Patient Information Leaflet

The Antegrade Continence Enema (ACE) operation

The Burdett Institute of Gastrointestinal Nursing

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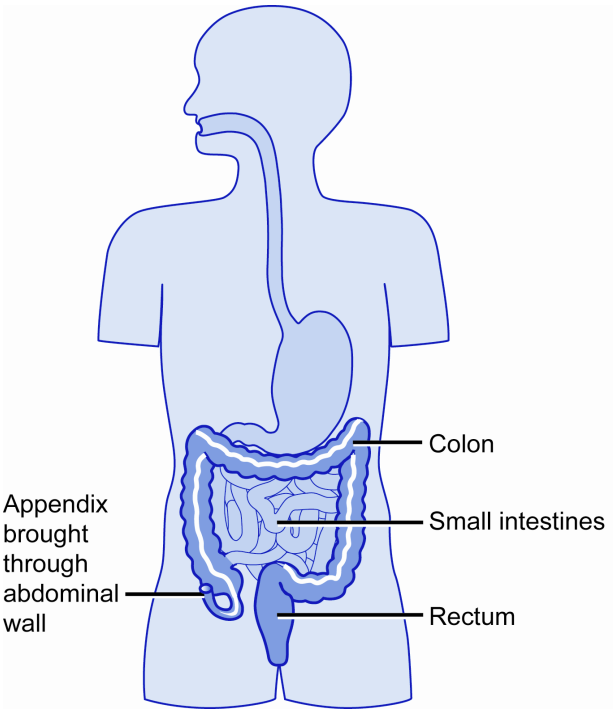
What is an ACE?

"ACE" stands for **antegrade continence enema**. This is a relatively new operation, designed to help with emptying the bowel. It is done for two main reasons - either because you are constipated and cannot open your bowels easily, or because you are troubled by leakage from the bowel. Some people have both problems.

The ACE operation makes a small passageway between the skin of your abdomen (usually low down on the right side) and your colon (large intestines: see diagram). The passageway is made from your own appendix (if you have one), or a small tube of bowel (if your appendix has already been taken out). This is brought onto the surface of your skin in a small opening or *ACE stoma*.



How will an ACE help me?

You can use the ACE to introduce an enema or fluid (usually both) into the bowel to stimulate it to empty. Because the washout is introduced into the right side of the colon, the whole length of the colon will usually empty, and you should not need to have another bowel action for a day, or even longer. If your problem is bowel leakage, this should mean that the bowel is empty and so there will be no stool down in the rectum to leak. If you were constipated, this should enable you to empty regularly and so avoid the discomfort associated with a full bowel.

Most people use their ACE once each day. A few people only need to use it every other day. Having an ACE does not mean that you will no longer have to spend time managing your bowels - it can take from 30 minutes to an hour for each irrigation from start to finish - so you should only consider this operation if you are prepared to spend this amount of time each day to empty the bowel.

What will happen in hospital?

You will probably come into hospital the day before or on the morning of the operation. It is important that the bowels are rested after this operation, so you may be given some medicine to make sure that you bowel is empty. Blood may be taken for routine tests as done before any operation if this has not been done at a “pre-assessment” visit. You will be asked some questions about your general state of health by the nurses and doctors on the ward, and this is a good time to discuss any further questions that you have about the operation.

You will be given some white stockings to wear during and after the operation and an injection each day. This is to help prevent blood clots in your legs.

What will happen when I come back from the operating theatre?

You will have a dressing in place over the wound on your abdomen, a drip in your arm and a catheter to drain your bladder. Some discomfort is to be expected. Painkillers are available and will be given regularly at first: please ask your nurse if you need something to help with discomfort.

When you are awake you will be able to start to take sips to drink, gradually increasing this until you can drink as you wish. When you are drinking well the drip in your arm can come out. You will usually be able to eat a light meal the next day. The catheter will usually stay in your bladder for one to three days. Your stitches or clips will be taken out about day seven.

The new ACE will usually have a catheter (tube) with a spigot into the stoma to ensure that the ACE does not heal over (see diagram). This catheter has a balloon on the inside end which is filled with water to make sure that it does not fall out. This will stay in for four to six weeks. It will be removed when you come back for your outpatients appointment and you will then be shown how to introduce an in/out catheter to administer the enema and/or washout.

