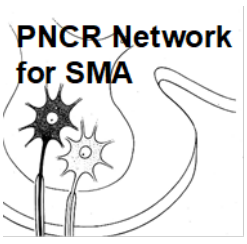
Adapted Test of Neuromuscular Disorders

(ATEND)

Manual of Procedures

Version 3.0

September 2, 2021



Background

This is a functional motor outcome assessment for individuals with a neuromuscular disorder who are not able to sit or transfer out of the wheelchair. The ATEND was developed by an international physical and occupational therapy working group (Tina Duong, Allan Glanzman, Amy Pasternak, Sally Dunaway Young, Leslie Nelson, Robert Muni Lofra, Terri Carry, Donnielle Rome-Martin, Elizabeth Maczek and Giorgia Coratti). Item construction was based on clinical experience and evaluation of very weak individuals with progressive neuromuscular disorders.

Qualitative review of experienced difficulties and clinical reasoning associated with testing of non-infants was interrogated to determine themes by this expert committee. The only validated scale for very weak individuals is the Children's Hospital of Philadelphia Infant Test of Neuromuscular Disorders (CHOP INTEND) developed for SMA1 infants. This assessment was developed based on our experience with the CHOP ATEND, a modified scale constructed from the CHOP INTEND. For older, weaker individuals with severe contractures, motor assessments are a challenge due to limitations in the ability to safely transfer or lie prone. Currently, there is no available motor assessment sensitive to capture changes in this older chronic population. Work is on-going to collect data to further develop and refine the scale properties with future plans for modern psychometric analysis.

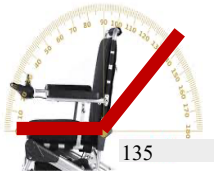
Scale Description and Development

- This is a 14 item assessment based on testing in the wheelchair in 2 positions: 1. Semi-Reclined 2. Supported Sitting
- An iterative approach based on CHOP ATEND items was performed with qualitative item review of experienced administration/scoring challenges and clinical reasoning associated with testing of non-infants was interrogated to determine themes. This assessment was developed based on our experience with the CHOP ATEND, a modified scale constructed from the CHOP INTEND. We reviewed 27 CHOP ATEND assessments performed in the wheelchair and found items that were not feasible to administer in an older, chronic population including rolling, side lying reaching, suspended hip and knee flexion and head and pelvic extension in prone suspension. Review of items that have been developed and validated in scales for non-ambulatory neuromuscular diseases emerged as relevant items to assess motor function in the wheelchair including Revised Hammersmith Scale (RHS) item 4 Hook lying, RHS item 1 Sitting, RHS item 3 Lifts head, Egen Klassifikation Scale Version 2 (EK2) item 4 Trunk control, EK2 item 5 Arm movement, EK2 item 13 Joystick controls, Performance of Upper Limb 2.0 (PUL2.0) item 22 Lift small weight, and Motor Function Measure-32 (MFM32) item 22 Finger diagram.
- The final ATEND has 14 items ranging from cervical, trunk strength to distal strength including arm and hand function based on contractures and the emerging changing phenotype from older, weaker individuals with neuromuscular disease. Test construct is based on a total score of 46.

Wheelchair Assessment and Positioning:

Patient is assessed in their wheelchair. Testing should be performed in the same wheelchair throughout all follow up evaluations.

- Assessment will be performed in 2 different positions:
  - Semi-reclined and supported sitting position
- Laterals used for supported sitting should be consistent throughout the evaluation
- Positioning
  - **Semi-Reclined:** Test should be performed with wheelchair seat tilted or reclined (seat back opened) to 135 degrees. If seat back cannot be open, then seat should tilt to 135 degree angle.



    - Mat or hi-lo table for positioning of lower limbs
      - For items that require the lower limbs to be raised up/supported, a hi-lo table can be used
        - Clipboard or evaluator hand may be used for support
      - The limbs should be positioned on support surface with the heels aligned according to the item start position and the table should be adjusted to the level of the wheelchair seat cushion.

    - Includes items 1-6
  - **Supported Sitting:** Seat to back angle set ≤100 degrees of recline or seat tilted ≤100 degrees. Includes items 6-14.
    - Leg rests will be removed for some items
    - Head can be supported on headrests, if headrest is curved an alternative firm flat base of support should be used.
- **Test Flow**
  1. Semi-Reclined
  2. Supported Sitting

A manual wheelchair may be utilized based on best clinical judgement if a wheelchair is not available. Clinical sensibility is required to assess safety when tilting the chair positioning backwards onto a support surface.

