



Montrose Access

# Managing toileting issues in people with Duchenne Muscular Dystrophy

Some  
Practical  
Guidelines



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**National Library of Australia Cataloguing-in-Publication data:**

Backhouse, Mathilde.  
Managing toileting issues in people with Duchenne muscular dystrophy : some practical guidelines.

Bibliography.  
Includes index.  
ISBN 0 9585865 3 5.  
1. Duchenne muscular dystrophy. 2. Toilet training.  
I. Lynagh, Steven. II. Title.

362.196748



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## INTRODUCTION

MontroseAccess is a therapy service for children 0-18 years with primarily physical disabilities throughout Queensland (Australia). Occupational therapist Mathilde Backhouse conducted a survey to investigate toileting patterns of boys and young men with Duchenne muscular dystrophy. A summary of the survey results is in the appendix. A more comprehensive report is available from MontroseAccess. Following the completion of the survey, this booklet was written to provide some general guidelines for the management of toileting issues for boys and young men with DMD.

DMD is a progressive muscle weakening condition affecting males and caused by lack of dystrophin in the skeletal and cardiac muscles<sup>1</sup>. The smooth muscles of the bowel and bladder and the sphincter muscles are believed to be largely spared until late in the course of the condition and even then bladder problems are most often reported to be secondary to scoliosis, surgery or a respiratory illness<sup>2</sup>. Bowel problems are often attributed to immobility and weak trunk muscles<sup>3</sup>.

Parts of the brain can be affected and regardless of their intelligence, most boys with DMD have a specific 'cognitive profile', which includes difficulties with complex attention, verbal fluency and non-verbal memory<sup>4</sup>. One third of boys with DMD have significant intellectual impairment and a proportion also have autism-like behaviours<sup>5</sup>, including lack of flexibility, impaired social skills and problems with attention.

Although bowel and bladder function are not thought to be affected directly by the lack of dystrophin in people with DMD there is a growing body of evidence to show that, for a range of reasons, some people with DMD do experience problems with managing their voiding issues<sup>6</sup>. This booklet has been written to assist young people with DMD, their parents and carers.

The booklet is divided into two parts. Part A briefly describes some issues related to potty training of boys with DMD and makes suggestions to assist with attaining toileting skills in the pre-school years. Part B provides advice on management of bowel and bladder problems found amongst boys and young men with DMD in the survey (appendix)



In the survey (appendix), most of the boys and young men with DMD attained toilet training at a similar age to the normal population. A few had significant problems in learning the skills of toileting. Two of these had significant autism and intellectual impairment and for them the issue of toileting became a major concern, which seriously impacted on family life.



Most parents followed common toilet training routines, such as regular sitting on the potty, rewards including praise and wearing no nappy in the daytime. For children with intellectual impairment or autistic spectrum disorder, specific toilet training techniques may be required.

Some general guidelines to assist with training children with DMD in learning toileting skills follow.

### 1. WHEN TO START TOILET TRAINING

Research has shown that there is no benefit in commencing training earlier than 27 months, as success is likely to take longer to achieve. Some children may not be ready to start training until later than this. Here are some questions to determine if your child is ready to be toilet trained:



- Is your boy aware when he wets himself?
- Is he interested in the bathroom, toilet, hand washing, dressing or related tasks?
- Is he able to temporarily retain body wastes, for example during naps or for 1-2 hours at a time?
- Can he physically sit well?
- Does the boy have a mental age above 2 years?

### 2. HOW TO PROCEED

- The child needs sensation of wetness, so whenever possible during the day, take nappies away. Disposable nappies are particularly unhelpful at this stage. Summer in Queensland is a good time to start toilet training, as families enjoy parks and outdoor activities where accidental wetting is not usually such a problem.
- For boys with DMD it is particularly important to provide a well supported sitting position on either a potty or a toilet with insert. Feet should be firmly grounded and the hole an appropriate size to ensure a feeling of security.
- Ask child to sit regularly on the potty – develop a routine. Optimum time for elimination is 20 minutes after meals, so include this time into the schedule.
- Ensure child drinks sufficiently, but avoid excessive juice or sweet drinks.
- Praise the child initially for just sitting on the potty. At the first sign of success, use praise to reward him. Model interest and curiosity about bodily functions by showing delight at the sound of tinkling, for example. Ignore the child when he does not use the potty/toilet to urinate - do not show annoyance. Do not expect child to help with clean-up unless they are 6-7 years old.



