

Medical conditions - Ron McMullen

Hydrocephaly	V-P shunt
Cerebral palsy	mixed type (spasticity, athetosis, ataxia) more pronounced on the right side wears AFOs to walk adductor tenotomies, heelcord release and hamstring surgeries in 1987
Right hemianopsia	right field of vision is missing in both eyes
Astereognosis	no depth perception
Nystagmus	rapid back and forth horizontal movement of eyes
Intellectual Disability	functions in the severe-moderate range receptive language - about 4 years
Autism	
Allergies	dust, mold, oak pollen, animal dander
Aphthous stomatitis	severe, multiple canker sores
Arthritis	in feet, knees, back
TMJ	Tempromandibular joint disorder Jaw/ear pain; more pronounced on left side

**Current medications for Ron McMullen
May 2011**

AM

Nexium (40 mg)
Minocycline (100 mg)
Allegra (180 mg)
Rhinocort (1 spray each nostril)
Guaifenesin (1200 mg)
Multivitamin
B-complex
1 Fibercon tablet
1 sodium docusate capsule
1 capful of Miralax /may increase to 1-1/2 capfuls if constipated (17g)
Glucosamine/Chondroitin (30 ml)
Calcium (1000 mg) (given 30 minutes prior to any other medications)

3 PM

Nexium (40 mg)
Minocycline (100 mg)

9 PM

Famotidine (20 mg)
Depakote ER (1000 mg)

PRN

Swab mouth with betamethasone sodium phosphate and lidocaine dental spray
Triamcinolone dental paste apply prn to canker sores/once per hour
Alomide eye drops apply prn 1 drop @ eye/3 x a day
Aurodex apply to affected ear(s) prn (numbing agent)
Elocon lotion apply to ears for itching as needed
Soma (250 mg) for acute TMJ pain
OTC Tylenol (500 mg)

Tylenol 3 w/ codeine 1 tablet every four hours
APAP w/ codeine #3 tablet

Vistaril (50 mg) 1 capsule every 2 hours/prn for agitation
Hydroxyine Pam (no more than 8/ 400 mg per day)

Percocet 1 tablet every 2 hours/prn for pain
Oxycodone/APAP 7.5-500mg (no more than 8 tablets per day)

Morphine sulfate 100mg/5ml 1 ml every 2 hours

Midazolam 12.5 ml to stop seizure or for medical procedures

Has had adverse or paradoxical reactions (extreme agitation) to the following drugs:

Valium	Amitriptyline	Tenex
Xanax (alprazolam)	Demerol	Desyrl (trazadone)
Prednisone	Avelox	Keppra

Has taken the following **NSAIDS** in the past:

Ibuprofen Naproxen Relafen (Nabumetone) Orudis (Ketoprofen) Celebrex

ILLNESS	SYMPTOMS	TREATMENT
constipation	asks to go to the bathroom frequently	increase fiber increase amt. of caffeinated soda Dulcolax after 3 days
middle ear infection	indicates ear hurts yells out frequently may slap his face irritable	check with otoscope (cloudy eardrum) contact doctor for antibiotics reduce demands
outer ear infection	indicates ear hurts yells out frequently irritable flinches when ear is wiggled or when ear drops are put in	check with otoscope (red irritated ear canal) contact doctor for ear drops reduce demands
shunt failure	extremely irritable may sleep for short periods and then wake complaining of a headache uneven dilation of pupils DOES NOT VOMIT	contact doctor EMERGENCY ROOM
sore throat	may not eat may become silly may become loud	reduce demands
TMJ	Irritable May slap face May point to ear	Reduce demands Pain medicine prn Soma (muscle relaxant) Check mouth guard for wear

ILLNESS	SYMPTOMS	TREATMENT
allergies	sneezing, drooling, red itchy eyes irritable	regular doses of antihistamine, decongestant, and steroid inhaler; eye drops as needed
aphthous stomatitis canker sores	begin as small raised red dots increase to lentil size and become yellowish and fluid filled drooling, wiping mouth with shirt extreme irritability when canker sores are large or numerous	apply triamcinolone paste topically as needed pain medication PRN up to 6 25 mg tablets of hydroxyzine a day (usual dose is 3 tablets) if large or numerous, reduce demands
arthritis	complains of foot pain; talks about arches; asks to see Pam (PT) or orthopedist; asks to change shoes	change shoes on request pain medication PRN
cold	sneezing; drooling; wiping mouth with shirt congested may gag on food because of drainage increased voice volume at risk for middle ear infection	regular doses of antihistamine, decongestant, and steroid inhaler reduce demands

