

It happens to me too

Breaking down the barriers faced by children and young people with bladder and bowel issues



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Foreword

There are over 21 million people in the UK who suffer with bladder and bowel control problems; 900,000 of whom are children and young people.

Independent research has shown that many children and young people are not accessing the help that is available to them as a result of the deeply entrenched stigma associated with their bladder and bowel control problems. Crucially, this impacts on their ability to interact socially and live as independently as possible in their local communities. The situation is compounded by the pervasiveness of social media in our daily lives and this presents many challenges for children to navigate.

This report, developed in partnership with the Paediatric Continence Forum (PCF), charities ERIC and Bladder and Bowel UK, the University of Bristol and Coloplast, addresses the key challenges faced by children and young people. In particular, it seeks to highlight the stigma associated with bladder and bowel problems and the varying ways in which young people can gain access to practical advice, setting out what they should expect from their local health and social care services. Early intervention, the provision of school nurses and timely referrals to specialist services all form the building blocks to good quality care. The solutions offered in the report are a step in the right direction and our children deserve no less.

As the Co-Chairs of the All-Party Parliamentary Group (APPG) for Continence Care, we have welcomed NHS England's Excellence in Continence Care (EICC) report and commend its recommendations which encompass the provision of a clear framework for local NHS leaders for delivering high quality bladder and bowel services. The continence community, which includes patients, healthcare professionals and providers are also supportive of these recommendations which will lead to better commissioning of services. However, to date, implementation has been painfully slow, notably given the lack of integration between health and social care, the ever present drive in the NHS to cut costs and a generally poor understanding of the clinical issues surrounding continence care.

Alongside the work of the APPG in monitoring the EICC's progress, we must now look forward to ensure that the recommendations are implemented in good time and that the stigma faced by children and young people with bladder and bowel problems is addressed directly.

This report puts forward a number of calls to action that, if implemented, will help to address some of the concerns raised in the report based on first-hand experiences of the patients themselves, user groups and paediatric continence specialists.

We are hopeful that this report will be the first step in helping to improve the lives of the children, young people and their families affected by bladder and bowel problems. The APPG looks forward to working with these groups and individuals to take the calls to action in the report forward and we will be seeking to encourage other Parliamentary colleagues to do so too.

For too long young people who suffer with bladder and bowel control problems have suffered in silence. Now is the time to act to help them get on with their lives.

Rosie Cooper MP

Co-Chair, APPG for Continence Care

Baroness Sally Greengross OBE

Co-Chair, APPG for Continence Care

Useful Links

Bladder and Bowel UK

Bladder & Bowel UK – Children and Young People
www.bladderandboweluk.co.uk/children-young-people
Bladder and Bowel UK – Helpline 0161 607 8219 or
bladderandboweluk@disabledliving.co.uk

Coloplast – Living with bowel / bladder problems

www.coloplast.co.uk/bladder-and-bowel/consumer/living-with-bowel-problems

ERIC – Kids & Teens pages

www.eric.org.uk/kids-teens

ERIC – Helpline

0845 370 8008 or helpline@eric.org.uk

Paediatric Continence Forum – Paediatric Continence Commissioning Guide

www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Continence-Commissioning-Guide-2014-PCF.pdf

The Excellence in Continence Care Report

www.england.nhs.uk/2015/11/continence-care

University of Bristol – Avon Longitudinal Study of Parents and Children (Children of the 90s study)

www.bristol.ac.uk/alspac

About The Report

In this report, the Paediatric Continence Forum (PCF), charities ERIC and Bladder & Bowel UK, University of Bristol and Coloplast have come together to raise awareness of bladder and bowel issues in the young, highlighting the experiences of those living with continence needs. Our purpose is to remove the social stigma of continence issues, reassure young people that their problems need not prevent them from achieving their life goals and offer guidance and advice on seeking help.

Furthermore, we would like to emphasise the key role of early intervention in diagnosing and treating continence conditions, of the need for peer and specialist clinical support to empower individuals and the importance of ensuring that those going through the transition from child to adult services do not get lost in the system and become forgotten. For some, the years of shame and embarrassment from teasing and bullying may mean that they have unmet mental and emotional needs. Additional support may be required.

Finally, in drafting this report, our main audiences are: children, teenagers, their families and carers. However, in as much as we believe in speaking to the public, we must also speak to those involved in the design and delivery of health services in order to bring about change. So we would also like to commend our report to clinical staff and NHS commissioners and managers. Many do a fantastic job at a time when NHS resources have been cut. Extra funding will always be welcome but our intention is to highlight, especially to health policy-makers, the need to support children and young people with continence needs so that they can go on to lead fulfilling lives in the future. Please heed the views and recommendations found at the back of this report.



The Paediatric Continence Forum (PCF)

The Paediatric Continence Forum (PCF) is an independent group of healthcare professionals that engages with the Government and healthcare organisations with the aim of improving paediatric continence services nationally. Formed in 2003, its membership includes key professionals, parent representatives and company supporters. The PCF has close links to ERIC (The Children's Bowel and Bladder Charity) and Bladder and Bowel UK (formerly PromoCon), plus formal representation from the Royal College of Paediatrics and Child Health (RCPCH), the Royal College of Nursing, the Community Practitioners' and Health Visitors' Association (CPHVA) and the School and Public Health Nurses Association (SAPHNA). PCF membership also includes researchers from the University of Bristol who have investigated the causes and consequences of continence problems in children and young people.



ERIC, The Children's Bowel & Bladder Charity

ERIC, The Children's Bowel & Bladder Charity, is the only charity dedicated to the bowel and bladder health of all children and teenagers in the UK. ERIC has been raising awareness of bowel and bladder issues since 1988. ERIC provides expert support, information and understanding to children and teenagers and enables parents, carers and professionals to help them establish good bowel and bladder health.



Bladder and Bowel UK

Bladder and Bowel UK provides a national helpline service for all children and adults with bladder and bowel problems, their carers and the professionals who support them. Our team of nurse specialists and product advisors are able to provide clinical and product advice as well as signposting to additional support services. Free resources are available on our website. In addition, we provide bespoke training, study days, an annual Symposium and special interest groups for health care professionals. We also work with national organisations such as NICE and NHS England and in partnership with industry offering consultancy services in all relevant areas including research and product development.



