



Bladder & Bowel UK

Supporting people with bladder and bowel problems

part of Disabled Living

Understanding bowel training for children with Hirschsprung's Disease and other Ano-Rectal Malformations (ARMs)



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Introduction

Hirschsprung's Disease is a rare congenital abnormality (it is present from birth) which affects specific nerve cells, called parasympathetic ganglion cells, in the colon (large bowel).

Normally, as the baby is developing in the womb the nerve cells grow along the intestines towards the rectum. In children with Hirschsprung's Disease the nerve cells stop growing too soon. This happens before the 12th week of development and the reason for this is not yet known.

The result is that these ganglion cells are not present in the rectum and are also absent in varying degrees along the length of the colon. Absence of the ganglion cells means that signals to the bowel muscles are not sent and the colon is unable to relax - this prevents movement of stools (poo) along the colon, resulting in severe constipation or, in some cases, complete obstruction.

Anorectal malformations (ARM's) are a group of conditions where the anus or rectum are not properly formed. They include, imperforate anus where the anus is missing completely and anal atresia, where the anus is not properly formed, or in the wrong place. The rectum and large bowel may also be affected in some cases. Approximately 50% of children who have ARM's will also have other conditions, including vertebral (spine), problems, cardiac (heart) anomalies, tracheal fistula (hole in the wind pipe), oesophageal (food pipe) anomalies, renal (kidney) and limb anomalies (often called VACTERL Association).

The incidence of these conditions is about 1:5000 live births, with boys being affected more than girls.

Following corrective surgery a number of children will continue to have problems with constipation and /or faecal incontinence and will therefore require ongoing advice and support, as well as structured bowel programmes.

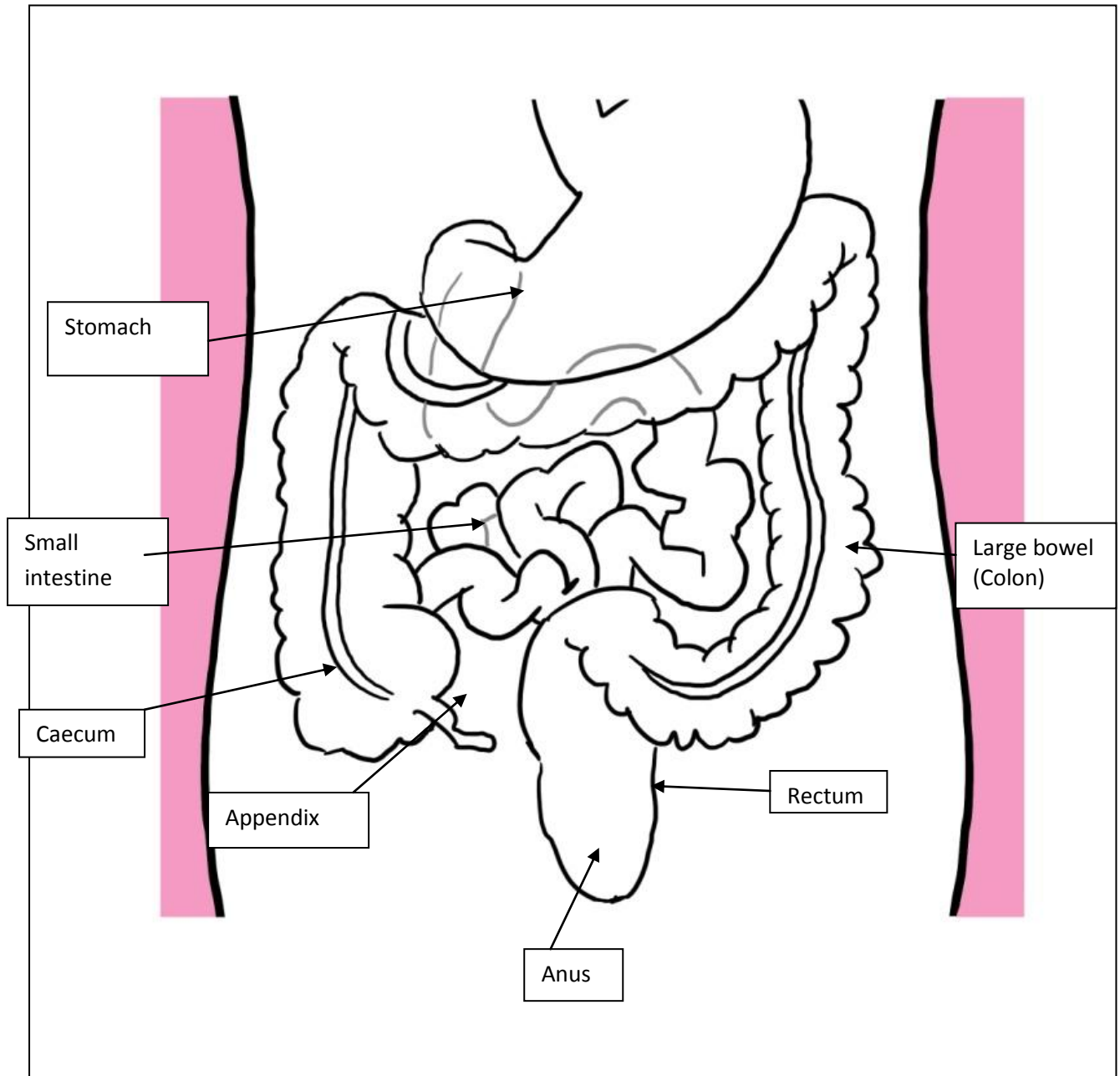
Children with Down's Syndrome and Ano-Rectal Malformations

