32 **TALKING ABOUT TRICKY TRANSITIONS WITH YOUNG MEN WITH DUCHENNE MUSCULAR DYSTROPHY AND THEIR FAMILIES**

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This paper draws on research (Abbott and Carpenter, 2010) for the UK Department of Health. This examined the views of 40 young men and their families (n=102 participants) about the transition to adulthood for young men with Duchenne muscular dystrophy (DMD). These young men were once expected to live only into their teenage years but now are living well beyond that. Families have had to respond to an enormous shift in expectations – not just about life expectancy itself – but about how to live and how to talk about end of life issues. There has been an absence of research which has explored these issues from the perspectives of young men themselves. In relation to the shifting realities of living with DMD, there was a strong mantra about 'living for the day'. Young men said they preferred not to think much about DMD but still wanted people to talk to about it on occasion. Parents said they often did not know what to tell their sons about the disease because they found themselves living with sons who they had simply not expected to be alive. Censorship, collusion, protection of self and others, and silence all featured in accounts from young men and their families. We propose that more emphasis needs to be placed on providing emotional and psychological support to young men with DMD so that dialogue about end of life issues can occur - with consideration given to individual preferences, communication styles, family dynamics and the benefits of peer support.