### 3. WHEN TO SEEK HELP

Professional intervention is not normally necessary unless parents are still concerned when the child reaches 4 years of age. For children with strong autism-like



Managing Toileting Issues in People with Duchenne Muscular Dystrophy tendencies it may be useful to see a professional<sup>7</sup>, such as an occupational therapist or psychologist, before 3 years of age, in order to develop strategies to:

- Help reduce anxiety associated with changes to routine
- Break steps into smaller components
- Overcome verbal communication impairments by using visual cues and prompts
- Manage any sensory abnormalities such as over-reaction to touch, light or noise.

#### 4. RESOURCES FOR TOILET TRAINING

There are many good books on the market for parents on toilet training children. Workbooks and explanatory books for children can also be useful, for example:



- *How you can be boss of the bladder.* A workbook for children available from the Continence Clinic, Royal Children's Hospital, Melbourne.
- *The Adventures of Plopsy the Poo* by Di Collis. Available from the Occupational Therapy Department, Gold Coast Hospital.
- *Mummy my poo is stuck!* by J. Nicora & Dr S. Barbalatt. Available from Paedpharm Products, PO Box 1674, Bondi Junction, NSW 2022. Tel 02 9300 1900; Fax 02 9387 6654.

## SECTION TWO: MANAGEMENT TECHNIQUES FOR BOWEL AND BLADDER PROBLEMS

The most common problems reported amongst young people with DMD through the MontroseAccess survey (Appendix) include:

- Urinary urgency - a sudden, compelling need to urinate immediately, often with some discomfort in the bladder
- Constipation - infrequent or hard stools, or difficulty passing stools.
- Holding without urinating for longer than 6 hours
- Bowel urgency - a strong, sudden need to pass a bowel movement.
- Urinary hesitancy - difficulty in initiating urination
- Urinary frequency in the daytime - needing to urinate more often than usual.



Some general advice for people with DMD is provided below.

### 1. MAINTAINING HEALTHY BOWEL AND BLADDER ROUTINES

Having a regular schedule of going to the toilet is helpful as the body can become used to eliminating wastes at a certain time, thus making the process easier and quicker. Regular elimination, both bladder and bowel, can assist in the prevention of constipation, bowel urgency, and urinary frequency.

Twenty to forty five minutes post-meal, the gut is most active – so capitalise on this and make up for weakened muscles by timing toilet visits then.

Many young men, once off their feet, do not use the toilet for the duration of their school or work day to avoid the need to be assisted with toileting. This may be due to the time it takes, the lack of privacy, the uncomfortable facilities and equipment, or the embarrassment of having to ask for assistance. It can lead to serious health concerns, as these young men generally drink almost nothing during the day to reduce the need to urinate. For these young men it is particularly useful to have a regular schedule of toileting set up with appropriate equipment and assistance provided

Many boys with DMD experience hesitancy - an inability to initiate flow despite the urge to go. The following strategies may assist:

- Having a regular routine of going to the toilet
- Provide boys and young men with some time alone in the toilet
- Use relaxation methods such as music, reading material
- Allow adequate time so that they are not rushed.

## 2. ADDRESSING DIET ISSUES

It is important to be aware of the problems associated with excess weight – as this places extra load onto already weakening muscles, including the heart, and can also affect the alimentary system. Once off their feet, there is a greatly reduced need for energy intake. Some young men eat several small meals a day and a few eat only one meal a day, though this may prevent regularity. For some young men, weight control is more difficult as eating is one of life's pleasures in which they can fully and independently participate. Diet can play a major role in prevention of constipation.

