted sleep is a serious inconvenience for most people, 80–90% use a large collecting bag at night (a night drainage bag). Night drainage bags are available both in disposable formats (without an outlet) and in reusable formats (with outlet). Night drainage bags without an outlet are emptied simply by cutting a corner of the bag. Night drainage bags for reuse require thorough rinsing every morning.



The night drainage bag is connected to the urostomy bag with the aid of a long tube and placed on the floor or hung from a special stand mounted to the bed. Some people place the night drainage bag in a washing-up bowl. If the urostomy bag is completely empty when the night drainage bag is connected, a partial vacuum can easily arise in the urostomy bag so it sticks to the skin around the stoma. The vacuum-effect is uncomfortable and prevents urine from flowing from the urostomy bag into the night drainage bag. If that happens, urine will flow back to the kidneys producing a throbbing pain. Any vacuum-effect in the bag can be avoided by allowing a small amount of urine to remain in the bag when the night drainage bag is connected^(11, p.42).

Restless sleepers may find that the tube between the bag and night drainage bag tends to become twisted, which may in turn twist the bag and block the flow of urine. Again, this means that the urine flows back to the kidneys, causes pain and increases the risk of infection.

Some people who have had a urostomy fit their beds with waterproof sheets as they have experienced leakage during the night.

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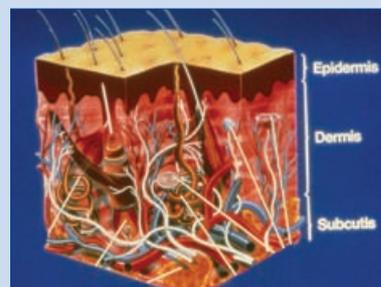
In order to guarantee that the urostomy appliance remains leak proof, it is vital to ensure that the skin underneath is smooth and healthy. However, both the stoma and the appliance itself can cause problems for the wearer.

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 form a film that protects the skin by keeping it moist, oily and slightly acidic. The slight acidity (pH 5–6) inhibits the 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 together with dead skin cells^(9, p.9).



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, cleaning under the adhesive and any leakage under the adhesive. 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 secretion diminishes^(9, p.8).

7.1.2 Maceration

Maceration is a process that erodes the skin. If the person perspires heavily or urine seeps 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.



When adhesive covers an area of peristomal skin, the adhesive must be able to handle moisture produced by the skin. The majority of modern urostomy adhesives contain hydrocolloids, which absorb moisture and urine and prevent maceration.

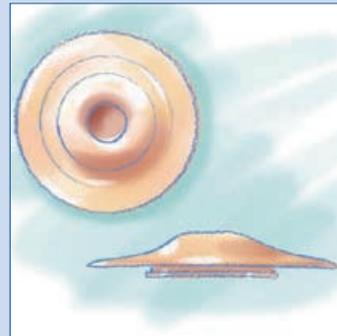
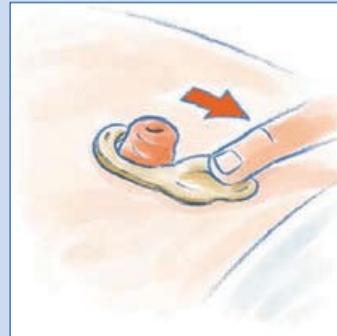
For those using an older type of adhesive without hydrocolloids, any maceration problem can be solved by switching to a hydrocolloid adhesive^(9, pp.10+17). Switching from an old occlusive adhesive to a hydrocolloid adhesive should be done with support from a professional as peristomal skin disorders are likely to occur for a period until the peristomal skin adapts to the changed situation.

A protective film can be used as a preventive measure, for example by people with very sensitive skin, during convalescence when the adhesive is changed frequently, and by people with a continent urostomy, where the adhesive tape over the stoma is changed every time they self-catheterise.

For further information about how to look after the skin please look at “Your guide to healthy skin” (Coloplast)

7.1.3 Leakage

There is always a risk that the adhesive will come unstuck and leakage will occur. But 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 seal properly. As a result, urine can easily seep under the baseplate, exposing the skin to urine. Depending on the constituents of the urine, the skin will be affected to a greater or lesser extent. Normal, fresh urine contains no harmful substances, while stale urine will be alkaline. Urine from a Bricker bladder or a urinary reservoir will also be alkaline because hydrogen ions are able to diffuse through the section of bowel used to construct the stoma. Alkaline urine will be more harmful to the skin's natural flora if the skin has become macerated^(9, p.61).



