



## Follow up of children undergoing antegrade continent enema: Experience of over two hundred cases ☆☆☆



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### ABSTRACT

**Purpose:** Antegrade continent enema (ACE) procedures have been used as a treatment of constipation and soiling. Little is known about the long-term results of these procedures, particularly as patients progress into adulthood. This study presents the long-term outcomes of ACE in children, with follow up into adulthood, over a fifteen-year period.

**Methods:** A prospective database of all consecutive procedures performed from 1998 to 2013 by a single surgeon in a regional centre was analysed. Operative details and follow up by both paediatric and adult clinicians and stoma nurses were included.

**Results:** During the study period 203 ACE procedures were performed in children with a median age of 9 years 7 months (3–17). Indications included chronic idiopathic constipation (CIC) resistant to medical treatment in 62% of cases, anorectal malformation in 18%, spinal cord abnormalities in 9% and Hirschsprung's in 7%. After an average follow-up of 5.5 years (0.5–15) 132 patients were still using their ACE. 113 (93%) regularly had a good result from the procedure, 8 a variable result and 1 poor. Soiling was prevented in 79 patients (75%), partially improved in 15 and persistent in 15. Over the study period 53 patients (26%) no longer used their ACE due to resolution of symptoms. In 32 of these patients the ACE was reversed at a median interval of 5 years from formation (1–12). In 17 cases (8%) the procedure failed with significant symptoms persisting. Four of these patients were reversed and a further 11 went on to have other procedures including 5 restorative pouches and 4 stomas. Of the patients that no longer required their ACE the majority (81%) had a pre-operative diagnosis of CIC. Only 7% of ACE procedures performed for CIC failed compared to 26% for spinal cord abnormalities.

**Conclusion:** Many patients continue to use their ACE to good effect in long-term follow up. In this study over a quarter had resolution of their symptoms permitting reversal. This was more likely if they suffered idiopathic constipation.

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The antegrade continent enema procedure has been performed in both adults [1] and children [2]. Indications have included functional constipation [3] and faecal soiling [4] and it has been successfully used for idiopathic constipation and a variety of organic diseases including anorectal abnormalities, Hirschsprung's and spina bifida. Results from the first few years of follow up suggest that symptoms can be improved in 70%–90% [3,5] of patients and a number can be reversed without recurrence of symptoms [5]. However the failure rate amongst adults may be much higher [6,7].

The aim of this study was to assess the long-term outcomes of the ACE procedure performed in children. A fifteen-year experience of the ACE procedure is evaluated with follow up into adulthood.

### 1. Methods

All consecutive ACE procedures performed by an experienced single surgeon in a paediatric surgical unit taking referrals from the North East of England from 1998 to 2013 were included. Patients were referred for consideration of ACE if they had significant symptoms of constipation or soiling that had persisted despite conservative treatment. During the early experience of the procedure patients underwent measurement of colonic transit time, but this was abandoned as routine since the decision to operate was seldom influenced by the results. Similarly rectal biopsy was initially universal but, having failed to identify any cases of Hirschsprung's disease, it is now performed selectively. The decision to operate is based on symptom severity and quality of life, with child and parental preference being the major issues.

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☆☆ Contributions: J.R. completed the data collection, performed data analysis and wrote the paper, P.C. helped with data collection and reviewed drafts of the paper, B.J. maintained the prospective database, helped with analysis and reviewed drafts of the paper.

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In this series all ACE procedures involved the formation of an appendicostomy by an open or laparoscopic approach. The operative procedure became simpler with time. Initially the appendix was detached, reversed and buried beneath caecal flaps. This has evolved to laparoscopic procedure to grasp the tip of appendix, then bringing it out to skin with no valve. All cases have a skin tunnel fashioned as described in Malone's original description [8]. Where the appendix was inadequate, had been previously excised or utilised as a urinary catheterisation conduit, a neoappendicostomy was formed from a flap of caecum. During the 15-year study period there was a move towards laparoscopic formation of appendicostomies. In selected cases (particularly where the caecum was mobile and the abdominal wall was thin) neo-appendicostomies were formed laparoscopically as well.

A database was held containing patient details, demographics, pre-operative diagnosis and operative details. Outcomes were also entered prospectively and updated from surgical, medical and stoma nurse records in both paediatric and adult services. As patients moved from paediatric to adult services they were referred to surgeons and stoma nurses within the same trust. Once a regular regimen was established patients were invited to clinic yearly or could contact the stoma nurses if there was a problem.