For maintenance of healthy bowels it is important to eat sufficient fibre or roughage<sup>8</sup>. This is the indigestible part of food which remains in the bowels, absorbing water as it moves along, thus becoming wetter and softer, and consequently forming a bolus which is easier to pass. The increased bulk of the bolus also stimulates peristalsis

in the colon, moving the bulk along more quickly. Some fibres are partially digestible e.g. the fibre in fruits and vegetables. The fibre in bran and other seed products are completely indigestible and these can cause obstruction if not taken with sufficient water, particularly in people with muscle weakness, so should be taken with care. It is advisable to consult a dietician for management of elimination issues, weight control and maximum nutritional benefit.

## 3. DRINKING SUFFICIENT FLUIDS

The Department of Health and Aging<sup>9</sup> recommends the consumption of at least 1.5 litres of caffeine-free fluid per day. It is most important that people with DMD continue to take in sufficient fluids, for the following reasons:



- Adequate hydration keeps the lungs clear and stops development of thick mucus, which can lead to infection.
- Sufficient fluid intake is necessary for prevention of constipation.
- Adequate daily caffeine-free fluids assist good function of the bladder.

In hot climates in particular, water consumption should be habitual and many young men carry a suitable water bottle or a water reservoir bag with a tube going to the mouth (such as a Kamelbak), on the wheelchair.

For those young men who restrict their water intake during the day to avoid urinating, it is important to encourage drinking and structure toilet visits to minimise embarrassment or interruption, especially at school, work and out in the community.

## 4. ACQUIRING SUITABLE EQUIPMENT

A person needs to be comfortable and at ease to ensure success on the toilet. For young men who are no longer weight bearing, correct equipment can make a big difference. Whilst the following equipment descriptions have suited many young men, there are often individual differences which may require careful trial of alternatives or customisation of seating or sling options.

### 4a) Bottles

Once boys are no longer weight bearing, a urinal bottle is the most convenient method of urinating. Introduction of the bottle when boys are in a wheelchair



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can sometimes be a problem initially, because the optimum wheelchair seating for people with DMD includes a snug fitting chair and a fluid filled pressure-relieving cushion. The snug fit precludes opening the legs to allow use of the bottle, whilst the pressure-relieving cushion prevents the ability to shift forward in the chair to access the bottle. The solution to these problems lies in the removal of one armrest to allow that leg to swing outwards.

Most young men use urinal bottles available from the chemist. Some alternatives bottles available include:

- Uribags - pocket urinals made up of a latex collection bag that folds away in a small 'film canister' sized funnel when not in use. They are discreet and small for easy storage and found to be useful especially when away from home. Available from some chemists or Syben Marketing 1800 647 495.
- Non-spill bottles have a one way valve at the neck
- Long neck bottles designed for wheelchair use are available from USA but are costly and some young men who have trialed them in Australia have not found them worth the cost.
- Innovations – some families have developed some original bottles, which are effective for them. Examples include Gatorade or juice bottles which young men find easier to hold, or which have a better 'fit'; flexible pipe extension to lengthen the neck for use over seat length of wheelchair.

**4b) Over-toilet commodes**

A mobile shower-commode chair is normally prescribed by the occupational therapist for bowel movements. In Queensland, it is provided through the Medical Aids Subsidy Scheme (MASS) free of cost to eligible people. These chairs are designed for easy, safe transport to and from the toilet and shower. Clothes are usually dosed and donned in bed.



The chairs have a metal frame, four swivel casters with brakes on the back two casters, a padded toilet seat with open or closed front, foot plates, arm rests and optional head rest and seatbelt.

There are a number of reasons for using this equipment:

- To minimise the handling and number of transfers required - bowel evacuations are done just before a shower is taken
- To provide postural support, comfort and security during toileting.

**4c) Lifters/Hoists**

The need to use a lifter or hoist in the home is often a difficult transition for parents. Parents have been lifting their son from birth and throughout the normal toddler years. They continue to lift and carry their sons throughout the period of transition (the primary school years) when they have occasional falls or periods of fatigue. Parents become slowly stronger and accustomed to the increasing load. They enjoy these opportunities for closeness and intimacy, unaware that the micro damage to their own backs may be slowly progressing, since there is likely to be no indication or pain evident. The introduction of a hoist, on the other hand, is a visual reminder that their son's condition is progressive. It is also a bulky item, consuming space in the bedroom and bathroom.