Urine 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^(9, p.73). Stoma paste is available in both a tube and as strips.

Stoma paste is available in both a tube and strips. 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^(9, p.73).

People with a continent urostomy tend to feel more secure about leakage than people with non-continent urostomies. However, leakage does occur in 2–3% of patients and the primary cause is inadequate drainage of the reservoir. For people with unreliable continent urostomies or those with a urostomy that that is difficult to keep leak free, a Bricker bladder appliance will often be used. A survey of 66 people with a Bricker bladder revealed that for 35% the worst aspect of having had a urostomy was leakage or simply the constant fear of it happening^(33, p.24).

7.1.4 Stripping

When an adhesive is removed, the outer layer of the skin is also removed. When the outer layer of the skin 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^(9, p.12). Many people with a stoma, especially those who use zinc oxide adhesives (occlusive), can develop a special 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 kind of 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 flange or skin protection^(9, pp.12+17). The picture shows the peristomal skin painted with gentian violet.



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 clean out of the follicles will leave an opening for bacteria to enter. These bacteria, usually staphylococcal strains, can cause folliculitis^(23, part 4, p.6). This condition 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 to trim them away, as shaving risks stripping the skin. If an electric shaver is used for removing the hair around a non-continent stoma, it is important to ensure that the shaver does not come into contact with urine. Whatever method is used, the stoma should be protected by a piece of gauze while the hair is removed⁽¹⁰⁾. If folliculitis is already present, it can be treated with gentian violet and a more gentle 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⁽⁹⁾. Contact dermatitis under the adhesive is usually due to leakage of urine 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^(9, p.45). 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 hypersensitivity to a specific molecule to which the skin is repeatedly exposed. Generally speaking, allergic reactions to adhesives are becoming more rare as the raw materials become better and better. 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^(9, p.7). 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^(9, p.13). 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^(9, p.14).



7.1.9 Warts

If the adhesive is not completely sealed against the skin, urine will be able to seep under the baseplate. Exposure of the skin around the stoma to urine 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. 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^(23, p.43).



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^(23, p.43).



7.1.11 Fungal infections

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 a urostomy, 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^(19, part 4, p.7). 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).



7.2 Problems involving the stoma

7.2.1 Mucous shreds

The part of the intestine used to construct the urinary diversion will have retained its blood supply and nerve endings and will therefore continue to produce the secretions that would normally lubricate the bowel. When mixed with urine, this mucous secretion produces thread-like structures commonly called mucous shreds. The production of mucous shreds is greatest during the first 2–3 weeks after the operation⁽²⁰⁾, and are initially brownish in colour. Later they become yellow and decrease in volume^(11, p.37) because the cells that produce the shreds reduce in number. However, the shreds never completely disappear. If there are many mucous shreds in the urine they can cause the sides of the bag to stick together, making it difficult for urine to drain into the bag⁽²⁰⁾, or they may block the outlet of the bag. Problems with excessive mucous shreds in the urine can be solved by increasing fluid intake⁽¹⁰⁾, ideally by drinking cranberry juice, which is thought to reduce the quantity of mucous shreds⁽²⁰⁾.

The shreds in a Kock's reservoir have to be rinsed out in order to avoid accumulations, infection and formation of stones. This is done by irrigating the stoma with water (approximately 50 ml) using a catheter. In the first months after the operation, the shreds will need to be flushed out daily, but after approximately 6 months, it is often enough to irrigate just a couple of times a week depending on the volume of shreds being produced. Those with a Kock's reservoir will have to continue flushing out shreds for the rest of their lives⁽¹⁵⁾.

7.2.2 Odour

Alkaline urine smells of ammonia ('fishy'), and any offensive odour of this kind, or the fear of odour from the ostomy bag, will be a familiar concern to the majority of people who have had a urostomy. Urostomy bags are made from materials that prevent any odour from escaping, but if the wearer neglects to wipe the outlet of the bag thoroughly after emptying or fails to change the bag daily, odour can easily be produced. The most common causes of odour are not drinking enough, a high volume of mucous shreds in the urine (typical in a continent stomas) or failure to change the bag often enough⁽²⁰⁾.

