

Letters to the editor

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Neuromuscular conditions for physicians – what you need to know

Editor – I welcome very much the excellent but very concise conference report on neuromuscular conditions by Edwards and Phillips.¹ However, its brevity results in some of the points raised by the speakers or in discussion being omitted.

Developing children into young adults is challenging, particularly as this should now include preparation for a working life.

As it is accepted that Duchenne muscular dystrophy (DMD) is a disease of adulthood,² much more thought needs to be given to the preparation of children with DMD for adulthood; this is a discussion that needs to begin long before the age of transition. By the age of attending secondary school, the following need to be addressed:

- > the young adult becomes the important person in the paediatric consultation rather than the parents³
- > a discussion about the need to prepare for adult life by withdrawal of parental care during adolescence (as is expected for able-bodied youngsters as they mature).⁴

The use of assistive technology (unlisted by Edwards and Phillips) – eg powered mobility⁵ and environmental control units⁴ – to facilitate personal independence both inside and outside the home supports the withdrawal of parental care. It has been suggested that 'decreasing the physical strain on parents may also facilitate the emotional separation that naturally occurs in most able-bodied youngsters as they mature'.³

Later, education needs to include:

- > exposure to appropriate role models, particularly to working adults with disabilities⁶

- > access to facilities to promote self-confidence, eg sport⁵ and camping⁷
- > access to work experience during their schooling.⁷

The appreciation of the work of the voluntary sector (eg Whizz-Kidz⁷) is often neglected in considering ways of supporting disadvantaged young people and again was not included in the list from Edwards and Phillips. ■

Conflicts of interests

The author has no conflicts of interests to declare.

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References

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- 6 Bender LF. 1980 presidential address to the American academy for cerebral palsy and developmental medicine. *Develop Med Child Neurol* 1981;23:103–8.
- 7 Whizz-Kidz. Work placements. Available online at www.whizz-kidz.org.uk/get-our-help/young-people/work-placements/upcoming-work-placements [Accessed 29 June 2016].