Basically two types of lifters are available:

- *Mobile* hydraulic or electric hoist with sling. It has a base on wheels, upright, yoke, boom and sling. The electric version is generally preferred as it provides a level of self-determination since the young men can operate the controls. It also operates more smoothly and is consequently more comfortable. The pivot frame is a popular choice for young men with DMD as it allows one carer to operate the hoist alone, and provides more knee and head room than most large hoists. This allows the patient to be freely rotated and makes the carer's job easier and safer, whilst the client will feel more secure. It is important to select a suitable sling as postural support should be comfortable and correct for this particular



Managing Toileting Issues in People with Duchenne Muscular Dystrophy condition. Following back surgery it is particularly important to have good back support and correct hip angle for several months. In Queensland, the Medical Aids Subsidy Scheme (MASS) can fund this type of hoist with a prescription from a therapist.

- *Ceiling track, hoist and sling* - the hoist is fitted to a track on the ceiling. A sling is fastened around the user, and attached to the hoist, which lifts smoothly and quietly. It has the advantage of being inconspicuous and convenient, requiring no storage space. This type of lifter is more expensive than the mobile hoist and at the time of writing the Medical Aids Subsidy Scheme (MASS) did not fund it.

#### 4d) Bidets

Bidets can provide a level of independence and privacy through their cold or warm water cleansing, and the better ones also provide a warm air dryer. Some bidets attach to the existing toilet. Others are an integrated system. Many bidets available from other countries do not satisfy the Australian Plumbing Code, which requires a mandatory vacuum breaker. Some of the bidets currently available and approved in Australia include:

- *Bodygenic Retrofit Bidet* – a stainless steel bidet unit that can be installed onto any existing standard toilet seat. It sprays cold water to cleanse the perineal area. It is operated by turning a capstan or long lever handle. Cost at time of writing approximately \$500. Available from Bodygenic (NSW) Ph 02 9150 4146; Fax 02 9150 4282; Mobile Phone 0412 068 005.
- Elio Micro Computer Operated Bidet is a toilet seat with a lid which replaces a conventional toilet seat and fits most toilets. It features a panel on the right side of the seat with a push button control of the front and rear spray jets, water temperature and heated seat. A knob is turned to control the water volume. Cost at time of writing \$1320. Available from Together with Nature (NSW) 02 9144 5221; Fax 02 9988 4832; email [tw@bigpond.net.au](mailto:tw@bigpond.net.au).
- Clos-O-Mat Combined Toilet/Bidet with push bar operated toilet flush and warm water spray 'douche' and a warm air drying spray. Cost at time of writing \$8000.00. Available from Clos o mat (VIC) Ph 03 9758 9633; 0417 009 633; Fax 03 9752 2716.

At the time of writing financial assistance was not available for these products through the Medical Aids Subsidy Scheme (MASS) in Queensland.

#### 4e) Bell or call system

A wide range of intercom or call systems is available for use during the night. They range in price from cheap systems available from electronic stores, to sophisticated systems available through specialist suppliers e.g. Vigil-Aide.



#### 4f) Continence products

Penile sheaths, also called Uri-sheaths, condom catheters, or external male catheters are made up of a sheath which fits over the penis and connects to tubing that leads to a drainage bag. These devices prevent the need to disturb carers during the night and can potentially be useful when going to nightclubs, on long-distance travel or other lengthy outings without access to carers or suitable toilets.

When trialing Uri-sheaths, it is wise to seek help from a continence nurse adviser who will ensure that the person is fitted with a sheath that is the correct size. The nurse can also provide education on applying and disposing of them, plus hints on how to ensure they stay on. It is advisable to practice wearing the Uri-sheath at home several times before trusting the device to be leak-proof on an outing.

Disposable or re-usable pads are large pads which are placed on the bed in the area most likely to become wet. They have a waterproof backing and absorbent wadding. They are designed primarily for mild urinary incontinence.

