Feedback

We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment please speak to a member of staff or contact the Patient Advice and Liaison Service (PALS):

Freephone (City Hospital campus): 0800 052 1195
Freephone (QMC campus): 0800 183 0204
From a mobile or abroad: 0115 924 9924 ext 65412 or 62301

Minicom: 0800 183 0204
E-mail: pals@nuh.nhs.uk
Letter: NUH NHS Trust, c/o PALS, Freepost NEA 14614, Nottingham NG7 1BR

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Nottingham University Hospitals NHS
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Nottingham Children's Hospital

Managing your child's ante-grade colonic enema

A guide for parents and carers

This document can be provided in different languages and formats. For more information please contact:

The Children's Renal and Urology Unit
E17 Paediatric Nephro-Urology Ward
Queen's Medical Centre campus
Tel: 0115 9249924 ext. 61408
Direct line: 0115 9709408

We are here for you

Introduction

This book has been prepared to help you understand the principles of Ante-grade Continence/Colonic Enema (ACE) treatment and to offer you advice regarding the management of your child's ACE.

What is an ACE and how does it work?

ACE is designed to facilitate emptying of the large bowel.

A passage is created surgically between the wall of the tummy and beginning of the large bowel. Through this passage saline with or without enema is administered once a day which completely empties the entire large bowel in an ante-grade fashion. It takes more than 24 hours for the large bowel to gather faeces; hence the child remains clean irrespective of his or her bowel control or underlying disease. This is the underlying principle of ACE.

Why does your child need an ACE?

There are several reasons why some children may need to have an ACE.

1. Congenital structural abnormalities that your child was born with, such as malformation of the anus and rectum.
2. Nerve supply problems, as a result of spinal abnormalities such as Spina Bifida.
3. Overflow incontinence often seen in children with severe constipation.

One thing that all of these children will have in common is the inability to become clean naturally or by using other methods of management.

Your child's doctor will talk to you in detail about the reason your child requires an ACE.

Don't expect too much too soon. It is likely that your child has had a bowel problem for a long time, and things will not always work perfectly from day one. It may take up to six months to achieve a predicable routine.

Don't be discouraged if continence is not achieved immediately.

This booklet may not answer all of your questions, or give all the information you would like, so please ask your doctor or nurse any questions, as we are always willing to help.

Notes and questions to ask when we next see you

My child has tummy ache when we are carrying out the washout

Some children experience some abdominal cramping initially, if this is the case slow down the speed or decrease volume of fluid inserted as this often helps. Washout fluid which has been stored in a cold room can sometimes cause discomfort. Keeping it in a warm room can sometimes relieve this problem.

Don't be too alarmed by this as it will take your child's body a while to get used to the washouts. If problems continue contact the hospital that preformed the surgery.

The ACE stoma seems to close up in between each washout.

This can be a serious problem and we suggest you contact the hospital if this happens. We will often suggest leaving the catheter in place for 24 hours, or the use of a ACE stopper in between washouts.

When can my child start back at school?

Your child can return to school as soon as they feel ready. It is advisable to inform the school about the surgery.

Will my child be able to stop taking the oral medications?

In some cases yes, in others it may take several months if not longer before the bowel begins to respond to the washouts without any oral medication being required. Every child is different.

Can my child still swim?

Yes, but most children feel more confident with a small dressing or plaster over the top.

How is the ACE made?

The purpose of the operation is to create a catheterisable channel from the tummy to the beginning of the large bowel. This can be done in a several ways:

1. The surgeon will use your child's appendix to make a channel (passageway) from the bowel and onto the skin's surface on the tummy wall (Figure 1). The stoma (the end that opens on the skins surface) will not need a bag, and will not generally leak (Figure 2).

