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Meeting report

Transition in Duchenne Muscular Dystrophy: An expert meeting report and description of transition needs in an emergent patient population (Parent Project Muscular Dystrophy Transition Expert Meeting 17–18 June 2011, Amsterdam, The Netherlands)

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1. Introduction

Ongoing improvement in medical care for boys and young men with Duchenne Muscular Dystrophy (DMD) has led to pressing concerns about well-being in an 'unexpected' population of adolescents and adults with DMD emerging over recent years and in various countries [1]. Though a curative treatment is not yet available, nowadays most individuals are expected to survive into adulthood. This has important implications for the medical and social sectors involved in transition from paediatric to adult care and from childhood to adulthood more generally. However, information and guidance for adolescents with DMD and their parents in transition may either be lacking or not adhered to (usually the latter).

In order to improve the process of transition for young men with DMD, a documentary "*DMD with a Future – The power to live*" [2] was made to describe and illustrate some important aspects of becoming and living life as an adult with DMD. After making the documentary, an expert meeting was held in Amsterdam, on 17th–18th June 2011 which aimed to achieve some consensus on how to improve experiences of young men with DMD at transition. This paper is a short synopsis of that meeting and the documentary, with a summary of key findings and points for action. The full report can be found in Supplementary data.

2. Context: transition in an emerging and novel patient population

Transition to adulthood, including the formal transfer of care from paediatric to adult services is a complex, time-consuming and ongoing process. It is important to note that transition is indeed a process and not a one off event associated with the handover of responsibility from one set of services to another. Young adolescents with a chronic disease are particularly vulnerable at the time of

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[1] On behalf of the Expert Meeting Participants on Transition and Adulthood in Duchenne Muscular Dystrophy. For full meeting report and list of participants please refer Supplementary data.

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transition as they may face different layers of disadvantage (e.g. social isolation, lack of access to employment, variable levels of affordable and good quality support) at the same time as facing greater physical challenges, health care skills and possible decline. There is evidence that a poorly planned transition process can have adverse effects on young people's health outcomes: a review of the literature on health transitions noted that poor transition processes result in worse outcomes in relation to mortality, long term prognosis and physical wellbeing as well as educational attainment and social circumstances [3]. In this critical period adolescents consolidate their identity, and develop their own preferences and desires for example in choices about education, where to live and how to take more control over health care decisions (or not). Challenges remain of maximising the autonomy of young men with DMD. Once in adult services, young adolescents in transition need to be encouraged to be more self-confident about being more assertive in managing their care, maintaining their own relationships with professionals and making decisions about health interventions and treatment [4]. Due to the life-threatening nature of DMD, discussions about advance care planning are extremely relevant. However, the fact that DMD is still seen as a paediatric disease complicates the process of transition. The culture of paediatric care is often very supportive and family-oriented. Therefore the transfer to adult care can be a shock to some families who sometimes experience the different culture in adult care as more difficult to negotiate (although we should note that some services are organised in a way which cuts across the child/adult division by offering a specialist muscle service across the life-course).

It is arguable that because DMD remains to be seen as a paediatric disease associated with a corresponding lack of adequate transition planning, young adolescents with DMD may not have been empowered or supported to develop more adult and assertive approaches to different aspects of their lives. This reinforces the need to develop an approach to transition which encourages the active participation of young men with DMD in key areas of decision making about their own lives [5].

3. A documentary on transition and adulthood in DMD

With this report the authors attempt to make a start in improving the process of transition specifically for young men with DMD. Within this context an informative documentary "*DMD with a Future – The power to live*" [2] was made to describe and illustrate important aspects of becoming and living life as an adult with DMD. This documentary highlights the experience of growing into adulthood for seven young men with DMD, one middle-aged man with Becker Muscular Dystrophy and five experts working with DMD worldwide. It was financed by Parent Project Muscular Dystrophy (PPMD) and based on semi-structured interviews. The interviews took place in Belgium, Denmark, the Netherlands, and the USA and were conducted by the authors of the documentary themselves and filmed by a professional cameraman. Analysis of these interviews highlighted six so called 'success factors' for transition into adulthood in DMD and were supported by all individuals interviewed:

Social and physical support leads to independence.
The importance of setting goals and reaching them in an inventive way.
Daily activities give satisfaction.
Acceptance, coping and optimism are vital.
Access to good medical and psychosocial information is vital.
Continuity of care during transition to adulthood is vital.

4. Parent Project Muscular Dystrophy Transition Expert Meeting

The expert meeting on transition and adulthood in DMD was held in Amsterdam, The Netherlands and lasted two days. It was attended by 20 participants in total representing clinicians, researchers, representatives from advocacy organizations (PPMD and DPP, including two who are parents of individuals with DMD) and young men with DMD themselves. Participants came from six different countries: Belgium, Canada, Denmark, Netherlands, UK, and USA.

Most of the expert meeting participants were asked to prepare a short presentation related to the main topic of the meeting: transition issues and adulthood in DMD. These presentations were given after watching the here described DMD documentary. Following each presentation a plenary discussion took place which was led by the meeting chair and ended with participants identifying their own, two key 'headline messages' from each presentation. At the end of the first day these key messages were collected and summarised in order to extract the most important themes in transition and adulthood in DMD so that a number of 'fact sheets' (i.e. educational tools) could be developed. On the second day the expert meeting participants were instructed to work on these key themes in two separate and randomly divided groups. Two rounds of working in these subgroups took place and after each round both subgroups presented their ideas and findings to the other subgroup. In order to prioritise and select themes which would translate into the various fact sheets a Delphi technique was adopted. Each participant chose the two themes they regarded as most important to be covered in fact sheets. This resulted in a consensus on six themes of use for men with DMD, their parents and professionals surrounding them, to be covered and in addition, a general guiding principle of major importance for transition in DMD; namely bringing about a paradigm change in thinking about DMD as a disease of childhood. The results of this exercise in which 12 participants took part were: