

CCSA Clinical Severity Assessment

Date: _____

Patient Name: _____

Participant Code: _____

Clinician: _____

Parent Name: _____

Please note: this form includes questions in several clinical domains. This form should be completed and handed back to the parent or guardian prior to them leaving the clinic visit, but can be emailed directly to the parent/guardian, if need be.

For Study Personnel Use, Only:

Coordinator Code: _____

STATE

Please describe the child's state.

1. Postictal? Yes

No

If 'yes', describe including duration since last seizure: _____

2. Unwell? Yes

No

If 'yes', describe: _____

3. Current meds: _____

4. Please note travel over past 24 hours: _____

5. Other comments: _____

6. Age of child at assessment (months): 0 - 6

7 - 14

15 - 17

18+

MOTOR DOMAIN

Gross Motor Function

- YOU CAN ASK PARENT TO SHOW YOU THESE SKILLS
- ENSURE THE CHILD IS TESTED FOR THE DURATION OF THE ACTIVITY AND SCORE ON THE HIGHEST LEVEL OF ASSISTANCE NEEDED DURING THE TASK

1. Head control in sitting - support trunk in an upright position if required

- Full, active range of motion to look left or right
- Limited range of motion to look left or right, lack of chin control
- Can get head into alignment whether momentary or longer
- No head control

2. Supine lying to sitting

- Moves from laying to sitting independently - good head and trunk control
- Moves into sitting with some limitations - lag in head control, or uses own arm to assist
- Minimal assistance to guide getting into sitting - a light touch, one hand held
- Pull child into sitting, child holds head in line with body through a portion of all the movement
- Pull child into sitting, may momentarily tighten muscles through the neck but does not align head with body
- No, minimal effort; full assist

3. Sit 20 sec - sitting on a chair

- Able to sit for 20 sec independently, fully safe, can step away from the child
- Able to sit for 20 sec under supervision (spotting, stand by assist) or may require use of one or both upper extremities to prop for maintaining sitting
- Sits for 20 sec with minimal assistance - a light touch, one hand held
- Sits for 20 sec with moderate assistance - two hands held, trunk support
- Sits < 20 sec with moderate assistance
- Maximal assistance, unable to maintain sitting

COMPLETE ONLY IF
≥7 MONTHS

COMPLETE ONLY IF
≥7 MONTHS

Gross Motor Function (cont.)

4. Sit to stand - extent of testing based on parent report of known motor skills, eg, if unable to get up from floor, start with getting up from chair

- Moves from sitting on the floor to stand independently, without using hands and stabilising independently
- Moves from sitting on the floor to stand but uses own hand(s) for support on self or furniture
- Cannot stand from floor, but stands from chair on own (may use own hands to get out of chair but independently)
- Stands from chair with minimal assist (one hand, one hand from assistant, light touch)
- Stands from chair with moderate assist (two hands, trunk support)
- Maximal assist, unable to stand from chair

COMPLETE ONLY IF
≥15 MONTHS

5. Stand 20 sec

- Stands independently for 20 sec, without limitations, can step away from the child
- Stands independently for 20 sec, with limitations - with supervision (spotting, stand by assist), wide base, bracing
- Stands for 20 sec with minimal assistance - one hand held, light touch
- Stands for 20 sec with moderate assistance - two hands held, trunk support
- Stands < 20 sec with moderate assistance
- Maximal assistance, unable to maintain standing position

COMPLETE ONLY IF
≥15 MONTHS

6. Walk 10 steps

- Walks without limitations, can step away from the child without fear of their falling
- Walks with limitations - eg, wide base, bracing, apraxia, stand by assist
- Walks 10 steps with minimal assistance - light touch, one hand held
- Walks 10 steps with moderate assistance - two hands held, trunk support
- Walks < 10 steps with moderate assistance
- Maximal assistance, unable to walk

COMPLETE ONLY IF
≥15 MONTHS

Gross Motor Function (cont.)