University of Bristol and the Centre for Child and Adolescent Health

The Centre for Child and Adolescent Health opened in May 2003 and is a joint initiative between the University of Bristol (UoB) and University of the West of England (UWE). The aim of the Centre is to promote the academic study of child health through inter-professional collaboration. It is staffed by a multi-professional team committed to research and teaching that makes a difference to paediatric practice, with an emphasis on the understanding of the current health problems of children and young people. The Centre team has expertise in trials, epidemiology, prevention and the combining of expertise in qualitative work with children and young people with quantitative analyses of large datasets, and integrating within randomised controlled trials.



Coloplast

Coloplast develops products and services that make life easier for people with personal and private medical conditions. Continence is right at the heart of Coloplast's story. While today the company is a multi-national firm operating in a number of areas from ostomy, urology and wound care, its origins started back in 1954 when community nurse Elise Sorensen contacted plastics manufacturer Aage Louis-Hansen with an idea. Following an operation she had seen her once outgoing sister become housebound, avoiding social situations in fear that her ostomy bag would split. The world's first disposable stoma bag was the answer. Coloplast continues to be committed to working closely with its customers to better understand their requirements and find innovative solutions to their everyday needs.



Executive Summary

There are over 14 million adults in the UK who have bladder control problems and six and half million with bowel control problems. In addition to this around 900,000 children and young people have bladder and bowel dysfunction.

In order to better understand the challenges faced by these young people, Coloplast commissioned a poll in 2016, the results of which make for stark reading. We found out that:

- A quarter of people think bladder and bowel issues only affect the elderly
- Almost half would feel 'uncomfortable' talking to loved ones about bladder and bowel issues
- Almost two thirds of young people aged 18 to 24 said they would be embarrassed to see a doctor about continence-related issues
- One-in-ten have avoided school, university, work or social situations due to bladder and bowel problems.

These findings confirmed our concerns that, as a result of the significant stigma that exists around bladder and bowel issues, many young people are not accessing the help that is available and some services are facing challenges in providing the support these young people need. A recent report by the Paediatric Continence Forum showed variation in specialist children's bladder and/or bowel care with gaps in service provision in some areas. This, in turn, is having a wide-ranging impact on young people's day to day lives; acting as a barrier in their social interactions and holding them back from achieving their aspirations.

Continence issues are not rare. Despite misconceptions that bladder and bowel issues are limited to young children and the elderly, the truth is that they can affect anyone at any age, including nearly a million people under the age of 19 in the UK. In fact, one-in-three people who responded to the World Continence Week poll admitted to having laughed so hard that they wet themselves at some point in their lives.

This report has been developed to help address the challenges faced by these 900,000 children and young people, including addressing the stigma that exists around bladder and bowel problems. It also provides practical advice for young people and sets out what they can expect from the health and social services available to them.

Dr Carol Joinson, Dr Katie Whale and Dr Helen Cramer from the University of Bristol set out research which has confirmed that some young people are going to great lengths to conceal bladder and bowel issues, risking serious distress, social isolation and the chance that an underlying condition goes untreated. In the words of one young man, continence problems can feel "not life threatening, but life ruining".

We are pleased to have a few profiles of young people sharing their first hand experiences of living with bladder and bowel issues. We start off with the stories of two children, Kane and Charlotte, as told by their parents. Both have been very brave in relating their accounts to us and we're grateful to them for sharing their experiences. Triathlete and journalist, Helen Croydon, and Shana Pezaro, who was diagnosed with multiple sclerosis aged 28, tell their stories about how seeking help has helped them achieve their goals in life.



In order to support young people, CEO of the children's bowel and bladder charity ERIC, Juliette Randall, speaks about the need for early intervention and specialist care in order to help children deal with their continence issues and outlines practical suggestions to some of the most common concerns expressed by young people, from deciding whether or not to tell a girlfriend or boyfriend, to what to do if your doctor doesn't understand what you are going through. June Rogers, paediatric continence nurse specialist from Bladder and Bowel UK relates to us the importance of ensuring continuity of care for those moving away from children's and into adult NHS services. Penny Dobson, Chair of the Paediatric Continence Forum (PCF), also sets out some of the challenges and issues facing bladder and bowel services for young people in the UK and how they are working to see these improved.

To help young people understand the services that are currently out there, we have also summarised some key aspects of the ground-breaking NHS England Excellence in Continence Care report. The report sets out practical guidance for commissioners, providers, health and social care staff, as well as information for the public on the management and treatment of continence issues. This information also reminds young people (and their carers) of their rights as patients with intimate healthcare needs.

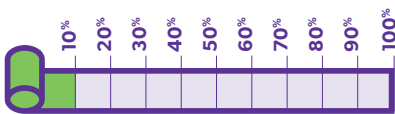
Currently too little attention is paid to the stigma facing young people with bladder and bowel problems. This report is intended to challenge those social anxieties and encourage young people to seek help and support in order for them to achieve their goals in life, that so many are currently being denied.

The Stigma Surrounding Bladder and Bowel Issues

Bladder and Bowel Issues: The Public Perception

Bladder and bowel issues affect an estimated 20 million people in the UK. Some 900,000 children and young people under 19 years old have bladder and bowel problems:¹

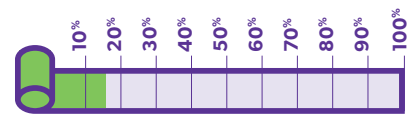
The scale of the problem



10% of school aged children wet the bed²



Up to **30%** of children suffer with constipation³



5-15% of children have daytime wetting⁴

Based on a Populus survey commissioned by Coloplast of a random sample of 2,096 UK adults aged 18+ from an online panel between 15 – 17 June 2016, we found the following:

Social Stigma



A **quarter** of people think bladder and bowel issues only affect the elderly



Almost **two thirds** of young people (18 – 24 year olds) said they would feel embarrassed to tell a doctor about bladder and bowel issues



Almost **half** would feel 'uncomfortable' talking to loved ones about bladder and bowel issues

A Common Problem



One in three people said they had 'laughed so hard they had wet themselves'



One in ten people have avoided school, university, work or social situations due to bladder and bowel issues

40%



40% of children and young people with bladder and bowel problems have said they were bullied because of their condition.⁵ The emotional impact of having bladder and bowel problems include^{6,7}: behavioural problems, stress on parents/carers, a strain on family relationships.

