

- Chest strap or harness if forward leaning is an issue and for securing trunk when transported in wheelchair in car or bus.
- Headrest. Boys with DMD have weak neck muscles and must have a headrest to prevent muscle fatigue, improve head positioning and also for neck protection when transported in the wheelchair in a car or bus.
- Pressure relief cushion built in or added to the seat.
- Ability to recline and tilt chair to accommodate fatigue and allow pressure relief (these should always be electrically operated to allow independence).
- Tray to allow upper limb activities, feeding, school or computer work. Consider angle adjustability and ability to move tray closer or further from client as tray position varies depending on tilt/recline of chair.
- Ability to adjust the wheelchair is essential as function changes and growth occurs. Modifications will need to be made to accommodate these changes.
- Boys must be able to demonstrate that they can operate a power wheelchair safely before it will be funded.

### Role of the therapist

The therapist's role is to maintain the best possible sitting posture as the trunk and spinal muscles become weaker. Changes and adaptations to the chair's posture supports may be required at times in order to maximise upper limb function and prevent secondary complications such as contractures, postural pain and development of scoliosis (curvature of the spine).

### Essential family considerations

- How is the family going to transport the wheelchair?
- Access into and around family home and school. Are house modifications required?
- Where will the wheelchair be stored and charged?
- Funding for the purchase and subsequent modification of the wheelchair.
- The environment in which the wheelchair will be used e.g. rural farm setting. Selection of chair may change depending on the setting.
- Family should also always have access to an adequate 'back-up' manual wheelchair in case the powered wheelchair requires maintenance or repair.

### Further information

#### Funding of the manual and powered wheelchair

Funding contribution by the Victorian Aids and Equipment (A&EP) program. Visit the Department of Human Services (DHS) website: [www.dhs.vic.gov.au/disability/supports\\_for\\_people/living\\_in\\_my\\_home/aids\\_and\\_equipment\\_program](http://www.dhs.vic.gov.au/disability/supports_for_people/living_in_my_home/aids_and_equipment_program)

Private funding will be required to cover the gap between the cost of the wheelchair and the contribution by the A&EP. Contact your Allied Health professional for advice on where to apply.

### References

Seating requirements for boys with DMD:  
[www.parentprojectmd.org/site/Docserver/filename?docID=150](http://www.parentprojectmd.org/site/Docserver/filename?docID=150)

Liu et al, Practical problem and management of seating through the clinical stages of DMD: Arch Phys Med Rehabil vol 84, June 2003.

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# Wheelchair considerations

for boys with Duchenne Muscular Dystrophy

Information for families and therapists



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# Selecting the right wheelchair for a boy with Duchenne Muscular Dystrophy

One of the main problems in Duchenne Muscular Dystrophy (DMD) is progressive weakness and loss of the ability to walk independently. In early childhood boys with DMD walk independently but fatigue quickly and fall more frequently than their peers.

With increasing age and weakness, walking becomes more difficult. By 13 years of age most boys are no longer able to walk. Wheelchairs provide an alternate form of independent mobilisation.

Using a wheelchair enables boys with DMD to keep up with their friends and to be fully included in school and family activities. This is critical for their social and emotional wellbeing.

This brochure is designed to help families understand about wheelchairs for boys with DMD. It will help them make the most appropriate choice for their child. It may also assist therapists new to this area.

## Types of wheelchairs

**Power** – battery-powered, allow boys to be independent.

**Manual** – pushed by someone else.

Younger children up to school age may continue to use a stroller. These are lighter and are sometimes preferred by families but they do not provide any postural support or room for growth.

## Typical mobility in boys with DMD

	Pre-school & early primary	Middle primary	Late primary	Secondary
5–50m	Walks	Walks	Walks or w/chair	W/chair
50 – 500m	Walks	Walks or w/chair	W/chair	W/chair
>500m	Walks or W/chair	W/chair	W/chair	W/chair
Type of w/chair	None or manual	Manual w/chair	Manual or Power w/chair	Power w/chair

NB: w/chair = wheelchair

## When to get a wheelchair

A standard manual wheelchair is initially provided for part-time use when a parent, therapist or school has identified a problem with managing long distances. This allows the child to conserve their energy for playing and learning.

Power wheelchairs are prescribed when independent walking becomes more difficult and falls become an increasing problem. This type of wheelchair allows boys to maintain independence in activities they are physically able to manage and find enjoyable.

### Aims of wheelchair prescription:

- provide assistance with mobility
- maintain optimal seating posture
- provide comfortable seating with appropriate pressure relief
- maximise upper limb function
- provide the most appropriate chair for their current needs, taking into account the progressive nature of DMD.

## Features of a manual wheelchair to consider:

- firm, narrow seat (allow room for growth)
- hips and knees positioned at 90° angles
- adjustable footplates to allow feet to be positioned flat
- full-length arm rests
- lap seat-belt
- brakes
- lightweight frame
- folding frame for easy transportation
- removable rear wheels to facilitate folding
- push handles set at the correct height for primary caregiver.

## Scooters

Motorised scooters are occasionally prescribed as an interim measure between a manual and a powered wheelchair, but they have limited use in progressive conditions. Scooters provide minimal postural support, have very basic electronics and can't be used around the home or in ride-on transport such as buses and taxis.

## Features essential for a power wheelchair

Once walking ceases, boys will typically require additional supports to maintain comfort and body alignment. Consideration should be given to:

- Height of the seat from the ground. High seats are difficult to transfer into.
- Lateral pelvis blocks to keep the pelvis level and provide extra stability.
- Lateral thigh/knee supports to prevent the legs rolling out.
- Firm backrest with support to accommodate loss of lumbar curve, scoliosis, kyphosis or hyperlordosis.
- Lateral trunk supports if leaning starts to occur. Consider swing-away pads due to hoisting requirements as the boys get bigger.
- Adequate width, full-length arm rests. As arm control declines, consider gutter armrests or elbow returns to aid in positioning.

(continued next panel)