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Young people with continence problems need better support at secondary school

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"Not life threatening, but life ruining"

Dealing with continence problems at school is difficult and a lack of support and understanding from staff has an adverse effect on young people's wellbeing and attainment.

About the research

Continence problems (daytime wetting, bedwetting, soiling and constipation) are among the most common paediatric health problems and it is often believed that they resolve with age.

However, our recent research found that this is not the case: continence problems often persist into adolescence.

In an average sized secondary school there could be around 30-40 young people with continence problems.

Continence problems are accidental and are not the child's fault.

Young people with these problems experience high levels of depressive symptoms, peer victimisation, poor self-image, problems with relationships and negative school experiences.

Most sufferers go to great lengths to conceal their problems from peers and teachers and this can cause them to feel socially isolated.

"always thinking about it, always worrying about it"

Under the Children and Families Act (2014) schools are required to provide appropriate support for children and young people with health problems.

However, our recent findings indicate that the needs of young people with bladder and bowel issues are not being met.

This project worked with young people and secondary school staff to produce and promote information resources for secondary schools to help them support young people with continence problems.

Policy implications

- Continence problems are common in young people, but some schools are not complying with their legal duty to make arrangements to support children with a medical condition.
- Addressing the challenges starts with educating teachers and other school staff.
- Secondary school staff need support to understand their responsibilities and to know how to respond to the unique needs of young people with continence problems.
- The statutory guidance from the Department for Education on 'Supporting Pupils with Medical Conditions at School' should include guidance for schools on clear and discreet procedures to make disclosing continence problems easier for young people.
- Young people with continence problems may need extra time during exams and additional support to catch up with missed parts of lessons.
- This requires a national approach to address unequal provision between schools.

Continence problem	Possible cause	Prevalence in adolescence
Urgency (sudden urge to urinate)	Overactive bladder	5%
Daytime wetting		3-4%
Bedwetting		2.5%
Soiling (faecal incontinence)	Constipation	1.5%

Research summary

This in-depth qualitative research, the first of its kind in the UK, explored the impacts of continence problems for young people at secondary school and the barriers to their effective management. The study also assessed current awareness, practices and future information needs of school staff.

- In 2015-16, in-depth interviews were conducted with 20 young people aged 11-19 with continence problems (as part of a larger study funded by the Medical Research Council).
- In 2018, a focus group was conducted with five young people aged 12-17.
- This research identified the range of experiences of young people with continence problems at secondary school.
- Focus groups were conducted in 2018 with secondary school staff (teachers, teaching assistants, school nurses, staff involved in pastoral care, safeguarding and additional needs support).
- Four schools in southwest England and Wales participated in the study comprising 15 participants in total.
- Staff in these schools helped us to learn about examples of good practice in supporting young people with continence problems.

Key findings

Teachers often lack understanding of continence problems in adolescence

"I went to my pastoral manager and said I needed a new toilet access card. But she wouldn't give me one and said that my daytime wetting should be sorted by now and that we were going to have a meeting to discuss why I still needed it"

Schools' perspective

Some teachers thought that continence problems affect only young children. Many were unaware of how common they are in young people and wanted to learn more about issues and treatments.

Many young people are reluctant to tell their teachers about their continence problems

"I'm just worried that if I did tell my teachers they might treat me a bit differently, and then other people might find out"

Disclosure to teachers was a source of anxiety for young people, who worried that teachers would not take them seriously or believe they had a real problem.

Continence problems are often considered a hidden disability because the majority of sufferers appear outwardly healthy.

Schools' perspective

If the school is not informed, this makes it challenging for teachers to provide appropriate support in line with the Children and Families Act (2014).

We found systems for disclosing health problems varied across schools, but it was most common for parents and/ or clinicians to contact the pastoral care/health team to discuss the child's healthcare needs and develop an individual healthcare plan.

Inadequate school toilet facilities make young people anxious to use the toilet

"There's only a sanitary bin in one of the toilets, so I have to try and get there before anyone else"

There was also a lack of facilities for young people to clean themselves and for discreet disposal of wet or soiled pads. School toilets sometimes lacked soap, toilet paper, and working dryers, and some had no locks.

This made using the toilet a potentially risky activity for participants because they felt vulnerable and highly anxious about being discovered.

Schools' perspective

In response to this, teachers said that lack of soap and toilet paper and defective locks and hand dryers should be reported to the school caretaking team.

Pupils with continence problems who had disclosed their condition were permitted to use the disabled toilet facilities, which provide a larger, lockable toilet cubicle with a private sink and space for changing clothes.

