

The Children's Hospital

Antegrade Continence Enema

Information for patients and carers



What is an antegrade continence enema (ACE)?

ACE is a procedure where the bowel can be emptied by passing fluid through a surgically created tube or 'tract', from an opening on the outside of the tummy directly into the bowel. This flushes water through the bowel and gives your child more control over when they have a bowel movement. When the bowel is empty, your child is less likely to experience soiling.

Why does my child need this operation?

Your child's Consultant Surgeon will have discussed with you the reasons why this operation might help your child. We would normally only offer an ACE when all other forms of treatment to control soiling or constipation have been tried. It may also be suggested as a bowel management method:

- if your child has had operations on their anus or rectum for reasons such as Hirschsprungs disease or ano-rectal malformation
- if your child has a neuropathic bowel (loss of sensation in the nerve pathways) due to spina bifida or trauma
- if your child has severe constipation and no other treatment has helped.

It can be difficult to decide whether your child should have this operation; it will mean that you and your child have to be committed to a routine of daily bowel washouts. Take time to ask questions and think about how this routine will fit into your lives.

What does the operation involve?

The operation is carried out under general anaesthetic. This means your child will be asleep throughout the operation.

Your child will normally be admitted on the day of their surgery. You will need to come to Level 1 of the Children's Hospital at the John Radcliffe Hospital.

Please make sure that you follow the fasting (starving) instructions which should be included with your appointment letter. Fasting is very important before an operation. If your child has anything in their stomach whilst they are under anaesthetic, it might come back up while they are unconscious and get into their lungs.

If your child has any medical problems or allergies, please tell the doctors before they come for their operation. Please also bring in any medicines your child is currently taking.

Your child's surgeon will talk to you when you arrive, to explain the operation in more detail and discuss any worries you or your child may have. They will then ask you to give permission for the operation to go ahead by signing a consent form. If there is anything you are still unsure about, please ask the doctor before signing the consent form.

The anaesthetist will also visit you to tell you about the anaesthetic and pain relief after the operation.

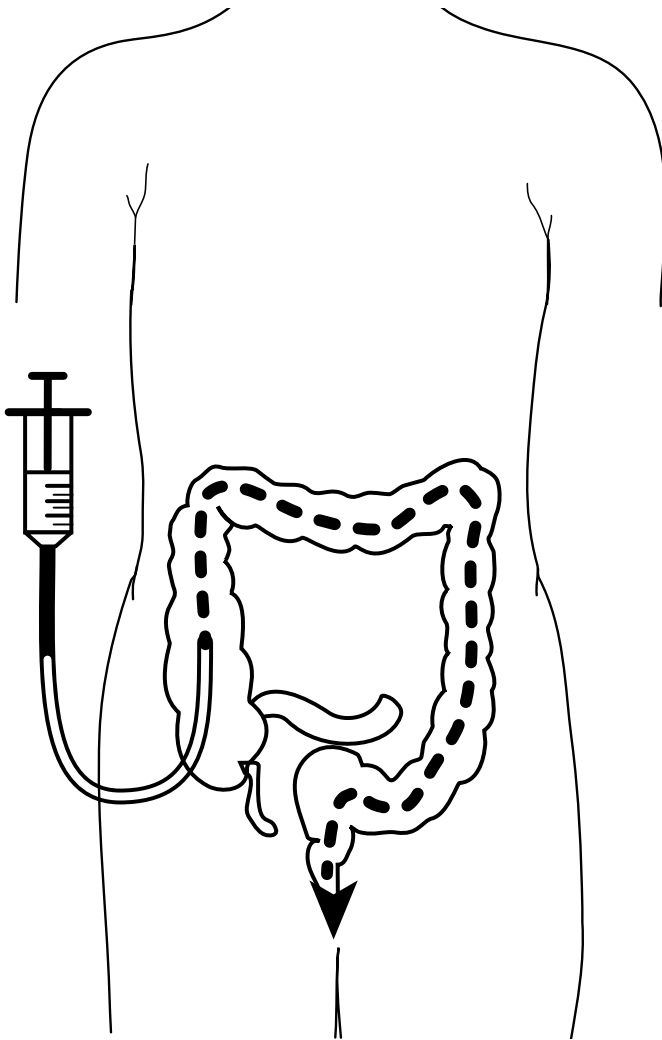
How is the operation carried out?

During the ACE operation the surgeon will make a small tube (tract) that links your child's bowel to the outside of their tummy. This opening is called a 'stoma'. If your child still has their appendix this will be used to make the ACE tract. If not, a part of their small bowel can be used instead.