Testing environment and equipment:

- Ideally test first thing in the AM or same time of day
- Test should be performed with the trunk positioned at 135 degree via tilt or recline in the wheelchair and <100 degree supported sitting position.
- Clothing: comfortable, loose clothing
- Spinal orthosis allowed. Should keep consistent if used for testing on initial visit.
- Allow caregiver to be present and give rest period if needed. Aim to complete the entire test without interruptions.

- Equipment/Supplies:
  - Wheelchair
  - Mat or hi-lo table
  - 10 g weight
  - Finger tap diagram
  - Clipboard
  - ATEND worksheets




Testing Administration and Scoring:

- Testing Positions
  - Semi-Reclined
  - Supported Sitting
- Use age appropriate strategies/instructions to encourage movement
- Keep in mind test **item objective**
  - Was the patient able to perform the intended task in the appropriate start position?
- **Scoring**
  - General Scoring Criteria:
    - Lower scores represent lower skill level
    - Higher scores represent higher functional ability
  - Limited By Contracture (LBC)
    - Item constructs need to be considered. These factors may impact item scoring.
      - Antigravity strength
      - Gravity eliminated
      - Contracture assisted movement
        - Consider joints that have >90 degree contractures: hip, elbow, knees
  - Cannot test (CNT)
    - Due to safety
    - Inability to obtain or tolerate start position
    - Wheelchair based assessment should be less of an issue
    - May be due to wheelchair set up - consider attempting to reposition wheelchair prior to determining “CNT”
  - Able to Test (per item): These items require each score level to be assessed within the item.
    - Items 1, 2, 6, 11
    - Put a checkmark √ next to item score if patient able to perform each scoring level within the item

- **Test Performance**
  - All items can be scored either based on observation or active movement following the individual item instructions
  - Up to 3 good attempts should be made to elicit the maximum performance with verbal encouragement. A good attempt means adequate positioning, patient engagement and ideal environment.

- Perform each test item in the order listed unless otherwise noted.
- Make a note in the margin of any comments regarding performance or scoring choice of that item
- If in doubt when choosing between scoring criteria, “score down”

Contractures:

**For clinical use and not required as part of ATEND scoring.*

- Contractures will be assessed bilaterally and documented for the neck, shoulder, elbow, wrist, finger, hip, knee, and ankle joints. Range of motion limitations will be classified as:
  - No limitation
  - Minimal limitation: Contracture present and limiting <20% of full range of motion
  - Moderate limitation: Contracture present and limiting 20-50% of full range of motion
  - Maximum limitation: Contracture present and limiting >50% of full range of motion
- Consider how contractures contribute to motor movement
  - Contractures may inhibit or assist movement
- Limited by Contracture (LBC) to be indicated for each item if contractures limits ability to improve on an item.

Summary of Contractures □ **Not assessed**	**RIGHT** Min<20% Mod20-50% Max>50%	**Comments:**	**LEFT** Min<20% Mod20-50% Max>50%	**Comments**
Neck Contractures	No / Min / Mod / Max		No / Min / Mod / Max	
Shoulder contractures	No / Min / Mod / Max		No / Min / Mod / Max	
Elbow contractures	No / Min / Mod / Max		No / Min / Mod / Max	
Wrist contractures	No / Min / Mod / Max		No / Min / Mod / Max	
Finger contractures	No / Min / Mod / Max		No / Min / Mod / Max	
Hip contractures	No / Min / Mod / Max		No / Min / Mod / Max	
Knee contractures	No / Min / Mod / Max		No / Min / Mod / Max	
Ankle contractures	No / Min / Mod / Max		No / Min / Mod / Max	

Brooke Upper Limb Scale:

- Will be assessed prior to initiation of the evaluation

Upper Limb Functional Score					
SCORE 6	**SCORE 5**	**SCORE 4**	**SCORE 3**	**SCORE 2**	**SCORE 1**
Starting with arms at the sides, the patient can abduct the arms in a full circle without shoulder or elbow flexion until hands reach overhead. 	Can raise arms above head only by flexing the elbow (i.e. shortening the circumference of the movement) or using accessory muscles 	Cannot raise hands above the head but can raise a cup with 200g weight in it to mouth using both hands if necessary. 	Can raise hands to mouth but cannot raise a cup with 200g weight in it to mouth. 	Cannot raise hand to mouth but can use hands to hold pen or pick up pennies or a checker from table; drive wheelchair 	Cannot raise hands to mouth and has no useful function of hands. 