The incidence of ano-rectal malformations, including Hirschsprung's Disease and imperforate anus, is much higher in children who also have Down's Syndrome. For these children it is particularly important to recognise that any problems regarding constipation or a delay in acquisition of bowel control is more likely to be due to the underlying ano-rectal malformation than to the Down's Syndrome.

Therefore, it is crucial that toilet training programmes are not delayed and that any soiling issues are not ignored in the mistaken belief that the delay in bowel control is linked purely to the fact that the child has Down's Syndrome.

Affected children should be closely monitored from infancy. Any bowel problems, such as constipation should be assessed and treated in a timely and appropriate fashion if they happen, so that when potty training is being considered, a bowel management programme is already in place and well established.

Diagram of gastrointestinal tract



Toilet training

Toilet training children who have ano-rectal abnormalities can seem like a challenge, because of potential ongoing bowel problems, particularly constipation and soiling. However toilet training should not be delayed solely on the grounds of either Hirschsprung's Disease (HD) or other ano-rectal abnormalities (ARMs). If there are no significant bowel problems then toilet training should be commenced as normal.

For children with Down's Syndrome, who also have Hirschsprung's Disease (HD) or other ano-rectal malformations (ARMs), toilet training can certainly seem like an almost impossible hurdle to overcome. However, it is important to remember that any difficulties relating to bowel control are more likely due to the underlying problem of HD or ARMs rather than to the Down's Syndrome itself.

It makes sense therefore to try and get the bowels in the best shape possible, prior to commencing toilet training: any constipation should be treated and any, explosive bowel movements etc investigated to see if a trigger can be found. This may mean adjusting medication or diet. It is helpful to discuss this or any other bowel problems with an appropriate health professional.



Bowel Training

Children with HD and ARMs need to commence a bowel training programme at a much earlier age than would normally be considered for potty training. Once all the surgery is completed the family should be advised to monitor the child's stools (poos) and to be alert to both the frequency and consistency of any stools passed.

If the consistency of the stools appears too loose, or too hard and infrequent then advice from a health care professional (HCP) should be sought. They may recommend medication to address the problem – either laxatives (such as Movicol Paediatric Plain) to improve the consistency and frequency of the stools if constipation is identified, or a medication to slow the bowel down (such as loperimide) if the stools are too loose and frequent. Loose and frequent stools are often associated with those children who have a problem with their stool moving too quickly through their bowel. This can be either because of increased transit time, or because they have a shortened length of bowel.

Constipation

Constipation is a very common problem in children who have ARMs. Therefore families should continually monitor both the frequency and consistency of their child's stools (poos). Parents should be alert to the problem of constipation developing – particularly if the following signs and symptoms are noticed:

- Less than three stools per week
- Difficulty or delay in passage of stool – often associated with the infant/child seen to strain
- May be associated with pain / discomfort
- Stools not necessarily hard

It is important to note that children can be opening their bowels on a daily basis and passing what appears to be soft or loose stools and still have an underlying constipation. If your child is passing stools more than 3 times per day then it would be advisable to speak with your local health care professional who can check if the frequent soiling is due to an underlying constipation.

NICE (National Institute of Clinical Excellence) makes clear recommendations about using laxatives including in children under the age of 2 years, who have often been excluded from laxative therapy in the past. Polyethylene glycol 3350 + electrolytes (e.g. Movicol Paediatric) is recommended as first line treatment although some children may need suppositories, enemas or irrigation.

NICE (2010) make the following treatment regimen recommendations for disimpaction (clearing out the bowel when it is blocked by large amounts of poo)

- Movicol Paediatric using an escalating dose regimen (gradually increase the dose) as the first-line treatment
- Movicol Paediatric must be mixed with water and then the plain one may be added to any cold drink.
- Add a stimulant laxative, such as sodium picosulfate or senna, if Movicol Paediatric does not lead to disimpaction after 2 weeks.
- Substitute a stimulant laxative singly or in combination with an osmotic laxative such as lactulose if Movicol Paediatric is not tolerated.
- families need to be aware that disimpaction treatment can increase symptoms of soiling and abdominal pain initially
- It is important that children undergoing disimpaction are reviewed within a week to check progress and adjust dosage regime if necessary

NICE also advise that rectal medications should not be used unless all oral medication has failed. Phosphate enemas should only be used under specialist supervision in hospital.

Maintenance

Maintenance therapy should start straight away for children with acute constipation or immediately after disimpaction. Available evidence and clinical experience supports the use of Movicol Paediatric as first line treatment for both disimpaction and maintenance. Although licensed from aged two years there is good evidence from case studies and clinical practice that shows it is effective in children under the age of one year (Michail et al 2004).