Dear Doctor:

My son, Ron McMullen, has an appointment with you later this month. He has a complex medical history, so I am sending you this information ahead of time. I am also including a DVD with a 3-minute video clip of his typical behavior in case that is not what you see on the day of his appointment.

Ron is a 32-year old male with multiple disabilities that include intellectual disability (secondary to extreme prematurity and hydrocephaly), mixed type cerebral palsy, and autism. Cognitively, he is functioning at about a four year old language level. He is shunted and had 6 shunt failures in the first 6 years of life; in November 2005 he had shunt failure and a complete shunt replacement was done with an accompanying 5-day stay in the ICU. In the year following this surgery he was diagnosed with complex partial seizures. In November, 2006, he was hospitalized for a Nissen fundoplication and repair of a hiatal hernia; due to complication he was hospitalized for 14 days. He has a severe medical phobia that was exacerbated by these experiences. Currently, his behavioral challenges are limited as he has a well-developed positive behavior support plan and support staff who have been with him for one to nine years. He does have irregular sleep patterns. He usually goes to sleep around ten, but when he is sick or in pain, he will wake a number of times, and then be sleepy then next day. He is not disruptive when he wakes; he turns on his light and stays in his room and then puts himself back to bed 30-60 minutes later.

Below is a brief history of his medical conditions:

On August 10, 2006 Ron had a generalized tonic-clonic seizure. For one hour before the seizure he became increasingly irritable after what had been a fairly healthy day. He was unable to tell us what was bothering him. The seizure started with a high-pitched screech. His left arm and leg flexed and started shaking, shortly after that his right arm and leg flexed and started shaking as well. During the last 30 seconds of the seizure he had difficulty breathing. The seizure lasted two minutes. Postictally, he was disoriented and sleepy. For the eight hours following the seizure, he alternated between moaning or shouting out every 5-10 minutes and sleeping. The sparse medical records that we have concerning his early years indicate that he once possibly had a febrile seizure. Earlier that year, we had seen a number of episodes that were similar in appearance to the postictal state after his generalized seizure (i.e., he laid down, complained of headache and alternately, moaned, shouted out or slept in 5-10 minutes intervals for 6-8 hours); we had thought this related to the sinus/ear infections for which he was being treated at these times. Following a similar episode on August 21, he was seen in the ER and cleared for shunt failure. The only atypical lab finding at that time was a blood glucose level of 195. The blood work was done at about 1 am on August 22; he had last eaten at 4 pm on August 21. He was diagnosed as having partial complex seizures. He started taking Keppra (500 mg bid) the evening of August 23. He had another episode on the evening of August 24 lasting from around 4pm to 10 pm. He had an MRI under sedation on August 29 without incidence. He received 12.5 ml midazolam syrup (Versed) and the seizure stopped within 10 minutes. He was taking 1000 mg of Keppra bid, but began experiencing rapid mood swings and increasing irritability. He was weaned off Keppra and began taking Depakote (ER). His last documented seizure was at the beginning of October 2006. Intermittent seizure activity was noted for five hours. He has shown no seizure activity since that time. His Depakote ER dose was reduced about a year ago from 1500 mg to 1250 mg daily due to daytime drowsiness.

Ron had multiple surgeries at age eight in order to become ambulatory. He currently walks with bilateral AFO's and receives botox injections in his low back and lower extremities every four to six months. His last botox treatment was May, 2010.

In November 2008, Ron was experiencing extreme pain and was diagnosed with TMJ, subsequent treatment with an extended release steroid injection and muscle relaxant (soma) provided temporary relief while a bite guard for fashion for overnight wear.

In May of 2009 Ron had a severe allergic episode accompanied by significant agitation (high oak pollen and mold counts and exposure to dogs twice in one week); a steroid shot provided relief within hours.

