



Seen and Unseen Physical Pain in Children

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When there's more than meets the eye...

How good are you at seeing pain?

- What is the site?
- What is the cause?













Seen Physical Pain

- Site is obvious
- Source is clear
- Behaviour is typical
- Child can verbalize it
- Generally easy to treat
- Resolves with treatment (or prevention) of underlying cause
- Use of simple analgaesia



But seen pain is still under-recognised and under-treated in children

If the pathology would be painful for an adult ---- it will be painful (usually more so) for a child

Unseen Pain

My hidden illness

by Ali



**Cambridge
Children's
Hospital**

How I look



How I feel



15-year-old boy with Ehlers Danlos Syndrome

Hidden pain case study 1...

- 6 year old boy
- Glutaric Aciduria Type 1
- Muscle wasting, Severe spasms and feeding issues
- Septic thumb
- Pressure sores – feet and hip
- One of three children
- Mom had died a year ago – Dad not able to care for him – admitted to a children's home
- Came to RCWMCH – blocked feeding tube and dehydration
- Referred by neurologist to Children's Hospice for intermediate care (awaiting placement)

BEFORE



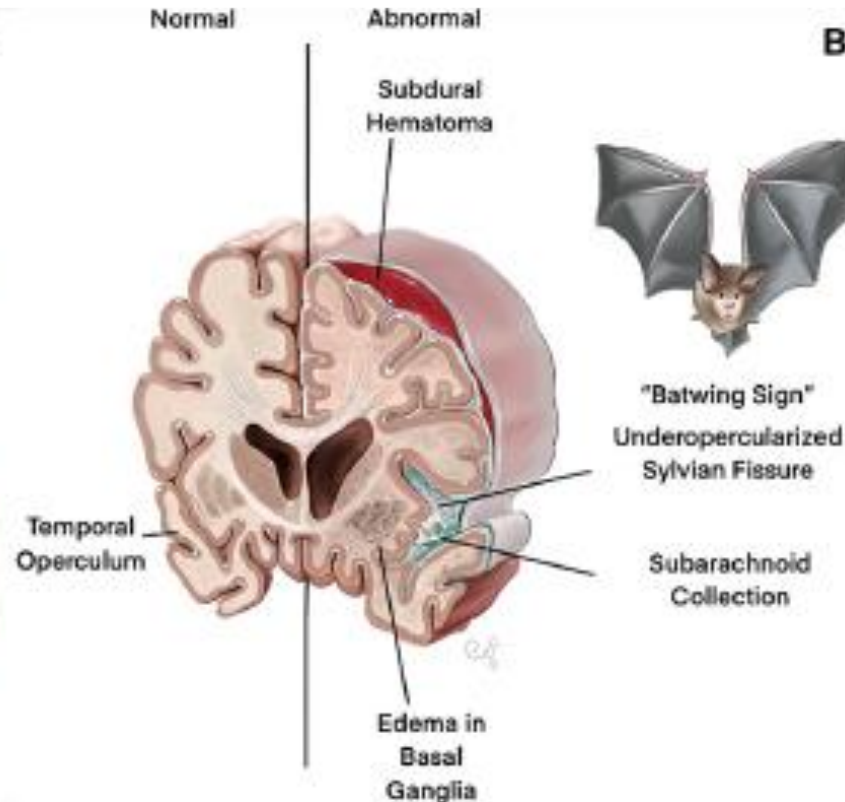
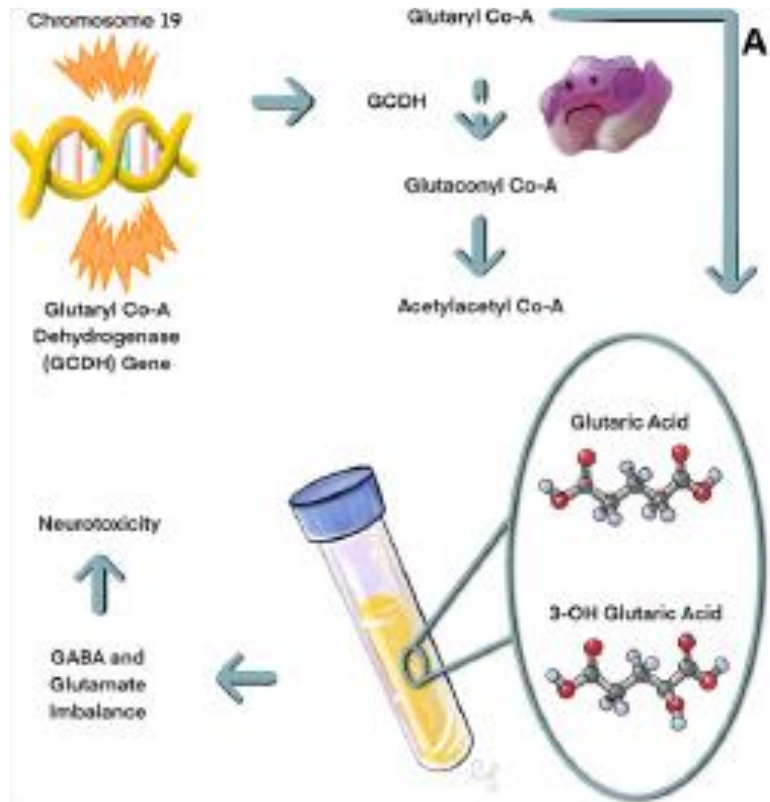
Hidden pain case study 1...

