



NM-SCORE (ENGLISH VERSION)

INTRODUCTION AND USER'S INSTRUCTIONS

The classification in levels of function or NM-Score categorize the functional abilities of individuals with neuromuscular diseases into 3 domains of motor function:

D1 domain: standing position and transfers

D2 domain: axial and proximal motor function

D3 domain: distal motor function

Facial weakness/function is not assessed by NM-Score even though a weakness or paralysis may cause a significant functional impairment.

The goal of the NM-Score is to classify motor skill performance and functional abilities of the individual into the appropriate level in each domain of motor function. Through interview, this tool measures the individual's motor performance in his familiar environment (home, work or school). In case of fluctuations in performance within the day or week, the level corresponding to the most typical performance has to be chosen. In case of indecision between two levels, the more impaired level has to be chosen.

In each domain, the level of function is described from "mild impairment = 1" to "4 = very severe impairment." The rating is completed for each domain of motor function. The classification system was created with the four levels of function to demonstrate a clinically noticeable difference between each level. The additional "Level 0" in each domain correspond to normal performances or performances identical to those of a healthy individual of the same age. The descriptions of each level are general and are not intended to precisely and completely describe the motor function of the individual. It is meant to give a general representation of the individual through the written description of each level in each of the domains.

The differences between each level of function depend less on the quality of the movement than on the individual's functional abilities, or the need for external assistance (equipment or human).

NM-Score is for individuals with neuromuscular disease from age 6 years old and older.

This classification is determined through a directed interview of the individual or his family (or through incidental observation, but not expected performance)

NM-SCORE CLASSIFICATION

NM-SCORE D1 : STANDING POSITION AND TRANSFERS

<input type="checkbox"/> 0	No impairment: Walking ability, running and jumping are comparable to their peers.
<input type="checkbox"/> 1	Mild impairment: The individuals can walk (walking distance > 500m) in town (sidewalks), in supermarkets and on uneven ground. Many individuals may run and jump but with reduced speed, impaired balance and/or compensatory strategies.
<input type="checkbox"/> 2	Moderate impairment: The individuals can walk over limited distances in the neighbourhood, within school or a workplace (walking distance < 500m). Very few individuals have the ability to run and jump.
<input type="checkbox"/> 3	Severe impairment: Upright mobility is very limited. Some individuals are able to take a few steps inside the home with an assistive device or another person to assist, but upright mobility is not the primary method of mobility.
<input type="checkbox"/> 4	Very severe impairment: Individuals cannot take any steps or stand up. No transfer of weight to the feet can be achieved to move from seated to standing position.

NM-SCORE D2 : AXIAL AND PROXIMAL MOTOR FUNCTION

<input type="checkbox"/> 0	No impairment: Seated ability, proximal motor function of limbs, and head control are comparable to their peers
<input type="checkbox"/> 1	Mild impairment: Individuals can stay in an upright, seated position for an unlimited amount of time (all day at school or at work) on a regular seat. Holding a seated position may be qualitatively abnormal due to postural kyphosis or a level of fatigue requiring the support of an upper limb or a chair back. Head control is normal for an unlimited amount of time.
<input type="checkbox"/> 2	Moderate impairment: Individuals can sit without support but for a limited amount of time. Individuals able to sit for unlimited amount of time will be classified in this level of function if: → the individual is unable to lift or carry objects above shoulder level and/or has difficulty carrying and handling of heavy objects and/or → head control is compromised or only possible for short periods of time.
<input type="checkbox"/> 3	Severe impairment: The seated position without support is limited to a few important and purely functional situations (dressing, positioning, donning/doffing a body jacket, sitting on the toilet).
<input type="checkbox"/> 4	Very severe impairment: Individuals cannot sit up unassisted. The seated position is only possible with the use of adaptive equipment.

NM-SCORE D3 ; DISTAL MOTOR FUNCTION

<input type="checkbox"/> 0	No impairment: Object manipulation and distal motor function are comparable to their peers
<input type="checkbox"/> 1	Mild impairment: The majority of object manipulation and distal motor function in daily life activities is preserved. Manual activities requiring greater strength are possible but with difficulty, affecting speed, fatigue levels and the need for compensatory movements. Intention tremors or a lack of precision can be the only impairment observed during the activity
<input type="checkbox"/> 2	Moderate impairment: Object manipulation and distal motor function are limited due to a lack of strength and/or poor control of movement. The individuals cannot perform certain manual activities requiring strength and significant dexterity. Easier manual activities are possible, fully performed but with difficulty, slowness, fatigue or need to compensate. The objects may be modified in order to facilitate their use (large pencil, adapted lids or covers)
<input type="checkbox"/> 3	Severe impairment: Individuals cannot perform manual activities requiring strength and significant dexterity. Object manipulation and distal motor function during easy manual activity may be partially accomplished. In order for these activities to be carried out in full, adaptive equipment or assistance from another person is required.
<input type="checkbox"/> 4	Very severe impairment: The great majority of object manipulation and distal motor function in daily life activities is very difficult or unable to be accomplished.