Ron was diagnosed with osteoarthritis in his feet and knees at age seventeen. Initially, his pain was treated with Tylenol with codeine, then ibuprofen, and then enteric aspirin. For the following eight years, he took the maximum dose of naproxen. When that was no longer effective, he was started on Relafen. He was on Relafen from September 2004 to February 2005 during which time he began to lose weight (30 lbs), developed a persistent cough, often gagging in the morning, had unexplained episodes of sweating, and became increasingly irritable. At this point we discovered he was having severe gastric reflux and he was treated accordingly. A dramatic difference in his behavior and appetite was seen within one week of discontinuing Relafen and being started on Nexium. Over the next year, we tried many different NSAIDs to try to control his pain: we tried a return to naproxen, then ketoprofen, and then Celebrex. We also tried Neurontin on the advice of his pain specialist, Dr. Swarm. With each

medication, we saw a return of his symptoms. He did not take any NSAID medications for a year, but continued to have difficulties with gastric reflux. He gained about 18 pounds during the first four months of being treated for reflux, but then his appetite dramatically decreased and he lost 13 of those pounds. He followed the dietary restrictions suggested for gastric reflux and the head of his bed was elevated as well as taking Nexium each morning and evening and 1 dose of pepcid at bedtime. Ron had an endoscopy in October 2006 which showed a hiatal hernia. He had his hernia repaired and fundoplication done on November 29. Following a barium swallow one week post surgery, he had a dilation on December 4. Noticeable difficulty in swallowing more textured foods, decreased appetite, increased irritability and complaints of pain resulted in his being hospitalized again on December 18. An additional barium swallow showed very slow movement of liquid through his esophagus. He began to be treated with Reglan and on December 21, an additional dilation and manometry was completed. Manometry showed the presence of reduced peristalsis. As of January 10, 2007 he was able to tolerate a regular diet and reflux precautions were lifted. He also began taking 1000 mg of naproxen per day for his arthritis. Within 3 days he had a severe breakout of mouth ulcers and naproxen was discontinued.

Ron has had severe aphthous stomatitis since he was 16 years old. Herpes was definitively ruled out. For three years he was on Thalidomide (200 mg daily) which greatly reduced the incidence, severity, and duration of outbreaks. Every month he had a WBC drawn by fingerstick at home. Occasionally, it was low. When retested, a week later, it has been in the low normal range. These incidents generally occurred when we believed he was sick (e.g. ear infection, cold). He was taken off of Thalidomide at the end of December 2004 as insurance would no longer cover it and the cost is prohibitive (over \$4000 per month). When Ron has an outbreak of ulcers, his pain is so severe that we alternate the use of Percocet with oral morphine. Since he has started treatment for gastric reflux, he has fewer outbreaks of mouth ulcers. Over the course of a month, he usually has a severe outbreak (4-5 ulcers at once) 1-2 times for 1-2 days. He may have a mild outbreak (1-2 ulcers) 3-4 times for 1 day. This often occurs in conjunction with symptoms of some type of infection (e.g., cold symptoms, ear infection). Currently, his mouth is swabbed with a compounded solution of betamethasone sodium phosphate and lidocaine dental spray at least twice a day; more if the ulcers are larger or multiple. Over the years, the medications we have tried for this condition include: triamcinolone, dexamethaxone, chlorhexidene gluconate (Peridex), lidocaine viscous solution, aphthasol, Astelin sprayed directly on the ulcers, prednisone, and thalidomide.

His history of ear infections from the age of six is as follows. He was treated for middle ear infection multiple times a year throughout his teens. He has had two sets of tubes; when he was thirteen, the second set was surgically removed when they had not come out after five years and had become infected. He has frequent colds/allergy/sinus infection symptoms. His frequent episodes of otitis externa are generally treated with Ciprodex or clotrimazole and betamethasone dipropionate lotion. He wears clear wax earplugs when he bathes and when he swims. One contributing factor might be that he drools when he sleeps. When he was younger and was not being treated for a specific infection, he had taken Augmentin (875mg) prophylactically.

A list of his current medications is attached.