**Scoring is based on Brooke Upper Limb Scale*

Part 1: Semi-Reclined Testing Position

Item 1: Active arm movement

Construct: Upper Extremity Strength, Active Range of Motion

Start Position:

- **Semi-Reclined:** Test should be performed with wheelchair seat tilted or reclined (seat back opened) to 135 degrees. If seat back cannot be open, then seat should tilt to 135 degree angle.
    - *Arms resting in patient's preferred position, either on the wheelchair armrests in maximal available elbow extension, or off of the armrests.*
- Elbow in Max extension

Stimulus: The examiner may support the forearm/elbow and passively move the hand or upper limb and ask the patient to try to replicate the movement. Examiner is able to support proximal joints to assess finger, wrist, and elbow movement.

Considerations:

- *Gravity assist, gravity eliminated, antigravity movements*
- *Be careful of positioning to avoid gravity assist in movement*
- *May passively move limb through desired actions initially to facilitate movement*

Score	Grading Criteria	Considerations
4	**Antigravity shoulder movement** – ELBOW off surface "Can you lift your arm without touching your hand to your body or wheelchair?"	• Must be open chain movement • **Closed chain:** Internal/external shoulder rotation with hand planted on wheelchair or body is invalid to score 4 • Pivoting not allowed either on wheelchair/body/other supporting surface
3	**Raises hand and forearm off surface / above height of elbow**	• Not able to test if elbow contracture ≥90º
2	**Any active WRIST movement**	• Antigravity OR gravity eliminated ok
1	**Any isolated FINGER movement**	• Antigravity OR gravity eliminated ok
0	**No movement of upper limbs**	

**Score both sides and tick (√) all active movement observed/ more than one box. Then select the maximum score for the best score.*

Item 2: Active Lower Extremity Movement

Construct: Lower Extremity Strength, Active Range of Motion

Start Position:

- **Semi-Reclined:** Test should be performed with wheelchair seat tilted or reclined (seat back opened) to 135 degrees. If seat back cannot be open, then seat should tilt to 135 degree angle.
- Adjustable mat or hi-lo table for lower limbs support should be positioned at the height of the wheelchair seat cushion. **Footrests and additional leg supports moved away**
    - Elevated leg rests may be used to position the lower limbs as long as the correct position is attained.
    - If severe knee flexion contractures prevent placement on a mat, a clipboard may be used to support the feet

- **Start position: Position legs as close to midline as possible**
- Head can be supported on headrests
- May support the leg above the ankle to eliminate friction from the surface distally
- If patient needs positioning, be careful to avoid gravity assist in movement. If the patient can only move from gravity-assisted position, this will count as 0/CNT for not reaching starting position.
- May need to support legs on mat/hi-lo table placed at seat height to assess score 2, 3, 4
- Support of lower limb in wheelchair for score 0, 1
- For Score of 3, feet must be positioned together (Hips will be in external rotation)

Stimulus: The examiner should ask the patient to move his/her lower limbs as required per item level.

Considerations:

- *Contractures may not allow full available extension*
- *Gravity assist, gravity eliminated, antigravity movements*
- *Hip/knee abductor guides in wheelchair preventing abduction of leg*

Item 2: Active Lower Extremity Movement (cont)

Score	Grading Criteria	Considerations
4	**Antigravity Hip movement** – Lifts Feet & Knees off surface	
3	**Knees in max available extension and ER lifts knees off surface – Feet together** – Knee off surface – No credit if knee off surface due to contracture 	• Test for Hip ADDuction/Internal rotation • Not able to test if knee contracture at 90 degrees (knees pointed toward ceiling), assess for score of 2. • Lower extremity must be in max available extension and must be able to move away from this • **Feet positioned together (no greater than hip width)**
2	**Gravity eliminated Knee movement** – Knee Extension/Flexion in hip ABDuction and External Rotation	• Legs do not need to touch surface if there are hip contractures • May support at foot and position into hip external rotation to test
1	**Any ANKLE movement**	• Must be antigravity or gravity eliminated
0	**No movement of lower limbs**	

