

## **Voiding Patterns of boys with DMD – an Australian Study**

By Mathilde Backhouse

Quote from a mother: “The biggest overall issue for my 19 year old is toileting. He gets urinary frequency, which is not an infection of bladder (had it tested). He needs to go all day, but often can’t produce. After one drink, he sometimes goes 3 times in the next hour. He needs to be reclined to be able to release urine. These problems are very interruptive at home as I have to take him constantly – it’s very exasperating. He wakes me 7-8 times a night. He also has occasional bowel urgency when out, which makes going out hard.”

I live in Brisbane, the capital of Queensland. I work as an Occupational Therapist with Montrose Access, a therapy service providing support to over 500 children around the state. Over a hundred of these clients have DMD. Montrose Access is the main service provider for this population in Queensland. Many of our clients live around the state, and the outreach team may travel by plane and hire car for over 1000 km to see them at home and school several times each year.

As we visited homes we noticed that many boys with DMD had voiding issues. However parents rarely mentioned them or asked for assistance. We often noticed boys with wet pants, boys wearing nappies at 4 or 5, wet mattresses drying out in the sun. When we asked, some of the issues included incontinence, frequency, urgency and constipation. At school visits, too, teachers often complained that some boys with DMD asked to go to the toilet much more frequently than their peers, and sometimes teachers believed that they were purposely avoiding tasks.

A literature search revealed that:

The function of the digestive and urinary tracts in humans with DMD is not generally thought to be affected until the very late stage of DMD or as a result of surgery or scoliosis. Although skeletal and cardiac muscles are affected, the function of some muscle groups including the sphincter muscles are spared. Despite this some studies have shown that people with DMD may experience urinary problems.

Caress and colleagues [3] investigated seven boys aged 7 to 14, diagnosed with DMD, who experienced urinary incontinence, including urinary retention, urinary incontinence, frequency and hesitancy. Most had undergone spinal fusion and were found to have problems with bladder wall sensitivity and sphincter control. The authors concluded that the urinary incontinence was most likely due to severe scoliosis or complications from spinal surgery. The problems in these cases were treatable.

A 2003 study [4] by MacLeod and colleagues, identified 46 out of a study group of 88 boys diagnosed with DMD as having urinary problems. Both walkers and non-walkers reported urinary problems of day and night time incontinence, frequency, urgency and stress incontinence. Urinary hesitancy affected only older participants. Of the 46 boys, 9 underwent medical evaluation, which revealed that 8 boys had a small capacity bladder and sensitive bladder wall and one boy had post-operatively developed urge incontinence. Although only one boy had sought medical consultation prior to the study, it was again noted that all these urinary conditions were treatable.

Bowel evacuation dysfunction is known to be a problem for people with neuromuscular diseases, especially in the non-ambulant phase (4, 7). Both constipation and diarrhoea have been reported in DMD and it has been suggested that both increased colonic transit time as well pseudo-obstruction are implicated and that these may be caused by atrophy and fibrosis of the intestinal smooth muscle (7). Causes of increased colonic transition time are mostly thought to be due to non-ambulance, reduced fibre and water intake and in the later stages, lack of abdominal muscle strength (9). The incidence of constipation in the normal population is around 15% (10).

In 2003, Montrose gave permission for me to survey a group of client families with a son with DMD. The aim of the survey was to investigate frequency and types of bowel and bladder problems of people diagnosed with DMD and identify links, if any, with mobility, eating patterns and drinking habits.

Secondly the survey intended to identify management strategies employed by families. This paper will not report on the results of the management strategies, however a booklet has been written incorporating the findings.