Ron receives Percocet, Tylenol 3, and Vistaril on a prn basis up to the daily maximum dosages. He also receives morphine sulfate 100 mg/5 mls prn - 1 ml every 2 hours (never more than 4 times a day). The use of these pain medications has been greatly reduced since he started taking minocycline. Other prn medicines include tramcinolone dental paste, Alomide eye drops and Aurodex. For medical procedures, he receives 25 mg of midazolam (Versed) 30 minutes prior to the procedure.

He has had paradoxical reactions (extreme agitation) to the following drugs: Valium, amitriptyline, Xanax, Demerol, Avelox, oral prednisone, Tenex and trazadone.

He currently takes no prescription or OTC NSAIDs because of his history of reflux.

Thank you for taking the time to read this.

Vicki McMullen

Behavioral Descriptors

		Behavioral Descriptors			
		3	5-6	7-8	9-10
1	<ul style="list-style-type: none"> laughing talkative making plans wants to go out few complaints 	<ul style="list-style-type: none"> occasional complaints of pain occasional protests of pain (a yelp) might refuse initially to leave the house, but if you wait and ask again, he'll comply will answer questions increasing complaints, but can be coaxed to complete one activity an hour 	<ul style="list-style-type: none"> will not answer questions - he perceives them as demands multiple refusals saying no protests when asked questions voice tone changes to a whine whines, asking for mom walks in circles occasionally, but can be redirected occasional shirt changes - can be redirected occasionally hitting wall, floor, and doors will say grandpa, radio hits leg jumps in chair 	<ul style="list-style-type: none"> multiple refusals saying no protests loudly when asked questions will eat only preferred finger foods amount of time spent walking in circles increases will tolerate staff/family sitting in his room with him which decreases walking in circles may be sweating cursing escalates demands to change shirt often door slamming hits doors/wall yelling frequently 	<ul style="list-style-type: none"> see 7-8 and add: will not answer questions - he perceives them as demands refusal to eat does not select comfort items (throws comb and refuses radio) constant walking in circles screaming mixed with cursing typically does not wear a shirt because requests to change his shirt occur every five minutes severe sweating proximity control may be needed to prevent hitting walls environmental control need to prevent door slamming appears to be in extreme distress
2	<ul style="list-style-type: none"> laughing talkative making plans wants to go out complains of foot pain 	<ul style="list-style-type: none"> more frequent complaints of pain yelps every 10 minutes beginning to mumble or curse (5-6x per hour) may clap or hit arm of chair occasionally repeatedly request comfort items becomes frustrated when he loses his comb mildly irritable 			

Corresponding Staff Responses

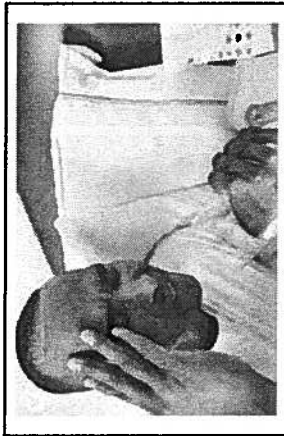
<p>1-2 • Ron is healthy - out in the community, he will engage in multiple work tasks</p>	<p>3-4 • 1-2 preferred community activities • choices based on pain/ irritability • encourage to look at books/shopping cards • engage in activity at least once per hour</p>	<p>5-6 • stay at home • encourage to sit in living room • encourage to watch videos</p>	<p>7-8 • reduce demands • reduce number of questions asked • encourage coping strategies • allow him to stay in his room if he chooses to do so • provide finger food at his request</p>	<p>9-10 • provide support and comfort as he allows • dress in shorts without shirt • encourage fluids • allow him to remain in his room • offer extra baths • Mom singing tape</p>
<p>Medication</p>				
<p>• Percocet every 4 hours</p>	<p>3 - 5-6 Percocet (every 2-3 hours) 4 - 6-7 Percocet (every 2 hours); 1 dose of morphine if there is an outbreak of mouth ulcers</p>	<p>• 1 Hydroxyzine every 2 hours • 1 Percocet every 2 hours • may need 1-2 doses of morphine</p>	<p>• 2 Hydroxyzine every 4 hours • 1 Percocet every 2 hours • no more than 8 of each per day • morphine as often as every 2 hours</p>	<p>• 2 Hydroxyzine every 4 hours • 1 Percocet every 2 hours • no more than 8 of each per day • morphine as often as every 2 hours</p>