- Very irritable – especially when fed and during episodes of spasming
- Unable to tolerate boluses → put on continuous pump
- Septic thumb was from biting due to pain
- Started on low dose morphine and Gabapentin and Music therapy
- Got Dad to visit more often
- Started to smile and to laugh
- Able to change to bolus feeds → gained weight
- Referring neurologist: “What have you done to him? He is a different child?”

AFTER



What was going on...



Macrocephaly



Neuro-irritability

Dystonia



Failure to thrive

Visceral Hyperalgaesia



Treatment:
 Protein restricted diet
 Special formula
 Carnitine

When ill: Metabolic crisis

- Catabolic metabolism → break down of muscle
- Increase in Glutaric acid
- Seizures
- Coma

Prognosis:

Normal lifespan if diagnosed before 6 years (newborn screening)
 Late diagnosis – irreversible brain damage but further damage halted
 Not diagnosed: Life threatening – die during metabolic crisis

Total pain

Glutaric aciduria type 1
Neuro-irritability
Painful spasms
Visceral Hyperalgaesia

Being looked after in a
children's home

Cultural

Physical

Psychological

Separation Anxiety
?Depression
(as young as 3 years)

Loss of connections
Joy from music

Spiritual

Social

Mother had died 1 year ago
Separated from father and siblings

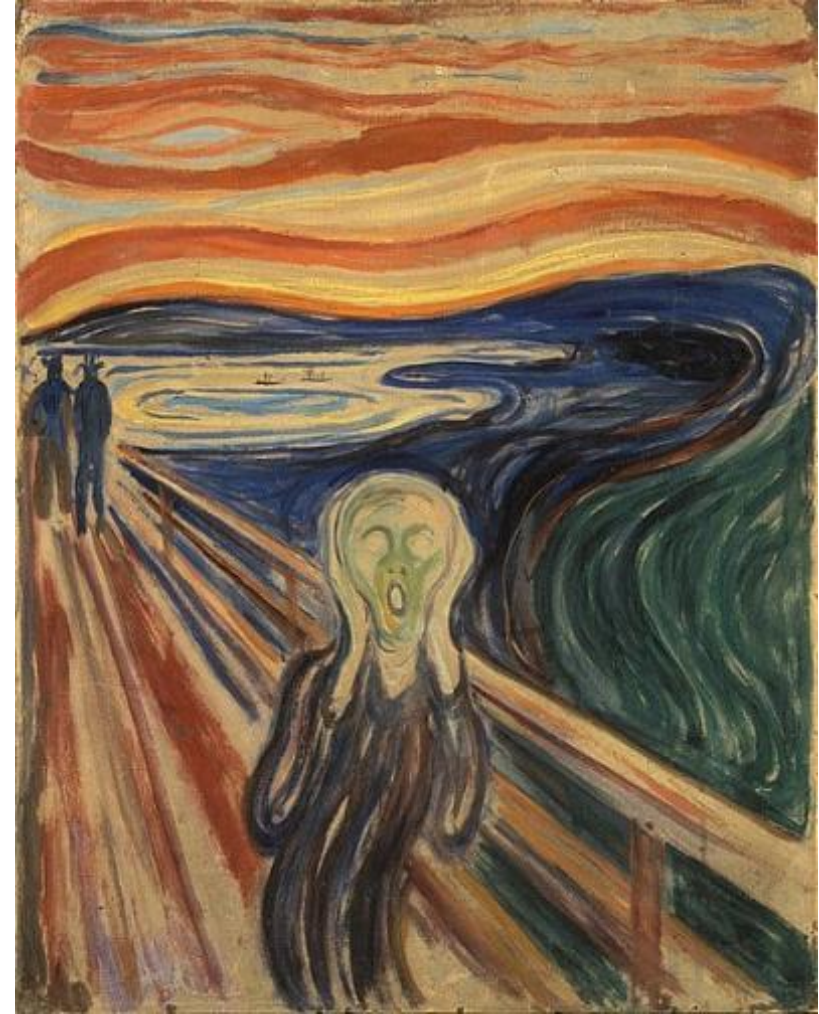


Hidden pain case study 2...

- 13-year-old girl
- Had bad Henoch Schoenlein Purpura two years ago – complex illness required Prednisone and Dapsone
- One relapse with rash a year later
- Seen by Child Psychiatry- Fainting and Leg numbness
- Complex psycho-social issues- bullied at school
- Chronic muscle weakness, chronic fatigue
- Lower limb numbness
