Duchenne muscular dystrophy: the older child

Duchenne muscular dystrophy (DMD) is an incurable and inevitably progressive muscle disease affecting almost exclusively boys. This information is presented to help you appreciate the way the disease progresses and the timing of its complications. Please note all timings are approximate.

Aged 8-11
During the junior school years, the boy with DMD will usually deteriorate. He becomes unable to climb stairs and finds walking even short distances increasingly difficult. He falls more and more often hence at some stage during this period he will almost certainly lose the ability to walk independently. Walking may be prolonged through the use of aids such as long-leg callipers, but these do not allow truly independent mobility.

Main Priority Areas
- Increasing need for support at school in lessons requiring any physical activity or indeed full-time, according to needs.
- Maintenance of independent mobility through provision of an electric chair with appropriate seating to maintain good posture.
- Housing needs addressed and adaptations should have been completed before stair climbing becomes impossible to allow independent mobility in the home.
- Medical/Orthopaedic surveillance of contractures and use of callipers etc.
- Consider needs for secondary education early (for example school adaptations, adapted w.c, and hoisting needs)
- Behavioural problems

Aged 12-14
This is a relatively stable period in the life of a child with DMD. He is independently mobile in his electric chair and has home and schools environments to be fully adapted to allow him maximum independence and dignity. He will be progressively losing upper limb function and should be provided with IT and classroom support to compensate for progressive loss of writing skills. The major medical complication at this stage is the development of spinal curvature for which surgery may be needed. Medical surveillance for heart and breathing problems are also important now and there will be increasing hospital appointments in this period. On the whole however, the boy is unlikely to require hospitalisation for these kinds of problems. Adolescent issues, including sexual frustration, will have the same importance to these boys as any others of this age.

Main Priority Area
Full access to school in mainstream or special education as chosen by the family. This includes full access to toilets with appropriate hoisting arrangements as necessary. Medical surveillance for back, heart and breathing especially.
Respite arrangements for the boy and his family

14+
The availability of surgical management for scoliosis and the medical management of cardiac and respiratory failure has allowed some boys with DMD to survive into their twenties. As the young man with DMD approaches his late teens he is susceptible to chest infections and requires closer medical surveillance. Weight loss and fatigue may be a problem at this stage his mobility may be restricted to hand movements only and he may require adaptations to his wheelchair controls to maintain control.
Main Priority Areas
• Attention to post school education/ employment
• Medical surveillance
• Respite care
This fact sheet may be used with the Duchenne Muscular Dystrophy fact-sheet (dated March 2002).
The Muscular Dystrophy Campaign has further fact-sheets on surgical correction, heart check, making breathing easier, anaesthetics and educational issues.

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