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Conference abstract

Transition to adulthood for young men with Duchenne Muscular Dystrophy

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Abstract

Introduction: Duchenne Muscular Dystrophy (DMD) is an inherited neuromuscular disorder which affects boys. Until recently the mean age of death was around 19 but there have been significant improvements in clinical management and they can now expect to live to around 25 years.

Purpose: To investigate, from their own perspectives, how the well-being of young men living with DMD, and that of their families, can be maximised, particularly at the transition to adulthood, and from children's to adult services. Theoretically, it drew on the social model of disability and recent critiques. It was an example of inclusive research, involving young men and a national family support group, as well as clinical services.

Methods: Postal survey of family carers in three regions followed by interviews with 40 young men age 15+ with DMD and their families about the issues they faced at transition to adulthood.

Findings: Family carers generally considered that transition planning at school leaving was poor or non-existent and that they lacked information about services. Once they had left school or college, the majority of young men lacked meaningful day time activities and friendship networks. There was good continuity of health care in one of the three regions.

Conclusion: Much effort has gone into producing policies and processes, with an uncritical assumption that this will lead to better outcomes.

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Keywords

transition, Duchenne

Presentation slides