Bladder & Bowel UK
Supporting people with bladder and bowel problems
part of Disabled Living

# The 'Right Care' approach for treating intractable idiopathic constipation in children.

## Comparing patient journeys

**Journey one – sub optimal journey**

James is wearing nappies when he starts nursery at school - he is three years old. His mum tells the teacher that she has been unable to toilet train him, so the teacher refers him to the health visitor (HV), who arranges a home visit. The HV gives mum some basic advice and arranges to phone her after two weeks. As little progress has been made, the HV does a second home visit and makes some more suggestions. She maintains phone contact and, after a further three months James, who is now three years and six months is passing urine in the toilet. He stops wearing nappies at school and is only rarely wet or soiled when there.

When James starts full time school aged four years ten months he has been using the toilet to pass urine, is having some daytime wetting, but not every day and still only rarely has a bowel motion in the toilet. As he is at school all day, soiling is now happening there about three times a week. The teacher is not always noticing and James bottom is getting sore, so mum speaks to them. It is agreed that spare clothes will be sent in for James to change himself. However, he is struggling to manage the changing independently, so school phone mum to attend when they notice he is soiled.

When James starts Year One, the soiling deteriorates. It is now happening nearly every day, school attendance is falling, which mum reports is due to abdominal pain. Mum gives up her part-time job, as when he is in school, she is called in numerous times to change him. The teacher refers him to the school nurse, who arranges a home visit.

The school nurse asks some basic questions, advises that James needs to be encouraged to drink more, eat some fruit or vegetables every day and sit on the toilet for five minutes after every meal. James becomes increasingly uncooperative and upset. He is reported to be struggling with behaviour at home and at school and is falling behind his peers with learning. When the school nurse does a follow up visit she asks more questions and finds that James is passing a very large stool once every 10 -14 days and his soiling and appetite is then better for 24 -48 hours. She suggests that mum takes James to the GP and refers mum to a parenting support group for James' behaviour.

The GP diagnoses constipation and prescribes lactulose 5mls x 3 daily. Soiling continues as before, but James is now opening his bowels every 8-10 days, so mum takes him back to

the surgery. A different GP suggests senna 5mls per day as well as the lactulose. James is reluctant to take the senna and within a couple of days soiling is worse and James has more abdominal pain, so mum stops all medication. James' behaviour and school attendance remain poor.

When James starts Year three aged 6 years 10 months other children refuse to sit near him and he is denying soiling and refusing to go to the toilet. His behaviour and progress continue to give cause for concern. The school nurse is involved again and refers James to the community paediatrician. When James is seen in clinic, the history from mum is unclear, the focus of the appointment is behaviour and an assessment for ADHD and autism is recommended. James is referred to CAMHS, where he completes the assessment process, mum is advised that he does not have ADHD or autism and he is discharged. As soiling continues, CAMHS refer James back to the GP and continence containment products are provided for him.

Soiling continues so the GP refers 8 ½ year old James to a hospital-based paediatrician. The history given by mum remains poor. The paediatrician recommends admission for disimpaction and James spends five days in hospital. He is discharged with a macrogol (Movicol) and an appointment for review in three months. Back at home James is reluctant to take the macrogol and mum often forgets to obtain a repeat prescription, so he then misses some doses. Gradually soiling resumes, James, now 9 years, continues to deny there is a problem and he is hiding soiled pants at home.

At his review appointment, James is prescribed a stimulant laxative alongside the macrogol and is referred for a blood test to exclude Coeliac's disease, to a dietician for trial of a milk free diet and to a gastroenterologist at the regional centre for rectal biopsy.

