

The impact of Covid-19 on CYP with continence issues

A briefing from the Paediatric Continence Forum

About the Paediatric Continence Forum

The Paediatric Continence Forum (PCF) is a campaigning group of health professionals, patient representatives and commercial members that engages with the Government and policymakers nationally to raise awareness of childhood bladder and bowel problems and to improve NHS services in this area of child health. We produce guidance and support for those who regularly come into contact with children who might be experiencing such issues, so that all children and young people across the UK can have access to best practice in health provision, in school and at home. Our members span commercial and third sector organisations as well as clinical health staff to ensure our work is comprehensive and as accessible as possible.

A Summary

As a result of school closures, combined with nurses being redeployed to help with Coronavirus, paediatric continence services are being reduced and in some cases ceased entirely, denying children the support they need and rely on. The shortage of resources available is likely to cause significant harm, not only to the mental health and esteem of children but also their safety. Children are more exposed to maltreatment due to families not understanding that wetting and soiling are a result of a bladder and bowel condition.

We would like to see:

- a. A minimum bladder and bowel service maintained during the pandemic crisis to deliver support to vulnerable children
- b. A commitment that bladder and bowel services will be re-instated once this crisis is over.

The impact of Covid-19 on children with continence issues

Paediatric continence issues are prevalent but misunderstood leaving children vulnerable

Approximately 1 in 12 children in the UK suffer from bowel and bladder conditions, including bedwetting, daytime wetting, constipation and soiling, amounting to roughly 900,000 children nationwide. Many families do not understand that wetting and soiling are the result of a bladder and bowel condition, and requires treatment. They believe their child is being lazy, naughty and defiant.

In these circumstances, punitive responses are common and can cause significant harm. We have evidence of children and young people being subject to physical abuse as a result of their continence issues. If families are left isolated and unsupported the chance of abusive responses to persistent incontinence are enhanced.

There have been many stories in the past when children have been severely maltreated, resulting in death in some cases, because of wetting and soiling problems. One such example is that of Victoria Climbié, whose notorious abuse and resulting murder led to substantial changes in child protection policies in the UK. Her carer and murderer said that he had started abusing her because of her incontinence. This must be prevented from reoccurring.

The safety net of schooling has been put on hold

Attendance at nursery or school is one of the key ways children can be monitored and supported if they have a continence problem. Schools' unparalleled experience with children makes them uniquely placed to understand when a child's continence is not developmentally typical or is causing poor school attendance or other issues that impact on a child's development, education and broader wellbeing.

It is often schools and nurseries that will be the first to recognize, highlight and treat a child with continence issues, as well as know when it is appropriate to seek more formal clinical or further support. Schools have strong relationships with families that are of invaluable importance in situations like this as they can adapt their support as appropriate. This support is currently inaccessible.

When treated this issue could have a minimal impact on a child's life. Without the support of schools, families who are not typically equipped with the knowledge or equipment – or sometimes most distressingly the patience – can become stressed and act counterproductively.

This vital resource in ensuring children with continence issues and their families are adequately supported is currently closed, leaving many children exposed. It is therefore vital that health services remain accessible to these families.

Health providers are being redeployed away from paediatric continence service

Specialist paediatric continence services are normally available for parents and carers to visit for information, support and treatment on how to help their child who suffers from bladder or bowel conditions. These services, when commissioned and run properly, are nurse-led and community based, and therefore improve the lives of children and their families while generating significant cost savings for the NHS. Many families rely on these services to meet children's continence needs, helping children receive effective treatment, and saving children from unnecessary emotional distress.

Paediatric continence services were not strong enough at a local level before the pandemic to be safely reduced now. Our 2017 FOI survey of all CCGs and devolved health boards found that over 58% of the providers who responded did not at the time of asking provide all four paediatric continence services, namely for bedwetting, daytime wetting, soiling and constipation. However, they are nevertheless being reduced.

Paediatric continence nurses are being told that their work is not considered essential, and that they will have to close their services, with a number being redeployed. One nurse has reported that she was told her, “enuresis service must be scaled back as it is a non-priority service”. Another nurse said, “*I worry about those who have just started on medication, either desmopressin or oxybutynin, as they need regular reviews*”. These nurses are concerned that a) they could no longer accept new referrals and b) the children on their caseloads would now not have any access to advice and support. Consequently, with children no longer being able to access these services, parents or carers are left isolated to deal with these issues themselves, without the equipment and information to properly deal with these issues, and all in an environment of heightened distress stemming from the pandemic itself.

Our recommendations

Bladder and bowel services have for far too long been a neglected service. We are very concerned not only about the existing service during the pandemic but also the long-term impact that the re-deployment of staff will have. We would like to see:

- a. A minimum bladder and bowel service maintained during the pandemic crisis to deliver support to vulnerable children
- b. A commitment that bladder and bowel services will be re-instated once this crisis is over.

The mental and physical wellbeing of those children who’s risk of abuse is heightened due to bladder and/or bowel continence issues needs to be safeguarded.

Contact details

e: Paediatriccontinenceforum@whitehouseconsulting.co.uk

w: <http://www.paediatriccontinenceforum.org/>

t: 020 7061 6355

a: Unit 225, The Metal Box Factory, 30 Great Guildford Street, London SE1 0HS