**Score both sides and tick (√) all active movement observed/ more than one box. Then select the maximum score for the best score.*

Item 3: Hip Adduction

Construct: Hip strength

Start Position:

- **Semi-Reclined:** Test should be performed with wheelchair seat tilted or reclined (seat back opened) to 135 degrees. If seat back cannot be open, then seat should tilt to 135 degree angle. Legs positioned *on adjustable mat/hi-lo table with hips and knee flexed and feet propped on the surface, with femurs positioned in neutral hip rotation. Thighs should not be touching the surface.*
- Evaluator passively positions one leg into full available hip abduction and external rotation and asks patient to bring the leg back to the starting position. The **goal of this item is to focus on the patient's ability to adduct the legs from the abducted position**. Evaluator must not stabilize non-tested leg.

Instruction: Can you bring your leg back to the start position and hold this position for a count of 3?

- Score of 1**: Feet hip width apart**, knees not touching. Patient able to hold knees apart for a count of 3
- Score of 2: Feet hip width apart, **hip in maximal external rotation**. Evaluator must not stabilize non-tested leg. Patient able to actively adduct leg back to neutral position (knees pointed to ceiling)

Considerations*:*

- *Examiner may add support at the heel using hand or clipboard.*

Score	Grading Criteria	Considerations
2	**Able to adduct to bring leg back to neutral with control & from External Rotation position** (score both right and left sides)	• Assess end range passive ROM Abduction and External Rotation • Must be able to move away from end range in the direction of hip ADDuction/internal rotation. • Not able to test if contracture at 90 degrees of hip rotation (knees pointed toward ceiling) • Must return from their full available range and have control throughout movement.

1	**Holds position – knees not touching, feet hip width apart for a count of 3**	• If the patient is only able to achieve adduction utilizing compensatory movements • Lack control with movement • Only able to complete part of the movement • Must be anti-gravity HIP ADD/Internal rotation • Not able to test if contracture at 90 degrees (knees pointed toward ceiling) • Must be able to move away from end range • Assess end range PROM Abduction and External Rotation
0	**Unable to maintain or achieve start position**.	

**Score both sides and select the maximum score for the best score.*

Item 4: Hand Grip

Construct: Grip strength

Start Position:

- **Semi-Reclined:** Test should be performed with wheelchair seat tilted or reclined (seat back opened) to 135 degrees. If seat back cannot be open, then seat should tilt to 135 degree angle.
- Put elbow in maximum available extension. May have elbow flexion contracture (see score 2 criteria)
- Upper limb supported (elbow on armrest, may support forearm/elbow, shoulder on backrest) while maintaining hand grip

End Position:

- Arm at 90 degrees to support surface; elbow lifts off surface
- Must maintain some active finger flexion throughout ROM of testing
- Hanging on finger contracture with no active muscle contraction does not count toward scoring criteria

Administration:

- Place finger in patient's hand until you secure **grasp, hand may support under the elbow**
  - *Important to use FINGER and not pen or any other instrument so evaluator feels active finger flexion*
- Slowly **lift the arm and hand,** creating traction on the arm towards end position **(90 degrees Shoulder flexion to the body)**
- Continue to draw the shoulder off the mat

Scoring Detail*:*

- *Objective to maintain grip throughout upper extremity movement*
- *Grip does not need to be full palmar grasp. Must have active flexion of any of the interphalangeal joints*
  - *Hanging on contracture is not considered active grip*
  - *Must feel active finger flexion*
- Record score at the point where the patient loses grip
- Note LBC if finger contractures are present and limiting the ability to provide a score

Item 4: Hand Grip--CONT

Score	Grading Criteria	Considerations
4	**Maintains hand grip with shoulder off surface**	• If not able to achieve correct start position, assess ability to get shoulder off surface while maintaining grip • Able to get full score with elbow flexion contracture if able to maintain grip and pull into elbow flexion against traction • Cannot hang on contracture; must feel active finger flexion
3	**Maintains grip with elbow off surface but shoulder on surface**	• If hand not able to touch mat due to contractures, assess ability to get elbow off surface while maintaining grip ○ CE may place hand under elbow and lift up towards ceiling to assess ability for patient to maintain grip • Cannot hang on contracture; must feel active finger flexion
2	**Maintains grip with forearm off surface but elbow supported on surface**	• Start Position: May have elbow flexion contracture • Not able to test if Elbow flexion contracture ≥90
1	**Maintains grip only with no traction**	• Must be able to actively flex fingers; full grip not required • Limited finger flexion ROM or finger extension contractures may impact scoring
0	**No attempt to maintain grasp or finger slips out**	

