Laurence S. Baskin, MD Hillary Copp, MD, MS Michael DiSandro, MD Anne Arnhym, CPNP Angelique Champeau, CPNP Christine Kennedy, CPNP

ACE Malone (Antegrade Continence Enema)

What is the ACE Malone?

The Antegrade Continence Enema (ACE) is a type of surgery designed for the child who has chronic bowel problems with bouts of constipation, diarrhea, and incontinence of stool. It is most often performed in children (or adults) who have neurogenic issues with their bowel, such as spina bifida. "ACE" stands for antegrade continence enema, which essentially means enema's from above, and the "Malone" was named for the surgeon who first described the procedure. The primary goal of the surgery is to create a catheterizable channel to the bowel for administration of enemas to produce predictable bowel movements. The ultimate goal is to gain better control of the bowels in order to prevent constipation and episodes of fecal incontinence.

How is the ACE Malone Surgery Done?

Most often (if available), the appendix is used. The appendix is a portion of bowel shaped like a tube and has no known functional or anatomical use. When using the appendix, one end is brought out to the skin on the abdomen, preferably the umbilicus (belly button), and the other end is left in the bowel. The opening on the skin is called an abdominal "stoma".

If an appendix is not present (due to previous surgery or congenital absence), then a tube will be made out of a piece of bowel. One end of the tube is placed in the bowel, at approximately the site of the appendix or beginning of the large bowel, and the other end is brought out to the skin on the abdomen.

Are any artificial parts used in the ACE Malone surgery?

For the standard ACE Malone, no artificial parts are used. However, in rare situations, when there is no appendix AND there is not enough bowel to use in order to make a tube, a small silastic "button" can be used. The button is an artificial part. When using a button, the bowel is brought up to the right

right lower internal abdominal wall. Then, the button is placed with one opening in the bowel and one opening on the skin. The button opening on the abdominal skin has a "plug". Therefore, the button can be "unplugged" when it is time to do flushes and then replugged when the flushes are complete, preventing any leakage of stool.

How are the flushes administered?

There are various ways to administer the ACE flushes. The 2 most common ways are via a syringe or a bag. Both begin with placing a small plastic tube (called a catheter) through the abdominal stoma and into the bowel. Then either a syringe or a bag with tubing is attached to the catheter and the solution is administered. Please see the illustration on **page 3** and the step by step procedure **page 8**.

How often are the flushes administered?

Most often, the procedure will need to be done once per day. Occasionally, some patients remain continent and free of constipation with every other day flushes. Less commonly, a child may have to do the procedure twice per day in order to remain continent. Twice per day flushes are usually only required in patients with decreased anal sphincter tone, such as imperforate anus.

How long does it take to administer the ACE flush?

The average amount of time is 30 minutes, start to finish. This varies depending upon who is doing the flush (child alone, child with assistance from caretaker, or caretaker alone). One of the goals of this surgery is *independence* for the child, therefore, it is preferred that the child do the flush by him/herself whenever possible.



Common Surgery Questions

How long will the surgery take?

The length of time for surgery varies. It may take anywhere from 2 to 5 hours. If it takes a little longer or shorter time, do not be alarmed. The operating room nurse, who you will the meet the day of surgery, will give you periodic updates on the status of the surgery.

Where is the incision?

The incision will be on the abdomen. In most, but not all cases, it will be down the middle. However, the length will depend on the particulars of your child's surgery.

In select cases, and when the only surgery being performed is the ACE Malone, the surgery may be done **laparoscopically**. This means that the surgery is done through a special telescope through a much smaller incision on the abdomen.

What preparation must be done prior to the surgery?

Your child will be admitted to the hospital the afternoon before surgery. A complete bowel cleansing will be started as soon as you arrive. This may require having a tube placed into the stomach via the nose (nasogastric or NG tube) to administer medicine (Golytely) to clean out the bowels. It is very important that the bowel is completely "cleaned out" of stool prior to the surgery. Depending upon the degree of constipation present you might be asked to start some bowel cleansing measures at home a day or two prior to coming the hospital. Antibiotics will also be started to decrease the risk of infection.

What can I expect post-operatively?