## 5. ATTAINING OPTIMUM POSITIONING

### 5a) Provide adequate postural support



Good bowel and bladder function relies on a comfortable sitting position. As the muscles supporting the trunk weaken, it becomes harder for boys to feel secure on a toilet. From an early age, it is advisable to provide foot support in front of the toilet for stability and a sense of security. Hole-reducers can also be useful in providing stability.

Boys who are still mobile, but losing their ability to adjust quickly to changes in body positioning, may tend to lean heavily on the toilet roll holder or other unsuitable hand-rest, especially when getting on and off the toilet. A grab-rail may be a good solution for this period. Many boys use the cistern or seat-lid to lean backwards for support. If this is a problem, there are detachable toilet-back rests available from disability stores. When boys are no longer weight-bearing, a mobile shower commode chair will provide suitable postural support.

### 5b) Lean forward for bowel movements

As seen in young children, the optimum body position for easy bowel movement is the squatting position, which opens the muscles of the pelvis, angles the anus for best mechanical advantage, braces and supports the abdominal muscles. When experiencing difficulty passing a bowel motion, experiment by positioning the feet on a high footstool and leaning the body forward, possibly with a pillow to apply pressure to the stomach.

### 5c) Lean back for urination

A number of young men with DMD experience difficulties in initiating flow. It has been found that widening the hip angle by winding the back of the wheelchair-seat back can assist. This also takes gravitational forces off the spine and, for those with scoliosis, straightens the back.

## 6. SEEKING APPROPRIATE PROFESSIONAL HELP

Parents in the survey were likely to seek medical advice mainly when their sons had constipation.

Unless boys are managing to minimise constipation with a good maintenance program of high fibre diet, adequate fluid intake and regular toilet routines, a visit to the doctor is indicated.

Most incidents of constipation and prevention of further episodes can be managed with a visit to the general practitioner who may advise the regular use of laxatives or even rectal medications such as enemas or suppositories. However in more severe or long standing instances a condition known as faecal impaction may develop.

When there has been no bowel evacuation for some time, the mass remains in the bowel and grows larger, becoming even harder to move, particularly with weakened trunk muscles. Watery fluids may escape around the bolus, causing "tracks" on pants, or even what appears to be diarrhoea. This may be interpreted by parents as a good sign of bowels moving again, but is in fact a signal that medical attention is required. The impaction needs to be cleared and a maintenance program reinstated. For severe problems the GP may choose to make a referral to a specialist, such as a gastroenterologist.



No boys in the survey had received medical assessment or intervention for problems with urinary urgency and frequency. Yet the literature shows that these should not be accepted as an inevitable aspect of DMD as they may be due to treatable conditions such as small capacity bladder or overactive bladder, known as dyssynergy of the detrusor muscle (bladder wall). Urodynamics assessment can provide accurate diagnosis and medications can be prescribed if appropriate.

The Australian Government Department of Health and Aging<sup>10</sup> in its publication "*Good bladder habits for everyone*", has advised that medical opinion be sought if difficulties are experienced with any of the following:

- Any involuntary leakage of urine
  - Loss of urine, regardless of amount, when you cough, sneeze, laugh, stand, lift or when leakage occurs with sport or other physical activity
  - An urgent need to pass urine, being unable to hold on or not getting to the toilet in time
  - Passing small amounts of urine frequently and consistently, e.g. more than eight times per day in small amounts of less than 200 mls (about the contents of a tea cup)
  - Having to get up several times overnight to pass urine
  - Bedwetting over the age of five years
  - Difficulty getting a stream of urine started or a stream that stops and starts instead of flowing out smoothly
  - The need for straining to pass urine
- 
- A sense that the bladder is not empty once urine has been passed.
  - A feeling of burning or discomfort while passing urine
  - If you are always thirsty and have to urinate frequently (you could be suffering from diabetes).

## 7. MEDICATIONS

Laxatives may be bulk forming, stimulant, osmotic or faecal softeners. Many are available over the counter at the chemist and almost all are made of natural products. Bulk forming laxatives may be counter-productive for faecal impaction if not taken with sufficient fluid.