- **Findings**

I interviewed 48 participants who were aged between 4 and 28 years of age. Participants lived at home with their families. One participant was below school age. Thirty-four percent of participants had learning difficulties to the extent that they attended special school or spent a significant part of the week in a Special Education Unit. The remaining participants attended regular school or were post-school. Twenty-four participants were from metropolitan areas (Brisbane or Ipswich), 16 from rural Queensland, 8 from large coastal towns close to Brisbane. Twenty eight percent of participants used prescription corticosteroid treatment to delay the progressions of muscle weakness. Nineteen participants (40%) had spinal instrumentation surgery.

**Table 1: Prevalence and t-test of urinary and bowel voiding problems and mean age of subjects (Total 48).**

<b>Bowel and bladder dysfunction</b>	<b>N</b>	<b>%</b>	<b>One-Sample Test</b>	<b>Age range of incidence</b>	<b>Mean age of incidence</b>
Daytime urinary urgency	19	40	t = 2.98 *	4-25	14.85
Constipation	17	35	t = 4.61*	9-25	15
Voiding postponement	16	33	t = 6.09*	9-25	16.44
Daytime bowel urgency	15	31	t = 5.19*	4-25	14.07
Urinary hesitancy	13	27	t = 6.50*	12-25	17.85
Daytime urinary frequency	12	25	t =7.03*	8-25	14.17
Abdominal pain or discomfort	12	25	ns	9-25	14.58
Fecal incontinence	9	19	t = 9.18*	10-25	14.89
Nocturnal urinary frequency	7	15	ns	8-25	17.57
Daytime urinary incontinence	7	15	ns	8-25	15.02
Diarrhoea loose bowels	5	10	ns	6-18	11.6
Nocturnal urinary incontinence	3	6	ns	14-19	16.37

**\*Sig. (2-tailed) = <.005, df = 47**

This table reports the prevalence of urinary and bowel problems experienced over half the time by participants. The one-sample test that showed significance have an asterisk, indicating the two tailed significance is less than .005, with 47 degrees of freedom. The last column shows the age range of the incidence.

The most common problems reported were daytime urinary urgency, constipation, voiding postponement, day-time bowel urgency and abdominal pain or discomfort.

Urinary urgency was the most frequently reported problem, experienced in the daytime, rather than the night. It was reported as young as 4 years of age. Robson and Leung (22) suggest that children with urge syndrome normally squat to cope with the urge to urinate, whilst children with DMD are limited in their ability to squat due to muscle weakness, causing the need to attend to toileting more frequently. Urge was experienced across the spectrum of ages, and, in practice, management of toileting issues once boys are non-ambulant becomes more complex (2), and urinary urgency further exacerbates this situation.

Constipation was reported in 35% of participants, considerably higher than the 15% reported in the general population. Based on the literature, constipation is expected to increase with reduced mobility (7), however in this study there was no significant association found between bowel problems and mobility. However there was a significant association between bowel problems and diet, specifically fussy eating. More of this later.

One third of the cohort reported urinary voiding postponement. Boys tend to purposely retain urine to avoid the problems of going to the toilet, often throughout the entire school or workday. Whilst voiding postponement is not intrinsically a problem, it can contribute to significant problems. Reducing fluid can impact on bladder and bowel health as well as pulmonary health (26). People diagnosed with DMD are advised to drink sufficient fluids to prevent thickening of the pulmonary mucus associated with the risk of pneumonia (26, 27). Parental comments indicated problems resulting from this practice included UTI's and urinary frequency after school. Robson and Leung (22) comment that incontinence, frequency, and urgency are common symptoms of urge syndrome and that voiding postponement may play a causative role.

Urinary hesitancy was experienced by almost a third of the cohort. As in Macleod's study, younger participants under 12 years did not experience hesitancy (6).

Urinary frequency in the daytime was reported in a quarter of the cohort. This is one of the problems often mentioned by teachers as a suspected work avoidance strategy, but is more likely to have an organic cause, based on the work of Macleod.

Bowel pain, though reported in 25% of participants, was not significant within the group according to the T test, and had multicollinearity with the other 2 bowel problems of bowel urgency and constipation.

