



Medical Aspects of an Ileostomy

By Professor C J Probert MB ChB(Birm) MD(Leic) FRCP FHEA

Surgical treatment of inflammatory bowel disease and familial adenomatous polyposis (FAP) may require the removal of a patient's colon (large bowel). When the ileum (small bowel) is brought to the surface of the abdominal wall an ileostomy is formed. The alternative to a long-term ileostomy for people with ulcerative colitis and FAP is an internal pouch.

At present, an internal pouch is not offered to people who have had surgery for Crohn's disease. In general, it requires a second or even third abdominal operation to create a pouch. The pouch can be thought of as a replacement rectum made from small bowel and means the ileostomy can be closed.

After surgery, which results in an ileostomy, most people find it difficult to believe that life without a colon can be completely healthy. They tend to think that the removal of several feet of bowel and the manufacture of an artificial opening, called a stoma, must make a great change in the workings of the body and present many problems needing medical advice. This is, in fact, not so and the majority of people with an ileostomy need very little advice or help from their doctors, unless they happen to suffer from another medical problem.

To understand how this can be, one needs to understand a little of the normal function of the large bowel (or colon) which has been removed. The large bowel is only found in land animals and its major

function is to absorb water from the food residue.

When animals first moved from the sea to the land, they moved from a world where water was plentiful to one where it might be very scarce and they adapted to this by developing a colon as one means of avoiding dehydration. Other than water, the only substance that is absorbed from the colon is salt.

All the other things we get from our food, which we need for energy and health are absorbed from the small intestine, is unaffected by the traditional operations for ulcerative colitis or FAP. Thus, people with an ileostomy get as many carbohydrates, fats and proteins, and just as many vitamins, from their food as anyone else. Some know well that they have just as much difficulty as anyone else in keeping their weight down!

The other function of the colon is to act as a reservoir for the waste products of the body (faeces) until there is a convenient moment for disposing of them into the lavatory. The colon, then, along with the rectum and anus help to maintain continence.

However, this function is not essential for health and, although this does not mean an ostomist is continent in the conventional sense, the ileostomy is managed by the stoma appliance (bag).

When the colon is first removed, it is common for the output from the ileum to be very watery for some weeks or months and then to become more firm. This is an example of the way the body adapts itself to different conditions; in this instance, the small intestine has taken over some of the water-absorbing action of the missing colon.

However, the output never becomes completely solid. In addition, the body cannot develop muscles around the stoma to act in the same way as the muscles of the anus which maintained continence. For these reasons, people with ileostomies have to continue to wear their bags (stoma appliances), however well their small intestines may adapt. In some instances, the bowel may be inactive for a short time and a bag may be left off very temporarily. (When it is necessary to replace a used bag with a fresh one, this is the best time.)

If the main function of the colon is the absorption of salt and water, how does its removal affect the person with an ileostomy? Under normal circumstances, there is little change because the kidneys are extremely efficient at compensating for the loss in the ileostomy output. Should the body get short of either salt or water or, more commonly both, the kidneys

conserve these substances and so the balance of the body is maintained. Such compensation occurs in a wide variety of situations, such as during hot weather or after vomiting.

This is how the average person with an ileostomy manages to eat and drink the same as anyone else, although he or she is losing more salt and water via the ileostomy than someone with a colon. However, it is important to realise that there is such a loss going on and try to compensate for it in order to throw as little strain on the kidneys as possible.

For this reason, anyone who has an ileostomy should try and drink more, especially in hot weather, and should make a point of taking extra salt with all their meals.

This does not apply to a few people who are unlucky enough to have heart or kidney trouble in addition to their ileostomy. If your doctor has told you to avoid salt or extra fluid, it is not because s/he knows nothing about ileostomies, but for some other reason. In this case you should discuss it with him/her.

As mentioned above, under normal conditions the kidneys are able to compensate for the loss, even if there is no extra intake. But if the losses are greater than normal it may not be possible to compensate in this way and a state of salt or water depletion may develop.

For this reason, a major increase in the ileostomy output due to an attack of

gastro-enteritis or a mild obstruction must be treated seriously and anyone whose ileostomy output increases by a pint or two in the day would be well advised to consult his/her doctor.

Salt

What are the symptoms of salt and water shortage? Loss of water leads to thirst which makes the person drink and, thereby, correct the loss, but people with ileostomies who lose extra amounts should try to start drinking before they become thirsty. Shortage of salt leads to general weakness, dizziness, a tendency to faint, abdominal cramps and ringing in the ears.

Again, people with ileostomies should try to prevent this by increasing their intake of salt as soon as they begin to lose extra amounts. Should extra salt be needed, it is best absorbed when taken with sugar; sachets of oral rehydration fluid bought from the chemists, or made at home by adding half a teaspoon of table/cooking salt and two teaspoons of sugar to a pint of water. However, in severe cases, an intravenous infusion may be necessary.

Food

Apart from water and salt, is there anything else that the person with an ileostomy needs to worry about as far as food and drink are concerned? It has been explained that s/he can eat a completely normal diet and get the same benefit from it as anyone else, because s/he has a completely healthy and efficient small intestine. But there are one or two small points about

the diet which may help his/her comfort.

Until the ileostomy has adapted, the output tends to be very fluid and in order to reduce the amount, it is helpful to avoid too much roughage. This stimulates the small intestine to greater activity, and not only does the roughage come through, but with it an extra large amount of water. Therefore, in the first few weeks and at any time that the output is more watery than usual.

