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# Occupational Therapy and Duchenne Muscular Dystrophy

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*By*

**KATE STONE, CLAIRE TESTER, ALEX HOWARTH,  
RUTH JOHNSTON, NICOLA TRAYNOR,  
HEATHER McANDREW, JOY BLAKENEY  
AND MARY MCCUTCHEON**



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# Preface

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This book has been produced by core members of the Scottish Occupational Therapy Focus group for Muscular Dystrophy. Based on the authors' knowledge and experience, the intention is to provide a resource that facilitates a flexible and informed clinical approach to occupational therapy with this client group.



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# 1 Duchenne Muscular Dystrophy: A Medical Overview

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**ALEX HOWARTH**

Duchenne muscular dystrophy is the most common and usually most severe form of muscular dystrophy (Kapsa et al., 2003). It is named after Dr Duchenne de Boulogne – a mid-nineteenth-century French physician, who was one of the first people to study and document some of the muscular dystrophies.

Duchenne muscular dystrophy is an X-linked recessive muscle-wasting disorder, involving progressive muscle weakness which normally becomes evident before the age of five years in an affected boy. A defective gene on the X chromosome (at Xp21 site) leads to a deficiency in dystrophin – a rod-shaped cytoskeletal protein which normally maintains the integrity of the muscle cell wall. Where dystrophin is deficient, there is an influx of calcium ions, a breakdown of the calcium calmodulin complex and an excess of free radicals. These changes lead eventually to irreversible destruction of the muscle cells. Dystrophin is also found in the brain and its deficiency is associated with cognitive impairment to a varying degree (Anderson et al., 2002; Leet et al., 2002).

In X-linked recessive inheritance, it is generally the males that are affected because the mutated allele on the X chromosome is not balanced by a normal allele, as it is in the case of females (males have X and Y chromosomes, whereas females have two X chromosomes). In approximately half to two-thirds of all cases of Duchenne muscular dystrophy, the mother carries the defective gene. In these cases, the female relatives of the carrier mother should be offered genetic counselling. The remaining cases arise through spontaneous mutation and, in these instances, female relatives will have the normal population risk of having an affected male child. For the general population, the risk of having an affected child is one in every 3,500–4,000 male births (Lissauer & Claydon, 1997; Nowak & Davies, 2004).

Female carriers are usually healthy, although a small number have a mild degree of weakness themselves and are then known as manifesting carriers. Daughters of affected males will all be carriers, whilst sons will not be affected, since a man passes a Y chromosome to his son. Each son of a female carrier has a 50% risk of being affected, and each daughter a 50% risk of being a carrier.

There are around 1,500 boys with Duchenne muscular dystrophy living in the UK at any one time. About 100 are born with the condition each year. Diagnosis is often made on clinical grounds supported by laboratory tests. The serum creatine phosphokinase is normally grossly elevated (normal values are in the lower hundreds, depending on the particular laboratory, but, in Duchenne muscular dystrophy, this figure will be in the high thousands). At this stage, a blood sample would also be sent to the genetics laboratory to look for a deletion or duplication on the X chromosome. If no deletion or duplication is identified, the next stage would be to proceed to a muscle biopsy. An absence of dystrophin staining on immunocytochemical staining together with the other changes typical of Duchenne muscular dystrophy, such as variation in muscle fibre size, muscle fibre necrosis, regeneration and replacement by fat, would confirm the diagnosis of Duchenne muscular dystrophy.

Once a mutation has been identified in a family, the female relative should be offered genetic counselling. Identification of carrier females requires interpretation of pedigree and specific tests: 70% of carrier females have a raised creatine phosphokinase level. Accurate carrier and prenatal diagnosis can also be made through DNA testing for gene deletion, duplication or point mutation. In the case in which a mutation has been identified in the affected male but not in the mother, there is a chance that the mutation has arisen in the ovaries of the mother. This is called Gonadal Mosaicism. However, tests for this are not available at the present time. In these cases, there is a 5% risk of having a further affected male child. Prenatal diagnosis should therefore be offered to these women.

## CLINICAL FEATURES

Symptoms usually begin between the second and sixth year of life (Rogers et al., 2001). The average age of diagnosis is 5.5 years, although children are usually referred for a medical opinion when much younger. Involvement begins in the proximal musculature of the pelvic girdle, proceeds to the shoulder girdle and finally affects all muscle groups, including the respiratory and heart muscles. Gower's Sign, in which the child uses his arms to crawl up his thighs into a standing position from a kneeling position, is diagnostically significant. Other indicators include: delayed walking; a waddling gait; toe-walking; a reluctance to walk; difficulty rising from a sitting or lying position; an inability to hop, skip or jump; frequent falling and stumbling; problems climbing stairs and running; cramp in the legs; and excessive fatigue. Enlargement of the calf, and sometimes of the forearm and thigh, is also characteristic. It is known as *pseudo*-hypertrophy because the enlargement of the muscle is not due to additional muscle fibres, but to replacement of the muscle fibres by fat and fibrous tissue. Progressive atrophy and weakness lead boys to

become wheelchair-dependent, usually at between eight and eleven years of age. Joint contractures at the hip, knee and ankle and spinal deformities (scoliosis, kyphosis and lordosis) are common complications.

