



# Getting it right for the child

Getting it right for the child is all about good communication and advance planning

## The Statement

- ▶ Even in areas where statements are not normally issued most children with Duchenne muscular dystrophy will still require one.
- ▶ It should clearly state what provision is required to meet each of the child's identified needs.
- ▶ A child with Duchenne muscular dystrophy may need support both physically and with their academic learning.
- ▶ Will require input from a range of professionals – including therapists.
- ▶ Input from the parents is vital – they may require support with this.
- ▶ Future needs must be considered as Duchenne muscular dystrophy is progressive – we need to take a pro active approach, not a reactive one.

## Annual reviews

- ▶ Always encourage parents to attend and ideally talk to them a couple of weeks before the review to go over any points that need raising and to ascertain whether they have any concerns.
- ▶ Ensure the statement is properly updated and states the current abilities of the child and their anticipated needs.

## Physical needs

- ▶ These will increase with time.
- ▶ Early consideration of equipment needs is vital (e.g. Mangar Elk lifting cushion, provision of hoist).
- ▶ As time goes by more 1:1 support will be required for assistance with toileting and personal care.

## Physical activity

- ▶ Risk assess.
- ▶ Adopt an inclusive approach to the PE curriculum but modify as required.
- ▶ Encourage participation in swimming, wheelchair football or horse riding as appropriate.

## Technology

- ▶ Most children with Duchenne muscular dystrophy will eventually find writing tiring so acquisition of keyboard skills at an early stage is vital.
- ▶ Children benefit from their own laptop and learning programmes.
- ▶ Extra time should be allowed for exams and alternative methods of recording considered.

## Emotional needs



- ▶ The child and their family are coping with an ever changing situation as the child's muscles weaken.
- ▶ Everyone in the child's family will be affected in different ways and will have different needs – siblings needs should not be ignored.
- ▶ The family of a child with Duchenne muscular dystrophy are travelling down a road that is unfamiliar to most other people – this can be an isolating experience.

## Support for children

- ▶ Children with Duchenne muscular dystrophy may require counselling support or may benefit from art or music therapy.
- ▶ School should be a positive experience for them so it is important to look for areas in which achievements can be made (art is often such an area).
- ▶ Be alert to possible bullying.

## Working with families

- ▶ Keep in touch – often building in an arrangement whereby you have a termly meeting or a fortnightly phone conversation is helpful.
- ▶ A home/school book works well for parents of younger pupils and/or those with learning difficulties.
- ▶ Be realistic in what you expect from parents – they and their child may be having very disturbed sleep patterns. Care routines can take up a large amount of time and are exhausting. Children may travel a long way on transport. They may have many appointments to attend. Homework may have a low priority.

## The future

- ▶ With recent advances in management and the commencement of clinical trials the future looks brighter for children with Duchenne muscular dystrophy.
- ▶ Academic achievement and the development of social skills are important and will help equip the child to be an independent adult able to enjoy a wide range of activities and experiences.
- ▶ Schools have a key role to play in this process.

## After school 16 +

- ▶ It is important to plan well in advance for post school activity.
- ▶ Educational options include mainstream colleges and universities and specialist colleges.
- ▶ [www.natspec.org.uk](http://www.natspec.org.uk) can provide details of specialist colleges.
- ▶ Many academically able pupils will wish to leave home and go to university.
- ▶ Financial issues in respect of the above need organising.

## After school - employment

- ▶ Employment options need thought - advice may be sought from Disability Employment Advisers at the Job Centre Plus.
- ▶ Pupils should be made aware of schemes like Access to Work which can assist them.
- ▶ Part time work may need to be considered because of fatigue.



## After school – other activity

- ▶ It is important that school has equipped pupils to enjoy a range of activities.
- ▶ If the young person does not wish to go into further education or employment they need to look at how they will spend their time and how they can maintain a good social life despite significant disability.

## From Muscular Dystrophy Campaign Inclusive Education Guidelines

(available [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) )

- ▶ In addition to enabling a child to fulfil his academic potential, school should also help children make friendships and develop a self-identity outside the family. Schools can play a vital role in assisting, allowing and encouraging a child to live and think independently. The role of education is ultimately to ensure that children mature in their understanding of themselves and their future.

## From Muscular Dystrophy Campaign Guide to Transition

(available [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org) )

- ▶ Transition to adulthood for young people with muscle disease involves navigating a vast range of subjects, services, professionals and individuals, in a field which is already complex, and at a time of life which is already vulnerable for most, whether living with muscle disease or not.

## Useful Literature

- ▶ An Introductory guide for families with a child newly diagnosed with Duchenne muscular dystrophy
- ▶ Duchenne muscular dystrophy – a guide for families with a child aged 5-12 years
- ▶ Duchenne muscular dystrophy – the Teenage years
- ▶ The Diagnosis and management of Duchenne muscular dystrophy – a guide for families
- ▶ Everybody's Different, nobody's perfect!
- ▶ Same but Different
- ▶ Hey, I'm here too! (for siblings/classmates)
- ▶ Behavioural issues in DMD
- ▶ Inclusive Education
- ▶ Guide to Transition

All available free of charge from the MDC [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)



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## Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK's London office are available on **0800 652 6352** or **info@muscular dystrophyuk.org** from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

**[www.muscular dystrophyuk.org](http://www.muscular dystrophyuk.org)**