Figure 1

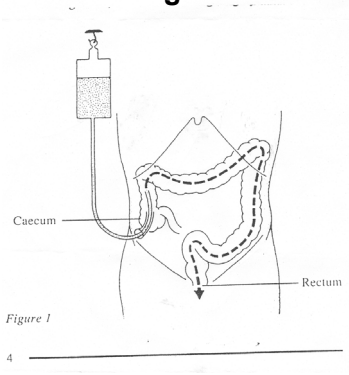
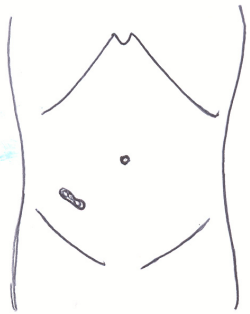


Figure 2



2. In children whose appendix is absent, a piece of bowel can be used to create a similar channel (Figures 3 and 4).

Figure 3

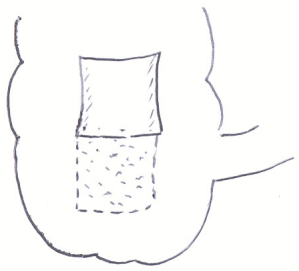
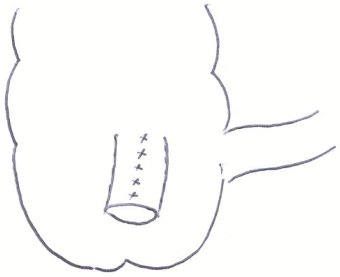


Figure 4



3. A button or a catheter can be inserted directly into the beginning of the large bowel (Figure 5).

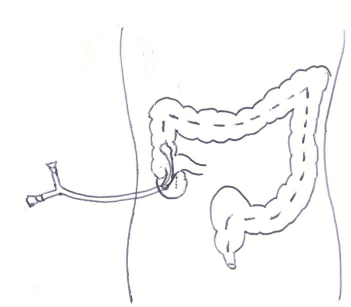
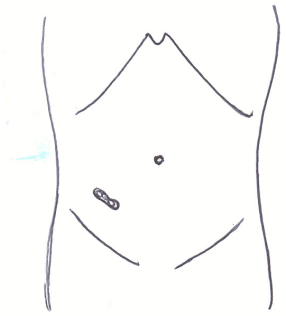
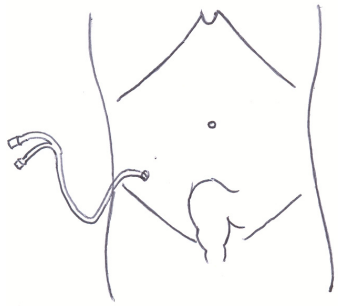


Figure 5

A **button** is a small plastic tube with a cap on. It is inserted through the ACE and usually stays in place all of the time between washouts.

A **catheter** is a small plastic tube which is inserted usually at the time of the washout and then removed after. In between the use of the ACE there is no plastic device through the stoma.





Your doctor will explain fully which method is preferable to your child.

If your child has a button then it is normally recommended that it is changed once every six months. However it can be removed and washed in warm water anytime after the first six weeks. The nurse will show you how to do this.

What is the best time to carry out the washout?

Most parents find it convenient to carry out the washout in the evening. But you can choose whatever time of day suits you best.

What is important is that you get into a good routine so try to do it at approximately the same time each day.

Some commonly asked questions

How do I get more catheters?

Your family doctor (GP) will prescribe your child's catheters and irrigation bags. Supplies can be obtained from your chemist or free prescription delivery service; both will need your prescription in good time.

New buttons can be obtained from your GP or community nurse.

My child leaks fluid rectally following the washout?

It may be that your child needs to sit on the toilet for a little longer.

In some cases it could be that your child needs a little less fluid inserted. If this is a regular problem discuss this with your nurse or doctor.

What happens next?

The prepared fluid is placed in a large irrigation bag. It is recommended that you insert a small hook next to the toilet to hang the irrigation bag.

Your child then sits on the toilet and the bag and tubing is connected to the catheter or button.

The fluid slowly runs into the ACE and after about 10 – 20 minutes a bowel action is passed into the toilet. It may take anything up to an hour to clear.

A padded toilet seat is often recommended to relieve your child's pressure areas, together with lots of in house entertainment!