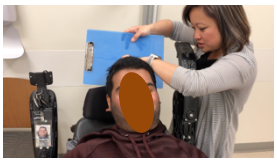
**Score both sides and select the maximum score for the best score*

Item 5: Head in Midline Semi-Recline Position Cont

Construct: Cervical active range of motion, Head control in semi-reclined position

Start Position:

- **Semi-Reclined:** Test should be performed with wheelchair seat tilted or reclined (seat back opened) to 135 degrees. If seat back cannot be open, then seat should tilt to 135 degree angle.
- Upper limbs supported in wheelchair or body
- Position patient with their **head midline**
  - Midline is considered within 15 degrees from center
- May be performed with non-curved headrest as long as headrest does not inhibit movement
  - Suggest using thin clipboard to provide flat/even surface for head rotation.

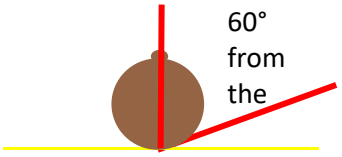


End Position:

- Head in Midline, *Score 1-2*
- Head rotation left and right back to midline, *Score 3-4*

Administration:

- *Objective: Ability to maintain **head in midline + active head rotation** back to midline*
- If the patient maintains head in midline for 5 seconds then turn the patient's head 90 degrees to the right and provide visual stimulation to encourage return to midline, then repeat to the left.
- Score of 3, must at least actively rotate head for 10% of available range
- If the head cannot be turned passively at least 60 degrees off midline, due to contracture, mark LBC
  - Score of 3 and 4 cannot be given



Score	Grading Criteria	Considerations
4	**Rotates from 90° maximum rotation back fully to midline**	• Must not have contracture of head rotation $>30^0$
3	**Actively rotates head part way towards midline (rotates 10% of available range)**	• Must not have contracture of head rotation $>30^0$
2	**Maintains head within 15° of midline for ≥ 5 seconds**	****Start assessment HERE** • Must be active head control • Score down if being held in midline by tracheostomy catheter or other head supports
1	**Maintains head within 15° of midline for ≤ 5 seconds**	
0	**Head falls to side and no attempts to regain midline**	

**Score both sides and select the maximum score for the best score.*

Item 6: Lifts head

**Transition item from Semi-Recline to Sitting*

Construct: Neck strength to lift head, active range of motion of cervical spine in 3 different positions: 135, 115 and ≤100 degrees

Start Position:

- Assessment will start from the **semi-reclined** position for score 3 and **supported sitting** for score 1
- Place clipboard behind the head. May consider taking head rest off for custom or curved head rest.
- Using clipboard provides flat/even surface for start position of head
- Arms should be on lap

Administration:

- *Objective: Lift head in semi-recline and supported sitting positions*
  - *Head must lift off, not trunk flexion*
- *Ask patient to lift head in all 3 positions starting with the 135 degree semi-reclined position, 115 degree and ending with supported sitting position* ≤100 degrees
- Instruction: Can you lift your head to look at your toes?

Score	Grading Criteria	Considerations
3	**Able to lift head with/without compensation from 135 degree trunk position** 	****Start assessment HERE**
2	**Able to lift head with/without compensatory movements from 115 degree trunk position** 	• Neck contractures
1	**Able to lift head with/without compensatory movements from ≤100 degree trunk position** 	• May lift in side flexion, protraction

0	**Unable**	• No movement • LBC due to contracture or spinal fusion/rods

*Score and tick (√) all active movement observed/ more than one box.

POSITION chair into supported sitting/ upright position for remainder of the test*

Part 2: Sitting Testing Position

Item 7: Ability to Balance in Wheelchair

Construct: Trunk Strength

Start position:
- **Supported Sitting:** Seat to back angle set ≤100 degrees of recline or seat tilted ≤100 degrees.
- Any side supports and/or armrests must be removed. A brace/TLSO, if any, is kept on.