Problems reported in less than 20% of participants included fecal and urinary incontinence, nocturnal frequency and incontinence, and diarrhoea. Bowel problems other than diarrhoea were not reported in children under 9 years of age.

## **Association with eating, drinking, mobility**

The study looked at a number of possible factors influencing voiding. These included spinal surgery, scoliosis, schooling, steroid use, Body Mass Index and psychosocial aspects. Only 3 had statistically significant associations with voiding, although the psychosocial aspects showed trends, which would be interesting to investigate in future. The factors that showed significant associations with voiding problems were:

**Mobility:** Of the 48 participants, 36 were non-ambulant, using an electric wheelchair and unable to weight-bear. Nine participants were in the transition stage, being ambulant but with intermittent use of alternate mobility such as electric scooters or manual wheelchairs for longer distances. None used callipers or walking devices. Three participants were competent walkers.

**Fussy eating:** Malnutrition and obesity are reported to be equally common in young adults with DMD, each occurring in about 44% of individuals (14, 15), with younger boys tending to experience obesity and older ones malnutrition (1, 16, 17). Sixty percent of participants had average food consumption and 15 percent above average. Twenty five percent of the participants ate less than average and some of these were reported to eat only one meal a day. Field observation at Montrose Access has shown a high incidence of fussy eating, with limited variety of foods consumed. Although exact content of diets was not assessed for this survey, 29 percent of participants were reported to be very fussy eaters who consumed a limited variety of foods.

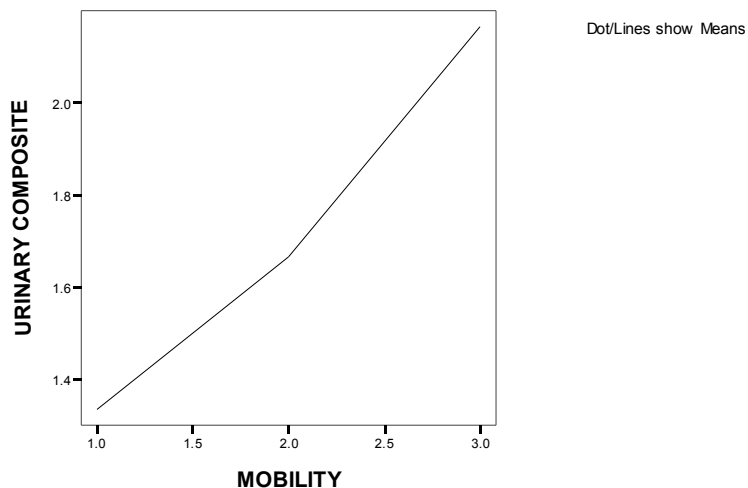
**Fluids:** Dehydration has been linked to constipation, urinary tract infection (UTI) and other problems(18, 19). The Australian Government Department of Health and Aging recommends minimum consumption of 1.5 litres of fluid daily (20). Forty four percent of the participants drank less than a litre of fluid daily. Fifty six percent drank in excess of one litre of fluid daily.

## **Associations between bladder problems and mobility**

When the types of urinary problems affecting more than 20% of participants were combined into a composite score, a significant variance was found between the means of the composite urinary scores and the mobility scores ( $F(2,45) = 3.543, p = .037$ ). Post hoc analysis showed that, as mobility decreased, overall urinary problems increased (see figure 1).