The milk free diet does not help so James returns to a normal diet prior to being seen at the regional centre. The rectal biopsy is normal, but as James, who is now 10 years old had to have manual disimpaction with the biopsy and continues to soil, the surgeon suggests an ACE procedure. He has a home visit from the regional specialist nurse and an ACE procedure is carried out when he is 10 ½ years old. James is finally fully continent in time to start secondary school and stops wearing the containment products provided via the continence service when he was 8. James chooses to go to a secondary school out of area, so that no one knows that he used to soil; he has missed out on numerous school trips and has never joined out-of-school clubs or groups due to his continence problems. Within a year, he has caught up academically with his peers, has a wide group of friends and is enjoying life. Mum is able to start looking for a new job.

**Journey two – optimal journey**

James is wearing nappies when he starts nursery at school - he is three years old. His mum tells the teacher that she has been unable to toilet train him, so the teacher refers him to the health visitor (HV), who arranges a home visit. The HV asks a number of questions, including checking when James passed meconium, when the problems began and developmental history. The HV discusses diet and fluid intake and as she suspects that James may have constipation, she arranges for a prescription of macrogol (Movicol

paediatric plain) with the GP. The HV explains to mum how the sachets need to be made up with water, but that juice can be added to disguise the taste if James is reluctant to drink it.

Mum gives the macrogol and the soiling improves slightly. The health visitor undertakes a follow up visit and provides advice on potty training. When she telephones mum six weeks later, James is passing urine on the toilet, but is still struggling with bowel incontinence and some withholding of faeces. He has finished the macrogol. The HV recommends a further prescription for the macrogol and refers James to the Community Paediatric Continence Service where he is seen by a children's continence advisor (CA).

The CA undertakes a full assessment, including abdominal examination and explains to mum and James, that James appears to have idiopathic constipation with faecal impaction. She explains what this means and discusses the importance of a disimpaction regime with macrogols and of then continuing with the laxative treatment and regular in order to prevent relapse, even if James appears to be passing stools without problems. Mum agrees she can manage the disimpaction at home and the CA provides contact details, in case of any concerns.

The CA undertakes a review one week later. As James appears to have passed a large amount of loose stools and as there no longer appears to be impaction on abdominal examination, she recommends a maintenance dose of macrogol and arranges to review James in a month. Mum is advised to contact her if there are any concerns in the meantime.

When James attends his review appointment, he is still having some soiling most days, but is working on toilet training. Mum is happy with progress. James maintains his laxative dose for six months and these are then gradually reduced as symptoms have resolved. He discontinues regular laxatives after nine months, is only rarely needing a sachet of macrogol and mum is told to contact the CA if there are any concerns. As there is no further contact James, now 4 ½ is discharged one year after his initial contact with the CA.

When James is just 7 years old he is referred back to the CA by the school nurse for possible constipation and soiling at least once a day in school. James is often denying the soiling, but occasionally it is leaking through his clothes so school are asking mum to collect him and take him home to shower and change. Mum is anxious about the impact on her work and upset to find that other children do not want to sit near him. The CA undertakes an assessment and mum says that James has never been fully clean, but she was happy previously as there were no symptoms and she assumed bowel continence would happen in time. The CA recommends disimpaction at home with a macrogol and reviews him a week later. James has improved, but there is still some soiling, particularly in the evenings. A stimulant laxative is prescribed, in addition to the macrogol and the CA discusses measures to support James in school. The CA contacts the school nurse and writes to school, who then agree to allow James open access to the disabled toilet, a space in the toilet to keep spare clothes and support him to toilet after lunch in school. They introduce a care plan written with mum and James, to ensure everyone is aware of their responsibilities and that there is good communication between home and school. They monitor the behaviour of other children towards James.

The CA maintains telephone contact with mum and after a month on the stimulant laxative, James continues to experience some soiling, and abdominal pain. She refers to the GP for a

blood test to exclude Coeliac's disease. The blood test is negative. The CA continues to provide support and adjusts doses of laxatives and confirms compliance with advice and medication.

