



**For professionals**



## **Duchenne muscular dystrophy - learning and behaviour**

### **Duchenne muscular dystrophy is a condition that causes:**

- muscle wasting - in all those affected
- changes to learning ability – in all, to some degree
- changes to behaviour – for some
- Mean IQ one standard deviation below average but most children are still within normal limits. For most children, the affects on learning will mean only a slight change in overall ability but for some, the effects will be much more significant.

### **Difficulties often reported in children with Duchenne muscular dystrophy**

- Early speech and language problems
- Not seeming to understand complex instructions
- Poor or fleeting eye contact
- Falling behind peers with reading and spelling
- Difficulty coping with a change in routine
- Higher than normal level of tantrums or aggressive outbursts
- Very passive behaviour, difficulty communicating, socialising and making friends.

### **When tested against able-bodied siblings**

No difference in skills:

- Vocabulary
- Visuospatial skills
- Rote memory – verbal & visual
- Abstraction/ conceptualization.

### **Regardless of IQ, performed more poorly in:**

- Digit span
- Comprehension
- Story memory
- Token test.

### **This indicates**

- Good single word comprehension

**but**

- Particular difficulties in comprehending complex verbal information
- Problems following 'strings' of verbal information
- Use of visual clues, pictures and routines can be helpful in overcoming these difficulties.

### **Non-progressive**

Understanding complex language seems to be a delay rather than a deficit and with correct support the children are usually able to 'catch up'.

### **Contributing factors**

On testing, lower academic achievement scores than their siblings.

Many factors could contribute:

- fatigue
- mood
- physical ability

However, research showed decreased verbal span to be more of an influence than any of the other factors.

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### **Slow language development – common difficulty**

Once communicative speech develops

- know factual information
- have vocabulary
- problem solving skills
- on a level with peers

**but**

- comprehension likely to be comparable to a child two years younger, therefore more difficulty following verbal instructions
- Many children have poor reciprocal social language.

### **Phonological processing skills**

Tests looking at estimates of intellectual function showed no differences between children with Duchenne muscular dystrophy and their siblings, however, the children with Duchenne muscular dystrophy did more poorly on:

- phonological awareness
- phonological memory
- rapid naming

Indicates difficulty with phonological processing skills. Processing speed and complex attention may also be problematic.

### **Poor phonological processing/comprehension**

In up to 40% - this combination of difficulties likely to cause problems with:

- reading
- spelling
- maths

Specific advice will be needed.

Similar difficulties to those found in children with:

- dyslexia
- reading disabilities
- strategies used for these children may be helpful
- better at sight reading than 'sounding out' words.

### **Self-esteem**

Physical weakness means:

- inability to keep up with their peers in the playground
- inability to be good at sports

If also experiencing difficulties:

- processing what is being said by teachers
- learning to read and decode speech sounds
- in the classroom

this is doubly damaging to their self-esteem and may lead to frustration.

### **How can we help?**

Remember that problems are likely to be due to the condition.

There are areas where these children do not usually experience difficulties:

- build on these strengths
- help alleviate learning related frustrations
- rote learning is generally good
- repetition
- routines.

### **Behaviour**

Particular behaviours reported (by parents) are:

- immaturity
- attention problems
- more social problems than unaffected siblings.

Could be arising because:

- not understanding as much as other children their age
- inability to follow complicated instructions causing decreased attention.

### **Autistic spectrum disorders**

Research has shown that a higher than expected number of children with Duchenne muscular dystrophy score at a level suggesting autistic spectrum disorders (ASD) than in the general population.

#### **The type of ASD qualities**

- Failure to use nonverbal behaviours for social interactions (poor eye contact, lack of social smiling)
- Failure to develop peer relationships (lack of interest in children)
- Lack of shared enjoyment (not directing other's attention to things of interest)
- Delay in spoken language
- Lack of varied, spontaneous make-believe play
- Lack of reciprocal conversation
- Circumscribed pattern of interest
- Compulsive adherence to rituals
- Restricted, repetitive and stereotyped patterns of behaviour were seen in some children, but this is not the predominant characteristic

It is thought likely that these issues will improve with age.

### **Other issues**

Intellectual function within normal limits.

Specific difficulties noted in:

- the ability to identify affect and interpret facial expressions. This may lead to social interaction difficulties and behavioural issues so support and intervention should be provided to assist with this.
- switching from one task to another, particularly if they are absorbed.

This may appear as not seeming to listen or being rude and disinterested.

- Attention Deficit Hyperactivity Disorder (ADHD) reported by 12-24% of parents.

These children tend to have poorer psychosocial adjustment.

- Remember the emotional responses of other family members are likely to have an effect on children's behaviour.

### **Recommendations**

- Full assessment required
- Problems may not be obvious from a 'quick look'.

### **Practical tips**

- be aware of the problems
- be consistent
- when giving instructions, ask the child to look at you
- break down complex instructions – be clear and concise
- break down tasks into steps
- encourage children to be well-organised and prepared for tasks
- encourage routines and provide structure
- thoroughly prepare children for new situations
- give clear boundaries and explain what is expected of them
- give praise when things are going well
- explain the reason for a decision
- try to provide a compromise
- provide advanced warning of changes e.g.. five minutes until...
- encourage early phonics learning
- ensure the teaching of subskills to assist reading and spelling
- use visual clues.

### **Learning and behaviour**

- Evidence is based on children with Duchenne muscular dystrophy as a group
- Indication of the types of difficulties that these children may be at risk of
- Not all children with Duchenne muscular dystrophy will have significant problems

**Each child is unique, individual assessment is vital and specific interventions should be tailored accordingly.**

### **What is Duchenne md? - Summary**

Complex genetic condition:

- affecting learning ability
- possibly affecting behaviour
  - these areas are non-progressive and can be improved with support
  - causes severe physical disability
  - life-limiting
  - effects can be slowed by medical/therapeutic interventions.

### **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 Muscular Dystrophy Campaign [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

- PPUK Learning and Behaviour toolkit - [www.actionduchenne.org](http://www.actionduchenne.org)

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