

Children's continence care: sub-optimal pathway versus optimal pathway

Toby and the sub-optimal pathway

- **Toby is 6 years old** – a lively, well-adjusted child who has a **persistent bedwetting problem**. At the first visit to the GP Toby's mother is told this is a common difficulty which he will "grow out of". No information or advice was given, apart from limiting drinks in the evening and waking him to toilet when parents go to bed (**this advice was not ideal**).
- **Toby is now 7 years old** and the bedwetting is having a negative impact on Toby and his family. He is also starting to have occasional **soiling accidents** and his mother notices **wet pants during the day**. This causes extra family conflict as his mother thinks (incorrectly) that Toby is being lazy about getting to the toilet. Toby is tired at school because of disrupted sleep – and becomes uncooperative and "difficult" at home. There is also the financial pressure of the extra washing and the cost of bedding protection/ disposable protection pads. There is an increased **risk of parental punishment/abuse** as Toby's mother finds it increasingly difficult to cope.
- The GP refers Toby to the **school nurse for an enuresis alarm** to help the bedwetting. **This is not appropriate** as there has been no proper assessment, and it is unlikely to be successful when there is constipation and bladder "overactivity" – the likely causes of daytime soiling and wetting. There is a 6 week wait for this treatment which fails after a further 2 weeks as Toby is not waking, but it is disturbing parents and his brother who shares his room.
- **Toby is now 8 years old**. The soiling is getting worse and Toby is called "smelly" by his peers and is being bullied at school. Toby feels **unhappy and isolated and his behavioural problems increase**. **His relationship with his parents is affected, as his mother continues to believe he is being lazy**.
- The GP prescribes a laxative but gives little advice on how to use it or how to adjust the dose. **Toby's soiling gets worse, and his school expresses concerns**, so his mother stops the laxative and returns to the surgery.
- The GP refers Toby to the **Child and Adolescent Mental Health Service (CAMHS)**. There is a waiting time of three months. Toby and his mother have two sessions with a mental health practitioner but with no improvement. CAMHS suggest a paediatric opinion. Toby meanwhile turns down the opportunity to go on a cub camp, and is falling behind at school due to tiredness and difficulty concentrating as he worries about his wetting, soiling and bullying.
- **Toby is now 9 years old** and is referred by the GP to a **paediatric gastro-enterologist**. **He is finally correctly diagnosed with faecal impaction and an acquired mega rectum as a result of long-term constipation (as mentioned this is also likely to be influencing his bladder problems)**. Toby starts the correct laxative regime in increasing doses, which require Toby to miss a week of school and is a challenge for Toby and his family to manage. However, they are given initial telephone support and three monthly clinic reviews and over the next year his bowel pattern gradually returns to normal, although he continues to need small daily doses of laxatives.
- Unfortunately, although the daytime wetting is better, he still has some bladder symptoms ("frequency" and "urgency") – and his bedwetting has not resolved. **As there is no community paediatric continence service in the area Toby is referred by the GP to a paediatric urologist**.
- After a 6 week wait Toby has a hospital urology appointment where Toby has a bladder and kidney scan and a flow test. Nothing abnormal is found. He is prescribed medication for his night wetting.
- **Toby is now 10 years old**. He is now clean and dry during the day – and has only the occasional night-time accident. He is able to stop the medication for night time wetting after six months. He is more confident and sociable, his behavioural problems resolved with the continence issues – and he attended cub camp for the first time.

Toby is a typical patient in a typical Clinical Commissioning Group.

Toby and the optimal pathway

- **At 5 years old (a year earlier)** Toby's bedwetting, daytime problems of "frequency" (needing to urinate more often than is usual) and constipation problems are identified by the school nurse at school entry. Neither Toby nor his mother were aware that Toby had a constipation problem and that this might be contributing to his bedwetting and daytime symptoms.
- In liaison with the GP, Toby starts on a **medication regime for his constipation**.
- Two months later Toby and his mother attend the **integrated community paediatric continence clinic**, where his constipation is reviewed; he is making good progress so his medication is adjusted. They are also given explanations about the causes and treatment for constipation and bedwetting, advice on diet and fluid intake and linked to supportive organisations, such as ERIC: The Children's Bowel and Bladder Charity and Bladder and Bowel UK.
- Six weeks later Toby is reviewed by the **paediatric continence nurse** at the clinic. His constipation is much better but he still has a bedwetting problem. His mother is advised about how to try reducing laxatives.
- The assessment identifies that an enuresis alarm would not be appropriate and would be too disruptive for the family (for example Toby shares a bedroom with his brother), so Toby starts on a **medication regime for bedwetting**.
- The paediatric continence nurse follows Toby up a week later by telephoning his mother. Toby is not completely dry at night so the medication dosage is adjusted.
- Twelve weeks later, at a follow-up clinic appointment, Toby reports that he is dry at night with medication and almost completely dry when he tries without; he no longer has urinary "frequency" and **his bowel pattern is now normal**; he reports that he no longer needs night-time protection pants.
- Toby's mother is advised to maintain dietary and fluid changes, to try and work out possible causes for wet nights, to use laxatives as required and to contact the service if there are any problems.
- The paediatric continence nurse provides a review by telephone **three months later**. Toby's mother was pleased to report that Toby is fully **dry at night without the medication and has not needed laxatives for two months**. The family know that they can return if problems re-occur.

Early identification of Toby's constipation problem and its effective treatment prevents:

- The more serious condition of impact with associated soiling;
- Referral to urology and paediatric gastroenterology;
- Toby having unnecessary investigations;
- Toby experiencing bullying at school and his family experiencing four years of stress and anxiety;
- Toby missing normal childhood social opportunities; and
- Risk of child punishment through parental intolerance of Toby's continence problems.

FINANCIAL INFORMATION

Analysis by provider	Sub-optimal	Optimal
Acute	£1,128 (53.26%)	£0
CAMHS service	£54 (2.55%)	£0
Community teams	£125 (5.90%)	£69 (21.69%)
Primary care	£295 (13.93%)	£45 (14.15%)
Pharmacist	£516 (24.36%)	£204 (64.16%)
TOTAL	£2,118	£318

Acute service expenditure represents 53.26% of the total in the sub-optimal scenario yet 0% of the total in the optimal setting. Identifying and treating the problem early in a community setting therefore prevents expensive expenditure on acute services. An optimal scenario not only increases value to the NHS, but also improves the quality of service and positive outcomes for the child and family.

Figures are based upon 2014/15 NHS Tariff costs.