- Sent to me from Rheumatologist - please help- can't find source of pain

Hidden pain case study 2...

- "I am so angry I want to scream, As I taste the saltiness of my tears forming a stream,
- I am so angry I want to scream. My legs are numb and I feel dumb, my fingers are stiff and I can't manage a whiff, I wish I can just throw myself off a cliff.
- At school people look at me with suspicion and reprieve.
- Maybe its fear that I may fall back collapse or give them a germ, tick tock tick tick there goes the freak!
- Teachers don't see me, they do a good job to ignore me. I try to explain, its me, just meak and mild me but it's still me, tick tock tick tock there goes the freak!
- My doctors argue infront of me, can't seem to answer any questions about me. Its mental they say, time to bring in psychology. Your body stiff, abdomen tender



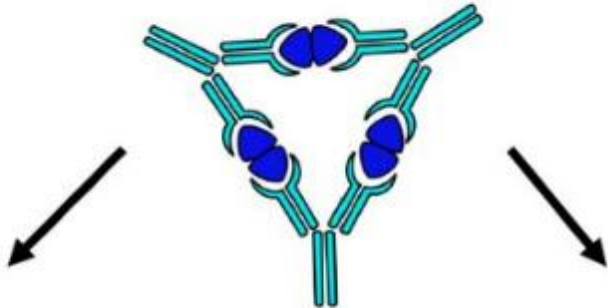
Hidden pain case study 2...

- Try and walk if you can remember. Pop the meds if your pain grows in temper. Tick tock tick tock there goes the freak!
- As I sit on the couch, the good doctor taking her notes. So how are you feeling? If only I can go on bended knees. Doctor won't you help me please? My parents sit by my bedside doting over me. As I lie in pain feeling that I am going insane.
- Frustrated by my agony I appreciate their supporting me, can't they just let me be, in all my misery. I am angry I want to scream. How can this be, it isn't me. I have been bullied and spawned. All because of something unknown. I am pale, tired and withdrawn. I just don't have the energy anymore.
- HSP you have won, now let me be done. You have taken away my dignity. What more do you want from me?"
- By Kauthar Button ..



What was going on...