*Populus interviewed a random sample of 2,096 UK adults aged 18+ from its online panel between 15th and 17th June 2016. Surveys were conducted across the country and the results have been weighted to the profile of all adults. Populus is a founder member of the British Polling Council and abides by its rules. Further information: www.populus.co.uk. 1 NHS England (2015) Excellence in continence care: Practical guidance for commissioners, providers, health and social care staff and information for the public <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf> 2 Sarici et al. (2015) Prevalence of nocturnal enuresis and its influence on quality of life in school-aged children 3 Tabbers and Benninga (2015) Constipation in children: fibre and probiotics 4 Swithinbank et al (2010) The natural history of daytime urinary incontinence in children: a large British cohort 5 ERIC summer survey results 2013 as summarised in the press release '40% of children with continence problems are bullied' <https://www.eric.org.uk/News/40-of-children-with-continence-problems-are-bullied> 6 NICE (2010) Guideline: Nocturnal enuresis - the management of bedwetting in children and young people (CG111) www.nice.org.uk/guidance/cg111. 7 NICE (2010). Guideline: Constipation in children and young people - diagnosis and management (CG99) www.nice.org.uk/guidance/cg99. *<https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf>

The “Life Ruining” Impact of Stigma

By Dr Carol Joinson, University of Bristol



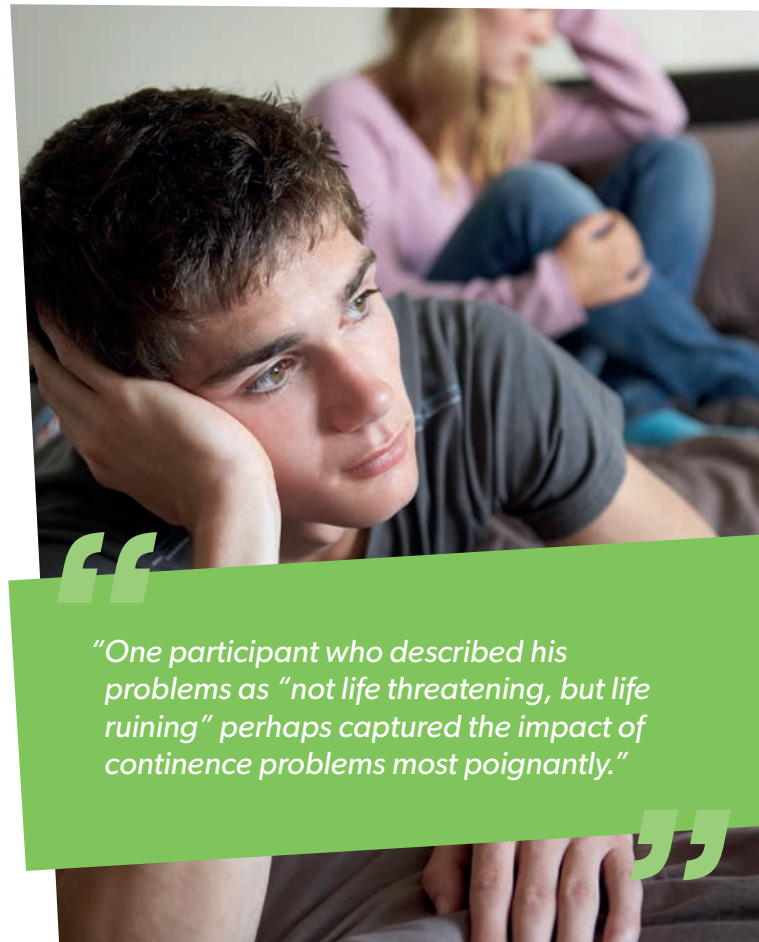
Continence problems are generally believed to affect only the very young or very old, but this is not the case. Researchers at the University of Bristol conducted a major study of continence problems in children and adolescents. The study, led by Dr Carol Joinson, was funded by the Medical Research Council and examined risk factors for continence problems using data from the Children of the Nineties study (<http://www.bristol.ac.uk/alspac/>). The study found that daytime wetting, bedwetting and soiling are common in school-age children and these problems can persist into adolescence, with around 1-3% of teenagers experiencing a continence problem. An important finding was that children who are still wetting frequently in the day and night by the time they go to primary school have a high chance of their problem continuing into adolescence.

The common (but mistaken) belief that continence problems are likely to resolve with age often causes delays in seeking treatment. There is a need to target these children for early treatment because these problems not only become harder to treat in adolescence, but are also more socially unacceptable and distressing. If continence problems are left untreated until teenage years, this can seriously undermine a young person's quality of life. Adolescence is a sensitive period of development when identity and body image are formed and peer acceptance is highly valued. Young people from the Children of the Nineties study who experienced continence problems reported experiencing depressive symptoms, peer victimisation, poor self-image and problems with peer relationships at school.

The University of Bristol study also conducted in-depth interviews with young people aged 11 – 20 years with continence problems. Participants reported that the shame and stigma of continence problems causes them to go to great lengths to conceal their problem and many actively avoid participating in social activities such as school trips and sleepovers. The constant pressure to hide their continence problem caused many young people to experience difficulties with friendships and to feel socially isolated. Dealing with continence problems at school is difficult and many young people in the study reported feeling frustrated at the lack of support and understanding from teachers, the effects on their learning, restricted access to toilets during class time, and very poor school toilet facilities. One participant who described his problems as “not life threatening, but life ruining” perhaps captured the impact of continence problems most poignantly.

Young people interviewed in this study also described their experiences of treatment. Continence problems are challenging to treat in adolescence and young people expressed a strong desire to be supported to self-manage their symptoms. Positive treatment experiences were reported when there was good rapport with clinicians and when young people felt they were fully involved in making decisions about their treatment. Findings of the study highlighted that there is a lot of work to be done to improve the treatment experiences of young people with continence problems. Many reported feeling frustrated about the lack of continuity in their care and the poor understanding of the wider impacts of continence problems on their lives.