SUPPLEMENTARY GUIDELINES IN CASE OF HESITATION BETWEEN TWO SCORES

NM-SCORE D1 : STANDING POSITION AND TRANSFERS

0 - No impairment: Walking ability, running and jumping are comparable to their peers

1 - Mild impairment: Some individuals may experience fatigue, decreased endurance, and falls. Travel on inclines may be more difficult and may require a person to assist. Ascending and descending stairs are possible with or without the use of a railing. Some individuals may participate in sports such as biking, soccer, swimming, and leisure walking, sometimes with small modifications.

2 - Moderate impairment: Walking is qualitatively compromised (fatigue, slowness, need to compensate). For many, use of an assistive device may be necessary. Use of a seating device (wheelchair, stroller, scooter) may be necessary due to significant fatigue with ambulating long distance. Falls may be frequent. Walking may be difficult especially on irregular terrain or inclines. Usually, individuals cannot negotiate sidewalks without assist (person or device). Ascending and descending stairs are only possible with a railing or another person to assist. Individuals can get up from a chair or the floor with upper limb support on themselves or a piece of equipment.

3 - Severe impairment: Outdoors travel requires use of a wheelchair, stroller, or scooter. If the individuals do not walk, they are however, able to stand with or without help. They can shift their weight to their feet during transfers that may require assist from another person or modifications. The individuals require assistance or are dependent upon another person for transfers from a regular chair or the floor.

4 - Very severe impairment: Individuals are dependent on another person for all of their mobility and transfers.

NM-SCORE D2: AXIAL AND PROXIMAL MOTOR FUNCTION

0 - No impairment: Seated ability, proximal motor function of limbs and head control are comparable to their peers

1 - Mild impairment: Once in a seated position, individuals can turn to catch an object. Heavy objects (school bag, shopping) may be difficult to carry. The activities of daily living such as grooming, washing their hair, putting on a pair of socks are accomplished entirely without outside assistance, but can be qualitatively affected (fatigue, speed or compensatory movements)

2 - Moderate impairment: Difficulties in maintaining sitting balance become apparent when individuals must use both hands to handle objects. Individuals are able to return to a seated position following a loss of balance in the trunk. Use of the upper limbs can be improved by providing support to the pelvis or the trunk. Use of manual wheelchair may be possible inside the home and over short distances within the neighbourhood, school or work (<500m). Activities of daily living, such as grooming, washing their hair, putting on a pair of socks are only partially accomplished or require modifications or assistance from another person.

3 - Severe impairment: Individuals require adaptations of their seating device to maintain a seated position for an extended amount of time throughout the day. Individuals can maintain head control during most functionally important activities but are sometimes limited in duration. Activities such as leaning forward, returning to sit from a forward position, rolling (front to back) in bed are often difficult without external support from equipment or assistance from another person. Individuals may have difficulties putting their forearms on the armrest of their wheelchair, raising the elbows off the bed or bringing food to their mouth. The use of a manual wheelchair is limited to the inside of the individual's home, in order to move around with greater independence, the individuals may need to use a power wheelchair or scooter.

4 - Very severe impairment: Often individuals do not have good head control in a seated position. The individuals are unable to raise their elbows off the bed/supporting surface. (comment on power vs manual w/c)

NM-SCORE D3 : DISTAL MOTOR FUNCTION

0 - No impairment: Object manipulation and distal motor function are comparable to their peers

1 - Mild impairment: Individuals have difficulty with some manual activities requiring greater strength, for example:

--For children: opening the cap on a tube of toothpaste, unscrewing a cap of a bottle, closing a pant zipper, closing a snap, buttoning up jeans, opening a package of individual cakes or certain yogurts

--For adults: using a bottle opener, opening a jar of jam, peeling potatoes with a knife, clipping one's nails, hammering on a nail, opening mail without adaptive equipment, opening a pressure cooker, carrying a full casserole in one hand.

2 - Moderate impairment: Individuals have higher difficulty with some manual activities considered easy, for example:

--For children: playing on a video game console, pressing on a remote control, writing, turning the pages of a book, holding a spoon in the hand to eat.

--For adults: spreading butter on a piece of bread, washing one's hands, spreading toothpaste, threading a needle, using a keyboard or an ordinary mouse, writing.

3 - Severe impairment: The individuals have relatively great difficulty however, can manipulate small objects placed on a table. The use of a power wheelchair is accomplished with hand controls.

4 - Very severe impairment: Individuals require adaptive equipment or assistance from another person (environmental control, computer interface, mini joystick, adapted games). Certain finger movements are maintained, but sometimes the driving of a power wheelchair and/or control of the environment are not accomplished with the hand because of the severity of the impairment.