A Immunoglobulin Complex



B

BONES



C

VESSELS



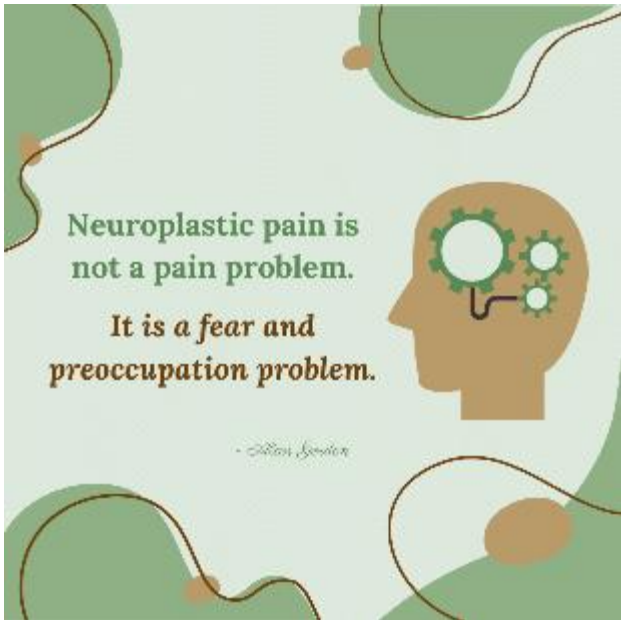
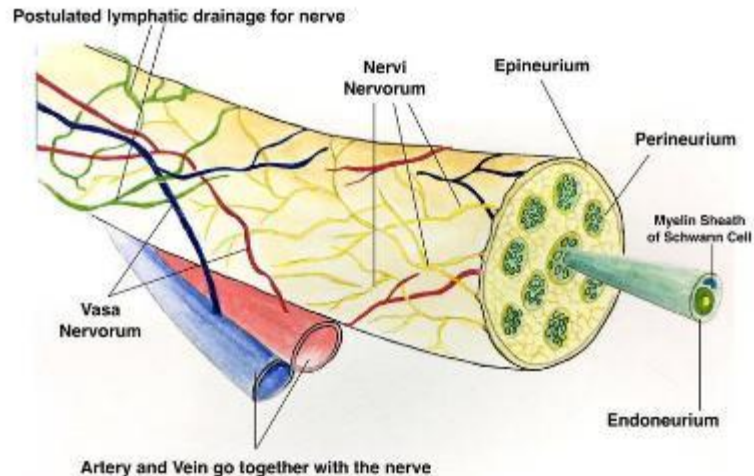
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GUT



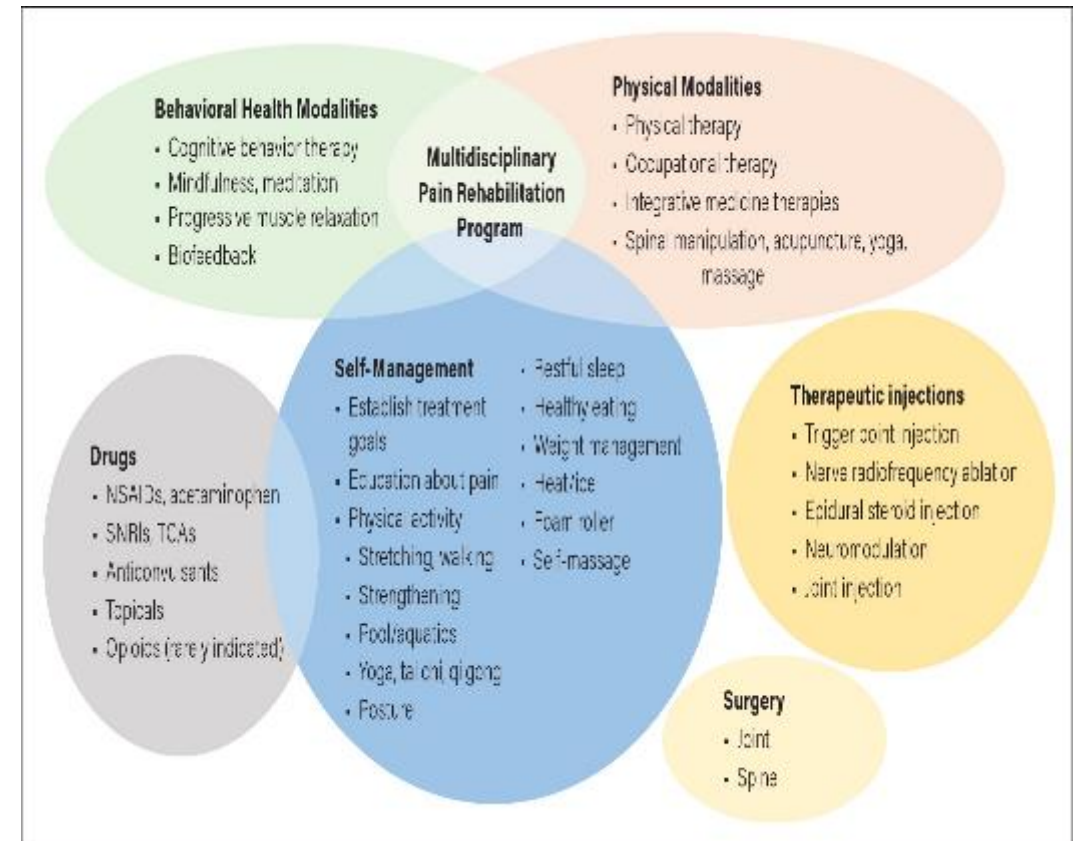
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KIDNEY



Hidden pain case study 2...

