

Rectal irrigation clinical toolkit

This toolkit is for both families and professionals to use and is organised into four sections which are colour coded. These hope to cover the whole journey a child and family will make through assessment and learning to use rectal irrigation to ongoing monitoring. Each section has a quote from the parents who made this study possible as an illustration of how each section could be used in practice.

Assessment

This section addresses the suitability of a child or young person to trial rectal irrigation. Parents / carers are integral to assessment which includes understanding children and parents' experiences of previous treatments, the need for a physical and emotional assessment and early discussion of expectations of irrigation.

Education

This section concentrates on the educational needs children and their families may have including how to address these in order to achieve confident and safe practice. It includes providing resources, choosing irrigation systems, teaching families to use and store supplies and the value in observing families undertake the initial washout(s).

Support and Problem Solving

This section will focus on supporting families to deal with irrigation system problems, changes to family circumstances, difficulties in achieving expected results and coping when encountering pain and discomfort. This section will also address levels of continuing support and monitoring and evaluating the rectal irrigation programme.

Resources

This section provides additional resources including internet links and three case studies drawn from a research project exploring parents' experiences of rectal irrigation.

Rectal irrigation clinical toolkit information & notes

Kit demonstrated to family (by whom and date):

Fluid to be used (amount, temperature and type):

Date to change the kit and ordering codes:

Family provided with learning resources to take / use at home:

Contact names and numbers:

Notes:

Assessment

Physical assessment

- Less invasive options have been considered and tried unsatisfactorily (e.g. oral medication, enema)
- Abdomen has been assessed for constipation (may wish to continue oral medication initially)
- Is there any hard stool in the rectum (empty this prior to starting irrigation)
- Assess anus (any fissures, haemorrhoids, tone, lax anus should not inhibit trial with irrigation)
- Discuss experience of use with additional continence devices (anal plugs etc)
- Does the child have sensation (previous surgery to anus parents / child concerned about discomfort)
- Note current medication (laxatives etc)

"we (can) have difficulty getting the catheter in if there is any faeces quite low down... if we then inflate the balloon it (can) burst and go all over the floor" so we use a "suppository just to clear anything that blocks the catheter".

Emotional

- Consider and discuss the child's response at physical assessment (engaging, compliant, upset, distressed)
- Discuss with children and their parents their feelings and expectations about undertaking irrigation
- Ensure there is a clear understanding of why irrigation is being considered as a treatment option
- Discuss and explore family lifestyle and communication within the family, does this support the irrigation routine?
- Discuss child and parents' initial worries and goals e.g. safe insertion of catheter, desired level of continence
- Discuss child and parents' longer term goals such as reducing medication (laxatives) or possibility of child becoming independent in managing their own bowel routine

"sitting in the consultant's room and actually talking about it, it sounds pretty horrific, but seeing it and watching how straight-forward it was gave us a bit of confidence to go and give it a try"

Child mobility and setting where washout undertaken

- Check there is a safe environment to undertake the washout (a risk assessment may be necessary in respite care settings)
- Is the child able to sit safely and securely on the toilet, or if conducted whilst lying down can the child transfer safely to the toilet? (consider OT / physiotherapy assessment if necessary)
- Position of the child for access to insert rectal catheter (on side, leaning / position on the toilet to facilitate catheter insertion)
- Does the child have hand / eye co-ordination difficulties any co-existing medical factors which may limit child's future independence?
- Consider the availability of toilets within the home
- Are there resources available to distract / engage child during and after irrigation?

"The problem is it takes a long time and I have three children and it's fitting it round activities and things. So it's a lifestyle change as much as it is a washing out because you have to be on the toilet 45 minutes to get a good washout"

Education

Location of washout and initial education

- Consider the location the washout will take place and carry out the education/teaching in this setting as well as the hospital/clinical setting e.g. home, respite
- Allow time for discussion and several attempts at conducting washout (if appropriate consider admission to hospital)
- Aim to undertake the irrigation with the child and parent the first time
- Discuss and identify the local support in the community, contact details are available

Once we got home we really needed help with “the logistics of trying to get her onto the loo dangling or sit her on a chair, a commode chair above the loo and then trying to wangle your hand underneath her to put the tube”

Education and teaching Resources

- Consider the use of DVD and child and parent information leaflets
- Use age appropriate child materials e.g. children’s story books, poo games and stories
- Local support systems
- National support groups
- Company web sites
- Demonstrate using the system
- Allow child / parent to practise with the system/equipment

The “DVD and booklets were great” and “she brought a system to show us and go through [using] it with us”

Evaluate readiness to use Washout

- Discuss what parents need to feel confident to use the system with their child and what they perceive as possible barriers?
- Do the parents talk positively about trying irrigation?
- Consider how can you motivate the parents / child young person?
- Is the child co-operative or resistant to the washout?
- Early thinking about involving the child in the washout can be helpful later
- Are the child’s worries being listened to?