A laxative medication<sup>1</sup> based on polyethylene glycol 3350 and containing electrolytes is frequently prescribed for clients with DMD. It works by preventing water from being absorbed by the body so that it can be used to dilute and evacuate faecal matter within the bowel. If taken according to instructions, it can usually be taken safely and for extended periods with good results. However, it is always best to discuss any constipation problems with a doctor prior to making a decision to take laxatives long term, as there are often a variety of factors to take into account e.g. some antibiotics and antidepressants may be causing the constipation.



## 8. MANAGING CARERS AND THE NEED FOR PRIVACY AND RESPECT

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<sup>1</sup> Movicol

### Managing Toileting Issues in People with Duchenne Muscular Dystrophy

Many young men with DMD have carers other than their parents to assist with toileting, both at school and at home. These carers are entering into the life of the young person with DMD at a vulnerable and fragile point. Whilst ambulant people are able to have complete privacy and independence during toilet visits, young people with DMD who are no longer ambulant are required to allow people, often strangers, to share their most private moments and deal with very intimate body parts.

Some suggestions to assist in this regard include:

- Allow young person to assist in the selection of the carer
- Consider the personal qualities of the carer – someone with whom the young man can feel comfortable – respect, dignity, good communication. Ensure confidentiality is assured
- Ask what help the young person would like, rather than presume
- Provide opportunity to be alone and private during the toileting process.

## 9. SCHOOL ISSUES



The school environment can be highly structured, particularly in secondary school. The specific needs of young men with DMD in regards to toileting at school therefore require anticipation and planning. Some brief points follow:

- Many people with DMD experience frequency and hesitancy. Teachers need to understand this and make appropriate allowances in terms of the timing and frequency of toileting visits permitted.
- The changing requirements for support need to be recognised and implemented in a timely manner – not too early, not too late. Students with DMD are unlikely to ask for assistance unless it is offered first. The physical support needs of boys change from total independence to supervision when falls are likely, and increasingly to more intense physical assistance. The transition phase from

walking to inability to weight bear is often relatively short, and the boys' needs require monitoring at a time when they may not be happy to be monitored in this area of their lives.

- Schools have stringent policies on manual handling of people and preparations have to be made well in advance of actual needs. This required prediction of the course and timing of the condition. Appropriate equipment needs to be selected and sourced and staff-training in place before the boys become non-weight bearers. Once off their feet, most boys would attempt to do all bowel movements at home, so that only a bottle is required at school for urination. However schools should endeavour to acquire a hoist, shower-chair, a place to lie down to change clothes and washing facilities for those occasions when a bowel movement, change of clothing or clean-up is required. Space is required to accommodate all this equipment plus the electric wheelchair and one or two assistants.
- In secondary schools in particular it can be difficult to access teacher aides to assist with toileting, without prior notice. This makes it difficult for boys with DMD to make impromptu visits to the toilet. Boys who experience frequency or urgency in particular need an appropriate action plan to be in place, so that they are not disadvantaged.

## CONCLUSION

The survey conducted by MontroseAccess in 2004 (appendix) found that many young people with DMD experienced problems with voiding and this, combined with their increasing dependence on equipment and carers, affected their lifestyle and participation in daily activities. Addressing medical issues and seeking the most effective equipment, appropriate routines and accommodating assistants can



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enhance maximum quality of life. Further resources and reading can be found in the  
reference and resources lists.

