Continence Promotion in Children with Additional Needs

Understanding bladder and bowel comorbidities – the importance of assessment: Information for professionals

Children and young people with physical and/or learning disabilities who have delayed bladder and bowel control are a particularly challenging group to manage. Moreover, there are associated systemic and localized comorbidities, as well as psychological issues that need to be considered in bladder and bowel management programmes.

Currently the published literature on this subject is limited. However there is evidence that incontinence is more common in children with disabilities (von Gontard, 2015; von Gontard et al, 2016). Several studies have identified a higher incidence of lower urinary tract symptoms (LUTS) in children with physical disabilities and learning difficulties (Duel et al 2003, Handel et al 2003, Hicks et al 2007, van Laecke et al 2001, and Roijen et al 2001) A study by de Waal et al (2009), identified that individuals with moderate to severe learning difficulties have risk factors for developing post void residuals (PVR) and a study by Ersoz et al (2009) found that a third of children with cerebral palsy had significant PVR. Despite this, evidence and clinical experience suggests that underlying co-morbidities of bladder and bowel problems are either missed or unrecognized.

The main issue is an apparent misconception that if children with additional needs present with wetting and soiling problems, the cause is assumed to be related to their physical disability, learning difficulty, or developmental delay, rather than an underlying bladder or bowel problem. As a result many of these children do not undergo a comprehensive bladder and bowel assessment. They have a 'pad assessment' and are issued with continence containment products in the mistaken belief they are 'not ready' to be toilet trained. This is a potentially dangerous situation, as untreated problems may cause significant long-term issues, including kidney damage, renal failure or intractable constipation.

Children with learning difficulties

Down's syndrome (DS) is the most common chromosomal abnormality and is associated with an increased risk of congenital conditions. It frequently presents with co-morbidities influencing

bowel and bladder function, including Hirschsprung's disease, duodenal anomalies, renal anomalies and bladder outlet obstruction. Despite this, renal and urinary tract anomalies in children with Down's syndrome have received less attention than other congenital problems.

In 1960 Berg et al found renal malformations in 3.5% of autopsies on people with Down's syndrome and later studies showed an incidence of up to 21% (Ariel et al 1991). Hypospadias has been calculated as occurring in approximately 0.3% of all live births, but in approximately 6.5% of boys with Down's syndrome a risk almost 20 times greater than in the rest of the population (Lang et al 1987).

The overall prevalence of renal and urinary tract anomalies, including posterior urethral valves, in the Down's syndrome population is 4-5 times greater than in the general population (Kupferman 2009). The development of a non-neuropathic neuropathic bladder also appears to be more common in individuals with Down's syndrome. The aetiology of this condition in Down's syndrome is not clear, but may be partially related to overtraining of the pelvic floor in an attempt to encourage the individual to stay dry, resulting in dysfunctional voiding. Dysfunctional voiding leads to functional obstruction due to associated urinary retention with high bladder pressures. Another contributing factor for some is the presence of abnormalities, such as unrecognized posterior urethral valves (Seki & Shahab 2011).

Hicks et al (2007) carried out a study to test the hypothesis that boys with Down's syndrome have bladder outflow obstruction secondary to detrusor sphincter dyssinergia. They identified high potential for renal injury: 50% of the boys studied required urinary diversion for dilated upper tracts following bladder outflow obstruction, 77% had bladder dysfunction and 68% had a history of wetting. They concluded that the high risk is not appreciated and outlined the importance of all children and young people with Down's syndrome, particularly those with wetting problems, having a detailed history taken and a bladder scan performed. Although most common in boys, this problem has also has been reported in adults and a female with Down's syndrome (Culty et al, 2006, Kai et al 2007)

Gastrointestinal abnormalities, both structural and functional, affect up to 77% of all individuals with Down's syndrome (Moore 2008). Hirschsprung disease and anorectal malformations, including imperforate anus are more common in Down's syndrome than in the general population. If these are not well managed and appropriately treated early in childhood may result in chronic problems in adulthood.

An audit of adults with Down's syndrome attending a hospital clinic identified that celiac disease occurred in 12%, constipation in 19% and unexplained diarrhoea in 19% (Wallace 2007). They recommended that specially designed protocols should be developed to help identify and manage these problems appropriately.

Constipation may be a particular problem for those with Down's syndrome and other learning disabilities, particularly because the onset of constipation can be insidious, difficult to detect and not recognized by those individuals who have reduced ability to perceive and report their symptoms. Often the first sign that constipation may be present is when soiling starts, due to underlying faecal impaction. Therefore, it is important not to presume that the development of

faecal soiling is due to the person having a behavioural issue or 'incontinence' – they need to be fully investigated for the presence of any underlying constipation.