It is very important to highlight the remarkable resilience of the young people interviewed in this study. Many refused to let their continence problem define them and they had developed effective ways of managing their symptoms. With greater awareness, support and funding, all young people with continence problems should be able to achieve their potential.



“One participant who described his problems as “not life threatening, but life ruining” perhaps captured the impact of continence problems most poignantly.”

Report Contributors

Dr Carol Joinson (Principal investigator), Dr Katie Whale, Dr Helen Cramer, Dr Jon Heron, Mr Mariusz Grzeda, Dr Anne Wright.

Living with Bladder and Bowel Problems

Kane's Story as told by his Mother

By Amy



This is our story about our son Kane who is 6 and has had severe constipation and an impacted bowel since he was 18 months old. As a toddler, Kane found it hard to go to the toilet - he would scream, cry, sweat and shake every time he needed a poo. We took him to see a doctor who prescribed a laxative treatment called Movicol.

Kane was eventually taking eight sachets of Movicol a day plus another laxative called Senna. Despite this, in July 2013, he managed to go 12 days without a bowel movement. He was examined in hospital and the doctors found large amounts of hard pebble stools on the left side of his abdomen. We also discovered he had an anal fissure, which would have been making passing a stool even more painful.

After not having a bowel movement for 28 days, Kane was admitted to hospital for an enema under sedation. Watching our young son go through this was not nice.

Kane was still eating and drinking and although he didn't complain much about tummy pain, his tummy became severely distended. A return visit to the hospital and an X-ray showed he was extremely blocked with stools. He underwent a phosphate enema and four days later he passed a large and offensive stool then did not stop pooing. He managed to fill the potty right to the top. After this incident Kane continued on his laxative medication and we were given open access to the hospital in case he relapsed.

We continued having regular appointments with the doctor and were told to try to decrease the medication. We went through a process of clearing out Kane's bowels at home by giving him two sachets of movicol and 25 ml of sodium picosulphate at night. Four weeks later nothing had really changed so we went back to the doctor in May 2014 and saw a clinical nurse specialist. After all we'd been through it still felt like we were getting nowhere even with the aggressive management.

Kane was admitted to hospital again a month later to be assessed by doctors. The week he spent in hospital was so straining and tiring, for him, for me and for our family. And it still felt like we weren't getting anywhere. We had to put a hold on everything we'd planned, including our honeymoon. My other son, who was 6 at the time, found it difficult and upsetting.

We were sent home after a week of being in hospital to try a TENS machine. Kane hated it and figured out how to turn the machine off. We also tried getting Kane to eat little shapes that the doctors could use an X-ray to view travelling through his bowels, but for some reason the X-ray didn't show anything, so that felt like a waste of time and effort.

We carried on with the laxative medication for a few months, then in February 2015 Kane had to go back to hospital for another enema, which caused him significant cramping and abdominal pain. He passed a very large stool after this and we were again told to increase his medication. Another month went by and Kane was admitted for another enema. This time he didn't pass the stool in hospital, it happened in his bed at home. Poo was everywhere.

Kane was having lots of poo accidents at this time. He would get upset if he had an accident and got messy, so I had to carry him to the toilet to avoid making a mess. It was hard to go out as a family because we always needed to go somewhere that had a toilet. We used to get stared at when we came out of toilets because Kane would spend half an hour in the toilet screaming in pain and crying. People would look at us as if to say 'what were you doing to him in there?' They would see a perfectly normal looking boy and not have any idea that he was suffering with chronic constipation.

It was about this time I came across the website of ERIC, the children's bowel and bladder charity. I found so much useful information there and was so happy to see that there were other families going through the same thing as us and talking openly about poo. People should talk more about poo – there is nothing wrong with being open about what you do in the loo! I used the Bristol stool chart to keep an eye on Kane's bowel movements. We keep the chart in the toilet and Kane adds the pictures of the different poos himself. It helps him understand what is happening to his bowels.

ERIC invited us to take part in an online TV show to launch their 'Let's Talk About Poo' campaign. I really enjoyed doing it as it helped me get the message out that people should talk more about poo and that it shouldn't make children and teenagers feel ashamed.

Today, Kane is still suffering with constipation. I recently did a fundraising skydive for ERIC to help raise awareness of children's continence problems. I am also campaigning for a Changing Places (fully accessible toilet) in our area as I feel everyone has the right to go in dignity. I recently asked Kane how he feels about having constipation and he answered saying it makes him feel sad sometimes as he can't always do the things he wants to do which breaks my heart because he's been through so much since the age of 18 months and he is now 6. We can't quite see the light at the end of the tunnel, but we know we'll see it one day.

Charlotte's Story as told by her Mother

By Sarah (names changed)

Little did I think that being admitted to hospital in December 2015 would lead to a journey that we have had. My daughter Charlotte was admitted with sickness that we just could not control and after lots of tests, one involving an ultra sound we were told that she had a faecal impaction.

I believe our issues started a few months before when I started to potty train Charlotte. She has a rare brain condition and has additional needs therefore potty training had been delayed until the age of 5 as she has been behind in all her milestones. While we focused on the wee side of things, poos were obviously more difficult and naturally we had lots of accidents in pants. Charlotte was holding onto her poo and having accidents when she simply couldn't hold onto it any more. I feel awful as I know I told her off for messing her pants and now know this probably contributed to making the issue worse. The hospital warned me as we left with our sachets of Movicol and instructions for disimpaction that we were on a long journey and Charlotte would be unlikely to come off the Movicol for at least a year. At the time, I did not believe them.

We went home and started the disimpaction process. Luckily it was the Christmas holidays so Charlotte did not miss school. Unfortunately, the disimpaction process was not fully explained to us in terms of stopping when she was passing brown water, like gravy. I therefore stopped too soon and tried to reduce the Movicol too quickly. It was then that a friend of mine recommended that I call ERIC and speak to one of their bowel and bladder helpline advisors. I can honestly say that this moment changed our lives for the better. I was very down and feeling helpless but the woman I spoke to was so calm and understanding and listened to me talk (even though I was talking through lots of tears) she explained that unless Charlotte had passed brown water then she had not been properly cleared out so she would recommend disimpacting Charlotte again. This thought filled me with dread but the advisor reassured me that we would be unlikely to resolve the problem without disimpacting again. Over the few days and weeks, I spoke to the helpline team regularly to touch base and discuss how things were going with disimpaction and then maintenance.