## RESOURCES

1. Therapy and support services are available to eligible people with DMD in these states:

MontroseAccess  
PO Box 50  
CORINDA QLD 4075  
Ph: (07) 3379 9200  
[www.montroseaccess.org.au](http://www.montroseaccess.org.au)

The Northcott Society  
PO Box 4055  
PARRAMATTA NSW 2150  
Ph: (02) 9890 0100  
[nc@northcott.com.au](mailto:nc@northcott.com.au)  
[www.northcott.com.au](http://www.northcott.com.au)

Novita Children's Services Incorporated  
Regency Park Centre  
171 Days Road  
REGENCY PARK SA 5010  
Ph: (08) 8243 8243  
[enquiries@novita.org.au](mailto:enquiries@novita.org.au)  
[www.novita.org.au](http://www.novita.org.au)

Rocky Bay Inc



60 McCabe St  
MOSMAN PARK WA 6012  
Ph: (08) 9383 5111  
[www.rockybay.org.au](http://www.rockybay.org.au)

St Giles Society  
PO Box 416  
LAUNCESTON TAS 7250  
Ph: (03)6344 2451  
Email: [Society@stgiles.org.au](mailto:Society@stgiles.org.au)  
[www.stgiles.org.au](http://www.stgiles.org.au)

Yooralla Society of Victoria  
PO Box 200  
FLINDERS LANE VIC 8009  
Ph: (03) 9650 4077  
[www.yooralla.com.au](http://www.yooralla.com.au)

2. Independent Living Centres in each state can provide information on appropriate equipment, suppliers and costs. See white pages for contact details.
3. Some examples of muscular dystrophy websites that provide relevant and up-to-date information and have opportunity to ask questions via email in a confidential manner:
  - i. Parent Project Australia Inc [www.parentproject.org.au](http://www.parentproject.org.au)
  - ii. MDA Association in USA <http://www.mdaua.org>
  - iii. Muscular Dystrophy Campaign in the UK  
[www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

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  - <sup>7</sup> Wheeler, *Toilet training for individuals with autism and related disorders*. 1998: Future Horizons Inc.
  - <sup>8</sup> Wahl M., *Gut reactions*. *Quest*, 2000. **7**(4).



<sup>9</sup> Australian Government Department of Health and Aging, *Good bladder habits for everyone*. 2004.

<sup>10</sup> Australian Government Department of Health and Aging, *Good bladder habits for everyone*. 2004

## APPENDIX

### *Investigation of bowel and bladder control in boys and young men with Duchenne muscular dystrophy: Results of a Survey*

MontroseAccess provides services throughout Queensland (Australia) to children under 18 who have a physical condition, including Duchenne muscular dystrophy (DMD). During 2004 a survey of 48 clients with DMD was conducted by occupational therapist Mathilde Backhouse to investigate bowel and bladder control in boys and young men with DMD.

DMD affects only males and results in progressive weakening of the muscles. The scientific literature indicates that, in people with Duchenne muscular dystrophy, the bladder musculature is not affected by lack of dystrophin<sup>1</sup>, and constipation can be expected mainly as a result of immobilisation once the boys and young men are permanently in wheelchairs<sup>2</sup>. In recent literature<sup>3</sup>, and in the experience of MontroseAccess therapists, bowel and bladder problems are more common than this picture indicates, and therefore a survey of client families with DMD was conducted to investigate this matter.

Parents of forty-eight boys and young men with DMD participated in the survey to investigate trends in bowel and bladder patterns. Three aspects in particular were considered:



1. Acquisition of toilet training skills.
2. Any specific problems currently being experienced with bowel and bladder function.
3. The effect of toileting problems on life style, particularly for non-ambulant young men. Parents were also asked about any strategies, equipment and clothing adaptations they had used.

The participating clients were aged between 4 and 28 years. They all lived at home with their families throughout Queensland, and school-aged boys attended local schools. Thirty-six were permanently in electric wheelchairs and the other twelve were ambulant, some with intermittent use of manual wheelchairs or electric scooters. Diet, academic level and some specific social and behavioural aspects of each boy were recorded so that simple statistical analysis could be done to find if there were any relationships between these characteristics and toileting issues.

A summary of the survey results follows.

## RESULTS

### 1. Acquisition of toilet training skills

The boys in this study, fitted well within the normal developmental milestones for toilet training. Over three quarters of boys were reported to be toilet trained by 36 months. About a third of parents reported that they had some problems in training their children, and most used strategies such as rewards, adjusting diet for allergies, introducing regular routines and wearing no nappy during the day. Very few parents sought medical or therapy advice during this time.

