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THE ILEO-ANAL POUCH OPERATION

This guide is designed to provide background information to the operation that you will shortly undergo. It aims to supplement verbal discussion, to answer common questions and to be readily available as an *aide memoir*. It cannot cover in detail every aspect of your individual operation and may not deal with some areas that are of particular concern to you. These can be dealt with individually.

You should feel free to ask about any aspect of your care. All your questions will be answered fully, honestly and in as much detail as you wish. In the heat of the moment it is easy for questions that you intended to ask to slip from your mind. You should note on paper any questions that you may have.

What is involved?

The aim is to remove all the large bowel (colon), including the rectum. The lower part of the small bowel is then used to construct a reservoir or pouch. This forms a substitute for the diseased rectum which has been removed. The pouch is then joined to the anus. An ileostomy is then made to divert the bowel content away from the pouch until it has healed.

About two months after the operation an x-ray of the pouch will be performed to ensure that healing has taken place correctly. A small tube is passed through the anus and dye is injected as an x-ray is taken. This is a rapid and painless examination. If the pouch has healed satisfactorily the ileostomy will usually be closed twelve weeks after the first operation. A small incision around the ileostomy is usually sufficient and it is not necessary to open the previous scar.

Is an ileostomy always required?

An ileostomy is when part of the small bowel is brought up onto the abdominal wall and a bag has to be worn. A temporary ileostomy is almost always required. You will be seen by the stoma nurse before the operation and the abdomen marked.

How many operations?

For patients undergoing an elective procedure it is normal to remove the colon and rectum and create the pouch and loop ileostomy at one operation. At a second operation the ileostomy is closed. For patients who require to have their colon removed as an emergency, or who have been very ill, or who have been on high doses of medications, it may be necessary to perform a three stage procedure. At the first operation, the colon only is removed and an end ileostomy is constructed. The rectum remains in place. Three months later, when fully recovered, the rectum is removed and the pouch constructed and protected with the loop ileostomy. A third operation to close the loop ileostomy is performed three months later.

Before the operation.

It is important that we know every medical issue that might affect you. What may appear unimportant to you may be essential for us to know. In particular we need to know all the drugs you are taking. You should bring them to the hospital in their original packet. Unless advised specifically to the contrary you should take all your drugs up to and including the morning of surgery. The exception to this are blood thinning agents, such as Warfarin, and diabetic drugs. These require special arrangements. Stop any Aspirin containing drugs 10 days prior to surgery.

Once you are asleep various tubes and lines will be inserted into your veins, the bladder and through your nose into your stomach. These will be removed during the first 2-4 days following surgery.

Pain relief.

Proper pain relief is very important for both holistic and physiological reasons. Your post-operative recovery will be slower if you do not have adequate pain relief. Patients often have an understandable reluctance to take pain relieving drugs. This is a mistake and may increase post-operative complications. The principal that underlies all methods of pain relief is that the drugs work best if you anticipate the pain. A small quantity of the drug taken regularly (even if pain free at that time) will work better than waiting for the pain to occur and then taking a larger dose.

Before the operation the anaesthetist will offering you two types of pain relief. The first is an epidural anaesthetic. This requires a needle to be inserted into your back and drugs are given through a fine catheter. The alternative is 'Patient Control Analgesia (PCA). With this technique you press a button as and when you feel the pain and a small dose of the pain relieving drug is administered. The advantage of these techniques is that a small quantity of the pain relieving drug can be administered on an on-going or regular basis and prevent the pain rather than treat it after it occurs. This is by far the most effective form of pain relief. Alternatively, regular injections can be administered. This is not as effective as they are usually administered after the pain has occurred.

After a couple of days adequate pain relief can normally be achieved by oral medication. Regular panadol, regardless of whether you have pain or not, is the foundation drug. If panadol alone is not adequate, additional, stronger painkillers and/or anti-inflammatory drugs can be taken on top of the panadol for break through pain. You should use panadol for background pain relief for a week after your operation. Many strong painkilling medications contain morphine, codeine or a derivative of these drugs. One of the side effects of these drugs is constipation.

The first 24 hours.

You may be nursed in a High Dependence Unit (HDU) where you are kept under constant observation. You will be attached to various monitors and numerous observations will be performed. The physiotherapist will visit you and will ensure your lungs are clear and free of secretions and exercise your legs.

The second 24 hours.

Much as day one, but you will be sat in a chair during part of the day.

Days three to five.

