



Association for the Bladder Exstrophy Community

HELPING CHILDREN WITH BLADDER EXSTROPHY NAVIGATE CONTINENCE CARE AT SCHOOL

WHAT IS BLADDER EXSTROPHY?



Bladder Exstrophy (BE) is a rare congenital disability affecting 1 in 50,000 children born per year that causes the bladder to form improperly during gestation. A child with bladder exstrophy is born with their bladder 'inside out' and positioned on the abdomen.

Bladder issues can have a devastating impact on a child's learning, development and well-being. For children with bladder exstrophy their continence problem may be 'chronic' - meaning it could persist for many years or keep recurring.

Bladder exstrophy can affect your student's self-esteem, social well-being, and even academic performance.

WHAT ARE SOME OF THE PROBLEMS ASSOCIATED WITH RESTRICTED ACCESS AND POOR SCHOOL TOILET FACILITIES?



Medical conditions such as chronic constipation, wetting and urinary tract infections (UTIs) can be caused or aggravated by the avoidance of, or limited access to, school toilets.



Restricted toilet access can cause significant anxiety which can have a direct ability on a child's ability to concentrate and affect their progress at school.



Students avoiding using the toilets at school because they are dirty, smelly, lack basic provisions, are not private enough, or because they're not allowed to go when they need to.



Limiting how much they eat and drink to avoid using the school bathroom. Not drinking enough water during the day can cause and aggravate problems with the bladder and bowel. It can also lead to dehydration and lack of concentration.

WHAT ISSUES DO CHILDREN WITH BLADDER EXSTROPHY FACE?



Frequent bathroom use



Wear diapers, pads or pull-ups



Accidents



Urine smell



Many surgical scars



HOW ARE ISSUES MAGNIFIED AT SCHOOL?

- Questions from classmates
- Missed class time/ recess / school
- Lack of privacy especially for boys
- Multiple trips to the bathroom
- Cathing takes a long time and requires supplies
- Storage for bathroom supplies and change of clothes

WHAT ARE THE IMPLICATIONS?



Not allowed to start preschool because "not potty trained"



UTIs/bladderstones/kidney damage



Missed school for surgeries/hospitalization



Bullying/teasing/family abuse



Low self-esteem



Substance abuse/depression/suicide

HOW CAN THE SCHOOL AND TEACHERS HELP?

- Add regularly scheduled, frequent breaks and allow the student to go to the bathroom without asking permission
- Plan ahead for field trips
- Provide appropriate bathroom space
- Store continence supplies and clothing changes
- Plan for accidents and manage soiled materials
- Support the student's privacy and dignity
- Develop a plan to respond to questions
- Be patient, understanding, and reassuring and avoid drawing attention to the student



For more information please visit
www.bladderexstrophy.com



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