In addition, urine always contains bacteria, so it is impossible to avoid odour escaping while the pouch is actually being emptied^(11, p.42). However, an open window or an aerosol air-freshener will often be sufficient to deal with any odour problem. Generally speaking, odour will be less of a problem if the urine is less concentrated. It is therefore important to maintain a high fluid intake. Any odour from the night drainage bag can be counteracted by cleaning it with water and white vinegar^(2, pp.22-23).

7.2.3 Urinary tract infections

Urinary tract infections are commonly seen in people with a urostomy, as the bacteria have easier access to the urinary tract than normal^(11, p.42). In the case of a reservoir, the risk of infection is especially high because a catheter is inserted into the stoma several times a day. This can introduce bacteria into the bag if the stoma is not cleansed carefully^(29, p.2). Constriction, ineffective one-way valves, or stones can also cause urinary tract infections.

People with a urostomy are advised to maintain a daily fluid intake of 2–3 litres to thoroughly flush out the stoma and prevent bacteria from causing an infection. Ideally, urine output should be at 1–2 litres a day. It is also a good idea to change the bag daily, so that bacteria do not accumulate and migrate to the stoma⁽¹⁵⁾.

Urinary tract infections are commonly caused by *Escherichia coli* bacteria, which bind to the mucous membrane of the intestine so firmly that the bacteria are able to withstand the body's natural defences and multiply undisturbed. The binding properties of *E. Coli* bacteria are inhibited by fructose, which is found in all types of fruit juice and by substances found in blueberry and cranberry juice. Therefore, cranberry juice is likely help prevent urinary tract infections (p. 35)^(26; 27, pp.92&97).

Typical symptoms of urinary tract infection are fatigue, a rise in body temperature, pains in the kidney region and cloudy and offensive-smelling urine. A urine sample should be taken by washing the stoma thoroughly and inserting a sterile catheter into the base of the stoma.

This procedure prevents bacteria from the skin or from the urine in the ostomy bag from contaminating the sample^(11, p.42).

It is very important for any urinary tract infection to be treated immediately, as infections can be spread to the kidneys and ultimately lead to kidney infection and stones^(11, p.42).

Urinary tract infections must be treated with antibiotics.

A urinary tract infection makes the urine more 'aggressive', which means that the adhesive will erode faster than usual⁽²⁰⁾.

7.2.4 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. 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.23). 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^(19, part 4, p.12).



7.2.5 Ureteral stenosis

Ureteral stenosis is a narrowing of the ureters (the two ducts that transport urine from the kidneys to the bladder) that is most commonly seen in patients with a Bricker bladder. Due to certain anatomical factors, a Bricker bladder is sited, whenever possible, on the patient's right side. This means that the ureter from the left kidney has to be stretched quite a distance to reach the Bricker bladder. Stretching the ureter in this way narrows it and impairs urine flow. Narrowing thus causes poor drainage from the kidneys and leads to impaired kidney function. Treatment consists of introducing a catheter into the ureter from the kidney to the Bricker bladder in order to keep the ureter open. Alternatively, a catheter can be introduced directly from the skin into the kidney^(19, part 1, p.19).

7.2.6 Stones

Approximately 20%^(19, part 1, p.19) of people with a urostomy will at some stage or other experience the formation of stones (mineral concretions) in the urinary tract. While the cause of this has not been fully established, it is thought that the change in the urine's pH, increased calcium excretion and recurrent urinary tract infections by bacteria are likely causes^(34, p.112). People with a urostomy of the Kock type will have an increased tendency for stones because the clips used for creating the reservoir bind calcium and thereby enhance the risk of stones forming. Certain types of medication and vitamin C also tend to promote stones^(2, p.23).



Stones may be removed with least damage by first crushing them with forceps inserted into the stoma and then flushing out the debris. If this is not possible, surgery will be required^(13, p.10). The stones in the picture were taken from a urostomy of the reservoir type. (Photograph kindly loaned by Berit Kisbye, Enterastomal Therapist at Skejby Sygehus, Denmark.)

7.2.7 Bleeding

Since the exterior of a stoma (Bricker bladder) was formerly the interior of a section of the intestine (p.11–12), 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^(19, part 4, p.10). 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^(23, p.44).