There were 5 boys who had significant problems in learning toileting skills. Two of these had significant intellectual problems and autism and never acquired full continence even into their teenage years.

### 2. Bowel and bladder function

Parents were asked if their sons had experienced any of a given list of bowel or bladder problems in the last 2 years. They were asked to rate the frequency of the problems. This summary reviews only those who experienced problems at least half the time.

Almost half of the boys had urinary urgency, i.e. a strong, sudden urge to urinate immediately. Cognitive, behavioural, dietary or academic factors were not statistically related to this problem.

Over a third had constipation. This correlated with cognitive and social factors but was not statistically related to being non-ambulant.

Bowel urgency was experienced by over a third of boys, who were more likely to be those who were fussy eaters or had low academic results. Boys who drank over a litre of water a day had fewer problems with bowel urgency.

Many boys in wheelchairs tended not to go to the toilet during the school or workday, and 'held on' for 6 hours or more. These boys also tended to drink less than a litre a day.

Almost a third of boys experienced urinary hesitancy, an inability to release urine despite feeling the need to urinate. All of the boys who experienced urinary



hesitancy were non-ambulant. Boys who ate regularly and well were more likely to have urinary hesitancy.

One quarter of the boys had to urinate in the daytime more often than parents considered to be normal. This was more common amongst boys who were socially shy. Urinary frequency was not statistically related to drinking more water.

A quarter of the boys had bowel pain and these were boys who tended to lack social confidence or skills rather than those who suffered from constipation.

One fifth of the boys had some bowel leakage and as expected, these boys also tended to have constipation.

Only a few boys experienced problems with wetting during the day or night, needing to toilet frequently during the night, or having loose bowels.

For a few boys, spinal surgery resulted in some urinary or bowel problems for a limited period after the procedure.

### 3. Lifestyle Issues

Toileting problems became an issue for some, though not all, young men once they were no longer ambulant, and had a marked effect on the lifestyles of many young men and their families. Parents had to assist their sons to toilet during the night as well as during the day. For the intensely private act of voiding, young men were now dependent on assistance of others at a time when their peers were totally independent. Times and places of individual and family outings and leisure events were designed around toileting schedules and many older boys did not stay away from home overnight due to the difficulties with toileting.

Families used a wide variety of strategies to cope with bowel and bladder problems. Constipation in particular was managed by a range of approaches including special

dietary regimes, laxatives and enemas, medical interventions such as bowel wash-outs and regular schedules for toileting.

Most non-ambulant boys effectively used mobile shower-commode chairs and bottles for toileting. About half the boys used Uribags (latex collection bags), particularly when on outings. Three quarters used a hoist for transfers. Many non-ambulant boys used larger shorts without underpants, but few other adapted clothing designs were in use.

## SUMMARY

Results of this survey indicate that boys with DMD generally did not have any greater difficulty becoming toilet trained than children without DMD, with the exception of those who also had intellectual impairment or strong autistic traits.

Over a third of the participants experienced urinary urgency, constipation, bowel urgency and 'held on' for over 6 hours at a time without urinating. Almost a third of participants experienced bowel urgency and urinary hesitancy. Of all these problems, only holding on for over 6 hours and urinary hesitancy were significantly related to being non-ambulant.

Toileting issues affected the life styles of those participants who were no longer weight-bearing, due to the complexity of equipment, assistance and accessibility required.

All efforts have been made to protect the privacy of participants and the author wishes to sincerely thank all the participating families for their contributions. A full summary of the survey findings is available by contacting MontroseAccess or the author.

<sup>1</sup> MacLeod, M., R. Kelly, et al. (2003). "Bladder dysfunction in Duchenne muscular dystrophy." Arch Dis Child **88**(4): 347-9.

<sup>2</sup> MDA Quest Volume 7 No 4 Gut Reactions [www.mdaua.org/publications/Quest/q74gut](http://www.mdaua.org/publications/Quest/q74gut)

<sup>3</sup> Caress, J. B., M. J. Kothari, et al. (1996). "Urinary dysfunction in Duchenne muscular dystrophy." Muscle Nerve **19**(7): 819-22.