Irrigation in hospital

From the fourth day after your operation washouts are usually started. Sometimes this is delayed by a few days if the surgeon feels that your bowel needs a little more time to heal.

With you sitting on the toilet, a nurse will insert a small amount of phosphate enema into the catheter using a bladder syringe. After waiting a few minutes, a small amount of salt water (saline) will be put in. There may be a resulting bowel action passed into the toilet within five to 10 minutes. If not, don't worry! Your bowels were completely cleared before the operation and you have not been eating very much. The nurse will give you a pad to wear as a precaution, as results can be a little unpredictable in the early days and you may leak some fluid from your back passage.

Some people experience some abdominal cramping with the enema. Again, don't worry too much about this - it will take your body a while to get used to the washouts.

Each day the amount of enema and saline put into the catheter will be increased a little, until you get the expected result - a bowel action in the toilet. You will be shown how to do the washout for yourself as soon as you feel up to it.

Irrigation at home

It is often a case of trial and error to find the right washout programme for you. Everybody's bowels are different, and there is no way of predicting what will work best for you. You may well go home before things are working perfectly, and often it is only once you are in the comfort and privacy of your own home, using your own bathroom, eating your own food and getting back to you normal life and activities that a routine will become established.

Most people find it convenient to irrigate the ACE in the evening as things are less rushed than in the morning, and there are usually fewer people trying to use the toilet at this time. Choose whatever time of day best suits you, it really does not matter, as long as you get into a routine and do it at approximately the same time each day. Half an hour after a meal is a good time, as the colon often has increased activity after you have eaten and so you maximise the likelihood of good bowel clearance. You will give your bowel the best chance of establishing a pattern if you do not vary the time too much.

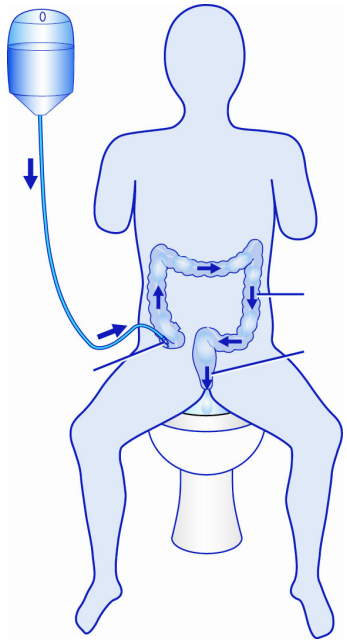
Don't expect too much too soon. It is likely that you have had a bowel problem for a long time, and things may not work perfectly from day one. Once you are home you can gradually increase the volume of enema and/or water until a satisfactory result is obtained. Experiment with different combinations of enema and saline. It is fine to use up to a whole enema. Most people substitute tap water instead of saline once at home.

Once larger volumes are used, you will usually find it more convenient to use an irrigation bag instead of a syringe for the water (see diagram). If you use an irrigation bag you should put the water in it before you start and run a little through the tubing so that you do not get an air lock. You will often need to be a bit inventive to find a way of holding up the irrigation bag next to your toilet. A hook or coat hanger onto a wall or shower rail may be possible. Others have rigged up camera tripods or other home-made devices! Most people end up using 200-500mls of water, but some use a litre or more of water and it is often trial and error to find the best for you. Don't be afraid to experiment!

For most people it will take 10-15 minutes to run the fluid in. Some people find that their bowels start to open almost immediately, others have to wait for up to half an hour. If nothing happens, try walking around a little or gently massaging your tummy as this can get the bowels moving.

As we have said, the indwelling catheter will be taken out at your follow-up appointment 4-6 weeks after your operation. You will then need to introduce an in/out catheter into the ACE to irrigate. Some people find the idea of putting a tube into the ACE a little worrying. But there is really no difficulty with this - you should not feel the tube going in, it should slip in easily as the lining of the bowel is moist (a bit like the skin inside your mouth), and you cannot do any damage. The catheter is soft and flexible and will simply bend around if it hits the bowel wall. You may need to push gently to get past folds in the bowel wall, so do not be afraid to apply steady but gentle pressure if you need to when putting the catheter in.