As a rough guide, the suggested starting maintenance dose for children following disimpaction is about half the dose required for disimpaction. However, the correct dose is that which produces the at least three soft, easily passed stools (poos) per week. Clinical experience has shown that the best way to reach the optimum maintenance dose is to slowly titrate (reduce) the dose of Movicol Paediatric down from the disimpaction dose until the optimum dose is reached.

Nice recommend the following regimen for maintenance

- Movicol Paediatric as the first-line treatment.
- Adjust the dose of Movicol Paediatric according to symptoms and response.
- Add a stimulant laxative if Movicol Paediatric does not work.
- Substitute a stimulant laxative, such as sodium picosulfate, if Movicol Paediatric is not tolerated by the child or young person. Add another laxative such as lactulose or docusate if stools are hard.
- Continue medication at maintenance dose for several weeks after regular bowel habit is established – this may take several months.
- Children who are toilet training should remain on laxatives until toilet training is well established.
- Do not stop medication abruptly: Gradually reduce the dose over a period of months in response to stool consistency and frequency.
- Some children and young people may require laxative therapy for several years, with a small minority requiring continued ongoing laxative therapy

Introducing laxatives

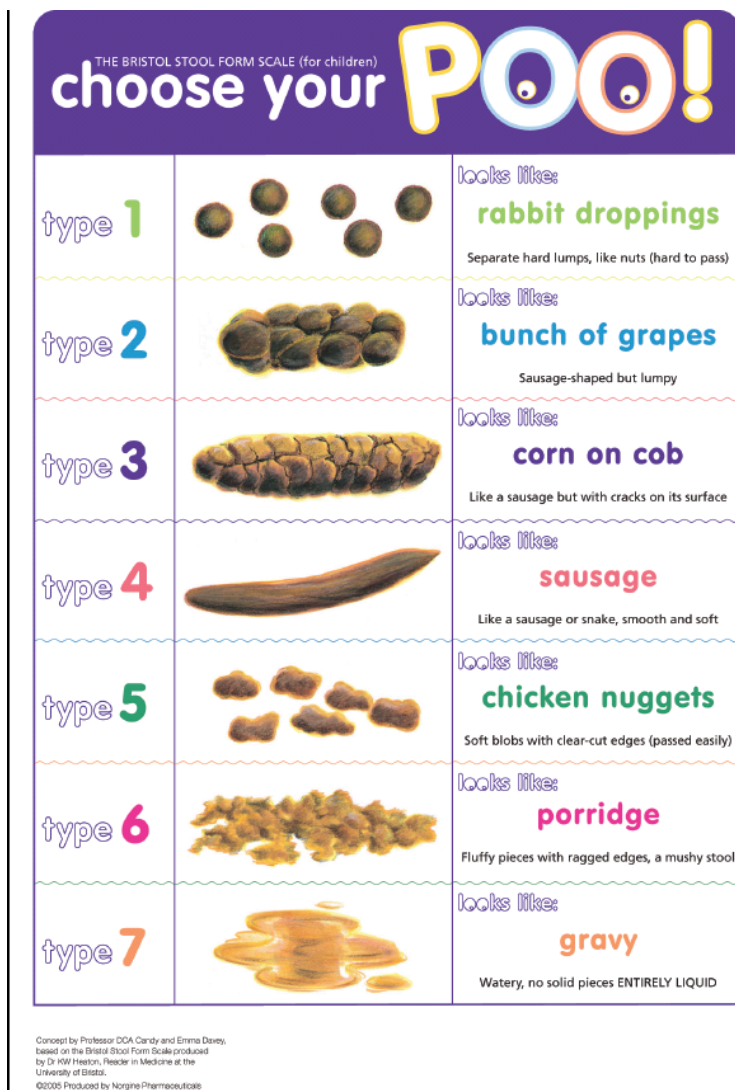
The child's stools should be regularly monitored with a note made of the frequency (how often the child is going) and the consistency - how hard or soft the stools (poos) are. An awareness of the child's 'normal' bowel habit will help ensure that problems are noticed early. The Bristol Stool Form scale is a useful tool to help monitor progress, with type 4 being the best consistency for stools (poos).

If there is any concern that the child is developing constipation then the introduction of laxatives should be discussed with the appropriate health care professional. It is generally recommended that Movicol Paediatric is the first line laxative of choice for children. In some cases the introduction of a stimulant as a second laxative is required to help facilitate complete bowel evacuations, this may be something like sodium picosulfate or senna. In all cases the dose each

child requires will depend on their response to the starting dose. The amount of laxative given should be increased or decreased in response to both the frequency and consistency of the stools.

If oral laxatives fail to fully treat the constipation and/or soiling then the rectal use of suppositories or enemas may be considered. Again, the health care professional involved should be able to advise appropriately.

