

## Colostomies and Other -Ostomies

### What is a Stoma?

A stoma is an opening in the body where a connection to an internal organ is brought out. The word comes from the Greek *στομα* (*stoma*), meaning a mouth (perhaps somewhat inappropriately), and the plural is *στοματα* (*stomata*), usually avoided in order not to confuse the reader.

### Different Types of Stoma

By far the most common stoma is a colostomy, where the colon, or large intestine, is brought out to a position on the left hand side of the abdomen. Much less common is the ileostomy, in which the ileum, or small intestine, is brought out to a position on the right of the abdomen. Both of these are usually formed as a consequence of cancer or other incurable condition of the rectum or colon, such as Crohn's disease, Ulcerative Colitis, or Diverticulitis, necessitating removal of all or part of the colon. Less common still is the urostomy, formed when an incurable condition necessitates removal of the bladder. In this case the ureters from the kidneys discharge into an isolated portion of the ileum, which is in turn brought to the surface. Statistically, the frequency of occurrence of the three types of stoma mentioned is currently in the ratio 6 : 3 : 2. Individuals with these conditions are known respectively as colostomates, ileostomates, or urostomates, or under the generic designation of ostomates. American usage is colostomists, ileostomists, urostomists and ostomists, and in France they are all varieties of *stomisé(e)s*.

A colostomy is formed when only the rectum or the lower part of the colon has to be removed, leaving a portion, typically more than half, of the colon to perform its normal function of removing water from the bodily waste, so that it produces a typical faecal output. A less common reason for forming a colostomy is uncontrollable incontinence, which is much easier to deal with if the output is on the abdomen, rather than in the conventional location.

The output from an ileostomy dribbles more or less continuously, as does a urostomy, and consequently they afford fewer alternatives for their convenient management than does a colostomy.

Sometimes a temporary colostomy or ileostomy is formed in order to relieve the load on the colon or rectum, so that it can more easily recover from a medical condition or from surgery. These cases are known as a "loop" colostomies, or ileostomies, because the relevant portion of the bowel is not cut through, but an opening is formed in a loop which is brought to the surface of the abdomen. Very often the decision to reverse a stoma of this type has to wait until the result of treatment of the diseased portion is known, and occasionally the outcome is such that reversal is impossible, and the stoma is made permanent.

### Self Image Problems

The reaction of a patient to having a stoma will depend greatly on whether he or she has been prepared for it. In the majority of cases the condition giving rise to the stoma will have been diagnosed well before surgery, and very often a programme of treatment will have been carried out before surgery. In these cases the patient will have had adequate time to learn about the realities of living with a stoma, although very occasionally the response will be complete denial, and unwillingness to learn anything about the condition. Patients who wish to know as much as possible about a stoma can usually arrange to have a discussion with a specialist stoma nurse to learn some of the medical facts, and the way that the stoma is managed in day-to-day living. It is usually a great advantage if they can also meet someone who has been living for a number of years with a stoma, who will represent the living proof that there need be no substantial change in the way they live.

It needs to be made clear that there is only one thing that a colostomate or ileostomate cannot do, and that is to use the WC in the conventional manner.

More difficult are the occasions when an untoward discovery in the course of abdominal surgery necessitates the planned procedure being changed, and a stoma formed, or in accident and emergency cases where a stoma is the only practicable solution. In these cases much depends on the mental resilience of the patient, and his or her determination to make the best of the situation. There is likely always to be the thought "How on earth can I live a normal life when I have a hole in my front discharging sh\*t (or some suitable euphemism)?", and it is these cases who benefit most from an early meeting with an experienced ostomate. When it is evident that an ostomate appears perfectly normal, and can point out that a stoma is simply a different way of discharging bodily waste, a more realistic attitude to the condition can usually be generated.

Other problems can arise with members of ethnic groups whose attitude to the functioning of the bowels has been dictated by centuries old ideas about hygiene. Typically, if they are prepared to have anything at all to do with a stoma, they may want to deal with it using only their left hands. It is likely to require a very tactful discussion to bring them round to acceptance of the fact that they owe their lives to 21st century technology, and they need to adjust to modern hygiene practices and ways of stoma management if they are to make the best of their lives.

### **After Surgery**

The patient may be disconcerted to encounter a number of unexpected problems in the course of recovery. Liquid intake will be carefully controlled until it is evident that the colon is performing its function of extracting water from its contents; this is reasonable, but what may take the patient by surprise is the change in appetite which can occur. When looking forward to a meal, it can be disconcerting to find oneself too nauseated to look at a menu, and have to have it read, or a selection made, by someone else. Quite profound likes and dislikes may develop, and the wine lover looking forward to a glass of red wine may be totally unable to face drinking the stuff! The patient can be assured that this will pass, and that normal preferences will return, typically after a few weeks, and often quite suddenly.