End position:
- Patient returns back to midline

Administration:
- *Objective: To assess ability to move trunk outside of midline and regain midline*
- Instruction: Can you bend forward and to the sides and return to upright position? Show me how you do this.

Score	Grading Criteria	Considerations
3	**Able to push him/herself upright from complete forward flexion by pushing up with hands**	• The upper body must reach all the way down and rest on the thighs, both hands must touch the foot support and the person must rise independently from this position. • Using the hands to support and propel the upper body is allowed.
2	**Able to move the upper part of the body > 30 degrees in at least one direction from the upright position** **AND** **Return to upright position**	• May be LBC (rods, fusion)
1	**Able to move the upper part of the body < 30 degrees from one side to the other** **AND** **Return to upright position**	• May be LBC (rods, fusion) • This may include weight shifts

0	**Is unable to change the position of the upper body or move away from the back of the chair.**	• Patients who sit in a permanent forward leaning position with support to the front of the body also score 0. • Unable to return to upright

Item 8: Ability to Move Arms

Construct: Upper extremity functional strength

Start Position:

- **Supported Sitting:** Seat to back angle set ≤100 degrees of recline or seat tilted ≤100 degrees.
- Arms resting in lap
- For score 0-2, may support forearm or elbow to observe distal movement of fingers/hands
- For score 2, may support elbow

Administration:

- *Objective: Observation of upper limb movement with appropriate supports*
- Instruction: Can you describe how you eat? Do you need your elbow on the table when eating? If so, do you use your other hand to help? May ask "Are you able to bring your hand to your mouth, show me".

Score	Grading Criteria	Considerations
3	**Able to raise the hand(s) above the head with or without compensatory movements**	• Can raise at least one hand above the head, compensatory movements are allowed.
2	**Able to raise the forearm against gravity**	• Any elbow flexion against gravity is acceptable. Compensatory movements are allowed. • May need elbow support at any height • Consider Elbow flexion contracture of >90 degrees. Gravity assisted vs. gravity eliminated (ok)
1	**Able to lift hands against gravity when forearm is supported**	• Can raise at least one hand against gravity. • Forearm support is allowed. • Gravity eliminated elbow flexion with elbow support. • Observe for active wrist extension from neutral or flexed wrist position, for example, by placing hand over edge of table and using hand and wrist muscles • Or uses an alternative option such as a raised desktop or surface

0	**Able to lift fingers against gravity.**	• Able to move FINGERS only • This would include the use of an aid to arm function such as a "neater eater" or mobile arm support • For example, drive a powered wheelchair if hand is placed or use a touch screen

*Score both sides and select the maximum score for the best score

Item 9: Shoulder flexion & Elbow flexion

Construct: Elbow and Shoulder strength, active range of motion

Start Position:

- **Supported Sitting** Seat to back angle set ≤100 degrees of recline or seat tilted ≤100 degrees.
- Remove laterals if positions shoulder in ABDucted position
- Remove arm rests if testing score 2-4.
- Arm and shoulder resting at side
- Elbow in maximal available extension

Administration:

- *Objective: Active Elbow flexion, shoulder abduction (open chain)*
- Ask patient to actively bend elbow
- Ask patient to abduct shoulder without hand planted on body or chair.

Score	Grading Criteria	Considerations
4	**Abducts or flexes shoulder to 60 degrees**	• Hand should not be planted on body/wheelchair for this test ○ Pivoting not allowed either on wheelchair/body/other supporting surface
3	**Abducts or flexes shoulder to 30 degrees**	• Hand should not be planted on body/wheelchair for this test ○ Pivoting not allowed either on wheelchair/body/other supporting surface
2	**Any shoulder flexion or abduction**	• Make sure movement is from shoulder not elbow • Must be an open chain task • Hand should not be planted on body/wheelchair for this test ○ Pivoting not allowed either on wheelchair/body/other supporting surface
1	**Flexes the elbow only against gravity**	• Must be antigravity movement. Elbow flexion contracture must not be $>90^0$
0	**No attempt to lift the arm**	

*Score both sides and select the maximum score for the best score.