While in the hospital the child will receive medication as needed for pain, at first through an IV and eventually by mouth. Many children will also have nerve blocks (caudal or epidural) to better minimize pain. It has been our experience that this has been a major improvement in recent years. The epidural catheter usually remains in place for about 48 hours. Younger children will be given pain medication (usually morphine) intravenously before the caudal wears

off completely. Most older children, and if your child has any spinal anomalies, are candidates for PCA (Patient Controlled Analgesia) pumps. This involves infusion of the pain medication through the IV to maintain a more consistent blood level of pain medication. Please discuss with the anesthesiologist, who you will meet the prior to surgery, what is the best form of pain control for your child.

For several days after the surgery, your child will have a tube in their nose called a nasogastric (NG) tube draining the secretions from their stomach. This is done because the bowels go to sleep after the surgery and do not function normally. Without the NG tube in place immediately after surgery, your child would experience a large amount of nausea and vomiting. This tube allows the bowels and stomach to recuperate and heal properly. During this period, your child will not be able to eat food. They will be receiving IV fluids to prevent dehydration. Once the NG tube is removed and the bowels begin to function, your child will be started on a liquid diet and advanced to a regular diet as tolerated.

Flushes will be started after the NG tube is out and the bowel begins to wake up. Initially the volume of the flush is small and then is gradually increased as tolerated on a daily basis. A schedule for the flushes, including the amounts and the type of solution, will be discussed prior to discharge from the hospital. We will make sure you feel comfortable and are fully capable of handling the flushes and trouble-shooting if there are problems. You will perform an actual "flush" prior to discharge.

Are any tubes left in place after we are discharged from the hospital?

Your child will have a catheter (plastic tube) in the abdominal skin stoma after the surgery. The end of the tube will be curled up and taped to the skin on the abdomen. This tube is left in place in order to keep the skin stoma open while wound healing occurs. In other words, this prevents the skin stoma from healing closed. This tube will be removed about three to four weeks after surgery. Most children describe the sensation of tube removal as strange or "feeling really weird", but not painful. Of course, the tape removal can be mildly

painful, but most children are used to and can prepare for this. A small amount of reddish-brown drainage at the tube site is normal. It is also to be expected that the skin around the catheter reddens and may have pus-like secretions around it. This is nothing to be alarmed about and is a natural reaction to the catheter. The catheter site can be cleansed with soap and water daily and as needed. Before you take your child home, we will help you to feel comfortable taking care of the catheter.

If you or your child are having concurrent bladder surgery there may be other "tubes" involved.

What is the follow-up after surgery?

Your child will usually be discharged from the hospital and on his/her way home on the fourth or fifth day after surgery. Of course, if there are other surgeries being done at the same time, the stay may be longer. The catheter in the stoma will be left in place, as mentioned above. An appointment should be made for three to four weeks after surgery to remove the catheter.

At the time of your child's follow-up visit, the catheter will be removed. Then the appropriate catheter size will be chosen and we will teach you how to catheterize the stoma. Depending on whether there are other concurrent surgeries, how far you live from the hospital and other factors, you may be asked to stay overnight in the hospital to assure that the catheterization goes smoothly and in case any problems or questions arise.

What should I look for in the immediate post-operative period?

Please contact our office (24 hours per day, 7 days per week) at (415) 353-2200 if you are concerned with any aspect of your child's progress after surgery. If your child exhibits any of the following you should also call our office:

- ◆ Temperature greater than 100.5 F
- ◆ Abdominal pain not relieved by prescribed pain medication
- ◆ Excessive bleeding from the incision (some spotting or blood stains on the dressing is normal)

- If the catheter falls out
- ♦ Can not flush catheter
- Unable to take in fluids
- Continuous vomiting
- Unable to catheterize new stoma/belly button
- No stool output with ACE flushes

Please note: It is normal in the early post operative period to have stool incontinence between ACE flushes and occasional constipation. It takes time to determine the ideal flush amount, solution and schedule for each individual child. Depending upon many factors, including the underlying diagnosis, degree of constipation prior to surgery, and effectiveness of "clean out" procedure prior to surgery, you can expect continued stool incontinence and/ or constipation anywhere from 1 week to 2 months after surgery. We will be adjusting the ACE program on a regular basis over the telephone until an appropriate program is determined.