It is a cliché but we have been on a journey over the last 19 months or so. The key to overcoming Charlotte's chronic constipation has been routine. She now sits on the toilet for 20 minutes in the morning after breakfast and in the evening after tea. We have slowly, very slowly managed to reduce the daily amount of Movicol that Charlotte needs, reducing by half a sachet every few months. I am so proud of Charlotte as she is now able to tell me when she needs the toilet and accidents are now few and far between.

It has not been an easy journey and I feel at times I have been obsessed by how much or how little Charlotte is pooing but the routine/support from ERIC has meant we have kept on track and continual improvements are being seen.

I wish more people would open up and not feel embarrassed about talking about bowel and bladder issues. It's only when you start talking in the school playground to friends that you realise how common these issues are and how we can all support each other with a little bit of knowledge.

Please note

If you think your child is constipated, take them to see a GP as soon as possible for assessment and follow up treatment if necessary. The NICE guidelines on Constipation in children and young people recommend that any underlying causes need to be ruled out when a child or young person is assessed by a health professional for constipation. For more information on recognising the signs and symptoms of constipation take a look at the bowel problems section of the ERIC website and the free downloadable resource: ERIC's Guide to Children's Bowel Problems (www.eric.org.uk/guide-to-childrens-bowel-problems). The Children's Continence Pathway is an online tool which has been designed to inform health professionals and parents about the assessment and intervention of children or teenagers with bowel or bladder problems. Information and resources are also available on Bladder and Bowel UK's website: www.bladderandboweluk.co.uk/children-young-people



Black Shorts – Helen’s Story

By Helen Croydon, Triathlete and Journalist



If you saw me run, or heard me talk about running, you wouldn't think I had a care in the world about it. It's my passion and I spend most weekends with triathlon club friends training or racing. I'm fit, slim and I've never had children.

But if you knew what to look for you'd spot the tell-tale signs of an exasperating problem. The first clue; I always wear black shorts. My sister bought me trendy orange patterned running leggings for Christmas last year and I didn't have the heart to tell her I couldn't wear them. Another is that whenever I run as part of a group, I'll be the only one with a big bag. I need a change of clothes you see, in case someone suggests coffee or the pub afterwards.

The problem? Sometimes I pee myself when I run. There I said it. This taboo affects one in three women and makes one in ten avoid running altogether. One in six athletes have even given up their chosen sport because of it. I love running too much to give it up but I can see why most wouldn't want to carry wet wipes and plastic bags to every training session.

I dismissed going to see my GP because I thought they would simply tell me I had a weak bladder and I should stop drinking diuretics like tea, coffee and alcohol (not an option!). Some 45% of women like me don't get medical help according to research carried out by Coloplast.

But training for my first marathon last year proved to be the final straw. It's one thing putting up with damp shorts for an hour or so. It's quite another when you're running for three hours and your ammonia-saturated shorts start to chafe. One day my inner thighs chafed so much that I couldn't shower or wear trousers for days. Enough! I went to see my GP.

I was expecting a dramatic verdict - a deformed bladder? Could I have injured it at some point? But my GP had seen my symptoms many times. She referred me to the gynaecological department at my local hospital and then I received physiotherapy.

Note that physiotherapy may not be right for children and young people and there are alternative treatments and specialist products out there that your doctor or nurse can recommend so that you can live your life again.

It is no overstatement to say that physiotherapy for my pelvic floor has changed my life. It started with simple squeezing exercises six times per day. I still leaked when I ran at first, but other things like going shopping suddenly became easier. I used to have to drop everything to find a toilet every hour, or leave meetings in the middle of important discussions to visit the loo.

Both of these examples are symptoms of 'urge incontinence', which often accompanies stress incontinence. After a few weeks of physiotherapy I could hold my bladder for hours.



"The important thing is to visit a doctor in the first place, get a diagnosis (if possible) and start considering some options that will make sure you live the best life possible."

As a journalist, I decided to write about my experience and surprisingly I found that many super-fit women like me suffer from weak pelvic floor muscles. Ab exercises and running both load pressure on the pelvic floor so if it's weak to begin with, it will get weaker. One personal trainer told me: "I see so many women with six packs because they work their upper abs so much, but if you ask them to do a star jump they wet themselves."

I'm six months into physio and I'm 75% cured. If I'm tired or near my period (when we have less control of our muscles) I still have occasional accidents. Being involved in competitive fitness I'm shocked that none of the popular fitness classes, books or instructors have emphasized the importance of strengthening this crucial muscle. If I'd started working on my pelvic floor years ago, I may not have missed out on so many post-run social occasions because I was too embarrassed to hang out in my damp running shorts.

"Some 45% of women like me don't get medical help according to research carried out by Coloplast."

'There is help out there' – Shana's Story

By Shana Pezaro, Multiple Sclerosis Patient Advocate



In the past when I heard people talk about continence issues, I assumed it meant 'losing control of your bladder or bowels'. It never occurred to me that the multitude of problems and difficulties I faced every day were, in fact, continence-related. Issues with my bladder and bowels had started in my teens. It was my 'normal' and I didn't realise that I could get help. For years I suffered horribly with constipation. I consumed vast quantities of figs, drank concentrated prune juice and tried every over-the-counter laxative I could find. Nothing worked. I was often bloated, tired and sluggish, extremely uncomfortable and my sex-drive was non-existent.

I got bladder infections at least three times a year. At one point I was put on long term, low-dose antibiotics as the urinary tract infections were constant. Aged 23, I asked my doctor why I kept on getting bladder infections. He replied: "Poor personal hygiene". I was mortified and never asked again. I have since been reassured that personal hygiene is not the cause of bladder infections.

Sometimes I'd need to pee, but I'd sit down and nothing would come out. Or I'd pee a bit, then 10 minutes later I'd need to go again. Sometimes I would suddenly, desperately need to urinate. Occasionally I'd wet myself before I'd reached the toilet. I would sometimes pee a little when sneezing, coughing, running, jumping, dancing or laughing.

