

The Paediatric Continence Forum

◆ The Paediatric Continence Forum ◆ 11 Hampton Park ◆ Redland ◆ Bristol ◆ BS6 6LG ◆
◆ Tel: 0207 368 3100 ◆ Fax: 0207 368 3101

Bladder and Bowel problems: affecting one child in twelve

In the UK, one in twelve children and young people suffer from bedwetting, daytime wetting, or constipation/ soiling.

These are often hidden problems which have a major effect upon the lives of children and young people. Occurring at a time of crucial emotional development, they are often associated with a loss of self-esteem and a very real fear of being bullied at school. Research has shown that many children with bedwetting feel isolated and “different” - and fear being “found out” and socially excluded from normal peer group relationships. Bladder and bowel problems can also reduce social opportunities, such as taking part in overnight school trips or sleepovers. In a proportion of cases, they are associated with a learning difficulty or a physical disability.

Stress for parents

They are also a source of stress for parents. Whilst most parents are positively involved and concerned, a significant minority (estimated to be about 30%), respond by punishing their children for wetting and soiling accidents. This can result in a “vicious circle” of increased stress, more accidents, potentially harsher chastisement and the risk of child abuse. This was of course the case for poor Victoria Climbié.

It is estimated that each child who wets the bed every night costs the family £27.50 a week (£1,430.00 a year) in extra washing, bedding and nightclothes. Each child who soils (twice a day) costs the family an extra £36.00 a week (£1,872.00 a year) (ERIC* Figures 2006). The cost for parents/carers of children with special needs is likely to be higher.

There are additional financial pressures for families of children with special needs. To save costs some NHS trusts are even rationing the number of pads for children with intractable incontinence, thereby causing additional hardship for families on limited income.

Requires early, active assessment and treatment

Bladder and bowel problems require early, active assessment and treatment, with services that are effective for the child and cost effective for the NHS. If services are not properly in place and children are not seen at a sufficiently early stage, there is a physical risk to the child; for example, daytime wetting is associated with urinary reflux – with its potential for kidney damage; if constipation is not dealt with early enough it can take months – sometimes years – to resolve; the child with bedwetting continues to suffer if the problem is left untreated.

If services are not integrated or effective, then families get passed from “pillar to post” – which is frustrating for the families and a waste of NHS money.

In 2004, the Government issued a National Service Framework (NSF) for Children, Young People and Maternity. This acknowledged that there were big gaps in service provision for children with bladder and bowel problems, which lead to inappropriate referrals and wasted resources. It also noted:

‘An integrated community-based paediatric continence service, informed by Good Practice in Paediatric Continence Service, ensures that accessible, high quality assessment and treatment is provided to children and their parents/carers in any setting’ (NSF 2004 The Ill Child Standard, p30).

Services are generally poor

A survey of 800 NHS paediatric continence clinics showed an inadequate and inconsistent picture nationally (ERIC 2006 and 2008). Most were single clinics, community-based and run by a maximum of two nurses, usually on a part-time basis; 40% of these clinics treated wetting only and not

constipation/soiling. Very few clinics (5%) dealt with children with physical disabilities and only one in three clinics said that they had easy access to a paediatrician.

The survey also showed a high degree of inconsistency across the country. There are models of good practice; services with trained multidisciplinary teams that assess and treat the full range of bowel and bladder problems “under one roof” – and have good integration with local social services, education departments etc. But these are in a minority. They need to be replicated nationally.

Government action is needed

The Paediatric Continence Forum (PCF) is a representative lobby group of clinicians, patient representatives and commercial members working to improve services and resources for children with bladder and bowel difficulties. Our aim is for children to have easy access to high quality, integrated continence services, wherever they live - as recommended in Part 2 Section 10 of the National Service Framework for Children, Young People and Maternity Services.

The Paediatric Continence Forum focuses its activities on persuading the Government, through the Department of Health, to do more to address these vital needs. We work constructively alongside national and local policy makers, decision makers and other stakeholders to fulfill our aims. We hold regular briefing meetings with MPs and Peers across all Parties.

Key elements of PCF’s current work programme

To improve standards and guide PCTs/ GP Consortia in setting up effective, efficient, good quality services:

The PCF is represented in the development and dissemination of two clinical guidelines from the National Institute for Health and Clinical Excellence (NICE) and is actively involved with a NICE guideline on the commissioning of paediatric continence services.

To encourage and support the establishment of more good quality and cost effective services:

The PCF is campaigning for continence indicators to be included in the Quality Outcomes Framework (QOF) and as a Quality Standard by the National Quality Board. We are developing a series of three Exemplars on paediatric continence, each with an outline of an ideal child’s “journey” through treatment; publication by the Department of Health. We have developed a model business plan to help PCTs commission paediatric continence services; this is being used by NICE in the development of the new Commissioning Guide.

To prevent continence problems and to maintain access to the best treatments, appliances and care:

The PCF is supporting ERIC in campaigning to improve water and toilet facilities in schools, through an update of the 1999 School Premises Regulations. We responded to government consultation on automatic generic substitution to ensure that children continue to have access to treatments that have been specifically developed and licensed for paediatric use and are responding to consultation on the current NHS White Paper.

We need the help of Parliamentarians from all political parties

To achieve our goals we need the help of Parliamentarians from all political parties to galvanise national policymakers in health to find ways to give paediatric continence services the priority they need, to encourage local health policymakers to provide adequate integrated services – and to reassure children and their parents that their calls for help are being acted upon.

For more information write to the PCF address or visit the ERIC* website www.eric.org.uk

*ERIC (Education and Resources for Improving Childhood Continence) is a national charity that provides information, support and resources to children and young people, their families and health professionals.