Recommendations for schools

- All schools should have a clear and discreet procedure for pupils to disclose continence problems that respects their privacy and dignity.
- Schools should have clear policies for appropriate use of toilet/medical passes during class that do not draw attention to pupils with continence issues and they should ensure that supply teachers are made aware of these policies. Pupils with continence problems should be allowed access to disabled toilets.
- There should be clear procedures for catching up with lessons and arrangements for exams.
- Schools should have a designated person with expertise in dealing with continence issues.
- Healthy drinking habits should be encouraged in schools and young people should not be prevented from using water bottles in class.
- Teacher training on common health problems should include continence issues.
- Bladder and bowel issues should be integrated into Personal, Social and Health Education (PHSE) lessons.

Key findings

Restricted toilet access is a barrier to effective management

"Some of the teachers just have to keep being told that if I need to go to the toilet, they need to let me go. Sometimes they forget and it's easy for them to forget, because I look normal, perfectly normal, so it's easy to not see that there's anything wrong with me, unless you actually know me"

Continence problems can be challenging to treat and often take many months or years to resolve.

A common treatment for urinary incontinence and urgency is 'bladder training', which focuses on establishing a regular schedule of toilet visits (every 2-3 hours) and fluid intake (6-8 glasses per day).

Requests to use the toilet during lessons are, however, sometimes met with resistance from teachers; in some cases young people have had wetting or soiling accidents in the classroom.

Schools' perspective

Most schools had rules limiting student toilet access during class, and granting requests was at teacher discretion. Teachers tended to be more lenient of girls' requests due to dealing with periods.

A common fear of granting unrestricted access was that some pupils would take advantage and skip lessons.

All schools had a form of medical/toilet access card that permitted identified students to leave class, generally without explanation.

This mostly worked well, but a common problem was that supply teachers were sometimes unaware of the card system. Such a system also requires students to have disclosed their continence problem.

Frequent toilet trips mean that young people often miss time during lessons or exams

"I missed out on eight marks because I had to go to the toilet constantly"

Repeated toilet trips during lessons meant that young people often fell behind in class.

It also impacted on exam performance. Many young people reported that they had lost time, were unable to complete questions or had reduced concentration due to anxiety about needing to use the toilet.

Very few young people were aware that they may be eligible for extra time during exams.

Schools' perspective

Teachers said that pupils can make arrangements with them to catch up on missed parts of lessons and they can ask them for a lesson plan, so they know when there may be a suitable time to go to the toilet.

The exams officer can arrange unrestricted access to the toilet and extra time during exams. Pupils could arrange to sit near the exit or take their exam in a separate room with easy toilet access.



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Recommendations

Department of Education

- Schools are legally required to have a medical conditions policy and provide adequate support to children with health conditions (Children and Families Act 2014). The department has a responsibility to ensure that schools are aware of the new duty and are effectively implementing it. Clear guidance should be provided outlining how schools can comply with their obligations regarding continence issues.
- The statutory '<u>Supporting Pupils with Medical Conditions</u> at <u>School</u>' guidance needs to contain specific guidance on managing continence problems in secondary schools.
- OFSTED should routinely check schools' policies for management of medical conditions.

Department of Health and Social Care

- DHSC should play a coordinating role in funding or further defining paediatric continence service provision, with Public Health England, to support progress against Public Health Outcomes Framework indicators 1.03 on pupil absence and 1.02 on school readiness.
- This issue requires closer working with the Department of Education on relevant policies and guidelines.

Directors of Public Health

- Local authorities could develop resources for secondary schools to improve staff awareness of continence issues, statutory obligations, and help them provide appropriate support to young people.
- School nursing services should be encouraged to play a role in working towards integrated paediatric continence services.
- School nursing services should continue to support children with continence problems and work collaboratively with school staff as they develop their procedures.

Paediatric continence specialists

- Could work to provide a policy blueprint for the Department for Education, local authorities, and academy trusts on the management of children with continence problems in schools and work to encourage this to be actively used nationally.
- Should continue to lobby for more detail about toilet provision and access within the Education School Premises Regulations (1999) for England and Wales.

Further information

Research programme: Medical Research Council (MRC). Increasing understanding of risk factors and outcomes associated with continence problems in children and adolescents. 2014-17 (Awarded to Dr Joinson). MR/L007231/1

Heron J, Grzeda MT, von Gontard A, Wright A, Joinson C. Trajectories of urinary incontinence in childhood and bladder and bowel symptoms in adolescence: prospective cohort study. BMJ Open. 2017;7(3):e014238. DOI: 10.1136/bmjopen-2016-014238

Grzeda MT, Heron J, von Gontard A, Joinson C. Effects of urinary incontinence on psychosocial outcomes in adolescence. European Journal of Child & Adolescent Psychiatry. 2017;26(6):649-658. DOI: 10.1007/s00787-016-0928-0

Whale K, Cramer H, Joinson C. Left behind and left out: The impact of the school environment on young people with continence problems. British Journal of Health Psychology. 2018;23(2):253-277. DOI: 10.1111/bjhp.12284

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ERIC - The Children's Bowel and Bladder Charity https://www.eric.org.uk/
The Paediatric Continence Forum (PCF). www.paediatriccontinenceforum.org