Sometimes it is necessary to first add an enema, such as phosphate, into the ACE to help stimulate the bowel before adding the solution. Your surgeon will prescribe this for your child if he feels it will be necessary.

Remember – Your child's bowels are completely cleared out before the operation, so do not worry if very little is passed for the first few days.

If your child has a catheter through the stoma, when will it be removed?

When it is time for your child's catheter to be removed your child will be asked to come back into hospital and a nurse or doctor will remove it. You will then be taught how to insert a plastic nelaton catheter through the stoma.

From now on you will insert and remove the catheter for each washout.

This leaves your child free from any tubes in between washouts.

What are the advantages of ACE?

The ACE procedure allows the administration of washouts to be instilled directly into the first part of the large bowel to empty it of poo (faeces) and as a result, promote continence.

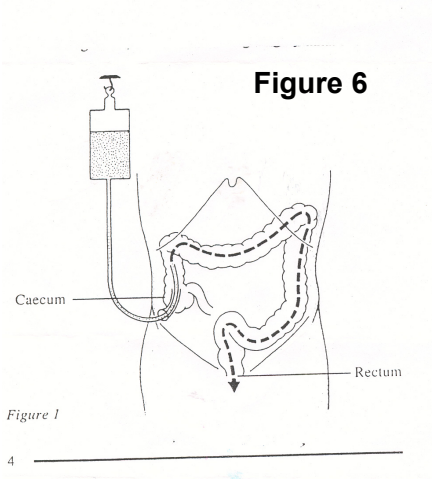
Complete faecal continence cannot be guaranteed, but we are hopeful that it will dramatically improve your child's present situation.

How will we use the ACE?

You can use the ACE to introduce an enema or fluid (sometimes both) into the bowel to stimulate it to empty (Figure 6).

As the fluid is introduced into the side of the bowel, the whole length of the bowel will usually empty. This will hopefully keep your child clean for the next 24 hours.

Figure 6



If your child's 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 and prevent soiling due to overflow incontinence.

How often will I need to carry out the washout?

Most children use their ACE once a day. A few only need to use it every other day.

It will take from 30 minutes to an hour for each irrigation from start to finish.

Please consider this carefully before your child has the operation.

What happens before the operation?

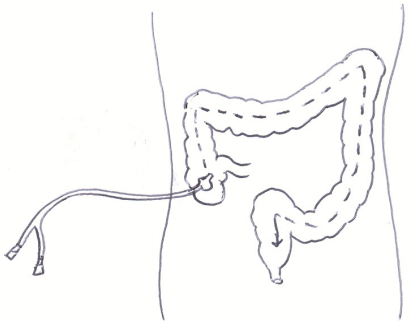
Your child **may** be admitted to hospital two days before the operation to empty the bowel prior to surgery.

This will involve taking oral medication and in some cases, enemas or even rectal washouts, in order to completely empty the bowel prior to surgery.

What happens after the operation?

Your child will return to the ward with an intravenous infusion (drip).

The new ACE will either have a catheter (tube) inserted into the stoma or a button (see figures below).



Both the catheter and the button have a balloon on the inside, which is filled with water to make sure it does not fall out.

Your child's length of stay in hospital will vary depending on the surgery required and your child's underlying problem.

When will my child have the first washout?

Washouts will usually start anytime between one to ten days after the operation depending upon individual cases and the surgeon's preference.

Your surgeon will discuss this with you when your child returns from theatre.

How is a washout carried out?

Whilst in hospital the nurse will teach you how to do this with the hospital prepared normal saline solution, but once home it is generally recommended that you make your own solution following these instructions:

1. You will need to make up a saline solution in order to perform the washout. The solution is made up of warm tap water with table salt added.
2. For every 500mls of warm tap water, one 5ml teaspoon of table salt must be added. It is very important for your child's health that you make this solution up as we instruct.

The amount of solution to be used is calculated on body weight and individual circumstances. The nurse or doctor will tell you how much to use before your child is discharged.