Duchenne muscular dystrophy is a life-limiting condition but, with improvement in management in areas such as the introduction of steroids (while the boys are still ambulant), postural management (once they are wheelchair-bound), spinal-fusion surgery, non-invasive ventilation and possibly more intense cardiac surveillance and management, the prognosis is improving. At present, many patients will die as a result of cardiac or respiratory failure (Eagle et al., 2002). Without ventilatory support, the average age of death is around 19 years but, where cardiac and respiratory functions are effectively managed, a survival to the third or fourth decade is not unknown (Brown, 2002; Bushby et al., 2005; Simonds, 2001).

Respiratory management is a subject that needs to be approached with sensitivity. In some cases, discussion of overnight ventilation may lead the family to appreciate fully for the first time that Duchenne muscular dystrophy is a life-limiting condition. Strong emotive reactions to this form of intervention may then ensue – total rejection on the one hand, an exaggerated sense of dependency on the other. In general, medical information may have to be explained several times to allow the families to absorb it fully and make fully informed decisions about future options.

## KEY POINTS

- Duchenne muscular dystrophy is the most common and usually most severe form of muscular dystrophy. It is a life-limiting condition.
- It is an X-linked recessive muscle-wasting disorder leading to a deficiency in dystrophin – a protein which normally protects the integrity of the muscle cell wall. Dystrophin is also found in the brain and its deficiency is associated with cognitive impairment.
- In X-linked recessive inheritance, it is generally the males that are affected. In approximately half to two-thirds of all cases, the mother carries the defective gene. Spontaneous mutation is responsible for the rest.
- Daughters of affected males will be carriers; each son of a female carrier has a 50% risk of being affected, and each daughter a 50% risk of being a carrier.
- About 1,500 boys are affected with Duchenne muscular dystrophy in the UK at any one time. About 100 are born with the condition every year.
- Diagnosis is often made on clinical grounds supported by laboratory tests. The serum creatine phosphokinase is usually grossly elevated. Duplication or deletion on the X chromosome would then be investigated through blood sampling. Muscle biopsy would be carried out if no deletion or duplication is found. An absence of dystrophin, variation in muscle fibre size, muscle

fibre necrosis, regeneration and replacement by fat would confirm a diagnosis of Duchenne muscular dystrophy.

- Accurate carrier and prenatal diagnosis can be made through DNA testing for gene depletion, duplication or point mutation.
- Symptoms usually begin between the second and sixth years of life. The average age of diagnosis is 5.5 years and wheelchair dependency occurs at between eight and eleven years.
- Involvement begins in proximal musculature of the pelvic girdle, proceeds to the shoulder girdle and finally affects all muscle groups, including the respiratory and heart muscles.
- The Gower's Sign (a characteristic method of transferring from kneeling to standing) is diagnostically significant. Delayed walking, a waddling gait, problems with stairs and running, leg cramps, excessive fatigue and pseudo-hypertrophy are other indicators.
- Prognosis is improving through developments in respiratory and cardiac management, the introduction of steroids, postural management and spinal-fusion surgery.



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## 2 The Occupational Therapy Process

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**KATE STONE, WITH CLAIRE TESTER  
AND MARY McCUTCHEON**

### **INTRODUCTION**

Occupational therapists have a unique role in supporting and working with young men with Duchenne muscular dystrophy and their families, as they can assess and evaluate an individual's physical, psychological and social needs.

The occupational therapist's focus is on maximising skills, promoting and enabling independence, as well as improving the quality of life of the family. It follows that occupational therapists normally have an ongoing role in the treatment of young men with Duchenne muscular dystrophy.

Individuals will have contact with many occupational therapists and they may have more than one occupational therapist at a time involved in their care. Occupational therapists can be employed by a number of different agencies, with each agency being responsible for providing different services. This can cause confusion for some families, so it is extremely important that they have a clear understanding of each occupational therapist's role.

The vast majority of parents and children, when they first encounter an occupational therapist, are usually not sure of the occupational therapist's function. They normally associate the occupational therapist with the issue that has brought them to the house, such as 'it's the woman about the bath' or 'the man that deals with the boy's handwriting'. Both of these are a small aspect of the services that an occupational therapist can provide and, therefore, each occupational therapist involved with the family needs to clarify what services their agency can offer.

Where there is good communication and cooperation between the different occupational therapy services, they can often offer better services than each individual service can provide.

This chapter defines occupational therapy and provides an overview of the skills that a therapist can offer when working with an individual with Duchenne muscular dystrophy.

## DEFINITION OF OCCUPATIONAL THERAPY

Occupational therapy is a health profession concerned with promoting health and well-being through occupation. Occupation in this sense means the activities that people have to do in their everyday life, such as personal-care tasks, like eating or bathing. It also includes other occupations, like housework, play, schoolwork and employment tasks. Occupational therapists work with people who have health problems to enable them to be as independent as possible in carrying out these occupations by helping them to regain their skills or by offering them alternative ways of participating in activities to improve their quality of life.