The operation is usually carried out laparoscopically, which means there will be only small cuts made to your child's abdomen (tummy). The surgeon will then use special narrow tools to carry out the operation.

The appendix or bowel will be made into a small tube and the tip of this will be brought out to the surface of your child's abdomen. It will be secured with dissolvable stitches. The other end will remain in the part of the large bowel known as the caecum.

A very narrow tube, called a catheter, will be inserted into the opening and will stay in place for the next 3-6 weeks. This allows the ACE tract to heal well around the tube and helps to keep it open, like a tunnel.



What are the risks?

All operations carry some risks. These will be explained to you in detail before you sign the consent form. However, the risks from this operation are low. The most common risks are:

- bleeding
- infection.

Anaesthetic

After having a general anaesthetic, most children recover quickly and are soon back to normal after their operation and anaesthetic. Some children may suffer side effects like sickness and a sore throat. These usually last only a short time and there are medicines available to treat them if necessary.

The exact likelihood of complications depends on your child's medical condition and on the type of surgery and anaesthesia they need. The anaesthetist can talk to you about this in detail before the operation.

In the anaesthetic room

A nurse or play specialist and one parent/carer can go with your child to the anaesthetic room. Your child can also take a book or game with them.

It may be possible to give the anaesthetic with your child sitting on your lap. Your child will either have anaesthetic gas to breathe, or an injection through a cannula (a thin plastic tube that is placed under the skin, usually on the back of the hand). Local anaesthetic cream (EMLA or Ametop, sometimes known as 'magic cream') can be placed on their hand or arm before injections so they do not hurt as much. It works well for 9 out of 10 children.

If the anaesthetic is given by gas, it will take a little while for your child to be anaesthetised. They may become restless as the gases take effect. If an injection is used, your child will normally become unconscious very quickly indeed. Some parents may find this frightening.

Once your child is asleep you will be asked to leave promptly so that medical staff can concentrate on looking after them. Your child will then be taken into the operating theatre to have the operation. The anaesthetist will be with them at all times.

What happens after the operation?

When your child wakes up and is ready to return to the ward, a nurse will take you to the recovery room to help collect them. Your nurse will make regular checks of your child's pulse, temperature and wound. They will also make sure your child has adequate pain relief to keep them comfortable.

Your nurse will use a pain assessment tool to help assess your child's pain score after their operation. This is a chart that helps to gauge how much pain your child may be feeling. You and your child will be introduced to this assessment tool either at your child's pre-assessment visit or on the ward before their operation.

Recovery from the anaesthetic

Once your child is awake from the anaesthetic they can start drinking but may need a 'drip' into a vein in their arm overnight, to make sure they are getting enough fluid. If they are not sick, they may also be able to have something to eat.

It is likely that we will be able to start the bowel washouts on the day of the surgery, particularly if your child's bowel is very full of faeces. We will show you how to do the washouts, so that you are comfortable doing them when your child returns home.

Whilst the catheter is in the ACE tract, your child may need a dressing around the catheter and the wound. This helps to protect the area while it is healing. The ward nursing team will show you how to clean the wound and apply this dressing.

Most children will go home within two days of surgery. Your child will need two weeks off school after the operation. They will need to wait four weeks before taking part in active play or sports. Your child can return to swimming after about four to six weeks, once the wound has healed well.

We will arrange to see your child six weeks after the operation for a follow-up outpatient appointment with the surgical team.

In between this time, your child will also have regular appointments to come to see the Specialist Nurse, to check on how the wound is healing. The Specialist Nurse will also show you how to change the catheter, once the opening in their tummy has healed. When the catheter is removed it will leave a very small hole (about 3-4mm). You will be shown how to insert a new catheter into this hole to continue with the washouts.

When the ACE tract isn't being used, you can insert an ACE stopper into the hole. This helps to keep the tract open so that it is easy to use.

Changing the catheter is a painless procedure and easy to do. You will soon feel confident in doing this every day.

Looking after the wound and ACE tract

The washouts

Following the formation of the ACE tract you will need to carry out the ACE washouts every day.

Warm water is used for the washouts. Use a syringe to gently push the water through the catheter into the bowel. Start off using small amounts and gradually increase the volume of water used until your child's bowels are effectively emptied, with no soiling between the washouts.

Movicol is a laxative which can also be used before the main washout to change the consistency of the stool, helping to achieve a good washout. Your child can either take this as a drink or it can be put straight into their bowel through the catheter.

Your child will need to sit on the toilet during the washout until their bowel is empty. This can take between 20 to 45 minutes. It may be worth buying a padded toilet seat and a foot stool so that they are more comfortable whilst sitting on the toilet.