Over the years, these continence problems increasingly impacted on my quality of life and my self-esteem. I became terrified of long car journeys and travelling. I would often go up to 10 hours without drinking any fluid and I wouldn't go anywhere unless I knew where the nearest toilet was located. I also had many other health problems, which seemed unconnected. I became increasingly ill and disabled and I was finally diagnosed with Multiple Sclerosis aged 28. It turned out that many of the issues I was experiencing with my bladder and bowels had this underlying neurological cause. However, I know many, many people who experience the same sort of continence problems as me, but for a multitude of different reasons.

There is help out there. I now have medication to stop bladder spasms; that has stopped the sudden urgency. I use little disposable catheters each time I urinate to fully empty my bladder; that has stopped the bladder infections and dealt with the retention. I use mini-enemas and suppositories to stimulate the muscles which open the bowel; that has stopped the constipation. (Taking laxatives was never going to work, I was literally coming at the problem from the wrong direction!) And there are many other treatments available including colonic systems, pelvic floor physio exercises, discreet anal tampons and botox.

"There is help out there."

Talking about continence problems can seem daunting and embarrassing. Yet my life has changed unbelievably for the better since I got my bladder and bowels under control. I now travel all over the world, I never worry about 'accidents' and I have regained my self-confidence and spirit. I have got my life back.

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"My life has changed unbelievably for the better since I got my bladder and bowels under control"

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Support for Children and Young People with Bladder and Bowel Issues

Living with Contenance Problems

By Juliette Randall, Chief Executive, ERIC, The Children's Bowel and Bladder Charity



The impact of bowel and bladder problems on young people goes far beyond health concerns, which sets continence conditions apart from other ailments. Unlike those living with conditions like diabetes or asthma, children and teenagers with continence problems have to manage their medical conditions and society's reaction to them.



Young people affected by wetting and soiling problems are more likely to be the victims and perpetrators of bullying and their self-esteem can be deeply affected by feelings of shame, immaturity, embarrassment and blame.

The stigma associated with continence is hard to break. It is fuelled by limited understanding of how and why bowel and bladder conditions develop, which is itself a product of society's reluctance to talk openly about wee and poo. Frank discussion about toileting at home and at school, as well as campaigns to raise awareness of the conditions, could help us come to terms with our squeamishness and create spaces for children, young people and adults to learn about bowel and bladder health.

Help is out there but it can sometimes be difficult to navigate. It is crucial that once a continence problem is recognised in a child and teenager, steps are taken as soon as possible to support and address them. My advice is for children and teenagers to speak to a health professional if they have any anxieties about weeing or pooing. There is no need to be ashamed.

Most schools have a school nurse linked to them. They often run a 'drop in' service so you can call in and talk to them in private. Another option is to visit the GP who will listen and give basic advice as well as knowing when to refer on to more specialist help. Alternatively, if a child, teenager or parent wants to talk to someone in private about the problem or the impact it may be having on them a call or email to the ERIC helpline may help. We have expert advisors who have been trained to provide information and support on daytime wetting, bedwetting, constipation and soiling.



"Frank discussion about toileting at home and at school, as well as campaigns to raise awareness of the conditions, could help us come to terms with our squeamishness..."

1. What if I tell my friends and they tell other people?

If you've decided you want to tell your friends about your condition but you're scared they'll spill the beans and the whole school will find out, try telling just one friend that you really trust. It's far worse to carry the weight of your secret on your shoulders than it is to share the load with a friend. You could create a pact with your friend where they tell you a secret and you tell them one. You might find this reinforces your friendship as well.

2. Should I tell my girlfriend/boyfriend?

If you trust them, you should tell them. They will find out one way or another, so it's best to get it off your chest as early as possible and not worry about it too much. They may be understanding and want to help you deal with it.

3. I'm scared of sleeping away from home because someone might find out and I'll get bullied

You shouldn't have to miss out on having fun because of your condition. There are lots of ways you can keep it hidden when you're away from home, for instance, use discreet absorbent underwear and special pyjamas; keep spare clothes and pads in your sleeping bag; use sprays to mask smells; have a code word or sign to notify your teacher or friend's parents when you've had an accident; spill a drink on your bed if you wet at night. The teen pages on ERIC's website (<https://www.eric.org.uk/Pages/Category/teens>) have useful tips on how to deal with your problem away from home.

4. I'm scared of having an accident at my friend's house and ruining the sheets/mattress

You shouldn't have to avoid spending the night at a friend's because of your problem. Use good quality absorbent products that you know work well for you and specially designed pants and pyjamas that won't leak if you have an accident. Take your own sleeping bag with a sleeping bag liner that will absorb any leaks. Take a plastic bag for dirty clothes that you can put at the bottom of your rucksack.

5. My doctor doesn't understand me / isn't helping

If you feel that your doctor or other health professional doesn't understand what you're going through or isn't helping you to manage your condition, you could ask your parents to have a word with them. If that doesn't work, you can ask to see a different doctor. In some cases, a team approach may be needed which includes other specialists and therapists so that the best solution can be found for you.

Health professionals can help young people develop the confidence to manage their condition and not let it take over their lives by responding to their concerns in a compassionate and understanding way, by explaining procedures and treatment clearly without using jargon, and by ensuring they understand that they're not to blame and that lots of other young people have the same problem.

6. I feel like I'm the only one going through this

It can sometimes feel like you're the only person in the world that has a problem with weeing or pooing, but this is not the case. Around one in 10 children and teenagers have a bladder or bowel problem, which means there's probably at least one other person in your year that has a similar condition. If you go online you'll find other teenagers with similar problems. Speaking to them should reassure you that you aren't the only person going through this. Chatting with other people can also help relieve the burden of the secret you're carrying and you may learn new ways of managing your condition.

Sometimes it may feel easier to get your information from the internet or through social media. However, be aware that some sites may not provide you with the information or assurance you need. Similarly, there is also the danger of cyberbullying. This is why it is always important to seek help and advice from people you trust like friends, family, and your doctor or school nurse.

Health professionals can help young people feel less alone by explaining how common their condition is, signposting to places where they can talk to others going through similar experiences, and putting them in touch with organisations that can help, like ERIC, The Children's Bowel & Bladder Charity.