The use of the Bristol stool chart below can help when adjusting the dose of any laxatives the child is taking. All children are different and you will be advised what stool consistency to aim for with your child, but as a general rule. If the poo consistency is 5-7 then consider reducing the laxatives and if the poo is type 3-1 then consider increasing the laxatives



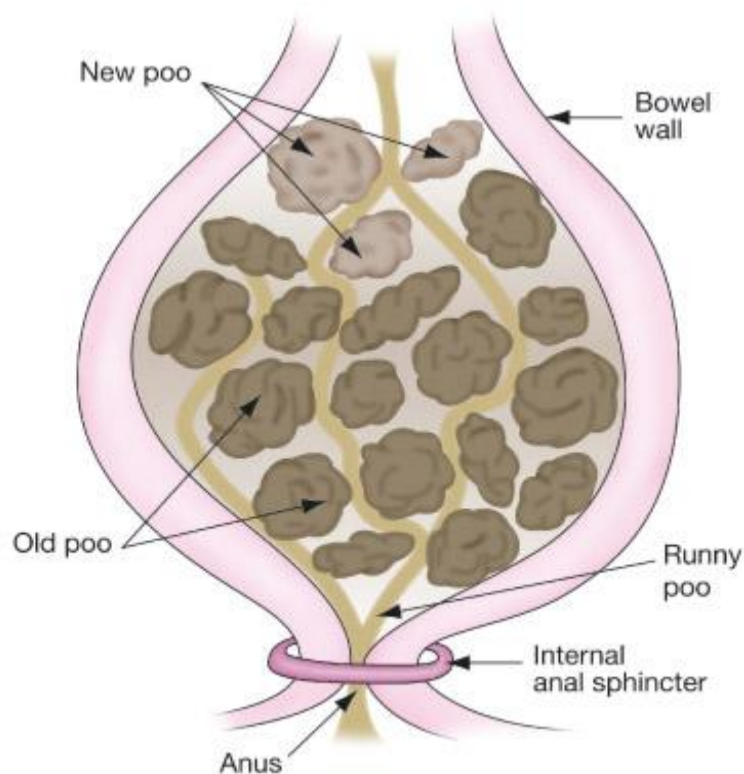
By Professor DCA Candy and Emma Davey, based on the Bristol Stool Form Scale produced by Dr KW Heaton, Reader in Medicine at the University of Bristol © Norgine Pharmaceuticals Ltd 2000

Overflow soiling

Constipation with overflow is the term applied to the condition where children soil (get poo leaking into their underwear, as a consequence of their bowel being partially blocked by faeces).

Prolonged constipation dilates the bowel and affects the normal sensations and reflex actions in the rectum and anus. Some of the stool (poo) in the bowel liquefies and bypasses the blockage caused by the build-up of hard stools. Because of the loss of normal control and sensation, this liquid then seeps out without the child being aware of it happening. Sometimes it is harder poos that break away from the larger lump and come out of the bottom, without the child realising.

This soiling can happen frequently throughout the day and sometimes can be mistaken for diarrhoea. Sometimes soiling may be the first indication that the child is constipated



Picture showing how a full rectum can lead to overflow soiling

Bowel programmes

Introducing a structured bowel training programme is important to ensure optimum bowel control is achieved.

- Introduce sitting on the potty or toilet after meals, as part of your child's daily routine. Some parents do this from the age of about 12 months
- Liaise closely with your health care professional to ensure any underlying problems with either loose stools or constipation is being addressed
- Introduce oral laxatives initially if constipation is present
- If oral laxatives are ineffective, then rectal preparations such as micro enemas or suppositories may be prescribed
- The aim is to ensure that by the time the child is in their third year (after their second birthday) they are able to achieve regular bowel movements (approximately 1-3 per day at least 3 times per week), which are easy to pass and with no soiling in between.
- If oral and rectal preparations fail to resolve any ongoing problems with constipation and or soiling, then rectal washouts should be considered

Sitting on the potty or toilet

All children with anorectal problems should be encouraged to sit on the potty or toilet after meals to make use of the gastro-colic reflex.

Encourage the child to 'push' by introducing blowing games as this will increase abdominal pressure and help the bowel empty.

Make sure the child can sit comfortably, using a seat reducer if necessary, and a step to ensure that their knees are slightly higher than their hips and their feet are flat on a firm surface.



Diet

Although there is no real evidence regarding the benefit of specific diets some parents find that different foods can affect their child's bowels and quickly learn what foods to avoid! Generally a balanced diet is recommended, with the child encouraged to eat 5 portions of fruit and vegetables per day. Any further advice specific to the individual child should be obtained from your local health care professional

Drinks

It is really important that children drink plenty of water-based fluids throughout the day. The colon is the part of the bowel that re-absorbs water and in a child with HD or ARMs it can be substantially shorter than in most children. 6-8 drinks spread evenly throughout the day will help keep the child adequately hydrated.