1	2	3	4	5
Behavioral Descriptors				
<p>Laughing Talkative Making plans No complaints</p>	<p>Laughing Talkative Making plans Complains of foot pain</p>	<p>Occasional complaints of pain Occasional protests of pain (may yelp once an hour) Might refuse to leave the house initially, but if you wait and ask again, he will comply Will answer questions Increasing complaints, but can be coaxed to complete one activity per hour</p>	<p>More frequent complaints of pain Yelps 2-3 times per hour Beginning to mumble or curse (2-3x per hour) May clap or hit arm of chair occasionally Repeatedly requests comfort items Becomes frustrated when he loses his comb Mildly irritable Will say grandpa; radio Walks in circles occasionally but can be redirected</p>	<p>Will not answer questions-he perceives them as demands Multiple refusals Saying no Yelps every ten minutes Mumbles or curses (4-5x per hour) Voice tone changes to a whine Asks for mom Rocks rapidly in chair Walks in circles, can not be redirected</p>
Corresponding Staff Response				
<p>Ron is healthy Out in the community Will engage in multiple work tasks</p>	<p>Ron is healthy Out in the community Will engage in multiple activities</p>	<p>1-2 preferred community activities Choices based on pain/irritability Encourage to look at shopping cards/books Engage in activity at least once per hour</p>	<p>Stay at home Encourage to sit in the living room Encourage to watch videos Provide finger foods</p>	<p>Stay at home Encourage to sit in the living room Encourage to watch videos Reduce demands Provide finger foods If walking in circles, allow for 5 minutes and then bring to living room and sit close</p>
Medication				
<p>Early morning pain medication Additional pain medication every 6-8 hours (preferably Tylenol)</p>	<p>Early morning pain medication Additional pain medication every 4-6 hours (preferably Tylenol)</p>	<p>Early morning pain medication Additional pain medication every 2-4 hours (may need to alternate Percocet and Tylenol)</p>	<p>Early morning pain medication Percocet every 2 hours</p>	<p>Early morning pain medication Percocet every 2 hours Soma or hydroxyzine based on assessment of pain and anxiety</p>

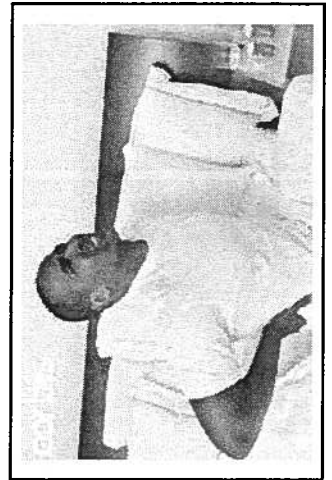
I feel sick.



My **head** hurts.



My **back** hurts.



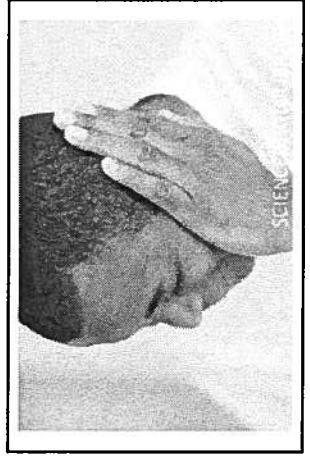
My **stomach** hurts.



My **throat** hurts.



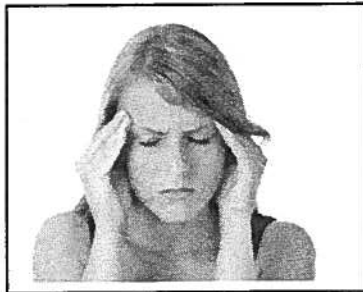
My **ear** hurts.