7.2.8 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^(19, part 5, p.11). Some people experience pain from a sliding hernia, and it may be unsightly^(19, part 4, p.13). Moreover, the bulge makes it difficult for the adhesive to adhere 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^(23, p.46).



7.2.9 Stoma prolapse

In very rare cases, the section of bowel used to create the urostomy 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 bowel^(19, part 4, p.14).

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.

7.2.10 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
- 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. Constriction of a urostomy will only rarely block the passage of urine, but if an obstruction is indicated, surgery will be required^(19, part 4, p.13).

7.2.11 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 enable urine to flow out adjacent to the stoma, usually from the underside. 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^(19, part 4, p.15).

7.2.12 Metabolic acidosis

When a section of the intestine is used for a urinary diversion, that section will remove hydrogen ions from the urine. This leads to the risk of developing chronic hyperchloremic acidosis.

Typical symptoms are weight loss, fatigue, weak appetite and intense thirst. About 10–20% of all people who have had a urostomy will suffer some degree of acidosis. The treatment is simple and consists of a dietary supplement of bicarbonate tablets – and possibly electrolyte therapy if the condition is very severe^(19, part 1, p.19).

7.2.13 Inadequate absorption of vitamin B 12

Vitamin B 12 is absorbed by a relatively small area of the small intestine. If this section of the small intestine has been used to form the urostomy, the patient can easily develop pernicious anaemia, which is a serious form of anaemia. The symptoms are fatigue, pallor, palpitations, tinnitus and paralysis of the tongue, which becomes smooth and glistening (raspberry tongue).

The symptoms disappear after vitamin B 12 injections. This condition is rarely seen now because surgeons use only the section of the small intestine that is located more than 15 cm away from the appendix, thereby maintaining the absorption of vitamin B 12^(19, part 1, p.19).

7.2.14 Phosphate precipitation

A urinary tract infection caused by bacteria of the strains Proteus, E. Coli, Klebsiella, Pseudomonas or Staphylococcus will make the urine more alkaline, and phosphate will precipitate as crystals. The crystals may be seen as a greyish-brown area around the stoma or as white flakes on the stoma itself. The stoma will also bleed slightly, and the urine will be bloodstained and have a strong odour. As a rule, the patient will have no pain. The condition is seen relatively rarely, as the one-way valve on the bag should prevent it.



The condition is treated by maintaining a high fluid intake, and by applying acetic acid (vinegar) on the skin around the stoma to re-establish the pH balance. Vinegar or vitamin C added to the bag will also counteract the alkaline environment. Use of a bag with a one-way valve and a night drainage bag to prevent bacterial access to the stoma should be recommended^(19, part 4, p.8).

7.2.15 Kidney disorders

Within 20 years of having a urostomy, the majority of people will have suffered some form of kidney disorder^(19, part 1, p.20), possibly due to frequent, recurrent urinary tract infections.

7.2.16 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. Oedema can occasionally be so pronounced that urine is prevented from flowing out. 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^(19, part 4, p.10).

7.2.17 Ischaemia

Ischaemia means inadequate blood supply. The stoma may become ischaemic if its blood supply is reduced. This might happen 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 destroyed. 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 destroyed entirely, a new stoma will need to be constructed immediately^(19, part 4, p.10).

8. Living with a urostomy

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8.1 Clothing

People who have had a urostomy can usually wear the same kind of clothing as they did before surgery, but it is important that clothing does not prevent the urine from flowing freely into the bag. Tight waistbands should be avoided since they can press against the bag and cause it to leak or may prevent the urine from leaving the stoma and instead it will return to the kidneys^(19, part 5, p. 7). For men, it may be more practical to wear braces instead of a belt, however some may prefer to wear braces only when wearing a suit jacket or other item of clothing on top.

People with an ostomy 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 ostomy bag better than trousers with a flat front. Also, in a large bag the urine is distributed over a relatively large area and will be less prominent. 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, such as a minicap, which takes up as little space as possible.

There are companies that design clothing and special underwear for people with a stoma.

(See also the section on stoma-site marking on p. 15).

8.2 Sport and leisure

There are few physical limitations to participating in leisure activities after having a urostomy. 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 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^(16, p.5). Weight-lifting should also be avoided since it might increase the risk of developing a sliding hernia (see hernia, page 28). For those engaging in more strenuous sports where they work up a sweat, the adhesive will be challenged^(19, part 15, p.12). 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 a urostomy, 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^(12, p.86).