NICE (2010) make the following recommendation for fluid intake:

| Age | Sex | Total drinks per day |
|---------------|--------|----------------------|
| 4 – 8 years | Female | 1000 – 1400 ml |
| | Male | 1000 – 1400 ml |
| 9 – 13 years | Female | 1200 – 2100 ml |
| | Male | 1400 – 2300 ml |
| 14 – 18 years | Female | 1200 – 2500 ml |
| | Male | 2100 – 3200 ml |

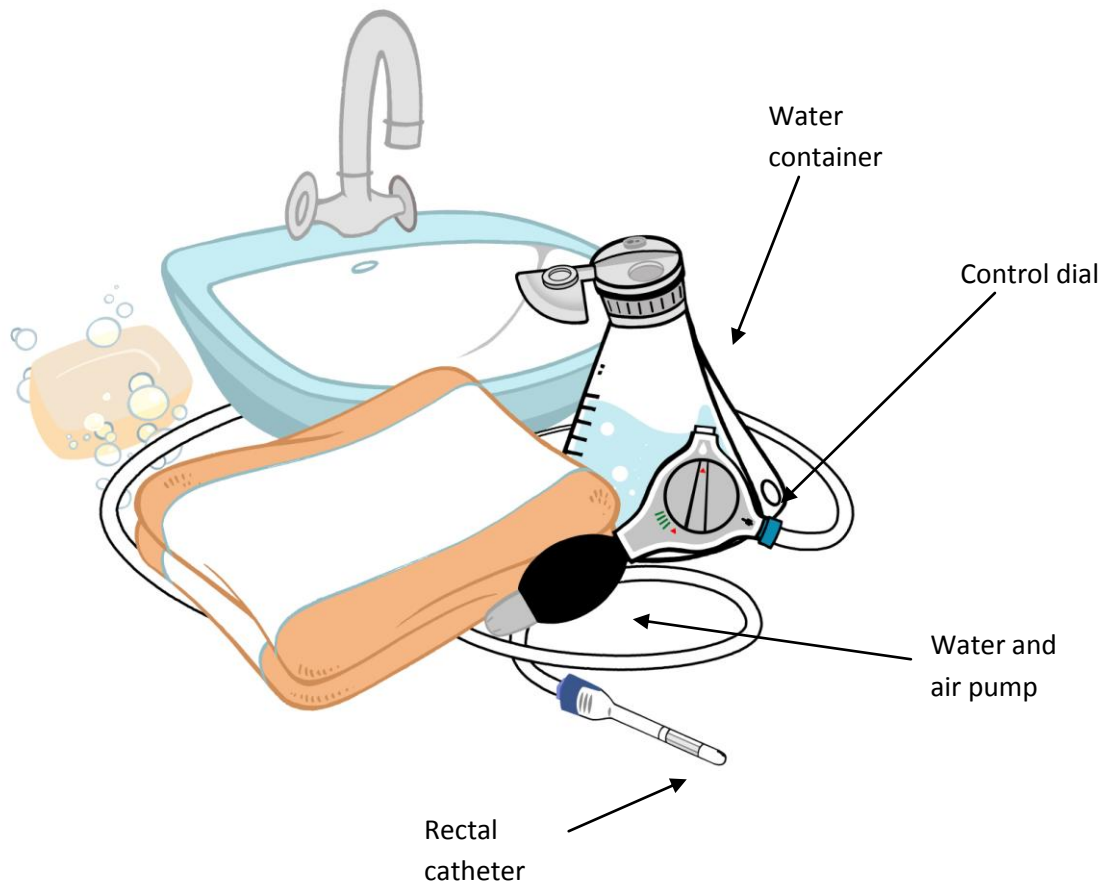
What are rectal washouts?

Rectal washouts (sometimes called transanal irrigation) are a way of emptying out the stools (poo) from the bowel, by introducing water (or other fluids) into the rectum and colon via the anus. Rectal washouts usually involve putting warm (body temperature) fluid (usually water) through a small tube (called a rectal catheter) into the child's bottom (rectum). The amount of fluid varies for each child.

There are a number of irrigation systems available. Some systems use a cone rather than a catheter, some can be used with children from age three years.

The irrigation is done while the child is sitting on the toilet or a commode and once the catheter or cone is removed the water, along with all the stool (poo) in the rectum and colon empties out into the toilet. The whole process takes around 30 minutes and usually keeps the child clean for 24-48 hours. This means the procedure needs to be done once a day or once every other day.

There are a number of different irrigation kits available. Below is one called Peristeen from Coloplast Ltd.

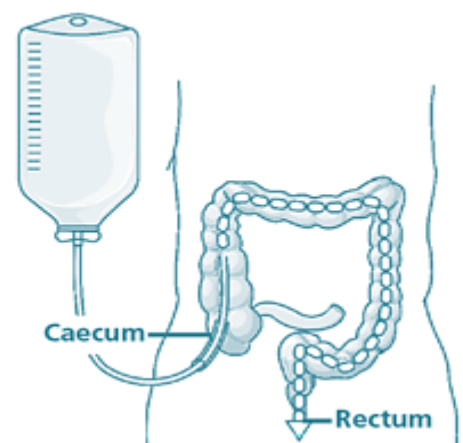


(M)ACE Procedure

The (M)ACE procedure, or antigrade colonic enema, also involves washing out the colon with a water solution while the child is sitting on the toilet.