Item 10: Knee extension

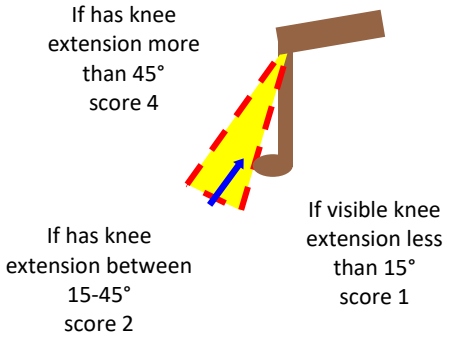
Construct: Quadriceps strength

Start Position:

- **Supported Sitting:** Seat to back angle set ≤100 degrees of recline or seat tilted ≤100 degrees.
- Unable to test 3 or 4 if ≥ 100 degree knee flexion contracture are present
- Evaluator hand to support under knee to maintain thigh horizontal to ground position
- Lift leg into appropriate position of 90 degrees knee flexion
- May want to remove leg rests to allow for freedom of knee extension movement

End Position:

- Active knee extension of >45 degrees



Administration:

- *Objective: Active knee extension*
  - o *Check to ensure movement is not passive knee flexion recoil*
  - o *Consider hand placement on quads for palpation of active contraction*
- Make sure patient understands desired movement
- May want to assess passive range of motion
- Consider LBC effect on ability to move into knee extension

Score	Grading Criteria	Considerations
3	**Extends the knee > 45 degrees**	• Unable to test if >100 degree knee flexion contracture
2	**Extends knee 15 to 45 degrees**	• Assess in line of site of knee joint • Unable to test if >100 degree knee flexion contracture
1	**Any visible knee extension**	• Consider palpating quadriceps • Palpation is to ensure there is quad activation and not just recoil from active knee flexion. • Do not score recoil from active knee flexion
0	**No visible knee extension**	

**Score both sides and select the maximum score for the best score.*

Item 11: Head Control - Sitting

Construct: Head control, cervical strength, and range of motion

Start Position:

- **Supported Sitting** Seat to back angle set ≤100 degrees of recline or seat tilted ≤100 degrees.
- Position the patient's trunk in an erect position with support at shoulder facing the examiner, shoulders and trunk neutral
- Make sure head is not resting on headrest
- Must be able to flex neck where chin (with mouth closed) is 3 cm from sternum to score 3 or 4

End Position:

- Active neck extension and/or co-contraction for head control

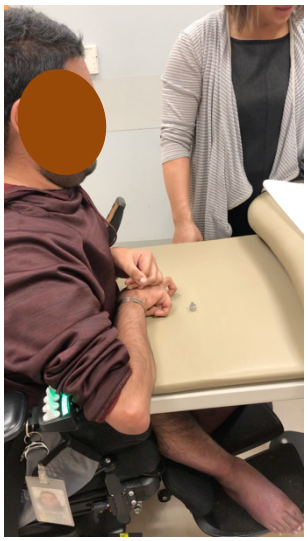
Administration:

- *Objective: Head upright + Active Neck extension*
  - Test ability to hold head in midline first
  - Test ability to lift head into neck extension and rotation
- Scoring details
  - If the patient cannot be positioned with head erect (score of 2) allow the head to fall forward
  - Support the chin with your thumbs at end range to keep chin off chest (score of 1 or 0).
  - Fusion/Rods: May not be able to test 0, 1, 4
  - Tracheostomy: Note unable to score 4
  - If LBC (tick box), Patient will never be able to achieve score 4 due to inability to fully flex neck
  - Head stacking = score of 2
  - Score of 4: Must have ≥ 60 degrees active rotation

Score	Grading Criteria	Considerations
4	**Attains head upright from flexion and turns head side to side within available ROM**	• Must have ≥60 degrees cervical rotation
3	**Able to right head back to midline from flexion**	• Start position: CE moves head to max available neck flexion • Compensation allowed
2	**Maintains head upright in midline for >15 sec (for bobbing or stacking head control score a 2)**	***Start assessment HERE* • Bobbing head control score a 2
1	**Maintains head in midline for >5 sec with the head tipped in up to 30 degrees of forward flexion or extension**	
0	**No response, head hangs**	• Neck flexion contracture with inability to maintain midline = 0, LBC

*Score and tick (√) all active movement observed/ more than one box..