Due to the lack of progress James is referred to a paediatric gastroenterology clinic for review. The diagnosis of idiopathic constipation is confirmed following a rectal biopsy. James is referred back to the CA for trial of suppositories, but when after a two month trial these fail to keep him clean, he is considered for transanal irrigation(TAI). The CA explains irrigation to James and his mum and mum agrees to try this, if James will co-operate.

The CA undertakes a home visit. She takes the transanal irrigation system, child and parent friendly patient information and explains the system to James, who agrees to have a go. Irrigation is undertaken with James helping to set up the equipment and inserting the catheter with his mum's help. The family agree to try to undertake irrigation daily. The CA contacts them 48 hours later and is told that the previous evening irrigation was done with no problems. They maintain telephone contact weekly for the next month and then two weekly for the following month, while the procedure is adjusted. After six weeks James is normally continent throughout the day. He continues to take laxatives.

The CA reviews James every 2-3 months for the next six months. Under this supervision he gradually reduces the amount of laxative he takes daily. As James remains clean he stops doing irrigation on Friday nights and if away from home overnight. As he normally remains clean for 48 hours, the frequency of irrigation is also gradually reduced. James participates in an overnight trip with cubs and school and has occasional sleepovers with friends.

After 18 months , James discontinues irrigation. He remains clean and his mum is advised to give him a dose of laxatives if he has any symptoms of constipation. He is discharged aged 9 years 9 months .

**Overview of costs**

| Analysis by cost category | Suboptimal Journey | Optimal Journey |
|---|---|---|
| Primary Care | £799.2 | £442.07 |
| Secondary Care | £19,333.33 | £199 |
| Medication / Medical devices | £32.6 | £2,822.98 |
| **Total** | **£20,165.13** | **£3,464.05** |

Apart from the differences in social impact and treatment of case, there is a cost saving difference of **£16,701.08** between the suboptimal and the optimal scenario

Costs breakdown

| Interventions | Number of Interventions | | Cost of interventions | |
|---|---|---|---|---|
| | Suboptimal Journey | Optimal Journey | Suboptimal Journey | Optimal Journey |
| **Primary Care** | | | | |
| GP | 4 | 2 | £ 144.00 | £ 72.00 |
| HV | 3 | 2 | £ 165.20 | £ 40.67 |
| HV phone follow up | | 8 | | £ 48.80 |
| school nurse | 3 | | £ 162.00 | |
| CAMHS | 1 | | £ 68.00 | |
| specialist nurse | 1 | | £ 61.00 | |
| Children continence advisor | | 7 | | £ 280.60 |
| Pediatrician | | | £ 199.00 | |
| **Total Primary Care** | | | **£ 799.20** | **£ 442.07** |
| **Secondary Care** | | | | |
| Pediatrician | 1 | 1 | £ 199.00 | £ 199.00 |
| Hospital inpatient admission | 5 | | £ 14,950.00 | |
| Gastroentorologist | 1 | | £ 135.00 | |
| Outpatient review appointment | 1 | | £ 135.00 | |
| Dietician | 1 | | £ 44.00 | |
| ACE Procedure | 1 | | £ 3,870.33 | |
| **Total Secondary Care** | | | **£ 19,333.33** | **£ 199.00** |
| **Medication** | | | | |
| Lactulose 15mls | | | £ 22.86 | |
| Senna 5ml oral solution sugar free | | | £ 0.10 | |
| Macrogol, Movicol Paediatric | | | £ 8.76 | £ 56.94 |
| Stimulant: bisacodyl 5mg tablets | | | £ 0.88 | £ 0.88 |
| Bisacodyl suppository 5mg dulcolax | | | | £ 12.48 |
| Peristeen System | | | | £ 457.68 |
| Catheters | | | | £ 2,295.00 |
| **Total** | | | **£ 32.60** | **£ 2,822.98** |
| Total cost | | | £ 20,165.13 | £ 3,464.05 |

*sources: Drug Tariff Sept 2017, PSSRU 2016

**For further information contact Bladder and Bowel UK**

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