It involves an initial surgical procedure (small operation) to form a catheterisable channel, usually using the appendix from the child's abdominal wall directly into their bowel.

The washout is carried out in a similar way to rectal washouts but in the case of an ACE, the water is put into the top of the bowel, so the washout is carried out from the top to the bottom.



Soiling and incontinence

Bowel control in all children with HD or ARMs can take longer to achieve than with other children. There are several reasons that soiling can occur:

- For those children who have had a large segment of bowel removed, the stools will descend into the rectum at speed. This is because there is less colon to absorb water from the faeces, making the stools (poos) loose. The child will not always have much warning that they need a poo and may not be able to get to the toilet in time
- For those children with chronic constipation, overflow soiling results in poo to leaking out; often the child will not be aware that this has happened.
- Sometimes it is difficult to get the dose of laxatives, given to resolve the constipation, exactly right, and this can cause the stools to become too loose.
- The muscles and/or sphincters of the child's bottom may have been affected by HD or ARM or resultant corrective surgery, which means the child has less control over their bowel motions.

If soiling is a problem at times then it is useful to be prepared for when you are out and about. Although you should also ask your health care professional for help with a formal bowel programme or washout procedure. The following can help:

- App's for your phone, like www.findatoilet.mobi can help locate toilets if you are in an unfamiliar area.
- RADAR keys can be obtained from Disability Rights UK. These keys allow you to unlock the locked disabled toilets in the community. Disability Rights UK also have an app you can download to your phone to find their nearest toilets.
- Protective pants can be worn, so that if the child does soil, the soiling is contained.
- Small disposable pads, can help if only a small amount of faeces is leaking out.
- Spare clothes and wipes
- Once the child is at school, it is important that teachers know about your child's diagnosis. They can ensure easy access to the toilet as soon as your child needs it

Enterocolitis

All parents and all carers need to be aware of the possibility of the child developing enterocolitis. This is a condition where the bowel becomes inflamed and infected. Typically there will be abdominal pain, fever, foul-smelling and possibly explosive diarrhoea, with vomiting. It needs medical attention promptly, as if left untreated, can be very serious. If enterocolitis is suspected then the family should seek medical attention as soon as possible.

Issues for schools

Children born with Hirschsprung's Disease and/or anorectal malformations may have ongoing bowel problems when they start school. This is particularly so if they have associated conditions that may cause a slight delay in normal acquisition of bladder and bowel control. The Equality Act (2010) requires all education providers to make 'reasonable adjustments' and supply auxiliary aids and services to children with disabilities. Therefore, children who have continence and toileting issues due to Hirschsprung's Disease or anorectal malformations should be provided for under the Equality Act.

Schools need to ensure that they provide an accessible toileting facility and clear guidance has been set by the Department for Education about the facilities that should be available in each

school (Advice on Standards for School Premises, March 2015). Schools also need to adhere to the Department of Education's publication 'Supporting Pupils at School with Medical Conditions' (December 2015). This states that:

- Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education
- Governing bodies must ensure that arrangements are in place in schools to support pupils at school with medical conditions
- Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of children with medical conditions are properly understood and effectively supported

Education providers have an obligation to meet the needs of children with delayed personal development in the same way they would meet the individual needs of children with delayed language.

Schools and other settings will have Hygiene or Infection Control policies as part of their Health and Safety policy. This will set out procedures schools will need to follow in case a child accidentally wets, or soils, or is sick while at school. The same precautions will apply for nappy/pad changing.

Asking parents to come into school to change their child is likely to be a direct contravention of the Equality Act (2010) and leaving a child in a soiled nappy or clothes for any length of time pending the return of the parent is neglectful, which is a form of abuse.

It is important that children who have known bowel problems and who will require attention during the school day have an individual health care plan (IHCP). An example of a care plan is included in the appendix and a generic care plan can also be downloaded from the Department for Education website.

Parents are more likely to be open about their concerns about their child's learning and development and seek help, if they are confident that they and their child are not going to be judged for the child's delayed bowel control.

Resources

Depending on the accessibility and convenience of a setting's/school's facilities, it could take about ten minutes to help an individual child change after soiling. This is not dissimilar to the amount of time that might be allocated to work with a child on an individual learning target. The time spent changing the child should be a positive, learning time, supporting development of independence.

If several children with continence needs enter a nursery or school, or other educational facility, there could be resource implications and the inclusion /deprivation element of the budget, which can be used to further enhance staffing, should be explored in the first instance. With the enhanced staffing levels within the early learning years and foundation stage, allocating staff to support children while dealing with continence needs should not be such an issue. Support will also need to be found for older children who are unable to manage their needs independently.

Job Descriptions in schools

Schools must ensure that the important responsibility of attending to a child's personal care and toileting needs is included within the job descriptions of appropriate staff. It is likely that most of the personal care will be undertaken by one of the teaching assistants. Any new such posts should have supporting the development of personal care, including promotion of independent toileting and other self-care skills, as part of the job description.