Discussion:

Healthcare professionals and relatives often have a low expectation for the children to become fully continent, so wetting problems are often attributed to an intrinsic inability to achieve continence, or to the development of a behavioural problem, rather than as a symptom of an underlying pathology. Furthermore, history taking may be difficult due to impaired cognitive function resulting in the existence of some problems may be masked or neglected, resulting in a delay in the true diagnosis of the problem.

It is important not to make assumptions about potential for continence or about the development of incontinence in children with physical disabilities or learning difficulties. They need to be fully investigated for bladder and bowel health with regular review and symptom investigation to help facilitate early diagnosis and prompt treatment intervention in order to prevent upper urinary tract and bowel deterioration.

There are currently no specifically studied integrated pathways in the UK for children and young people with disabilities that highlight possible co-morbidities influencing bladder/bowel function, especially in regards to progressive and adequate transition from paediatric to adult care.

In many cases families and healthcare providers are not aware that all children with physical disabilities or learning difficulties, but particularly those with Down's syndrome, may have an increased risk of an underlying co-morbidities affecting their bowel and bladder that may result in urinary incontinence and faecal soiling; problems that are too often attributed to their disability. The consequence is that these children are rarely provided with any form of continence assessment or treatment. This increases the risk of urinary infections, as well as renal and intestinal compromise.

Some groups, including those with Down's syndrome have a high incidence of dysfunctional voiding, polyuria and risk of dehydration. Dysfunctional voiding and the related detrusor sphincter dyscoordination/dyssinergia (DSD) are causes of increased intravesical pressures and increased post-void residual. However, the ability to understand the need for regular medication may be reduced as a consequence of communication issues, depression and autism. So management is often difficult.

Necessary interventions for some may include regular medication; clean intermittent catheterization (CIC) or self-intermittent catheterization (CSIC); enemas, rectal irrigation or bowel washouts (ACE). However, these can be difficult or impossible due to postural issues (scoliosis, wheelchair bound), reduced dexterity (cerebral palsy, muscle/bone disease in MPS3, etc.), depression, autism, aggressive behaviour and/or reduced communication ability.

Diagnosis of urinary and bowel issues is frequently late. Some do not present with incontinence so are not investigated and diagnosed until they have a problem, such as urinary tract infection.

It is only when their history is taken that clear abnormal voiding patterns or bowel movements are identified. Many of children with additional needs (particularly those with autism) 'hold on', have very infrequent voiding and are therefore at high risk of developing dysfunctional voiding with large residuals. Vulnerability is increased in those who cannot verbalise their feelings.

Comorbidities influencing bladder and bowel issues in children with physical disabilities and learning difficulties are:

- A late diagnosis, which may be due to difficulty communicating or an assumption that the urinary and fecal problems are part of delayed toilet training due to the disability
- Reduced dexterity and postural issues
- Renal Failure
- Associated metabolic conditions e.g. Fanconi's Disease
- Psychological conditions e.g. depression, or processing differences e.g. ADHD, autism
- Short Bowel Syndrome
- Gastrointestinal feeding
- Dietary intolerances
- A paradoxical or allergic reaction to essential medication
- Forgetfulness regarding medication intake or deliberate avoidance
- Lack of clinical knowledge and experience with these conditions, at home or among healthcare professionals

A transition plan also has to be put in place for these patients, with specific tailoring for their age, abilities and home circumstances.

Implications for practice

- All children with delayed bladder and bowel development should have a comprehensive bladder and bowel assessment undertaken by a clinician with knowledge and expertise in this area
- All children with physical disabilities and learning difficulties should have a bladder and bowel assessment as soon as any bladder or bowel concerns are raised or in their second year (whichever is earlier)
- It is not acceptable to provide any child with delayed toilet training prescribed continence containment products without the child having a comprehensive bladder and bowel assessment. They should be assessed and treated in line with the 'Guidance for the provision of continence containment products to children and young people A consensus document (2016) available from http://www.bladderandboweluk.co.uk/wp-content/uploads/2016/12/final-Guidance-Paed-product-provision-doc.pdf

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Bladder and Bowel UK
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Bladder and Bowel UK offers advice and information on all bladder and bowel issues in children and young people, including those with additional needs. We have a range of resources that will help parents, carers, professionals and schools cope with incontinence and offer a range of training packages. We work in collaboration with the NHS, third sector organisations and the commercial sector to promote improvements in continence care across the UK. We are involved in projects with NHS England and National Institute of Clinical Excellence (NICE) to improve continence services within the National agenda.