Sometimes introducing the catheter will cause the bowel to contract, so that you cannot get very much of the catheter in. It is best just to wait a minute or so as this contraction will pass off. There is no rule about how far to insert the catheter. About six inches is fine for most people, but a few get leakage of water around the catheter unless they put it further in. You will need to hold the catheter in place as the natural activity of the bowel will tend to push it out.



Once you are back to your normal activities, there should be no restriction to what you can do because of your ACE. You may feel more confident with a small dressing or stoma cap over the ACE in certain situations such as sport, swimming or during sex, but this is entirely up to you.

How long should I stay off work?

The time taken to get back to normal activities varies a lot for different people. Do as much as you feel comfortable doing. If you need to take painkillers these may make you drowsy, so you should avoid driving or operating machinery. If lifting causes you discomfort you should avoid it.

Most people need about four weeks off work, but this will depend a little on what you do, and it is important for you to pay attention to your body, and only do as much as you feel able.

You should try to avoid excessive walking or sitting still until your wound has healed. It would also be unwise to go swimming until the area has completely healed. You can resume sexual activity as soon as this feels comfortable.

Equipment needed at home for the ACE

- *Intermittent (nelaton) catheters.* Any make is fine. Size 12fg, standard male length suits most people. You can wash the catheter and re-use it for up to one week.

- *Enemas* Standard Phosphate enemas (not micro enemas) work best for most people.

- *Bladder Syringes* The enema should fit directly into the catheter, but you may find that a syringe with a catheter tip easier for small amounts.

- *Irrigation bag and tubing*

Those we use are:

Dansac water container with hinge (Code 95200-0000)
Dansac tubing with connector (Code 95215-0000)
Dansac regulation clamp (Code 95210-0000).

OR:

Coloplast stoma irrigation bag (Code 1511, comes with its own tubing and regulation clamp).

All of the above items are available on a GP's prescription from your pharmacy. They are unlikely to hold a stock of all items, so do not wait until you have run out to order more!

Making the saline

At home you will need to make your own saline if you do not choose to switch to tap water. Do this by dissolving one level teaspoon of ordinary household salt (not low salt alternatives) in 500mls of boiled water. Make sure that you allow the saline to cool completely before you use it to irrigate.

Are there any long-term problems with an ACE?

The honest answer to this is that we do not know what is likely to happen in the distant future, as this is a new operation, particularly in adults.

A few people find that the ACE simply does not work - either irrigation does not lead to a predictable bowel emptying, or there is still some soiling between irrigations. It is important that you understand that we cannot guarantee how your body will respond to ACE irrigation when deciding whether to have an ACE operation. If you do not get good results, we will obviously work with you and make every attempt to make it work. If at the end of the day we fail, you will not usually need to do anything about the ACE. You can simply stop using it, although it would be possible to close the ACE if it were causing you problems.

At the moment it seems that the main problem, experienced by a few people, is that the ACE has a tendency to close up with time, especially if you do not use it regularly. For this reason we recommend that you pass a catheter into the ACE every day (even if you are not irrigating every day). All you need to do is slip the catheter in and take it straight out again - there is no need to leave it in at all. If you do notice that the ACE is getting tighter, or that it is difficult or uncomfortable to pass the catheter, please let us know sooner rather than later. Do not wait until the ACE has healed over completely.

Your surgeon will try to make sure that your ACE is continent, and does not leak stool, fluid or gas. A few people find that there is some minor leakage, especially immediately after the washout. This is more likely if a length of bowel rather than the appendix has been used for your ACE (the appendix has some natural “non-refluxing” tendencies). If you do get a little leakage, you may prefer to wear a stoma cap over your ACE as this will collect any leakage and filter out any smell from wind. If wind is a particular problem, you may need to try cutting out foods which cause wind for you (fibre-rich foods produce extra wind for a lot of people).

It is possible that your bowel may stop responding to irrigation with time. We do not yet know how likely this is. If this does happen, we can always try different fluids, or different amounts.

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