Continent urostomies

For those with a continent urostomy, the reservoir should be drained before engaging in any sports activity.

8.3 Swimming, showers and baths

Swimming

People with a urostomy should not be deterred from going swimming. If the situation allows and in the right surroundings (e.g. at the beach), it will not harm the stoma if no adhesive or bag is worn while in the water. However, after swimming it is important to dry off the skin around the stoma very carefully before attaching new adhesive^(19, part 15, p.7).

Wearing the appliance while swimming is not a problem as the adhesive can withstand getting wet. Afterwards, the appliance should be dried carefully to avoid any skin irritation due to moisture. The best way to camouflage the bag is for women to wear a patterned swimsuit (not a bikini) and for men to wear boxer shorts.

The minicap (see p. 38) was designed to give the maximum comfort and discretion for activities like swimming.

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^(2, p.24). In public places such as public swimming pools, however, 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.

8.4 Sauna and sunbathing

The stoma will not be harmed by spending time in a sauna, even if the bag is not worn. In public saunas, however, a bag must always be worn.

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

8.5 Transport and travel

A urostomy rarely causes major problems during traveling. However, there are certain issues to be aware of^(30, p.23; 33, p.24).

Immediately after surgery it is not advisable to drive a car. 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 a night drainage bag in the glove compartment so that the bag can be drained at any time. A night drainage bag is also handy for long journeys. However, in very hot weather ostomy products should not be left in the car as the heat may damage the adhesive.

People with a urostomy who travel by car either as the driver or passenger must wear a seatbelt like everyone else. Although a 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 accessories for seatbelts that will ease pressure on the stoma^(36, section 10).

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^(19, part 5, p.7). It is also important to bring waste disposal bags so that stoma waste can be disposed of discreetly. On long journeys where it is difficult to empty the bag, a microbag connected to a large leg-bag may be a good solution.



When travelling in hot climates the wearer will perspire more heavily, this will cause 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 adhesives and bags 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.

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 take 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^(14, p.10-11). It may also be useful to pack products for cleansing and protecting the skin around the stoma in case it is affected by heat and a change in humidity. People with a urostomy are generally advised to drink 2–3 litres of fluid per day (p. 35), and in a hot climate this is especially important because of the increase in fluid loss due to perspiration.

Leakage can be a problem for people with a urostomy. While sleeping, the person cannot control pressure on the bag and it can become twisted and leak. While travelling it may be a good idea to take water-proof sheets to protect the mattress in case of leakage.

When camping it is a good idea to sleep on a camp bed that is raised off the ground, so that urine can flow from the bag down into the night drainage bag^(2, p.25). Alternatively, if the tube to the night drainage bag is stretched out, there will be sufficient suction in the night drainage bag to allow the person to sleep on an airbed.

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⁽¹⁰⁾. 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^(11, p.42). Some companies also offer people with a stoma a 'No Waiting Card', which states in several languages that the bearer of the card has a urostomy 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^(36, section 10).

If there is any doubt about the quality of the drinking water when travelling, bottled water should be purchased for cleansing the stoma to avoid a gastrointestinal infection^(11 p.42).

Continent urostomies

People with a continent urostomy should take plenty of catheters when travelling abroad, and, as a safety measure should always use bottled water when draining and irrigating the reservoir⁽¹⁸⁾.

8.6 Returning to work

The majority of people who have had a urostomy can go back to work after the operation. A survey of 66 people with a urostomy found that 79% resumed work after their surgery, although some changed their working conditions^(33, p.22). At least 8 weeks of recuperation is needed before attempting physically demanding tasks such as heavy lifting, vacuum cleaning or gardening. The body will usually protest if the person is doing too much. Sick leave of 2–4 months after the operation is typical^(13, p.9).

Any work involving heavy lifting can be harmful to a person with an ostomy because there is a risk that the strain will cause a sliding hernia (see p. 28). Such work may have to be replaced with less physically demanding tasks^(19, part 5, pp.11-12) or by using a precautionary hernia belt.

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 appliances and dispose of waste. In most cases having a urostomy causes no work-related problems, and very few people who have undergone surgery need 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 a stoma 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.

If the toilet and bathing conditions in the home are insufficient for nursing the stoma, in some countries it is possible to apply for financial support to renovate the amenities^(16, p.6).