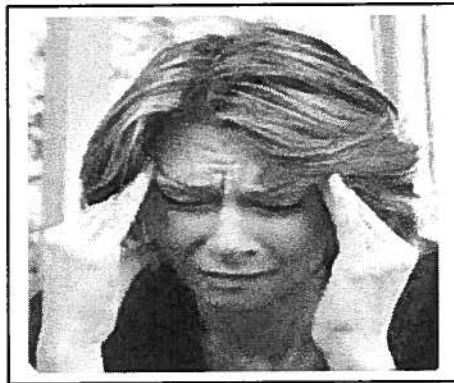
My **headache** feels like a



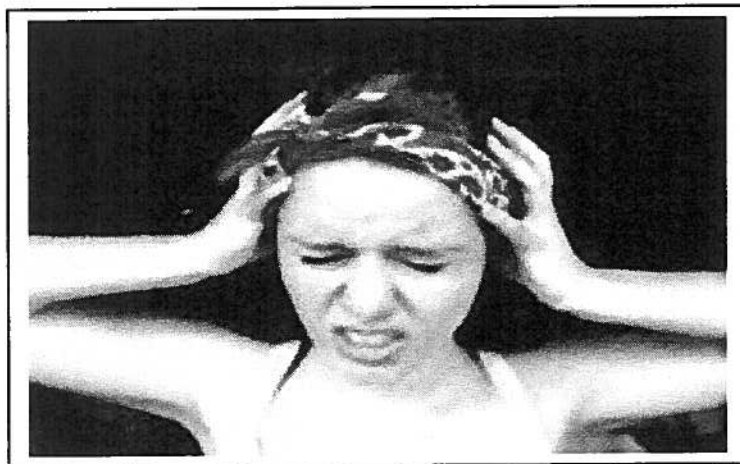
1



2



3



4

AM MEDS ____

Date:

PM MEDS ____

LAST NIGHT'S SLEEP + 0 -

Behavior rating: 8-12 ____ 12-4 ____

Specific medical conditions/complaints

URINE ____ BM ____
PRN meds: Tylenol OTC
Tylenol 3
Percocet
Morphine

CANKER SORES NONE 1-3 4 or more

APPETITE POOR FAIR GOOD

Behavior rating: 4-7 ____ 7-10 ____

Specific medical conditions/complaints

URI NE ____ BM ____
PRN meds: Tylenol OTC
Tylenol 3
Percocet
Morphine

CANKER SORES NONE 1-3 4 or more

APPETITE POOR FAIR GOOD

PC	HK	Meals	Medication	CA	MM	Overnight	PO	Exercise	MS

Video Letters/phone calls Games Bake Read book Make lunch
 Bench Shopping cards Planner Ron vacuum Ron laundry Work at Webster
 Trip to _____ Trip to _____

Compliance with tasks:
Very good Good Fair Poor

Compliance with tasks:
Very good Good Fair Poor

Comments:

Comments:

Time	Staff	Time	Staff	Time	Staff	Time	Staff

AM MEDS ____

Date:

PM MEDS ____

LAST NIGHT'S SLEEP + 0 -

Behavior rating: 8-12 ____ 12-4 ____

Specific medical conditions/complaints

URINE ____ BM ____
PRN meds: Tylenol OTC
Tylenol 3
Percocet
Morphine

CANKER SORES NONE 1-3 4 or more

APPETITE POOR FAIR GOOD

Behavior rating: 4-7 ____ 7-10 ____

Specific medical conditions/complaints

URI NE ____ BM ____
PRN meds: Tylenol OTC
Tylenol 3
Percocet
Morphine

CANKER SORES NONE 1-3 4 or more

APPETITE POOR FAIR GOOD

PC	HK	Meals	Medication	CA	MM	Overnight	PO	Exercise	MS

Video Letters/phone calls Games Bake Read book Make lunch
 Bench Shopping cards Planner Ron vacuum Ron laundry Work at Webster
 Trip to _____ Trip to _____

Compliance with tasks:
Very good Good Fair Poor

Compliance with tasks:
Very good Good Fair Poor

Comments:

Comments:

Time	Staff	Time	Staff	Time	Staff	Time	Staff

Non-communicating Children's Pain Checklist – Revised (NCCPC-R)

NAME: _____	UNIT/FILE #: _____	DATE: _____ (dd/mm.yy)
OBSERVER: _____	START TIME: _____ AM/PM	STOP TIME: _____ AM/PM

How often has this child shown these behaviours in the last 2 hours? Please circle a number for each item. If an item does not apply to this child (for example, this child does not eat solid food or cannot reach with his/her hands), then indicate "not applicable" for that item.