Some of the tubes may be removed. You may be permitted some fluid by mouth and you may pass some flatus (wind) through the anus.

Days five to ten.

You will start eating, moving around the ward, have a bath and generally return to normal, but limited, activities. Your ileostomy will start to work but maybe a little erratic. Patients recover at different speeds and you should not be concerned if your progress appears slower than you anticipated.

Even though you have an ileostomy you may, from time to time, pass mucous or stool *via* the anus. During the first week you may pass some blood.

Going home.

You will normally return home 10-16 days after your surgery, but this will vary with your progress and home circumstances. You will obviously be tired and you should plan to rest during each day. You should avoid domestic activities for at least the first three weeks. Sitting in a high backed chair can reduce the strain on your abdominal wound as it is easier to get up out of.

Recovery over the first six months.

Over the first six weeks you should gradually increase the exercise you take. You should avoid strenuous exercise for four weeks. 'Little but often' should be your aim and a short walk two or three times a day is better than one long walk. Gradually increase the distance you walk over the next few weeks. The surgical wound has almost returned to full strength at ten days so it is almost impossible to 'over exercise' yourself to the extent that you damage the surgical area. If you feel comfortable doing a particular activity then it is very unlikely you will do yourself any harm. In general it is sudden, unplanned movements that cause problems.

At six weeks you will be only 80% fully recovered. As you start to feel better the likelihood is that you will overdo it and at this stage a couple of days of feeling well (and overdoing it) will be followed by a bad day as your body compensates. You have been warned! In general you should stop if you feel tired or if you feel pain. To fully recover to the point that you feel you have not had an operation will take three to six months, depending on your age and pre-operative fitness.

For medico-legal reasons you must not drive for four weeks.

Bathing and showering.

It is quite safe to get your wound wet with a shower or quick bath two or three days after your operation. However, long soaking baths with a Jeffery Archer novel should be avoided for at least three weeks as the wound will become soft and the scab may become infected. Adding salt to the bath will not help heal the wound and may make your skin dry and tight. After washing, pat the wound dry with a clean towel. A bath mat helps prevent slipping and a towel hooked around the bath taps can be a helpful lever when you try to get out. It can also be reassuring to have someone else in the house the first time you have a bath, even if you do not need help.

Sleep.

Changes in your routine, restricted movement, lack of exercise and wound discomfort will interrupt your normal sleep pattern or wake you during the night. Uninterrupted sleep is more valuable than 'cat-napping' so you may find it helpful to take a pain killer before you go to bed. You can resume sexual activity when this feels comfortable.

Eating.

Your appetite will not be good for some weeks after surgery and you may feel aches, bloating and indigestion after meals. These symptoms usually disappear as you become more active. You should take small, frequent meals with a good intake of protein (lean

meat, dairy produce, fish *etc.*). A small amount of alcohol can improve your appetite and is not usually harmful.

The wound.

Wounds progress through several stages of healing. You may experience:-

- unusual tingling, numbness or itching sensations.
- a slightly hard or 'lumpy' feeling as new tissues form.
- pulling around the stitches or staples as the wound heals.

This is normal. Do not pull at any scabs as they act as a natural dressing and protect the new skin underneath. They will fall off when no longer required. You should seek help if any of the following occur:-

- the wound pain increases
- the wound becomes more reddened or swollen
- there is any discharge from the wound.

Work.

Your return to work depends on many factors, including your occupation, age and general health. You will definitely require one month off work, but many will require up to two months and some may require a third month. It is better to feel completely well before you return to work rather than have to take more time off a few weeks or days later because you have returned to work too early.

At six weeks you will be about 75-80% back to your pre-operative state. It will take three to six months to be 100% recovered.

Your post-operative bowel habit.

This operation removes the colon and rectum. The rectum is then replaced with a small bowel pouch. The small bowel pouch does not have some of the important characteristics of the rectum, such as the ability to store faeces. Immediately after the ileostomy is closed, the pouch may work six or more times per day.

The functional results following a pouch are not always perfect. There may be episodes of urgency and occasional episodes of incontinence of either flatus (wind) or faeces. Understandably, patients find these problems distressing, but they do improve enormously over the first three months and even further over the next six months. Some patients notice an ongoing improvement for up to two years. Depending on your individual circumstances it may be necessary to prescribe some Imodium to help you.

Detailed information on how to improve your post operative bowel habit is available on a separate advice sheet.

Surgical trainees.