8.8 Diet and fluid intake

There will often be a loss of appetite during the first 4–6 weeks after a urostomy procedure. It may therefore be necessary to supplement the diet with high-protein, high-energy drinks. People who have had a urostomy can eat and drink whatever they want unless the surgeon or stoma care nurse advises otherwise. However, if the person gains a lot of weight, there may be major problems in getting the adhesive to adhere properly, and a weight loss programme will be required.

Eating certain foods (such as asparagus, shellfish and curry) may cause the urine to have an offensive odour and a cloudy appearance. Beetroot and certain types of medication may discolour the urine so that it is mistakenly suspected of containing blood^(36, section 7).

Fluid from the blood stream will constantly flow (due to osmotic pressure) into the section of intestine used to construct the stoma. The osmotic pressure in that section of intestine is higher than in a natural bladder, so people with a urostomy produce more urine than those without a urostomy. As a result, people with a urostomy must drink more than others to maintain their fluid balance. A daily fluid intake of 2–3 litres is recommended and will also help prevent the development of urinary tract infections (p. 26). People who have had a urostomy are advised to drink 300 ml (approximately 2 glasses) of cranberry juice every day if they have problems with urinary tract infections. Cranberry juice contains substances that inhibit the binding of *Escherichia coli* bacteria to the intestinal wall, thus preventing urinary tract infections (p. 26). For those who do not like the taste of cranberry juice, it is also available in capsule form.

8.9 Psychological factors

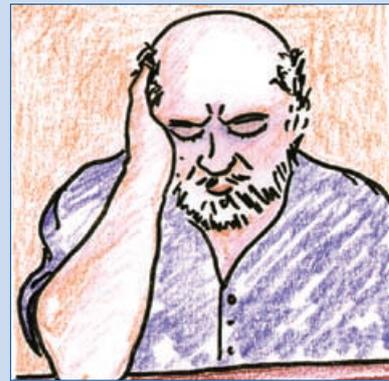
As mentioned earlier, the siting of a urostomy is far from being purely a physiological procedure with practical aspects. The person's cultural practices and traditions, social life, self-image, religion and sexuality are affected by the surgery. The effect of the stoma on an individual depends on the 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 urostomy surgery^(19, part 5, p.14).

Loss of control

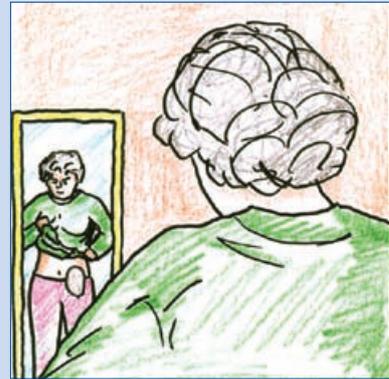
A large part of growing up and becoming an independent individual is achieving control and autonomy. By the age of 2–4 years, most children have learned to control their bladder and are aware that contact with body waste is unhygienic. This control over the bladder is suddenly lost after having a urostomy (particularly for people with non-continent stomas). It is not uncommon for people to feel that they have been reduced to the 'nappy stage' along with the attendant shame.



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 ^(19, part 2, p.2).

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 a urostomy, 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 ^(19, part 2, p.2). A survey of 66 people with a Bricker bladder showed that for 24% of respondents, the worst aspect of the surgery was the change in body appearance. Women tended to be more concerned with this change than men ^(33, p.29). It is important that people with an ostomy put ideas of the familiar symmetrical body aside, come to terms with their loss, and learn to embrace life once more. Again, personal resilience (both intellectual and social) is critical in determining how well the individual copes with the situation ^(19, part 3, pp.18,20).



Changes in sexual ability

As discussed in the section on sexuality on page 37, the ability to perform sexually can be affected by a urostomy, particularly in men. One study found that of 30 people who had surgery to form a Bricker bladder, approximately half were distressed by their inadequate sexual abilities, because their libido (sex drive) remained unaffected. 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 urostomy surgery, some people react with depression, weariness and a sense of pointlessness ^(30, p.23). An interview-based survey of 34 stoma patients revealed that 20% still had difficulty coming to terms with their situation a year after surgery ^(30, p.29). 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 ^(3, p.16) because it has reminded them that they cannot live forever, and they learn to distinguish between the important and unimportant things in life. The survey mentioned above indicated that almost two thirds of respondents – especially those with a continent stoma – had gained a brighter outlook on life after the operation and had become more patient, more tolerant, less materialistic, and generally more appreciative of nature and life itself ^(25, p.15; 30, p.25).