According to Blom-Cooper (1989, p. 14), the public and other professionals can have false and damaging stereotypes of the functions of occupational therapy and he recommended defining occupational therapy as follows:

‘Occupational therapy is the assessment and treatment in conjunction and collaboration with other professional workers in health and social services, of people of all ages with physical and mental health problems, through specifically selected and graded activities, in order to help them reach their maximum level of functioning and independence in all aspects of daily life, which includes their personal independence, employment, social, recreational and leisure pursuits and their inter-personal relationships.’

This definition was created in the era before community care and does not include the educational aspects of the occupational therapy profession. A recent study by Creek (2006) looked at 37 different definitions of occupational therapy, with a view to creating one definitive definition; they did not succeed in this task, which is not surprising when one considers all the different elements of occupational therapy.

The philosophy of occupational therapy states that occupation is central to normal human existence and that its absence is a threat to health. It also holds that all individuals are of value and are inherently different and that a therapist must work with the individual to select meaningful activities to maintain personal well-being in a relevant social and cultural setting (Turner et al., 2002).

Occupational therapists work with all age groups in many different settings. Health boards or local authorities and government agencies can employ them, as can voluntary organisations and charities. Others work in housing agencies and education authorities, and some are in private practice. There are also occupational therapists working in universities and for commercial companies. Appendix I illustrates the basic knowledge base of occupational therapists.

The settings in which occupational therapists work are numerous and the following is a list of the main areas in which people with Duchenne muscular dystrophy may cross paths with occupational therapists:

- hospitals and clinics;
- wheelchair services;
- schools and nurseries;
- disabled-living centres;
- social work offices;
- housing agencies;
- hospices;
- equipment suppliers;
- charity organisations like the Muscular Dystrophy Campaign;
- job centres;
- in their own home.

Occupational therapy is a process of assessment, planning, intervention and evaluation. This is a continual process with people with Duchenne muscular dystrophy, as their needs and the needs of their carers are constantly changing.

In order for treatment to be effective, occupational therapists have to work closely with the family and other professionals involved with the family to ensure that treatment goals are realistic and achievable. Treatment is more effective if a proper assessment of the issues is carried out.

## **ASSESSMENT**

The main goal of assessment in occupational therapy is to get a clear understanding of the individual, their social circumstances and their environment, in order to develop a treatment plan which will improve the quality of life of the person and their family. The quality of the assessment carried out will have a direct correlation with the quality of the treatment interventions (Turner et al., 2002).

Ideally, in the atmosphere of evidence-based practice, standardised assessments should be used to measure the effectiveness of occupational therapy interventions. A standardised assessment is one which has been administered to a selected population and standard scores have been obtained that can be used to set a scoring procedure. The test is usually administered in a set way and the person being assessed is measured against the standardised sample to identify their level of performance.

At the time of writing, there are no standardised occupational therapy assessment tools that are specific to people with Duchenne muscular dystrophy. Occupational therapists and other professionals have created many standardised tests that could be used to assess certain functions that are problematic for people with Duchenne muscular dystrophy, but, if another professional has created the assessment, their objectives for testing may be entirely different from an occupational therapist's. This should be considered when selecting standardised assessments.

There are many standardised assessments that can be used to measure specific issues, such as handwriting, activities of daily living and cognitive assessments, etc. Due to the variety and number of these assessments, it is not possible to cover these within this chapter. However, the following reports (Edmans et al., 2001) include some considerations that should be taken into account when selecting standardised assessments which may be useful:

- What client group was the test designed for?
- How valid and reliable is the test?
- Is it validated for an occupational therapist to administer?
- How easy is the test to use?
- How long does it take to complete the test?
- Will an individual with Duchenne muscular dystrophy have the stamina, functional ability and concentration to complete the test?
- Is it age-appropriate for the individual?
- Is the issue important enough for the individual to warrant very detailed assessment?

Assessments are used to identify problems and how these problems are affecting the lifestyle of the individual and the family. They are also a basis for deciding whether occupational therapy interventions will be of assistance to the family.

The following are the main issues that Leeson (1995) recommends assessing for a child with special needs. These areas of assessment are equally relevant for a child with Duchenne muscular dystrophy. Additional areas need to be assessed with young adults and each individual will have other issues that may require assessment.

## EXPECTATIONS

The first issue that an occupational therapist has to assess is what the family expects from their service. They may have made a simple request for information regarding equipment, etc. and may only wish to have that information supplied without further assessment or treatment. The occupational therapist's first assessment will be to decide the level of assessment that is required for each referral. That being said, the occupational therapist should inform the family of interventions that are available from their service. This could be in the form of a simple leaflet.

The occupational therapist then has to establish what issues are important for the family so that the initial assessments and treatments focus on the problems that are causing the most anxiety to the family. When and where the assessments are carried out also needs to be clarified.