Item 12: Pick up 10g weight with fingers



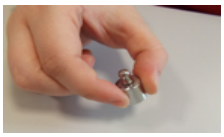
Construct: Finger Strength

Start Position:

- **Supported Sitting:** Seat to back angle set ≤100 degrees of recline or seat tilted ≤100 degrees.
- Height of table/clipboard: at level of umbilicus or patient's preferred functional height to facilitate task
- 10 gram Weight placed on table in front of patient within reach of his/her fingers

Administration:

- Instruction: "Are you able to pick up the weight using any method?"
- Scoring detail/diagram:
  - Can pick up weight any method (any/multiple fingers)
  - To score 1 they can grip/pinch 10g weight only



Score	Grading Criteria	Considerations
2	**Able to grip and lift weight off surface**	• Any grip or hand/finger position ok • No sliding off table
1	**Grip weight only**	• LBC: Finger contractures
0	**Unable**	

**Score both sides and select the maximum score for the best score*

Item 13: Touch diagram squares

Construct: Finger dexterity, Active range of motion

Start Position:

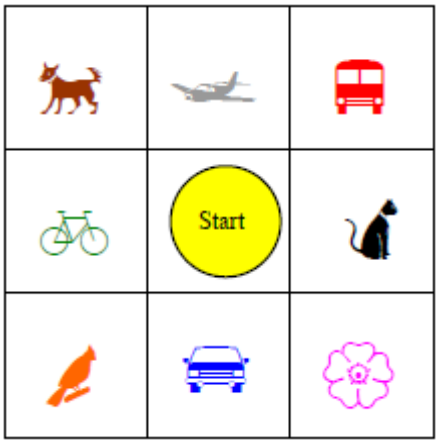
- **Supported Sitting:** Seat to back angle set ≤100 degrees of recline or seat tilted ≤100 degrees.
- Place the patient in front of a table/clipboard adjusted to their preferred functional height, forearm on the table; the elbow may or may not be resting on the table.
- One finger, chosen by the patient (or the thumb) is placed at the center of the diagram below, on the word “start”.
- The position of the legs is unimportant.

Administration:

- *Objective: Ability to pick lift finger and move on diagram*
- Instruction: Ask the patient to hide each drawing with their finger.
- Scoring detail/diagram: For all scoring levels, the hand and/or the other fingers may give support. If the finger touches the lines, the score is limited to 2.

Score	Grading Criteria	Considerations
3	**Raises the finger and places it successively on the 8 drawings of the diagram without touching the lines**	• Must lift finger and touch all diagram without touding the line.
2	**Raises the finger and places it imprecisely on 1 to 8 drawings of the diagram**	• Must lift ≥finger
1	**Cannot raise the finger to place it on a drawing, but can *slide it* on at least one drawing**	• Must slide in any direction at least one to one drawing
0	**Cannot raise the finger, nor slide it onto a drawing**	

**Score both sides and select the maximum score for the best score*



Item 14: Ability to control joystick

Construct: Finger dexterity, Active range of motion

Start Position:

- **Supported Sitting:** Seat to back angle set ≤100 degrees of recline or seat tilted ≤100 degrees.
- Positioned in upright driving position, controls in situ

Administration:

- *Objective: How patient drives his/her wheelchair*
- Instruction: What kind of joystick do you use to control your chair? Show me how you control your wheelchair. Has it been adapted in any way to suit your needs?

Score	Grading Criteria	Considerations
3	**Uses a standard joystick without special adaptation**	• Standard joystick means as issued by wheelchair suppliers positioned on either the right or the left of the chair.
2	**Uses an adapted joystick or has adjusted wheelchair in order to use joystick**	• Scores 2 if any adaptation has been made to either the joystick or to its position on the chair. • Adaptation means increasing length, altering range of motion, moving its position on the chair (ie. midline), use of 2 hands • Includes adapted joysticks such as mini-proportional to alter sensitivity thresholds, or adapted joystick tops for accommodation
1	**Use other techniques to steering than joystick such as blowing, sucking systems or scanned driving.**	• Scanned driving needs minimal strength and can be placed anywhere. • Blowing/sucking systems are seldom useful in NMD. This category is also meant for new techniques and for persons who can partly operate their wheelchair but need assistance for special maneuvers such as turning the chair or driving on uneven surfaces or in cold weather.
0	**Unable to operate wheelchair. Needs another person to operate it**	• If there are caregiver controls in situ due to cognitive issues rather than physical abilities, please make a note of this