Mentally also, there may be temporary changes, possibly as a consequence of several hours of anaesthesia. The person who has been active for sixteen hours a day may be perfectly happy looking at the bricks in the wall for an hour or two. The patient who thoughtfully brought into hospital a collection of audio books may be disappointed to discover that with a concentration span of no more than twenty seconds it is impossible to get past the first paragraph. Again, these limitations will disappear, although it may take several weeks to return to normal.

### **Stoma Appliances**

One of the most evident features of a stoma is that, barring a specialised management technique (see the next section), the possessor of one has little or no control over the discharge from it, which therefore has to be collected in some form of reservoir pending disposal. This invariably means some form of adhesive junction, and one of the first worries of a new ostomate is how the skin will behave with something stuck to it continuously. Memories of soggy white skin under adhesive plasters fill the new ostomate with horror, and the first thing to make clear is that there is no comparison between adhesive plasters and the adhesive flange of a stoma appliance. The adhesive material used on stoma appliances is a very advanced formulation, which nourishes the skin so that the area it covers is often the best skin on the ostomate's body. In the USA, even cosmetic face masks are made from it.

Colostomates and ileostomates use an appliance which is attached by an adhesive flange to

the abdomen. Considerable heat is generated by arguments over whether this should be referred to as a bag or a pouch, and although it never has the access arrangements which one normally associates with a pouch, there are some who would feel insulted by a reference to a bag. Others, whose lives have probably been saved by the surgery which left them with a stoma, will be happy to abide by the saying "Better a bag than a box". In any case, in France it's a pocket. When meeting an ostomate for the first time, it is as well to be sensitive to the way in which they refer to the appliance. In these notes, the term bag will be used, simply because the word is shorter. Urostomates will have either a drainable bag, or a tube leading to a reservoir, normally located on the leg during the day, and beside the bed during the night. The latter have no problem with bag or pouch arguments!

There are innumerable variants of stoma bags, but the fundamental classifications are one piece or two piece, and for each, drainable or closed. A closed bag, when it is full, is removed, emptied, and discarded. A drainable bag has an opening at the bottom, closed with a clip or a fold, so that it can be emptied without removing it, and it is more relevant to ileostomates. The one piece bag, when it requires to be changed, is removed from the abdomen, discarded, and a new one fitted. A two piece bag has a flange which can remain attached for two or three days, with the bag portion being separately detachable and replaceable. It is a matter of personal choice which is preferred, but it has to be borne in mind that the flange and coupling arrangement of a two piece bag is inevitably bulkier and stiffer than the flange of a one piece bag, so that for comfort many ostomates prefer the one piece bag.

Two other appliances, plugs and caps, are covered in the next section.

## **Stoma Management**

The traditional method of managing a stoma is simply to collect what comes out, and dispose of it as required. With the exception of some techniques which are not relevant to this account, ileostomates and urostomates have no option but to operate in this way. Colostomates are in a better position, because there are a number of options open to them which can afford them more flexibility in their way of life.

The simplest and most basic of these is the plug: a means of closing the stoma using a foam plug which will prevent the passage of solid matter, but will allow gas (wind, or flatus) to escape. This works on the principle that if nothing is getting out, the colon tends to stop pushing, so that the user can choose when to empty the colon simply by taking the plug out. However, some users find that it isn't quite as straightforward as this. There is usually also some slight degree of discomfort associated with this method, and it is not widely used: colostomates tend either to love it or loathe it.

Another approach to colostomy management is based on the fact that if the rectum has been lost, which stores faecal matter until the person wishes to discharge it, it is possible to use part of the colon to perform this function. This is achieved by irrigation, which involves introducing about a litre of warm water into the stoma, causing the contents of the lower part of the colon to be expelled. Patients, who have lost only the length of colon required to enable it to be brought out to a conveniently placed stoma, can typically achieve two or even three days continence by this method, and instead of a bag can wear an adhesive cap about the size of a credit card, which incorporates a carbon filter to deodorise expelled gas. Those who adopt this technique are even able to forget, for most of the time, that they have a stoma. Irrigation constitutes a considerable saving in the cost of appliances, and for this reason is extensively used in the USA, where ostomates have to pay for their stoma needs.