Living with a Contenance Problem – Moving from Children’s to Adult Services (Transition)

By June Rogers MBE, Paediatric Contenance Specialist, Bladder and Bowel UK



Bladder and bowel problems are topics that people don’t often talk about so it might feel at times that you are the only one who has such a problem. However, it may surprise you to know that across the country around 900,000 children and young people are affected by a problem with either their bladder or bowel or both and over the years I have had hundreds of children and young people with similar problems that you are experiencing.

While many children’s problems will resolve before they reach adulthood a number of children will have more complex problems that continue into teenage years and adulthood. So if you are amongst those young people who will require ongoing care then it is important that you are prepared for the move from children’s to adult services.

When you were younger you probably felt that lots of people were making decisions for you but as you get older it is important that you have the opportunity to make decisions of your own. However, in order for you to make the right decisions, you will need to have a good understanding about your condition and the range of treatment and management options available.

How do you make sure that you know what the best treatment options are?

The best way is for you to ask a lot of questions! If you feel anxious about asking questions or feel that you may forget what you need to say then write everything down.

Bladder and Bowel UK has a confidential helpline for people to ring and ask for advice and information regarding any aspect of bladder and bowel care, products or services. If you are not clear what your options are or want more information then do give us a ring. An example of why it is important to ask questions is from a phone call we had last year:

A young man rang the helpline as he was due to go to university and had an ongoing problem with bedwetting. He rang to ask about where he could get disposable pants from as he would not be able to cope with washing lots of wet sheets. While we were chatting it transpired that he had had the bedwetting problem from childhood and was told that it was something he would eventually grow out of. However at aged 18 years the problem persisted and the young man was resigned that it would carry on into adulthood. He had not been assessed nor had any treatment so we spent some time explaining to him about bedwetting, including causes and treatment options and signposted him where he could get further information. We advised him to go and see his GP to discuss the best treatment options and to contact us again if he needed any further advice or information. He phoned us a month later to say that his GP had prescribed some medication (DesmoMelt) and he was now dry! He was obviously delighted and wished he had questioned the original advice that he would ‘grow out of the bedwetting’ much earlier.



What does ‘transition’ mean?

‘Transition’ is the move from children’s to adult services and is said to be: ‘... a purposeful planned process that addresses the medical, psychosocial and educational/ vocational needs of adolescents and young adults with chronic physical and mental conditions as they move from child-centred to adult-oriented Healthcare systems’ (DH 2006).

How can you prepare for your transition from children’s to adult services?

It is important to realise that transition should be a process, not a single event, and although it does not start at the same age for everyone, it should be started to be discussed sometime in your early teens. It is recommended that you are involved with writing a Transition Plan so that your views and opinions are taken on board. Your doctor or nurse will help you with this.

Where can you find more information?

Bladder and Bowel UK have a dedicated telephone helpline if you want to speak to somebody for further advice and information: 0161 607 8219.

The NHS is aware of the importance of a good transition process and so has produced a lot of documents – some of which are below. If you don’t want to read them all then let your parents know where they can find them when they are looking for more information.

CQC (2014) From the Pond into the Sea: children’s transition into adult services. Care Quality Commission, Gallowgate. Available at: https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf

DH (2006) Transition: Getting it right for young people. Department of Health, London. Available at: http://webarchive.nationalarchives.gov.uk/20130124072700/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4132149.pdf

DH (2008) Transition: moving on well. Department of Health, London. Available at: https://www.bacdis.org.uk/policy/documents/transition_moving-on-well.pdf

NICE : Information for the general public about the transition process. Available at: <https://www.nice.org.uk/guidance/ng43/ifp/chapter/What-is-transition>

Improving Bladder and Bowel Services

By Dr Penny Dobson MBE, Chair, Paediatric Continence Forum



It is commonly thought that bladder and bowel (continence) problems only concern older people, yet we know that about 1 in 10 children and young people are also affected. Recent research highlights just how much this often hidden problem restricts their lives – reducing their self-confidence at critical moments and causing difficulties at school. We know that most continence conditions are treatable – but research tells us that the associated stigma and feelings of embarrassment prevent many from coming forward for help.

The challenge for locally based paediatric continence services is to be friendly and accessible – as well as clinically effective. Too few UK services are properly integrated – with a “one stop shop” for the full range of continence problems. The clear message from young people is that they want to build up a relationship of trust with one clinician – and not have to tell their story to different clinicians in different places. Remedying this situation is a key focus of the Paediatric Continence Forum (PCF), a national campaigning group of specialist nurses and doctors, supported by industry.

The PCF agrees that more needs to be done to increase government awareness – and the awareness of those commissioning services at local level – of the needs of this often neglected group. The PCF carries out direct work with MPs, Peers, NHS England and Public Health England to get messages across and to develop commissioning initiatives. The PCF’s own NICE-accredited Paediatric Continence Commissioning Guide (2014, updated 2015), provides a template for good service delivery. The needs of children are sometimes overlooked and we believe that this Commissioning Guide, when followed, will help to ensure better provision of paediatric continence care on the NHS.



Yet, it is an uphill task in the current financial climate. Too often government objectives – for example, to encourage more community-based, preventative services – are translated “on the ground” to cuts in these very services! A most recent example is the unintended consequence of the 2015 transfer of school nurses and health visitors from public health to local authority control. School nurses and health visitors play an important role at Level/Tier one in identifying continence problems early – and in carrying out the most straightforward treatment approaches. Unfortunately cash-strapped local authorities are decommissioning these roles, thereby reducing the routes for children and young people to seek help (this is particularly problematic in areas where there are no Level/Tier 2 paediatric continence services).

Amongst its other activities, the PCF is identifying and promoting the specific savings that can be made from setting up a properly integrated, community-based paediatric continence service compared to one which relies on inappropriate referrals to secondary care. A summary of our 2017 survey of paediatric continence services nationally can be seen on the Paediatric Continence Forum website - providing us with up-to-date information and enabling us to identify where services are below standard and to lobby for high quality NHS care.

Finally, in response to the 2017 General Election, the PCF produced a manifesto calling on the government to help children with bladder and bowel issues. This can be found on page 15 at the end of this document as a reminder that there is still much to be done to care for children and young people with continence care needs.

“We know that most continence conditions are treatable”



Where can you find more information?