0 = NOT AT ALL 1 = JUST A LITTLE 2 = FAIRLY OFTEN 3 = VERY OFTEN NA = NOT APPLICABLE

I. Vocal

1. Moaning, whining, whimpering (fairly soft).....	0	1	2	3	NA
2. Crying (moderately loud).....	0	1	2	3	NA
3. Screaming/yelling (very loud).....	0	1	2	3	NA
4. A specific sound or word for pain (e.g., a word, cry or type of laugh).....	0	1	2	3	NA

II. Social

5. Not cooperating, cranky, irritable, unhappy.....	0	1	2	3	NA
6. Less interaction with others, withdrawn.....	0	1	2	3	NA
7. Seeking comfort or physical closeness.....	0	1	2	3	NA
8. Being difficult to distract, not able to satisfy or pacify.....	0	1	2	3	NA

III. Facial

9. A furrowed brow.....	0	1	2	3	NA
10. A change in eyes, including: squinching of eyes, eyes opened wide, eyes frowning.....	0	1	2	3	NA
11. Turning down of mouth, not smiling.....	0	1	2	3	NA
12. Lips puckering up, tight, pouting, or quivering.....	0	1	2	3	NA
13. Clenching or grinding teeth, chewing or thrusting tongue out.....	0	1	2	3	NA

IV. Activity

14. Not moving, less active, quiet.....	0	1	2	3	NA
15. Jumping around, agitated, fidgety.....	0	1	2	3	NA

V. Body and Limbs

16. Floppy.....	0	1	2	3	NA
17. Stiff, spastic, tense, rigid.....	0	1	2	3	NA
18. Gesturing to or touching part of the body that hurts.....	0	1	2	3	NA
19. Protecting, favoring or guarding part of the body that hurts.....	0	1	2	3	NA
20. Flinching or moving the body part away, being sensitive to touch.....	0	1	2	3	NA
21. Moving the body in a specific way to show pain (e.g. head back, arms down, curls up, etc.).....	0	1	2	3	NA

VI. Physiological

22. Shivering.....	0	1	2	3	NA
23. Change in color, pallor.....	0	1	2	3	NA
24. Sweating, perspiring.....	0	1	2	3	NA
25. Tears.....	0	1	2	3	NA
26. Sharp intake of breath, gasping.....	0	1	2	3	NA
27. Breath holding.....	0	1	2	3	NA

VII. Eating/Sleeping

28. Eating less, not interested in food.....	0	1	2	3	NA
29. Increase in sleep.....	0	1	2	3	NA
30. Decrease in sleep.....	0	1	2	3	NA

SCORE SUMMARY:

Category:	I	II	III	IV	V	VI	VII	TOTAL
Score:								

USING THE NCCPC-R

The NCCPC-R was designed to be used for children, aged 3 to 18 years, who are unable to speak because of cognitive (mental/intellectual) impairments or disabilities. It can be used *whether or not* a child has physical impairments or disabilities. Descriptions of the types of children used to validate the NCCPC-R can be found in: Breau, L.M., McGrath, P.J., Camfield, C.S. & Finley, G.A. (2002). Psychometric Properties of the Non-communicating Children's Pain Checklist-Revised. *Pain*, 99, 349-357. The NCCPC-R was designed to be used without training by parents and caregivers (carers). It can also be used by other adults who are not familiar with a specific child (do not know them well).

The NCCPC-R may be freely copied for clinical use or use in research funded by not-for-profit agencies. For-profit agencies should contact Lynn Breau: Pediatric Pain Research, IWK Health Centre, 5850 University Avenue, Halifax, Nova Scotia Canada, B3J 3G9 (lbreau@ns.sympatico.ca).

The NCCPC-R was intended for use for short or long-term pain in the child's home or in a long-term residential setting. If suspected *pain after surgery or pain due to procedures conducted in hospital* are the reason for measuring pain, the **Non-communicating Children's Pain Checklist – Postoperative Version** should be used. It can be obtained by contacting Lynn Breau. Information regarding the NCCPC-PV can be found in: Breau, L.M., Finley, G.A., McGrath, P.J. & Camfield, C.S. (2002). Validation of the Non-Communicating Children's Pain Checklist - Postoperative Version. *Anesthesiology*, 96 (3), 528-535.