It is quite common in the UK, but much less well known in France, where there are doctors who haven't heard of it, and pharmacists who actively advise against it.

## **Physical Rehabilitation**

One of the things which new ostomates may find difficult to believe is that, barring infection or surgical problems, and apart from a loss of strength of some 5% per week of inactivity, they are just as fit, or unfit, as they were before surgery. As far as a stoma is concerned, the integrity of the abdominal wall is dependent largely on the muscle which runs from the lower part of the ribcage to the pelvis: the *rectus abdominis*, commonly known as the "abs". It is not normally necessary to cut this muscle in the formation of a stoma, merely to divide the muscle fibres, so no substantial weakness should result from the surgery..

Anyone who has enjoyed an active life before facing the prospect of an ostomy, and who wishes to continue such an active life with a stoma, should consider undertaking a suitable exercise programme to train the *rectus abdominis* (the "abs") before surgery, if possible, and resuming it at an appropriate time after surgery. It is essential, however, that such a programme is not embarked upon without prior discussion with the consultant responsible for the patient. One other piece of advice is essential: "Stop if it hurts!"

## **Hernia Prevention**

Because the colon needs a larger opening in the abdominal wall, colostomates have a greater risk of a hernia than do ileostomates and urostomates, and even if they do not intend to engage in vigorous activities, they would be well advised to follow an exercise programme to strengthen the *rectus abdominis*. Invariably, all ostomates are advised not to lift anything heavy, but are seldom given an answer to the question "How heavy?". At least in the first month or two after surgery, it is desirable to avoid any effort which necessitates holding the breath, because this increases the intra-abdominal pressure, and could be the cause of a parastomal hernia, where a portion of the intestine finds its way through the hole in the *rectus abdominis* made for the stoma.

There is in fact a simple test which can be applied: "If it makes you grunt, don't do it", so if in doubt, always apply the Grunt Rule. As rehabilitation progresses, and strength is built up, the patient will learn to judge what is reasonable, but in the early days caution is advisable. A parastomal hernia is very difficult to correct. New ostomates are often recommended to wear a support garment or belt when doing anything other than light work, and unless the patient has a strong *rectus abdominis* this is a good idea. In the longer term it is desirable if possible to train the *rectus abdominis* so that an external support is unnecessary.

## **Participation in Sport**

Do not allow the foregoing section to convey the impression that ostomates have to be permanent invalids: nothing could be further from the truth. The fundamental principle is to build up the integrity and strength of the abdominal wall, principally by continuing to train the *rectus abdominis*, and at any time only to undertake activities which are comfortably within the patient's capability. Advice is readily available on the Sporting Activities pages of [www.stomadata.com](http://www.stomadata.com) and [www.stoma.fr](http://www.stoma.fr), regarding the training which is desirable for any chosen sport, and by way of example, there are ostomates who engage in dinghy sailing, powerlifting, scuba diving, and even American football.

It is perhaps worth mentioning that swimming, which is frequently mentioned as an excellent exercise for patients recovering from abdominal surgery, can place particularly heavy loads on the *rectus abdominis*. It is suggested that reference should be made to one of the Technical Notes on "Swimming after Abdominal Surgery" on the Sports Activities page of

www.stomadata.com or www.stoma.fr, and if necessary, further advice obtained before returning to swimming.

### **Ostomates and the French Health Service**

As in the UK, patients in France with chronic conditions get their supplies free, or to be more precise, they obtain 100% reimbursement of the sum which CMU (the French Health Service) considers they ought to cost. Depending on the product and the pharmacy, the patient may have to pay up to about 5% of the cost, which may be recovered from a *mutuelle* (top-up insurance). In order to obtain the nominally 100% reimbursement it is necessary for the patient's *medecin traitant* (GP) to complete a form, the "*Protocole de Soins de Santé*", which is then submitted to CPAM (the Benefits Office) in Toulon (for the Var). Once this has been approved, reimbursement will be automatic when the *Carte Vitale* (social insurance smart card) is presented at the pharmacy. Some doctors seem to be unfamiliar with this procedure, and will require it to be pointed out to them. The provision is valid for five years, after which time it will have to be renewed.

In the event that the patient requires supplies before approval for 100% reimbursement has been obtained, it will be necessary to pay the appropriate proportion of the cost, and reclaim it once approval is granted. In this case it is essential to keep the invoice issued by the pharmacy, and stick on it the peel-off labels from the boxes of supplies to which it refers, before submitting it to CPAM. Without these labels CPAM will not issue the refund, and probably won't explain why!

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