It is helpful to do the washout at the same time each day, to establish a pattern. Half an hour after a meal can be a good time as the bowel then has an increased activity level. This may help to clear the bowel more effectively.

The washouts can take a few weeks to get right, so don't worry if you don't have perfect results immediately.

You will be shown all the equipment that you need to carry out the washouts at home. You will be given a small supply of equipment to take home. You will then be given a prescription to get further equipment through your GP.

Dressing

The wound on your child's abdomen where the stoma has been formed may need to be covered with a dressing for the first couple of weeks. You will be given a supply of dressings before you go home and will be shown how to dress the wound and secure the catheter.

There may be a small amount of clear discharge or bleeding from around the ACE tract at first. This usually settles within two weeks. It is better for the skin around the ACE tract to go without the dressings as soon as possible, otherwise the skin can become sore.

If you have any worries about this you can ask the nurse at your GP Surgery for advice, or can contact the ward for support.

Washout equipment

- 1 litre jug
- Foley catheter (make sure this is the correct size)
- Spigot
- Large 50/60ml bladder syringe
- 5ml syringe
- ACE stopper
- ACE stopper dressing
- Medication (e.g. Movicol)
- Warm water – 20mls per kilogram of child's body weight (up to a maximum of 1 litre)

How to do the washout

- Assemble the equipment.
- Measure out the water and Movicol (if to be used).
- Wash your hands.
- Help your child to get comfortable on the toilet.
- Insert the catheter as you have been shown.

Remember, if you are using a catheter with a balloon, inflate the balloon with 3 to 5mls of water, and gently pull back the catheter until the balloon stops it coming out. This helps to make sure that the catheter is in the right place so that the entire bowel is washed out.

- Fill up the large syringe with the warm water.
- Attach the syringe to the catheter.
- Gently push the water into the catheter.
- Once all the solution has run in, either remove the catheter, or replace the spigot if you are leaving the catheter in.

REMEMBER TO LET DOWN THE BALLOON before you remove the catheter.

If you are using Movicol through the ACE tract, you will need to put this in half an hour before the main washout, to allow it to take effect.

After the washout

- Wash all the equipment with hot, soapy water and rinse thoroughly. Store in a clean place, ready for the next washout.

As your child grows, you may need to increase the amount of water you use, up to a maximum of 1 litre.

Common questions and answers

Q. How often do I need to do the washout?

A. Every day at first. You may then find you can reduce it to 2-3 times per week.

Q. What do I do if we have no result?

A. Leave it until the next day. Do not repeat the washout. If your child has no result again the next day, contact the Specialist Nurse or the ward nurses. Make sure your child is drinking plenty of fluids.

Q. Why does my child still have accidents?

A. If your child is soiling between washouts you may need to adjust the amount of water you are using. You could increase the amount by 100 to 200mls, but up to no more than 1 litre. Your Consultant may advise using Movicol to help change the consistency of the stool before the washout. Please contact the Specialist Nurse or ward nurses for advice.

Q. Can my child eat whatever they want to?

A. Everyone should eat a well balanced diet. If you find that some foods cause discomfort or increase soiling, try to avoid them. Making sure your child drinks enough water throughout the day is the best way of keeping their stools soft and their bowel healthy.

Q. Can my child bath or shower with the catheter in?

A. Yes, it will help to keep their skin clean.

Q. When can my child go back to school?

A. Your child can return to school usually about ten days to two weeks after the operation, if they feel that they are ready. They may still feel quite tired after the general anaesthetic and the operation, so might want to have a gradual return to school. Talk to their teacher to plan their return.

Q. Can my child play sports and go swimming?

A. Once the catheter is out and the wound has healed (after about 4 weeks) your child can gradually build back up to full activity, including sports and swimming. If your child wants to, they can use an ACE stopper or a plaster to cover the ACE tract opening when they go swimming.

Q. Can we go on holiday?

A. Absolutely! Just remember to take adequate supplies with you. Some parents have reported that when on holiday a change in the water used for the washouts can affect the results. You might want to use bottled water rather than tap water.

Q. Is my child more likely to get appendicitis?

A. No, making their appendix into a tube stops this from happening.

Q. Will there be any problems with the ACE tract itself?

A. There may be some problems, for example, with wound healing or difficulty in inserting the catheter. If any problems do occur, please contact the ward. Please do not try to fix your child's ACE tract, as this could cause a more serious problem.

Q. How do I get supplies of the equipment we need?

A. The equipment is available on prescription and can be ordered on request from your GP. It is possible to have the items delivered to your house using a Home Care delivery company.

How to contact us

If you have any questions or concerns about your child once you return home, please call us:

Tom's ward:

01865 231 264

or 01865 234 109

(24 hour)

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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