### **Figure 1:**

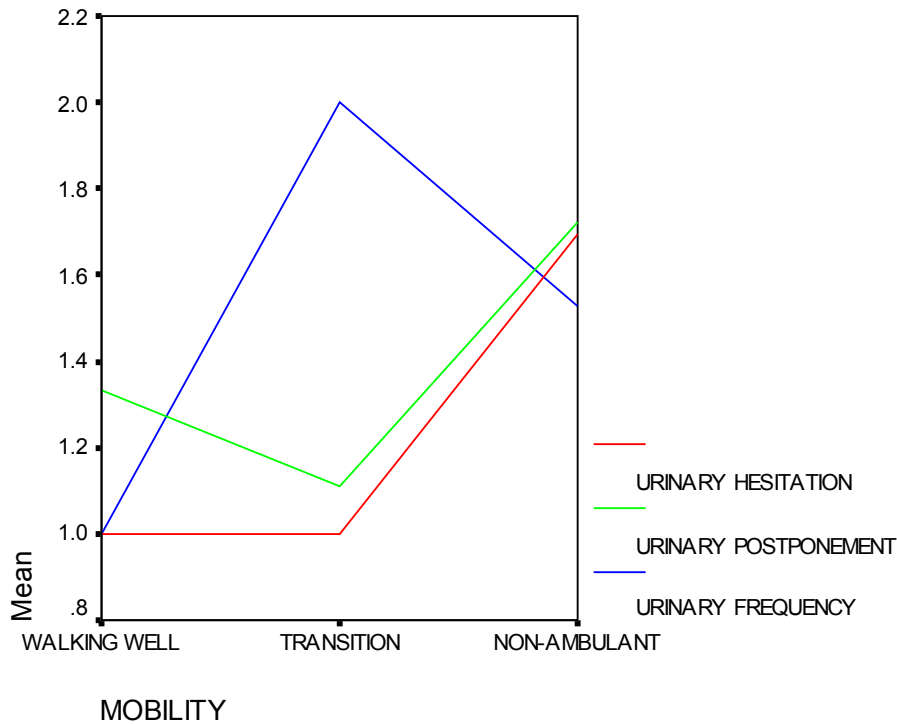
**Post hoc analysis of means of mobility scores and urinary composite scores**



When analysis of variance was performed on separate urinary problems, significant differences were found between the mean of mobility and the means of urinary hesitancy ( $F(2,45) = 5.536, p = .007$ ) and voiding postponement ( $F(2,45) = 3.462, p = .040$ ). Variance between urinary frequency and mobility was also significant ( $F(2,45) = 3.847, p = .029$ ). The transition group experienced the main problem with frequency, whilst urinary hesitancy was experienced by the non-ambulant group. As expected, the non-ambulant group employed the strategy of voiding postponement to avoid toileting during their day at school or work. Voiding postponement was significantly related to reduced drinking ( $F(3,44) = .5.075, p = .010$ ). Urinary frequency, reported by a quarter of the cohort, was significantly associated with mobility, however it was the transition group that experienced the greatest problem with frequency, rather than the non-ambulant group. This may indicate a social-emotional basis as this period involved increasing awareness of physical decline. The transition group also experienced more urgency and hesitancy than the walkers, but less than the non-ambulant group. One explanation may be that, once the boys are in wheelchairs, there is the added trouble and embarrassment of asking for assistance with such a personal task, and requiring more time, suitable equipment and space. This may mean they post-pone their voiding and consequently experience more urgency and hesitancy.

**Figure 2**

Post hoc analysis of means of mobility scores and urinary hesitancy, frequency and postponement scores