After a program has been established, what do I need to look for?

After the tube has been removed and a flush program has been well established, you should call our office (415) 353-2200 if any of the following occurs:

- ♦ Excessive vomiting
- ♦ Unable to or difficulty with catheterization of the stoma/belly button
- ♦ No stool output with ACE flushes
- ◆ If there is leakage of stool from the stoma site or from the rectum between flushes
- ♦ If you make **any** changes to the flush procedure or solution

What complications can occur with the ACE Malone surgery?

While uncommon, as with any type of surgery, there are potential risks involved. These risks vary greatly with each individual child, therefore, we will discuss potential complications and risks with you on an individual basis.

ACE Malone Procedure, Step by Step

Procedure	Helpful Hints
1. Wash hands	 Wash hands as well as possible Gloves are not needed! However, if a caretaker or friend is doing the flush, they may want to protect themselves by using nonsterile, non-latex gloves
2. Assemble equipment	 Equipment needed: Catheter Water soluble lubricant Large syringe or feeding bag Flush solution (usually water) Assemble equipment with in reaching distance from the toilet
3. Lubricate catheter tip, and while sitting on the toilet place the catheter into the stoma, through the tube and into the bowel	 Do not use force. If slight resistance is felt, it may help to twist the catheter. Each child is different and if when catheterizing resistance is met, often times it helps to aim the catheter downward. With practice, you and your child will learn how it feels when inserting the catheter. The distance the catheter should go in is different for everyone. Your individual

4. While remaining on the toilet,	distance will be described and demonstrated for you at the 3-4 week follow up appointment In most cases the flush
instill flush solution: Syringe technique - Fill large syringe with water, attach filled syringe to end of catheter, instill solution, repeat until desired amount of solution has been instilled Bag technique - Fill bag and tubing with desired amount of solution, hang bag above you, connect tip of tubing to catheter and let the solution run in	solution will be water. Occasionally, in select situations such as persistent post operative constipation or concern regarding metabolic disturbance a different type of solution may be used • There are various ways to instill the solution. We have found that the instillation via a large syringe seems to be the most effective in flushing out the stool in a timely manner.
5. Withdraw the catheter gently and slowly, remain on toilet for 20 minutes	20 minutes is usually a sufficient amount of time for complete emptying, every child is different, adjustments will be made on an individual basis
6. Wipe the anal area with toilet paper	It is important to clean the anal area thoroughly to prevent skin breakdown and to assess continence
7. Clean the catheter and equipment and store in a clean container	 You may clean with liquid soap & water The equipment is all reusable
8. Wash hands thoroughly	

See the next page for contact information.

Laurence S. Baskin, MD Hillary Copp, MD, MS Michael DiSandro, MD Anne Arnhym, CPNP Angelique Champeau, CPNP Christine Kennedy, CPNP

Contact Information:

Laurence S. Baskin, MD
lbaskin@urology.ucsf.edu
Hillary Copp, MD, MS
http://www.urology.ucsf.edu/faculty/contact?fid=505
Michael DiSandro, MD
http://www.urology.ucsf.edu/faculty/contact?fid=509

Appointments & Location

UCSF Medical Center, Parnassus Campus 400 Parnassus Avenue, Suite A-610 San Francisco, CA 94143-0330 Phone 415/353-2200 Fax 415/353-2480

Children's Hospital & Research Center Oakland 747 52nd Street Ambulatory Care 4th Oakland, CA 94609 Phone 510/428-3402

PEDIATRIC NURSE PRACTITIONERS

Anne Arnhym, CPNP

Certified Pediatric Nurse Practitioner

Pager: 415/443-0541

anne.arnhym@ucsfmedctr.org

Angelique Champeau, CPNP

Certified Pediatric Nurse Practitioner

Pager: 415/443-5632

Angelique.Champeau@ucsfmedctr.org

Christine Kennedy, CPNP

Certified Pediatric Nurse Practitioner

Pager: 415-443-0703

KennedyCE@urology.ucsf.edu