Liberating the NHS: Achieving Excellence and Equity for Children
Muscular Dystrophy Campaign response

Introduction

- The Muscular Dystrophy Campaign represents the estimated 60,000 children and adults in England affected by one of more than 60 different types of muscular dystrophy and related neuromuscular conditions. These are rare and very rare conditions which weaken and/or waste muscles. They can cause lifelong disability and/or premature death.

- There are currently no cures or treatment and without multi-disciplinary care most patients and their families experience a further reduction in quality of life and for some conditions, shortened life expectancy.

- We welcome the proposed NHS Commissioning Board for specialised services, and believe this to be a necessary step towards a National Neuromuscular Service for these neglected conditions. However, we also have serious reservations regarding the impact of the proposed move to GP Commissioning for non-specialised primary and secondary care for the 71,000 children and adults with muscular dystrophy and related neuromuscular conditions.

- We have previously highlighted our concerns regarding the current structure of specialised commissioning for people with rare and very rare conditions. We have shown that patients with neuromuscular conditions face a postcode lottery in accessing the specialist multidisciplinary care they require. This has had devastating consequences, with young men with Duchenne muscular dystrophy dying on average 10 years earlier in some parts of the country compared with others, due to a lack of specialist care.

- A National Neuromuscular Service, commissioned by the NHS Commissioning Board through regional specialised commissioning would end the scandal of patients in one part of the country being denied the life-saving care awarded to others, and we would support the creation of the Board.

- However, we remain concerned by the lack of clarity regarding specialised commissioning for rare and very rare conditions. We welcome the proposal that specialised services will be commissioned by the new NHS Commissioning Board; but await further details as to how the NHS Commissioning Board will be funded, the structure of the regional outposts and how these outposts will relate to GP consortia.

- Furthermore, there has been a worrying lack of detail regarding the non-specialised aspects of care for patients with these complex conditions. Neuromuscular conditions are complex multisystem disorders, requiring primary, secondary, tertiary and sometimes quaternary services and clinical evidence is clear that such multidisciplinary care at all of these levels can not only can dramatically extend life-expectancy and transform quality of life for patients with these conditions, but also save vital funds, by preventing unplanned emergency admissions and through reducing the length of hospital stays.

- We urgently seek clarification as to how the NHS Commissioning Board will interface with the rest of the system commissioned by GP’s to provide essential factors of this multidisciplinary care such as community nursing, speech and language therapy, continuing care and on-going physiotherapy.
We are worried that the lack of knowledge among GPs could seriously jeopardise standards of multidisciplinary care offered to these patients. The Muscular Dystrophy Campaign 2010 Patients Survey has revealed a serious lack of understanding and experience among GPs of neuromuscular conditions, many of whom only have one or two patients with a neuromuscular condition at their practice. Without this knowledge, it is hard to see how GPs will be able to make appropriate and timely referrals to both specialised and non-specialised services, and coordinate care for these complex and rare conditions.

Answers to selected engagement topics:

A. Are there examples of good local best practice from LINks or other groups or organisations in engaging with children, young people and their families?

The Muscular Dystrophy Campaign has a national network of patient groups representing the 71,000 people with neuromuscular conditions. We would be happy to facilitate greater engagement with our patient group for GP consortia and the NHS Commissioning Board.

C. What might the NHS Commissioning Board need to consider when developing a plan for promoting and extending choice and how might it best include children and families?

Due to the scarcity of available specialist services for many children with neuromuscular conditions, patient choice is simply not an option. Indeed, many patients would prefer the focus to be on equity in accessing services – an end to the postcode lottery for both specialised and non-specialised services.

G. We would welcome thoughts on appropriate areas for quality standards and the balance between inclusion within adult standards and child-specific standards.

We recommend a Care Standard for neuromuscular conditions based on the internationally-agreed standards of care Duchenne muscular dystrophy has been recommended as published in the *Lancet Neurology* journal in January and February 2010. The Care Standards are the result of an extensive review process by 84 international experts in the diagnosis and care of Duchenne muscular dystrophy. It is widely agreed by leading clinicians that the implementation of these standards of care for Duchenne muscular dystrophy for all neuromuscular conditions, would ensure the appropriate level of care for all patients with these conditions.

K. How can GP consortia pool risk and expertise for the purposes of commissioning children’s services?

To manage the risk of affording costly specialised services for children with rare neuromuscular conditions, regional and national commissioning of these specialised is essential to share the costs among a larger population base.

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1 The Lancet Neurology *The Diagnosis and Management of Duchenne Muscular Dystrophy* (January 2010)