Child Protection

The normal process of changing, or supporting a child to change or use the toilet, should not raise child protection concerns. There is no requirement for two members of staff to be present unless there have been malicious allegations or other specific concerns. Few setting/schools will have the staffing resources to provide two members of staff for changing a child and enhanced Disclosure and Barring Service (DBS) checks are carried out to promote the safety of children in childcare and education settings. A student on placement should not change a child unsupervised.

All staff should be encouraged to remain highly vigilant for any signs or symptoms of improper practice, or safeguarding concerns, as they do for all activities with children.

Summary of how school staff can help support children with Hirschsprung's Disease (HD) and Anorectal Malformations (ARM's) – particularly those children who also have Down's Syndrome

- Understand, that any bowel problems or delayed control is the result of the abnormality in the development of the child's gastrointestinal tract, which could include their anus, rectum and bowel
- Recognize that the achievement of full bowel control can take time and some children may require further surgery in order to be able to achieve this
- Ensure that affected children have an Individual Health Care Plan drawn up in conjunction with the parents, child where appropriate, and school nurse or other appropriate health care professional, to ensure that the child's toileting needs are appropriately managed in school
- Support any bowel or toileting programme that is in place, by allowing free access to the toilet
- Promote independence as much as possible by supporting the child, to enable them to self manage their toileting in an age / developmentally appropriate way
- Be alert to possible bullying, name calling or hurtful comments and minimize any potential for this by addressing any soiling accidents in as discrete way as possible
- Respect the child's right to privacy about their condition – the child and family should decide how much and exactly what other pupils are told about the condition

References and further sources of information

Equality Act 2010 and schools: Departmental advice for school leaders, school staff, governing bodies and local authorities (May 2014)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315587/Equality_Act_Advice_Final.pdf

Managing Bowel and Bladder problems in Schools and Early Years Settings. Bladder and Bowel UK (2006)

Supporting pupils at school with medical conditions: statutory guidance for governing bodies of maintained schools and proprietors of academies in England (December 2015)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-at-school-with-medical-conditions.pdf

National Institute of Clinical Excellence (2010), 'Constipation in children and young people: diagnosis and management '. NICE 2010
<https://www.nice.org.uk/Guidance/CG99>

Understanding Anorectal Malformations (ARM's). Bladder and Bowel UK 2012 (updated 2017)

Understanding Hirschsprung's Disease. Bladder and Bowel UK 2012 (updated 2017)

Useful links

Ano-Rectal Malformation society (ARMs)

Information and support for families caring for children with ARM's

Email: reachingout2families@gmx.com

Bladder and Bowel Uk

Bladder and bowel UK, part of the charity Disabled Living, provides qualified impartial advice and information regarding products and services for children and adults with bowel and/or bladder problems

HelplineTel: 0161 607 8219

Email: bladderandboweluk@disabledliving.co.uk

Website: www.bladderandboweluk.co.uk

Breakaway

Breakaway are the UK's only residential weekend activity breaks designed for young people aged 4-18 with bowel and /or bladder diversions/dysfunctions, and their families.

<http://www.breakaway-visits.co.uk>

Champs

CHAMPS is an appeal set up to raise awareness of children with Bowel and Bladder disorders, dysfunctions and diversions. They raise funds that will directly benefit children by supporting research, awareness campaigns and support groups www.champsappeal.co.uk

Childhood Constipation

A web based information resource for parents, carers, health professionals and children.

www.childhoodconstipation.com

Contact a Family

Contact a Family is a UK charity for families with disabled children. We offer information on specific conditions and rare disorders as well as advice regarding related issues such as benefits and finance e-mail: info@cafamily.org.uk

Diversions

Diversions is a support network, based in the North West of England, for families with a child or young person living with a bladder or bowel diversion/dysfunction Email: diversions@live.co.uk

Down's Syndrome Association

Provides information and support regarding all aspects of Down's Syndrome

Langdon Down Centre

2a Langdon Park

Teddington

Middlesex

TW11 9PS

Tel: 020 8614 5100

Email: info@downs-syndrome.org.uk

ERIC

UK based site providing support and information with separate sections for children, parents and professionals dealing with wetting, constipation and soiling.

Helpline: 0845 370 8008

www.eric.org.uk

South Australia Department for Education and Child Development

An Australian website with health care plans for a variety of health conditions, including continence problems, that might result in a child needing additional support in school

<https://www.decd.sa.gov.au/supporting-students/health-e-safety-and-wellbeing/health-care-plans>

Vacterl Association Support Group

A UK based support group for families of children born with vacterl Syndrome

www.vacterl-association.org.uk

Contenance Care Plan for Schools and Nurseries

To be completed by the School Nurse or other Health Care Professional in conjunction with the classroom staff and parents.