8.10 Social perspectives

In the UK, a person who has undergone urostomy surgery is often referred to as a 'urostomist'. 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 a urostomy have far more interesting qualities than the fact that they have undergone ostomy surgery. The surgery rarely has an effect on what they can do afterwards. To avoid stigmatisation, more neutral language such as '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. Odour, the fear of odour, and the changed body shape may cause some to avoid physical contact with others. However, most people who have had a urostomy 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 (see p. 32, 34, 36, and 37).



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 that the situation is far worse than is actually the case^(19, part 5, p. 2-4).

8.11 Sexuality

Sexuality is an important part of life for both young and older people and this does not change because of ostomy 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. Interview-based surveys have shown that it is common for people who have undergone urostomy surgery to suffer from sexual deprivation as a consequence of the operation and because the relationship with their (sexual) partner has changed because of the stoma. For the majority, however, their libido remains the same^(30 p.22) 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^(25, p.15).

8.11.1 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^(19, part 5, p.3).

8.11.2 Psychological aspects

People who have had a urostomy procedure will be affected to varying degrees and for varying lengths of time by grief, fear of mortality, depression, and altered body image, all of which will affect their sex drive^(19, part 14, p.21). 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 urine 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 urostomy 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 a urostomy 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^(19, part 5, p.3).

8.11.3 Practical aspects

Although the stoma will not be hurt by intercourse^(24, p.1), the bag can get in the way, and can be seen, felt and even 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. Reusable bags should be emptied beforehand. The bag can be made more discreet by using a special cover made of a fabric to match the clothing, or a piece of clothing that will camouflage the bag, such as a T-shirt, girdle or a scarf worn around the waist^(19, part 5, p.4).



A special minicap for use in intimate situations is available in most countries. The minicap is a small bag that holds about 100 ml, which means that it will be filled within approximately 1 hour depending on how much the person has had to drink. The bag is practical, discreet and comfortable because it takes up very little room and has no outlet to chafe against the skin. In addition, the interior of some of the bags contain a gauze-like material, which absorbs urine leaving the stoma and prevents any 'sloshing' by the bag. The minicap can be covered by a beige textile for added comfort.



8.11.4 Male sexuality

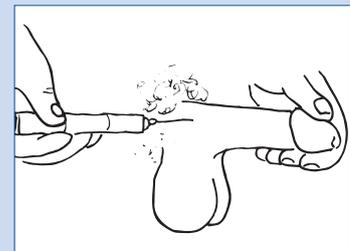
Sexual activity can be resumed as soon as the man has recovered from surgery, but in many cases after surgery there will be physiological effects that will influence the ability to perform sexually.

If the bladder was removed because of cancer, the prostate gland, seminal vesicles, and sometimes the urethra are also usually removed. This is major surgery, and damage to nerve pathways and blood vessels is inevitable. Libido (sex drive) and the ability to achieve orgasm remain unaffected, but erection and ejaculation will not be possible in the majority of cases. A survey of 29 men who were sexually active before urostomy surgery, indicated that 90% had erectile dysfunction (inability to achieve full erection) after surgery^(33, p.23). Another survey of men with a Bricker bladder indicated that even if they suffered erectile dysfunction, 41% of the men were able to achieve orgasm by masturbation^(30, p.11).

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

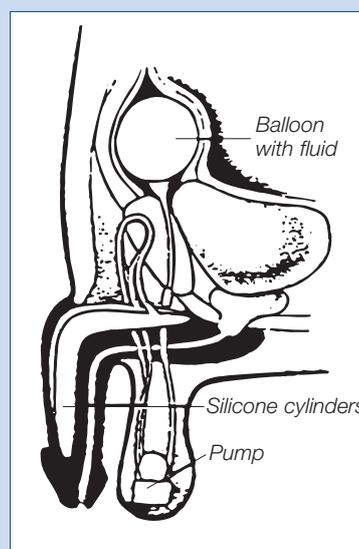
Various methods can be used to help a man who has had a urostomy to have conventional sexual intercourse, even if he has erectile dysfunction.