7. Hand function - Evaluate using the child's own objects

- Able to freely manipulate objects including small objects eg transferring objects from hand to hand (fully formed, upper limb is free of support)
- Consistently uses thumb when grasping small objects eg small pieces of food
- Rake grasp - Uses only fingers or inconsistent thumb when grasping small objects eg small pieces of food; consistent function (feeds self, plays, etc.)
- Active grasp and hold large object, - eg toy for the size of the child's hand, child's own spoon or cup
- Holds object only if placed in hands for at least 2 seconds - eg small toy, small ball, spoon, cup. May throw the object within 2 seconds
- No hand use

8. Reaching

- Reaches for small objects accurately (i.e. hits the target smoothly)
- Reaches for small objects with difficulty (dysmetria, poor targeting, needs assistance (weakness).
- Reaches for large objects or people
- Bats at or pushes away objects or people or eye/face rubbing - intentional
- No intentional reaching

9. Altered Muscle Tone

Definitions:

Severe hypotonia:

- No resistance to clinician movement of joints; full or excessive range of motion; hyperextensibility
- Observed across all or most joints

Mild hypotonia:

- Some resistance to joint changes; full passive joint ROM; hyperextensibility limited to joints of hands, ankles, and feet
- Observed across all or most joints

Normal tone:

- Body parts resist displacement; momentarily maintain new posture when placed in space; can rapidly follow changing movement imposed by examiner

Mild stiffness:

- Some resistance to change of joint position in part of or throughout the whole range;
- Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder of the ROM.

Severe stiffness:

- Passive ROM limited; unable to overcome resistance of muscles to complete full range without modifying position or stabilizing other body parts
- Increased muscle tone such that passive movement is difficult. Affected part(s) may be held in flexion or extension

Gross Motor Function [Altered Muscle Tone] (cont.)

Instructions

- If there is asymmetry, score the worst affected side
- The patient can have a mixed picture of tone in both upper and lower extremities. Mark where each joint is graded on the grid
- Record the tone of each joint
- If there is mixed tone within a limb (eg increased tone in the ankles and low tone at the knees or hips) - score the limb on the aspect of altered tone that is most severe
- Contractures are graded in the setting of the overall tone in that joint

Severe Hypotonia	Mild Hypotonia	Normal Tone	Mild Stiffness	Severe Stiffness
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Axial					
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Shoulder					
Elbow					
Wrist					

Upper limb score: Right / Left

Hip					
Knee					
Ankle					

Lower limb score: Right / Left

Overall Picture of Muscle Tone

10. Distribution of chorea

- Absent
- Upper limbs
- Upper limbs and trunk
- Generalised

Gross Motor Function [Overall Picture of Muscle Tone] (cont.)

COMPLETE ONLY IF
#10 COMPLETE

10A. Duration of chorea

- Absent
- Intermittent, less than half of exam
- Common, half or more than half of exam
- Persistent, all of the exam

11. Orofacial Dyskinesia - duration

- Absent
- Rare
- Intermittent, less than half of the exam
- Half or more of the exam
- All, nearly all of the exam

COMMUNICATION DOMAIN

COMPLETE ONLY IF
≤17 MONTHS

1. Language (non-verbal)

- Consistent single words in signs or device or gestures eg uses head for yes or no, pointing (finger or hand), blinking, switch, or eye gaze; single choices with a device
- Inconsistent or rare use (1 or 2 occasions throughout interaction) of single words in signs or device or gestures eg uses head for yes or no, pointing (finger or hand), blinking, switch, or eye gaze; single choices with a device
- No gestures for communication

2. Language (non-verbal)

- Verbal communication is accompanied by facial expression, gestures (body language) and eye contact in a social setting, normal
- Sentences or Phrases - 2 or more words -signed or device; multiple choices/proficient with a device, reduced social orientation
- Inconsistent or rare use (1 or 2 occasions throughout interaction) of single words in signs or device or gestures eg uses head for yes or no, pointing (finger or hand), blinking, switch, or eye gaze; single choices with a device
- No gestures for communication

COMPLETE ONLY IF
≥18 MONTHS

Communication (cont.)

COMPLETE ONLY IF
ONLY IF
<15 MONTHS

3. Speech (verbal)

- Purposeful vocalisation
- Non purposeful vocalisation
- No vocalisation

COMPLETE ONLY IF
15-17 MONTHS

4. Speech (verbal)

- Single words - vocal - eg yes or no
- Purposeful vocalisation or word approximation
- Non purposeful vocalisation
- No vocalisation

COMPLETE ONLY IF
≥18 MONTHS

5. Speech (verbal)

- Sentences of Phrases - 2 or more words - vocal, normal for age
- Sentences of Phrases - 2 or more words - vocal, but not normal for age
- Single words - vocal - eg yes or no
- Non purposeful vocalisation
- No vocalisation