Some patients may have part of their operation undertaken by a surgical trainee. A trainee is normally, but not always, under the direct supervision of the consultant. It is important that, as part of their training, trainees gain independent experience whilst consultant cover is still immediately available. There is a substantial body of surgical literature that shows the outcome of operations undertaken by properly supervised trainees is no worse than those performed by the consultant.

What can go wrong?

You will be undergoing a major operation. Major operations are sometimes complicated by adverse events. That said, the surgeons, anaesthetists and nurses caring for you have an extensive experience in what is, to them, a routinely performed operation.

It is unusual for patients undergoing this surgery to die as a result of their operation. Most patients undergoing this procedure are young and if patients have significant pre-existing medical problems, it is not usually appropriate for them to have this operation. However, previously fit patients may develop a heart problem or blood clots in the legs as a direct consequence of this operation.

There are two potential major problems specific to the pouch procedure. The first is a leak where the bowel was joined (the anastomosis). This is a serious complication (5-10% chance) and may require a second operation as an emergency.

The second potential problem is damage to the nerves in the pelvis that supply the bladder and genitals. The whereabouts of these nerves is known and every effort is made to avoid damaging them. On other occasions their post-operative function appears compromised even though there was no evidence that they were damaged during the operation. Studies have shown that even if the nerves are shown to be working at the end of the operation, patients may still be impotent.

If the nerves are damaged there may be problems with micturition and, in men, impotence. The available data regarding nerve damage is not of high quality. The best available information suggests that in men under 50 years the risk of partial or complete impotence is probably less than 10%. For those aged 50-60 years the risk of partial impotence is 40% and total impotence is 10%. For men aged over 60 years the risk of partial impotence is 10% and total impotence is 40%. The equivalent damage in women is vaginal dryness. Less commonly, damage to these nerves can lead to problems emptying the bladder.

Other complications are possible, as after any surgical procedure. These include drug reactions, post-operative bleeding, deep vein thrombosis, heart and lung complications and wound infections. This list is not exhaustive and if you have any concerns about the possible side-effects or complications you should ask about them before you sign the consent form.

The long term results.

The function of the pouch usually continues to improve over many months. The aim is to reach a situation where the pouch opens four to six times a day, no medication is required, there is no activity at night and there is no leakage or incontinence. This is obtained in 60-70% of patients. In 20-30% of patients, the result is not as quite as good in that the pouch may work more frequently during the day, higher doses of medication are required, there is activity during the night and there are small episodes of incontinence. In women, there may be discomfort during intercourse because the surgery passes close to the posterior vaginal wall.

In about 10% of cases there is a poor outcome in that the pouch function is not good, even with high dose medications and patients are up two or more times during the night and they need to wear a pad 24 hours a day. In a small number of patients (less than 3%), the pouch function is so poor that an ileostomy has to be raised or the pouch removed.

Pouchitis

Some patients may develop inflammation of the pouch. This appears to be similar to the inflammation seen in ulcerative colitis. The cause of the pouchitis is not known. In the majority of cases, a course of Flagyl (an antibiotic) is sufficient to settle the pouch. In some cases it may be necessary to give repeated courses of Flagyl. In a small number of patients, continuous medication is required. Probiotics may help some patients.

How will my lifestyle will be affected?

The vast majority of patients with an ileal pouch return to a near normal lifestyle within a few months. This includes participation in all their previous activities, including sport and

travel. Patients with a pouch should take care if traveling to countries where they are likely to get diarrhoea. They will be susceptible to infective diarrhoea and the consequence will be more dramatic. Every precaution should be taken to ensure that water and food is clean and anti-diarrhoeal medications should be carried. It would be wise to ensure that you have adequate health insurance.

Can I have children?

The pouch procedure is frequently performed in young women who wish to have children. Many women have had children following the pouch procedure. However, any operation in the pelvis does have the potential to compromise the ability of women to conceive naturally. Occasionally assisted contraception may be required. During the pregnancy the pouch may work more frequently, particularly during the night.

Many women with a pouch have delivered their child by normal vaginal delivery. However, this is a matter that should be given serious consideration. As indicated above, continence can be a problem following construction of a pouch. The integrity of the anal sphincters is crucial to continence. Even after a normal, uncomplicated vaginal delivery, the anal sphincters never return to the status they were before birth. In pouch patients this may make the difference between perfect and imperfect continence. For that reason many surgeons who perform pouches recommend an elective caesarian section. This is a matter which should be discussed with your obstetrician and with the surgeon who constructed the pouch.