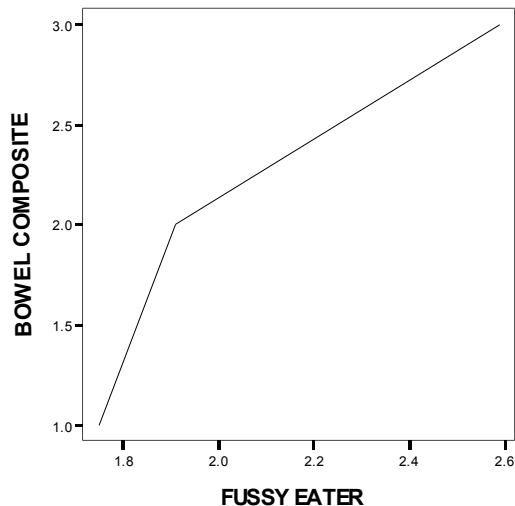


**Relationships between bowel problems and diet**

Multicollinearity was found between constipation, bowel pain ( $p = .000$ ) and bowel urgency ( $p = .011$ ). These three variables were collapsed to form a composite bowel problem variable. A significant association was found between the means of the bowel composite scores and the fussy eater group ( $F(4,43) = 3.936, p = .008$ ). Post hoc analysis showed that participants who were fussy eaters experienced greater problems with bowels (see figure 3). Specifically, post-hoc analysis showed fussy eaters experienced more frequent bowel pain ( $F(4,43) = 3.433, p = .041$ ) and bowel urgency ( $F(4,43) = 4.320, p = .005$ ).

In this study no significance was found between the means of mobility and composite bowel problems.

**Figure 3**  
**Post hoc analysis of means of bowel composite scores and fussy eating scores**



### **Qualitative data**

Of the 17 participants reported to have constipation, 12 had sought medical advice for this problem. Of this group, five participants used stool softeners or laxatives regularly, and three had received whole bowel irrigation for impaction. Four used enemas or suppositories regularly. Two participants reported that they used to have constipation but that this was no longer a problem after 18 years of age. One of these attributed this to improved drinking habits. The other had no explanation. Antibiotics were thought to cause constipation in the short term for two participants, and bowel urgency in another.

Twenty-three participants reported at least one urinary problem. Only three participants had sought medical advice for urinary problems: one for bed-wetting and two had been assessed and treated for UTI's. No participants had any investigations for urgency, frequency or hesitancy. As a direct consequence of voiding postponement, two participants reported regular urinary tract infections and two participants required exceptionally frequent toileting after school.

The importance of good positioning and appropriate equipment was mentioned by seven of the parents. For example, one mother said, "He can't start the flow if he is sitting wrongly". Urinary hesitation was overcome in several cases by reclining the chair, thus widening the hip angle.

Of nineteen participants with spinal rodding, only two participants reported bowel or bladder problems following the spinal instrumentation surgery. One participant used enemas for some months following surgery, while the other reported, "...no sensation, no desire to go; no indication of the needs to go until after it happens" since the surgery. One participant reported that he had difficulty releasing urine since the development of his scoliosis, and had found that leaning back could relieve this.

Anxiety or mental discomfort played a part in hindering effective voiding in four participants. Parents' comments were: "He wouldn't use public toilets and had to work to overcome this"; "Listening to music helps him to relax and concentrate with urinary hesitancy problems".

Thirteen parents reported that effective bowel and bladder evacuation was hindered by the fact that their sons needed assistance and equipment with toileting. Some parents reported that school staff called them from home or work to assist with their sons' bowel movements.

- **Outcome of study**

The three most surprising findings of this study were the high incidence of urinary problems reported, the lack of association between bowel problems and non-ambulance and the high levels of bowel and bladder problems experienced by the transition group. The lack of medical referral for urinary problems was also surprising, given the impact these problems had in daily life. In relation to the urinary findings, this study supports the findings of MacLeod (6), and medical referral is indicated for these problems.

Future study: Dietary aspects need closer examination. A closer examination of social and personal influences may also be useful, particularly the aspect of anxiety and mental discomfort.

In Queensland, therapists are learning to ask clients and parents specific questions about bowel and bladder voiding problems. Many boys are consequently being identified with voiding issues and medical referrals are resulting increasingly in prescriptions of bladder stabilisers such as Ditropan. Therapists are also ensuring strategies are in place at home and school to allow respect for privacy and maximal independence in toileting matters. A booklet entitled "Some guidelines for management of toileting issues in boys with Duchenne muscular dystrophy" (29) has been prepared for parents and teachers as an outcome of this study and may be found on the MontroseAccess website [www.montroseaccess.org.au](http://www.montroseaccess.org.au) .

**References:**