“Emotionally I think it’s quite a difficult thing to have to put something up your child’s bottom”

Support and Problem Solving

Initial follow up

- Telephone family following first irrigation at home and arrange visit or appointment if any problems encountered
- Arrange to contact the family weekly until they are confident with the washout system
- Contact again a month after starting using system to evaluate success and discuss any issues
- Encourage parent to seek support e.g. professional, support group or resource if they encounter difficulties
- Consider using text or email to contact and support the family, if available and in line with local policies
- Liaise with community staff to provide additional support

"They could have offered me a phone call or even called in to see me because I do think it's a procedure you have got to be very confident of using and to begin with you do need back-up support"

Ongoing/community support

- Discuss who the family's community support is and how, when and who is going to contact them
- Discuss who could be an additional family member/friend to act as support / back up
- Contact the GP with information regarding the treatment plan
- Consider if the child's school needs to be involved
- Discuss the involvement of social care agencies for young people who will not be able to become independent
- Discuss the training of other carers or professionals in the future

"I did have contact details but I feel that you as a person shouldn't have to do that. They want you to use the system so therefore they should be prepared to take the time out to give you a call to check (a) is everything going ok and (b) do you feel confident enough to use it"

Additional support and resources

- Provide information about appropriate web sites
- Details of local support groups and meetings
- Provide information about national support groups and contacts
- Provide information about hospital clinic times and contacts
- Provide opportunities to meet other families
- Discuss parent wellbeing and feelings associated with washout, which may change over time

"We were quite terrified to be honest. Well I don't need to tell you how invasive it is and as a parent it is really quite a hard thing to do to a child because it just doesn't seem right you know"

Resources

Websites

<http://www.spinal-injury.net/>

<http://www.bladderandbowelfoundation.org/bowel/bowel-problems/anal-irrigation.asp>

www.shinecharity.org formerly ASBAH

<http://www.mhra.gov.uk/Publications/Safetywarnings/MedicalDeviceAlerts/CON105651>

<http://www.coloplast.com/urologyandcontinencecare/spinabifida/education/>

The following case studies include extracts from several parent interviews to create short stories regarding the experiences of families of rectal irrigation. All names have been changed to protect anonymity.

Case Study 1

It's quite stressful, it's a big commitment and you worry about hurting your child and it upset me at first, doing it with my son. To start with it took two of us to do it so that we could support each other. He still sometimes gets upset when he knows it's time to do his washouts but the impact on all of us of him not being clean is so much harder than getting through his five minutes of worry about the washout. He chats about it to other people now in a really happy and confident way and it doesn't stop us from doing anything. We take it on holiday even doing it in a caravan, it is a bit tricky but it's about being confident and practising and really being prepared.

Using the irrigation was hard to start with especially when there was no visible or only a little result and we were thinking this can't be right. He would complain about a sore tummy and it was distressing for us when he was complaining, but now we have been doing it for a while we realised it was just the sensation of the water going in, but it was really hard to work out the difference between new feelings and discomfort. It took about a month or so for him to relax and not worry about having it done and it's just part of everyday life now. If we are out for a full day, I make sure it's done in the morning, I think about what he's eaten and if he looks bloated this helps me decide if we can go an extra day between washouts.

Having a point of contact with someone who knew about irrigation helped us work through our problems and worries about washouts. Getting in touch with the nurse (in the hospital or community) was easy, we could pick up the phone and someone was there or they would call back, or text or email. We feel really positive about irrigation and see it as part of life not a chore, you have to be positive about trying because if you are positive then your child is more likely to be positive.

Case Study 2

We had tried several different ways to get our son going to the toilet to have his bowels opened. Oral medication resulted in him soiling and we never knew when it would work so it was uncontrollable. We also thought it was too strong and caused him tummy ache and after a few weeks he'd start being sick and it wouldn't work at all. We tried suppositories and enemas but they didn't help him get clean, they were also unpredictable and seemed to take a long time to work. So he was always constipated, he never really went to the toilet for a poo and was very smelly when he soiled in his nappy.

At first, the irrigation was a bit difficult, we needed to empty the hard poo before we could start and make sure he was comfortable and happy to let us try the washout. We do it in the bathroom, and we needed help from the occupational therapist to get a safe toilet seat as he sits for about twenty minutes after the washout, we chat or he reads or plays games. He really wanted to go swimming and not wear pads once he realised his friends didn't use them. Emotionally it was quite hard because although he wanted to be clean and go swimming he wasn't sure about using the irrigation. Sometimes he says "I don't want to do it" and if we can't bring him round to doing it we have to wait, but then he soils and has pain and asks for his washout to be done.

Case Study 3

Finding out that irrigation was a choice for our daughter was difficult, as sometimes nurses or doctors just don't know what's available to try; they had never seen irrigation before and were reluctant to use it. We pushed to try it and asked the nurse to help, she showed us the DVD and we thought it was good, we chatted to another family and that really helped. We spent time looking at the booklets with our daughter, used pictures and stories at home to help her understand. We used a teddy to play with, and practice on, as best we could. The training with the nurse was great, I took her grandma (my mum) with me as she helps out when I am at work and we all learnt together.

We had a very short instruction in the hospital on how to use an irrigation system, so at first we didn't have much confidence which really didn't help us or our daughter. We were really worried about the size of the washout tube but when the small one was produced it was much better. Finding someone to help us use the washout in the community was a problem at first, the local team wasn't that confident using irrigation but the link person from the company really helped. At first it took a bit of practise to put the system together and then remember how to use it, but we soon got quite expert at it. If it leaks or breaks it's a bit frustrating but we now make sure we have a spare. We found that storing it in the right place was important (not in the cold) and having one at my mum's house rather than just sharing one and then finding I had forgotten something was much easier. We are now very confident and have even gone on to train our district nurses how to use it as part of her respite care.