Name of Child _____ Date of birth _____

First name (please print) Surname name (please print)

School/Nursery _____ School Nurse _____

Completed by _____ Designation _____ Date _____

Routine personal care/supervision required

Support needed

- | | |
|-------------------------------------------------------------------------------|------------------------------------------------------------------|
| <input type="checkbox"/> Indicates when toilet is needed | <input type="checkbox"/> May need to be changed |
| <input type="checkbox"/> Needs toilet timing | <input type="checkbox"/> Will always need to be changed/assisted |
| <input type="checkbox"/> Has continence aids (e.g. wears nappies or catheter) | |

Generally support will take about _____ minutes _____ times each day

Type of Support - Will need to support related to:

- | | |
|------------------------------------------------------------------|---------------------------------|
| <input type="checkbox"/> Independent toileting (please describe) | |
| <input type="checkbox"/> Prompts | <input type="checkbox"/> Timing |
| <input type="checkbox"/> Encouragement with fluid intake | <input type="checkbox"/> Other |

☐ Assisted toileting (please describe)

- | | | |
|---------------------------------------------------|----------------------------------------------------------------------------------------------|---------------------------------------------------|
| <input type="checkbox"/> Verbal Prompts | <input type="checkbox"/> Assistance with clothing | <input type="checkbox"/> Assistance washing hands |
| <input type="checkbox"/> Supervision | <input type="checkbox"/> Support to weight-bear | <input type="checkbox"/> Support for transfers |
| <input type="checkbox"/> Encouragement with fluid | <input type="checkbox"/> Assistance with hygiene (eg cleaning body, menstruation management) | |
| <input type="checkbox"/> Lifting onto toilet | <input type="checkbox"/> Other | |

☐ Catheterisation (please describe)

- | | |
|------------------------------------------------------------------------------------------------------|-------------------------------------------------------------|
| <input type="checkbox"/> Programs which allow for catheterisation at (specify preferred times) _____ | |
| <input type="checkbox"/> Self-managed | <input type="checkbox"/> Self-catheterises with supervision |
| <input type="checkbox"/> Other | |

Contenance care plan (contd)

Contenance Supplies

Equipment/continence aids that are required _____

Location of equipment/Continence aids _____

Emergency contact for supplies _____

Unplanned events

Are there any events, not covered in this plan, which could happen infrequently? If so, please give details of what could be expected and how it could be managed (eg child is usually continent but could wet or soil occasionally; can change and clean up independently but will need supervision and/or reassurance).

If any of the following occurs then the school are to contact the family immediately

If the following occurs the school is to contact 999 prior to calling the family

If family member unavailable on case of emergency please indicate name/relationship to child/contact number

Additional information attached to this care plan

☐

Training schedule for any required procedures

☐

Individual emergency plan (if different to standard first aid)

☐

General information about child's condition

☐

Other ([please specify] _____)

Names staff who have agreed to carry out the care and undertake any further training as necessary

This plan has been developed for the following services/settings:*

☐

School/ College

☐

School trips

☐

Nursery

☐

School Transport

AUTHORISATION AND RELEASE

I have read, understood and agreed with this plan and any attachments indicated above. I consent to the care being carried out on by child by the named staff members above and by appropriate others only in the case of an emergency

School staff member Name (please Print) _____ Role _____

Signature _____ Date _____

Parent,guardian (Please print) _____ Date _____

Signature _____

Adapted from <https://www.decd.sa.gov.au/supporting-students/health-e-safety-and-wellbeing/health-care-plans>

Assessment form for children who will not open their bowels on the toilet
e.g. will only pass stools in a nappy

| | |
|---------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------|
| Date completed: | Completed by: |
| Child's name: | Date of birth: |
| Toilet training readiness checklist completed? | Yes/No |
| How often does child open their bowels? | |
| What is the consistency of the stools passed (use Bristol Stool Form Chart re stool type) | |
| Child's behaviour before opening bowels? | |
| Child's behaviour following opening of bowels (e.g. does he / she indicate that they have been)? | |
| Is the child seen to 'hold on'? | Yes/No |
| Does the child ask for a nappy to open their bowels? | Yes/No |
| If 'yes' and no nappy available what does the child then do? | |
| If 'yes' the nappy available what does the child then do? | |
| Does the child appear to experience pain on defecation? | |
| Is there any general anxiety about using the toilet / potty? | Yes/No |
| If 'yes' is it related to all toilet / potties or only specific ones? | |
| Does the child use the toilet / potty appropriately to empty bladder? | Yes/No |
| If the problem appears to be due to constipation / hard stools / anal fissure refer to GP/specialist service for treatment as appropriate. | |

Further Information

Bladder and Bowel UK

Disabled Living

Tel: 0161 607 8219

Email: bladderandboweluk@disabledliving.co.uk

Website: www.bladderandbowel.co.uk

Bladder and Bowel UK (formerly PromoCon) provides impartial advice and information regarding products and services for children and adults with bowel and/or bladder problems

This booklet has been designed to help those involved with the care of children with Hirschsprung's Disease or anorectal malformations – particularly those children who also have Down's Syndrome to understand the treatment involved and why long term good bowel management is so important.

This booklet is part of a series for children with bowel problems.

Titles of other booklets currently available in this series:

'Talk about going to the toilet'

'Talk about constipation'

'Understanding constipation in infants and toddlers'

'Understanding toilet refusal – the child who will only poo in a nappy'

'Understanding Hirschsprung's Disease'

'Understanding Anorectal Malformations (ARMs)'

Illustrations

Les Eaves

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