ADMINISTRATION:

To complete the NCCPC-R, base your observations on the child's behavior over the past **two hours**. ***It is not necessary to watch the child continuously for this period.*** However, it is recommended that the observer be in the child's presence for the majority of this time (e.g.; be in the same room with the child). Although shorter observation periods may be used, the cut-off scores described below may not apply.

Eating/Sleeping Subscale: Items on the Eating/Sleeping subscale may not occur during the two-hour observation. In this case, the rating should be based on the child's behavior over the day of the observation.

All other subscales: At the end of the observation time, indicate how frequently (how often) each item was seen or heard. This should not be based on the child's typical behavior or in relation to what he or she usually does. A guide for deciding the frequency of items is below:

0	=	Not present at all during the observation period. (Note if the item is not present because the child is not capable of performing that act, it should be scored as "NA").
1	=	Seen or heard rarely (hardly at all), but is present.
2	=	Seen or heard a number of times, but not continuous (not all the time).
3	=	Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the child for a few moments during the observation time.
NA	=	Not applicable. This child is not capable of performing this action.

SCORING:

1. Add up the scores for each subscale and enter below that subscale number in the Score Summary at the bottom of the sheet. Items marked "NA" are scored as "0" (zero).
2. Add up all subscale scores for Total Score.
3. Check whether the child's score is greater than the cut-off score.

CUT-OFF SCORE:

Based on the scores of 71 children aged 3 to 18 (Breau, McGrath, Camfield & Finley, 2002), a **Total Score of 7 or more** indicates a child has pain. This was accurate in the study group 84% of the time. A Total Score of 6 or less indicates a child does not have pain. This was correct in the study group 77% of the time.

USE OF CUT-OFF SCORES:

As with all observational pain tools, caution should be taken in using cut-off scores because they may not be 100% accurate. They should not be used as the only basis for deciding whether a child should be treated for pain. In some cases children may have lower scores when pain is present. For more detailed instructions for use of the NCCPC-R in such situations, please refer to the full manual, available from Lynn Breau: Pediatric Pain Research, IWK Health Centre, 5850 University Avenue, Halifax, Nova Scotia Canada, B3J 3G9 (lbreau@ns.sympatico.ca).

Appendix A. The Non-Communicating Adult Pain Checklist—NCAPC

Name of individual _____ Observer: _____

Date _____ Sum score when individual is not in pain _____

The individual's behavior is being evaluated due to:

How often has the client been showing the down listed behaviors within a 10 minutes period?

Item #	Sub-category	Item description	Not at all	Just a little	Fairly often	Very often
1	Vocal reaction	Moaning, whining, whimpering (fairly soft)	0	1	2	3
2		Crying (moderately loud)	0	1	2	3
3		Screaming/yelling (very loud)	0	1	2	3
4		A specific sound or word for pain (e.g. a word, a cry, a type of laugh)	0	1	2	3
5	Emotional reaction	Not co-operating, cranky, irritable, unhappy				
6		Being difficult to distract, not able to satisfy or pacify				
7	Facial expression	Furrowed eyebrows, raising eyebrows	0	1	2	3
8		A change in eyes including (squinting of eyes, eyes opened wide, eye frowning)	0	1	2	3
9		Turning down of mouth	0	1	2	3
10		Movements of the lips and tongue (lips puckering up, tight, pouting, or quivering, teeth grinding, tongue pushing)	0	1	2	3
11	Body language	Moving more or less	0	1	2	3
12		Stiff spastic, tense, rigid	0	1	2	3
13	Protective reaction	Gesturing to or touching part of the body that hurts	0	1	2	3
14		Protecting, favoring, or guarding part of the body that hurts	0	1	2	3
15		Flinching or moving the body part away, being sensitive to touch	0	1	2	3
16		Moving the body in a specific way to show pain (e.g. head back, arms down, curls up)	0	1	2	3
17	Physiological reaction	Change in facial color	0	1	2	3
18		Respiratory irregularities (breath holding or gasping)	0	1	2	3

Sum score _____