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## Application of occupational therapy in Duchenne muscular dystrophy

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## Introduction

Duchenne muscular dystrophy (DMD) is a severe and common childhood muscular dystrophy that results in progressive muscular weakness and wasting. It is an X-linked recessive disorder in which the patients have intragenic out-of-frame deletions or duplications of one or more exons of the dystrophin gene. The common presentation of DMD includes abnormal gait and difficulty in rising from the floor. As a result of muscle weakness and contractures of the Tendon Achilles (TA), the patient loses the walking ability. Though DMD was considered as a childhood disease, current treatments and therapies have improved the survival (Kinali, Manzur & Muntoni, 2007).   
James, a 19-year old male, has a long history of progressive muscle weakness. He lives with his father, mother and a younger sister. None of his family members has any musculoskeletal difficulties. He acquired normal motor skills in the first year of his life. However, he did not walk until age 16 months, and he started to have a lordotic posture while standing by the age 2 years. In the subsequent years, he suffered the muscle weakness especially in arms, pelvis and legs. By age 9, he required orthotic braces to assist walking and within the next two years, he was confined to a wheelchair. In his early teen years, he was able to eat, write and type on a keyboard. However, his capacity has declined over the years.   
He was diagnosed with learning disability in his early school but has progressed through the grades with tutorial assistance. Support was provided to James by an occupational therapist for 30 minutes a month. The OT made sure that he could easily access papers, books and was able to use his wheelchair in the classroom. A special education teacher at school implemented the strategies and modifications necessary to provide him with an appropriate learning atmosphere. He graduated from university with a degree in accounting and a bank hired him. He approached his local therapy occupational therapist (OT) to arrange for the required funding and assistance. The OT assessed and developed a care plan for James and arranged for a case conference inviting the parents, bank representative (employer) and funding agencies for financial assistance. Finally, a suitable work location on the ground floor was found for James. He also qualified for Independent Living Fund from the agency and employed a personal assistant to help him at work and home. He got a fund for a special keyboard and hands-free telephone for using at the Bank (Bushby et al., 2010; Stone et al., 2007).

DMD is a multisystem and multilevel disorder affecting biological, emotional, social and psychological well-being. The patient is more tired than usual and cannot catch his breath. Patient may also experience weakness in language development and learning problems. A preschooler may seem clumsy and often fall. He might be having trouble in climbing stairs and getting up from the floor. Problems may be encountered with emotional adjustment. Several school identified difficulties with children include difficulty in completing handwriting task, typing on the computer, entrance and exits from classrooms, etc. By age 10, braces may be required to aid in walking, and the patient may be wheelchair dependent by age 12. With time, arm strength becomes more of an issue and independence of the patient is compromised. The patient needs help in eating, drinking, turning in bed and bathing. Overall, the activities involving arms, legs and trunk require assistance and mechanical support. Ventilator support, airway clearance and heart medications may be required if the patient is in forties (Bushby et al., 2010; Stone et al., 2007).

## James’ occupational performance compared with usual performance

Compared to the average person with DMD, James performed far better in education and life. His success is owed to the individual education plan that addresses to his learning problems. Occupational therapist also played a significant role in promoting his independence and involvement in decision making. The OT helped James in self care activities by proving assistive devices such as the power wheelchair with a joystick and removable armrests. Chest straps gave the necessary lateral support when the scoliosis worsened. He was able to eat, write and read independently with the help of arm supports and slings. The development of contractures was significantly delayed in his case because of the education provided by the OT regarding appropriate positioning and motion exercises (Bushby et al., 2010; Stone et al., 2007).

## Recommendations for OT treatment

James received an appropriate OT treatment that helped him in his daily chorus at work and home. However, there could be certain additions to the OT treatment to make life more comfortable for James. Since he is confined to a wheelchair, the entrance door that he would use to access the bank may need modification. Hence, this modification of the door is highly recommended. Similar modifications should also be made in the toilet area near the James workstation. Secondly, transport facility should have been arranged for James for daily commuting, attending treatment and leisure activities. Since James is using a powered-wheel chair to move about, he will need a car or van with a ramp or lift. Also, he should be allowed for parking near the workplace. Flexible working to allow for health appointments and breaks from the workstation should also be negotiated with the employer (Bushby et al., 2010; Stone et al., 2007).

## References

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