COMPLETE ONLY IF
≤17 MONTHS

6. Receptive Language - Clinician tests this

- Responds to language (ie name and other) with eye contact or similar (smile, alerts, quiets, calms) for at least 10 s (out of 30s of direct conversation)
- Responds to voice or language- response short lived and fleeting
- Does not respond

7. Receptive Language - Clinician tests this

- Follows 2 step commands, eg close your eyes and stick out your tongue; take the ball and give it to...
- Follows 1 step commands, eg hand me the toy, touch your nose, close your eyes
- Responds to language (ie name and other) with eye contact or similar (smile, alerts, quiets, calms) for at least 10 s (out of 30s of direct conversation)
- Responds to voice or language- response short lived and fleeting
- Does not respond

8. Alertness and attention is observed in the child's activities in relation to interactions and engagement with the environment (Munde 2009).

- Alert/attentive and engaged in sensory activities with a person (eg watching, listening, smiling) consistently when offered, normal
- Alert/attentive and engaged in sensory activities with an object (eg watching video on ipad, listening)
- Awake but attention has to be drawn by examiner or surroundings for most of the exam
- Awake but not attentive/interactive to the examiner or surroundings for most of the exam
- Drowsy or asleep for most of the exam

VISION DOMAIN**1. Fixing and Following - Follows in well-lit room, 10cm from examiner's face, without voice prompt**

- Fixes and follows examiner's face consistently
- Fixes, occasionally/inconsistently follows examiner face
- Fixes only, does not follow
- Blinks to bright light (otoscope on maximum power)
- Does not fix, follow or blink to light

Vision (cont.)

2. OKN - Use the standard OKNDrum app on ipad (minimum 10 inch) at full intensity in darkened room held 5-10 cm from the child's eyes for 30 seconds. Both directions tested.

- Normal OKN
- Ignored OKN - notice then look away
- Inconsistent OKN, Reduced OKN (movements present but reduced in amplitude, or loss of one visual field.
- No visual field. Absent OKN

3. Eye Alignment

- Normal
- Dysconjugate, intermittent
- Dysconjugate, constant

4. Roving

- Not present
- Intermittent
- Persistent

5. Nystagmus

- Not present
- Intermittent
- Persistent

(if selected nystagmus) **Please specify type of nystagmus (can select more than one)**

- Horizontal
- Vertical
- Rotatory

OTHER CLINICAL FINDINGS DOMAIN

1. Distribution of dystonia

- Absent
- Focal, one joint of posture of the body
- Segmental, affecting 2 or more joints in a segment
- Generalised, affecting most of all the body

(if scored dystonia) **Duration of dystonia**

- Absent
- Intermittent, less than half of exam
- Common, half or more than half of exam
- Persistent, all of the exam

2. Hand Stereotypies

- Absent
- Rare
- Less than half of the exam
- Half or more of the exam
- All, or nearly all of the exam

3. Leg Crossing

- Absent
- Rare
- Less than half of the exam
- Half or more of the exam
- All, or nearly all of the exam

4. Bruxism

- Absent
- Rare
- Less than half of the exam
- Half or more of the exam
- All, or nearly all of the exam

Other Clinical Findings (cont.)

Please describe hand stereotypies observed (if selected):

5. Central and peripheral (can select multiple)

- None
- Irregular breathing - Observe/auscultate hyperventilation, breath holding or pauses
- Irregular breathing with facial color change (pallor or cyanotic lips)
- Abdominal distention due to air swallowing or constipation

6. Peripheral - pull off socks or gloves, leave for 5 minutes before assessment (can select multiple)

- None
- Cold feet
- Cold hands
- Discoloured (hands or feet)

7. Consolable

- Not required, content and relaxed
- Consoles on own to become content and relaxed
- Readily consolable, reassured by touching, distraction, talking
- Takes time to console -- more than 2 minutes
- Unable to console

8. Hyperactivity or disruptive behavior

- Relaxed and settled
- Rare
- Less than half of the exam
- Half or more of the exam
- All, nearly all of the exam

OTHER CLINICAL FINDINGS DOMAIN

Indicate in the tick boxes below the items that were difficult to observe during the exam:

Item	Difficult to Observe
Vision	
Gross motor function	
Fine motor function	
Communication	
Alertness/Attention	
Eye alignment/movement	
Altered muscle tone	
Dystonia	
Dyskinesias	
Stereotypies	
Autonomic function	
Behaviour	
None	

Any additional comments: _____