You should avoid such things as cabbage, lettuce, nuts, tomato skins and orange pith and keep to milky and starchy foods which are easily absorbed. Some people with ileostomies may have a very small opening, or a narrowing of the bowel where it passes through the abdominal wall, and may find that they too need to avoid roughage. It produces colic through getting stuck in the narrow bit of the bowel.

One IA member once looked at a very hard pea and wondered if it would go through his rather narrow opening. An hour or so later, he found that his fears had been justified because he got a severe attack of abdominal pain, which only passed off when the same pea was seen emerging from his stoma!

There is no reason why someone who has an ileostomy should not eat and enjoy everything. After all, the operation has been done to restore health and, in health, people eat what they enjoy.

Some eat more sensibly than others, taking a good mixed

diet with plenty of protein and vitamins, while others live on bread and scraps. The person with an ileostomy will get by on either, but naturally his/her health will be better on the better diet as would anybody else. Similarly, many people without an ileostomy find that certain foods upset them.

Some people with ileostomies may find certain foods make the ileostomy more runny and this means the bag needs to be emptied more often and may not stick on quite so long. They will have to make up their own minds whether they continue eating these foods or not.

A word of warning on this point is necessary. It is the natural thing to assume that anything that goes wrong with one's bowels must be due to something eaten previously; yet it may have nothing to do with the food.

For example, someone may take some particular food, such as a fried egg, and the next day have an over-active ileostomy. S/he then assumes that this was due to the egg and, therefore, thinks that s/he must always avoid fried eggs for the rest of his/her life! This is a great pity as it means abstinence from the pleasures of the table. This is unnecessary if, in fact, the upset was not due to the fried egg, but to some quite different cause, such as a germ.

Therefore, people with ileostomies (and others) should experiment and only avoid those foods which consistently upset them.

Alcohol

A further good example of this problem is alcohol. In some people, with or without an ileostomy, this makes the bowels more watery and a few may find that some restriction is necessary, though it is always worth experimenting.

One lady reported in January that, at Christmas, she found that her ileostomy would stand up to port, sherry, gin and cider, but (regretfully) she said, "It wouldn't take beer".

A year later, she reported: "It's all right now - it can take beer as well!"

Odour

Another problem which may affect the diet is that of odour. This is one of the common difficulties which have not yet been overcome.

There is an enormous variation between different people. Some of them having no ileostomy odour difficulties at all and others finding this a real handicap. We do not understand why this should be. Certainly, some people find that certain items of food produce more odour from the output than others, such as fried onions, baked beans, cucumber, fish and a host of other items that have been named by different people as responsible for ileostomy odour.

But there is no agreement at all among those who do have an odour problem about these points. One finding one item of diet a problem while another can eat this food without trouble, but will develop an odour from some other food. Yet another person, of the

same hygienic standards and with an inside that is identical with the other two, will be able to eat anything without trouble.

Therefore, the only thing to do is to find out what suits you and decide whether or not you wish to avoid any particular food which always seems to produce an odour.

The stoma care nurse and the doctor

It has been said that the person with an ileostomy has little need of a doctor if s/he knows how to look after him/herself and s/he is, in fact, a completely normal person, except for the absence of a colon. Most hospitals in which specialised bowel surgery takes place will have a nurse whose role it is to help with stoma care; such a nurse is often called a stoma care nurse. Most stoma problems can be dealt with by these nurses. S/he will often have a greater training in such problems and anxieties arising from having a stoma than most doctors.

Everyone should know when things are not going right and when they ought to contact their stoma care nurse or doctor.

Mention has been made of the danger of an overactive ileostomy which is pouring out large quantities of fluid. This is a condition which needs careful watching, although the majority of such episodes settle very satisfactorily. On occasions, as has been said, it is necessary to replace the loss of salt and water by an intravenous infusion.

Therefore, it is advisable to report any such episode to the doctor so that s/he can keep an eye on things.

Similarly, episodes of pain, prolapse (protruding) or retraction (indrawing) of the stoma should all be reported. In most cases, no action will be required, but a stoma care nurse or doctor can assess the seriousness of the condition much better if s/he has been able to see how it has developed. It is difficult for them when suddenly confronted with an emergency with no previous knowledge of how it started, how quickly it has changed and how different the behaviour of the stoma is from normal.

Stoma care nurses can advise on any complications that may occur and in deciding whether a surgeon's opinion is necessary or not and with what degree of urgency.

In conclusion, the only medical problem posed by removal of the colon is that the body is less efficient in retaining salt and water.

The digestion is completely normal, but in ileostomists there may be mechanical problems caused by a narrow opening. Like everyone else, people with ileostomies vary greatly and need to be sensible in what they eat, neither being faddists, thinking that lots of things are bad for them, nor stupid and ignoring the fact that certain foods may upset them.

Medical advice should be sought for complications such as a sudden large

increase in the output, abdominal pains, retraction or prolapse of the stoma.

Although these things may happen to anyone, they are rare.

© IA (The ileostomy and internal pouch Support Group)

IA National Office
Peeverill House
1-5 Mill Road
Ballyclare
BT39 9DR
Tel: 0800 0184 724
e-mail: info@iasupport.org
www.iasupport.org