The PCF’s 2017 FOI report: An examination of paediatric continence services across the UK - www.paediatriccontinenceforum.org/wp-content/uploads/2017/10/An-examination-of-paediatric-continence-services-across-the-UK-PCF-August-2017.pdf

The Paediatric Continence Commissioning Guide - www.paediatriccontinenceforum.org/wp-content/uploads/2015/09/Paediatric-Continence-Commissioning-Guide-2014-PCF.pdf

Children’s continence care: sub-optimal pathway versus optimal pathway - www.paediatriccontinenceforum.org/wp-content/uploads/2017/07/PCF-Tobys-sub-optimal-versus-optimal-pathway-14th-March-2017.pdf

What Support, Care and Treatment should the NHS Provide?

The Excellence in Continence Care Report

Although continence issues can affect anyone at any age, there has historically been very little guidance to help NHS services meet people's needs. The Excellence in Continence Care (or EICC) was published by NHS England in 2015 to fill that gap and provide local NHS leaders with a clear framework for delivering high quality bladder and bowel services. EICC offers reassurances to both adults and young people about the care that they should expect to receive.

Following the publication of EICC, progress in its implementation has been slow in both adult and children's services. Several factors are to blame including the disjoint between health and social care, ignorance over patient rights and access to services and a poor understanding of the clinical issues in continence care.

Providing integrated services

EICC, drawing on evidence from previous reports, reiterates that the best clinical outcomes are achieved when care is integrated across primary, secondary and community settings. For children and young people, there should be one community-based service covering day and night time wetting, soiling and constipation problems. All staff providing continence assessments must be trained. Advice on conservative treatment should be offered prior to more in-depth testing and surgical interventions. There should also be clear and effective referral and care pathways to further care including education, Child and Adolescent Mental Health Services (CAMHS) and social services.

Within this health economy, it is essential to ensure organisational leadership of continence via a paediatric continence nurse specialist with input from a multidisciplinary team when appropriate.

Identifying and assessing young people

Local services should seek to identify people with continence issues who may be at risk. Early intervention can help children and young people to better manage their conditions.

Once identified with a potential bladder or bowel issue, it is essential that all children and young people receive a comprehensive assessment by a trained healthcare professional to look for 'red flags' (warning signs of an underlying condition). If necessary, individuals should be referred on to specialist services for care.

An expert assessment is particularly important for those who do not respond to treatment. Young people should not be given 'containment products', such as absorbent pads, to manage the symptoms of incontinence without first receiving an investigation to see whether there are any underlying bladder and bowel problems. In fact, "it must be the exception, rather than the rule, that children and young people are provided with containment products."

"It is essential that all children and young people with a bladder or bowel problem have a comprehensive bladder and bowel assessment by appropriately trained staff"

Treatment and ongoing support

Anyone with a continence problem should have timely access to help. Bladder and bowel services for young people should employ a paediatric continence nurse specialist and treat anyone under the age of 19, including those with complex needs such as learning difficulties and/or physical disabilities.

For ongoing support any young people with continence problems should have access to a Community Paediatric Continence Service (or CPCS).

There should also be local pathways through which healthcare professionals can refer them on to other services, such as specialist care, social services or mental health services, when this is appropriate. People with bladder and bowel problems should be supported to self-manage their condition as, in many cases, the issue can be completely resolved.

"People with bladder and bowel problems should be supported to self-manage their condition as, in many cases, the issue can be completely resolved"

Decisions about care

Bladder and bowel services should ensure that people with continence issues are supported to take an active role in managing their own care. This includes patient and parental involvement in the type of care they may need and shared decision-making over their treatment and the services provided by the NHS.

Further details of Excellence in Continence Care can be found at <http://bit.ly/1IjwYE8>

PCF Call to Action in Children and Young People's Services



About 1 in 10 children and young people are affected by bladder and bowel problems which, as set out earlier in this report, can cause significant difficulties and often prevent them from achieving their goals in life. In order to improve the situation for this often-neglected group of children and young people, the Government needs to heed the advice of the experts.

✓ All young people should have access to integrated, well-resourced paediatric continence services

Bedwetting, daytime wetting, constipation and soiling can all substantially impact upon a child's emotional and physical development. This can be alleviated with timely and appropriate treatment. Each area of the UK should have equitable access to an integrated (offering services for each area of continence "under one roof"), well-resourced, community-based paediatric continence service, led by a specially-trained paediatric continence nurse to provide consistent, age-appropriate, good quality care for each child and young person. However, in practice this provision varies considerably across the UK; only 31% of English CCGs have an integrated service, compared with 60% of Health Boards in Northern Ireland, 23% in Scotland and none in Wales.

✓ A Commissioning Guide should be utilised to improve the quality of services

The PCF's Commissioning Guide is accredited by NICE and endorsed by the Royal College of Paediatrics and Child Health (RCPCH), the Royal College of Nursing (RCN) and the Community Practitioners' and Health Visitors' Association (CPHVA). It provides clear advice to commissioners and healthcare professionals on how to commission integrated, community-based paediatric continence services. It outlines how identifying and dealing with these problems early saves children from unnecessary emotional distress - and saves NHS resources by reducing expenditure on complications that require hospitalisation. This guide should be used widely to improve the quality of paediatric continence services nationwide but recent PCF research indicates that only 50% of English CCGs; 80% of Northern Ireland Health Boards; 30% of Scottish Health Boards and 42% of Welsh Health Boards are utilising this crucial resource.

✓ Continence should be considered when making policy on young people's health, disability and education

While continence services are largely determined at a local level by CCGs and Health Boards, continence also impacts upon other policy areas, including education. For example, of the 800,000 children and young people with a physical or learning disability, approximately half have continence difficulties. Continence can also affect a child's educational experiences, with a 2014 survey by the Association of Teachers and Lecturers showing how only 31% of nursery and primary schools had a written policy covering continence. We are calling on all four nations of the UK to consider the role of paediatric continence services when considering issues relating to childhood health, disability and education in a joined-up manner, so that continence issues are fully addressed as part of wider policy making.

A manifesto for improving paediatric continence services across the UK can be found here <http://bit.ly/2wOt0QC>

The PCF Paediatric Continence Commissioning Guide: A handbook for the commissioning and running of paediatric continence services can be found here <http://bit.ly/28RC1hk>