- 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.

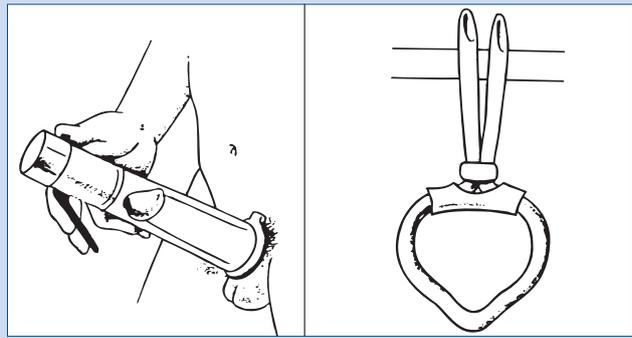


Needles used for intracavernosal injection are the same type used by people with diabetes to inject insulin. The first injection must be administered by a physician, and thorough training is required before the man can self inject. The prostaglandin is first dissolved in a solvent and then drawn up into 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^(21; 19, part 4, p.18).

- 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 within 5–10 minutes. Side effects in the form of a slight itching and stinging can be experienced by a female partner^(36, section 11).
- 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^(36, section 11).
- If the nerves 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⁽³¹⁾.
- 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^(19, part 4, p.18).
- 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^(19, part 4, p.19).
- 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^(19, part 4, p.19).
- 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^(36, section 11).



If the person has had a reservoir operation (p. 9), or an orthotopic bladder replacement (p. 13), there is a greater probability that erectile function will be fully or partially preserved. In some cases the erectile dysfunction is psychological (performance anxiety), influenced by the emotional reaction to the changes caused by the urostomy^(19, part 5, p.4).



8.11.5 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.

A procedure to remove the bladder will also entail removal of the urethra, uterus, Fallopian tubes, ovaries and a portion of the anterior vaginal wall. This shortens and narrows the vagina, and natural lubrication of the vagina in response to sexual arousal may be diminished. This will result in dryness and pain during intercourse, especially if more than a third of the vagina has been removed. Any problems can be alleviated by finding a different position for intercourse, by oestrogen therapy or by moistening the vagina with saliva or lubricant jelly^(11, pp.36 & 43).

Women who have had urostomy procedure because of incontinence or bladder dysfunction will often achieve a more active sex life after the operation because they no longer need to use incontinence pads or catheters^(33, p.24).

8.12 Pregnancy

Having a urostomy – or reservoir in the case of a continent stoma – does not prevent a woman from carrying a pregnancy to term and having a normal delivery. However, in addition to regular obstetric examinations, women who have had a urostomy should also see a physician with enterostomal expertise^(19, part 5, p.4). 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. Delivery usually proceeds normally^(16, p.5).



If there is any indication that cancer has spread to the bladder, the surgeon will also remove the urethra, uterus, Fallopian tubes and ovaries and part of the vagina^(3, p.11). Women who undergo this procedure will be unable to conceive. However, the vast majority of women who develop bladder cancer are beyond child-bearing age. Young women who do develop bladder cancer should consider whether they wish to have more children. It is possible to remove the eggs prior to surgery for subsequent use in artificial insemination with a surrogate. If the woman has had an orthotopic bladder replacement (p.13) and therefore does not have a stoma, it is important that the muscles of the pelvic floor are not placed under too much strain. If this does happen, the child will be delivered by Caesarean section^(19, part 5, p.4).

8.13 Children and adolescents with a urostomy

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 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. Patient associations can often put teenagers in contact with other young people in the same situation^(36, section 12).

8.14 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 urostomy 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 urostomy 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^(19, part 5, p.14).

8.15 Support groups

A great deal of information about having a urostomy is available, but inevitably there are unanswered practical, psychological and social questions. Because relatively few people have had a urostomy 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 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.

UK	www.uagbi.org
USA	www.uoa.org
Denmark	www.COPA.dk
Sweden	www.ilco.nu
Norway	http://www.kreft.no//forkreftpasienter/pasientforeninger/norilco
Italy	Telephone no. +39 33 36 61 41 21
Spain	A.C.C.U. Telephone no. +34 91 5426326
France	www.fsf.asso.fr
Germany	www.ilco.de
Netherlands	http://www.stomavereniging.nl

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Y

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