Outcomes included continued use of the ACE at last follow up, reasons for discontinuation, reversal of the ACE and further operations required for the underlying condition including stomas or resections. Frequency of ACE use, type of irrigant used and time taken to perform the enema were recorded. The usual unit policy was to commence saline wash-out shortly after the procedure on a daily basis. If this was found to be insufficient at subsequent follow up the regimen was changed to the osmotic laxative Klean-Prep<sup>R</sup>, containing macrogol, followed by the stimulant laxative bisacodyl. The result of the enema was categorised by patients as regularly good, variable or poor. Patients were questioned about the degree of soiling at any time between enemas and any spontaneous bowel activity.

Complications related to the ACE procedure were recorded including any catheterisation problems and the need for re-operation due to complications. During the study indwelling plastic stoppers (Medicina UK) were introduced to maintain the tract. The use of a stopper was included in analysis. Wound infections requiring antibiotics and/or intervention and overgranulation requiring treatment were recorded.

### 1.1. Statistics

The chi-squared test was used to compare independent groups where the outcome was categorical, in this case proportions. A *p*-value of less than 0.05 was taken as statistical significance.

## 2. Results

### 2.1. Study Group

During the study period 203 ACE procedures were performed in children at a median age of 9 years 7 months (3–17). Indications are shown in Table 1. The highest number of procedures was performed

**Table 1**  
Indications for ACE Procedure.

Indication	Number of Cases (%)
Chronic Idiopathic Constipation	126 (62)
Anorectal Malformation	36 (18)
Spinal Abnormality	19 (9)
Hirschsprung's Disease	15 (7)
Spinal Tumour	4 (2)
Cerebral Palsy	1
Muscular Dystrophy	1
Fragile X Syndrome	1
Sphincter Injury	1

**Table 2**  
Use of ACE.

Outcome	Number of Patients	Details	Rating of outcome
Continued use	132 (65%)	Irrigant used: Saline: 62 (48%) Klean-Prep <sup>R</sup> : 38 (29%) Bisacodyl: 29 (22%) Not specified: 3	Regular good result: 113 (93%) Variable result: 8 (6%) Poor result: 1 (1%) No soiling: 79 (75%) Occasional soiling: 11 (10%) Persistent soiling: 15 (14%)
Reversed; symptoms resolved	32 (16%)		
Not used; symptoms resolved	21 (10%)		
Failed	18 (9%)	4 Reversed 10 further surgery 5 restorative pouch 1 IRA 4 stomas	

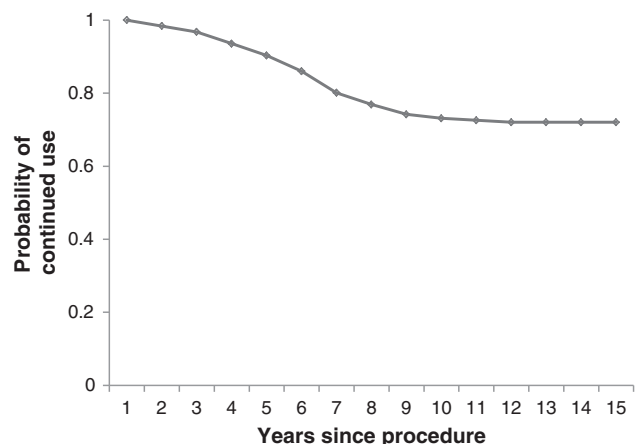
for chronic idiopathic constipation (62% of cases) defined as functional constipation with no established anatomical or pathological cause. This was usually only performed after at least three years of attempted medical treatment.

In this series 83 (41%) of the ACE procedures utilised an open approach to identify and mobilise the appendix. 114 (56%) ACE procedures were performed laparoscopically; after its introduction in this unit in 2003 this became the standard by 2005. 6 (3%) cases involved the creation of a neoappendicostomy from the caecum either open or laparoscopically.

### 2.2. Use of ACE

Median follow-up was 5.5 years (0.5–15). At last follow up 132 patients were still using their ACE as shown in Table 2. The median frequency of use was 4 washouts per week (1–7). Table 2 shows the irrigant that had been established by the last follow up. Where data were available on function in 122 patients, 113 (93%) described regularly having a good result from the procedure, 8 a variable result and 1 poor. Soiling was prevented in 79 patients (75%), partially improved in 15 and persistent in 15.

Over the study period 53 patients (26%) no longer used their ACE due to resolution of symptoms. In 32 of these patients the ACE was reversed at a median interval of 5 years from formation (1–12). The fall off in use of the ACE is shown graphically in Fig. 1. Of the patients that



**Fig. 1.** Change in use of ACE (for those that were able to use it initially to successfully manage their bowels) over time.

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