- Treatment
- Failed Psyche-admission
- Narrative therapy
- Gabapentin for neuropathy
- Psycho-social support for parents
- Emails with teacher/school principals
- Adolescent Chronic pain support group



Top tips for seeing unseen pain...

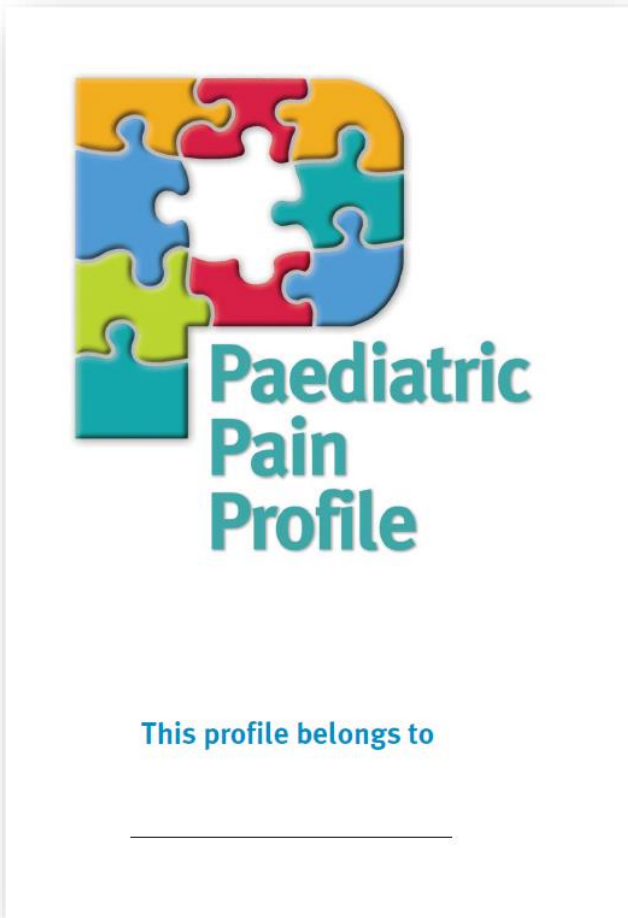
- Listen to the patient/caregiver
- Be aware of pain-related behaviours (including unusual ones) and tools for assessing pain in non-verbal children
- Think patho-physiologically
- Use common sense
- Understand neuro-plasticity



Revised FLACC score

| (REVISED) FLACC Scale | | | |
|---|--|--|--|
| SCORING | | | |
| Categories | 0 | 1 | 2 |
| Face | No particular expression or smile. | Occasional grimace or frown, withdrawn, disinterested, Sad, appears worried. | Frequent to constant quivering chin, clenched jaw, distressed looking face, expression of fright/ panic. |
| Legs | Normal position or relaxed; usual tone and motion to limbs. | Uneasy, restless, tense, occasional tremors. | Kicking, or legs drawn up, marked increase in spasticity, constant tremors, jerking. |
| Activity | Lying quietly, normal position, moves easily, regular, rhythmic respirations. | Squirming, shifting back and forth, tense, tense/guarded movements, mildly agitated, shallow/splinting respirations, intermittent sighs | Arched, rigid or jerking, severe agitation, head banging, shivering, breath holding, gasping, severe splinting. |
| Cry | No cry (awake or asleep) | Moans or whimpers: occasional complaint, occasional verbal outbursts, constant grunting | Crying steadily, screams or sobs, frequent complaints, repeated outbursts, constant grunting. |
| Consolability | Content, relaxed | Reassured by occasional touching, hugging, or being talked to: distractible | Difficult to console or comfort, pushing caregiver away, resisting care or comfort measures. |
| Each of the five categories (F) Face; (L) Legs; (A) Activity; (C) Cry; (C) Consolability is scored from 0-2, which results in a total score between zero and ten. | | | |
| References: | | | |
| Merkel, S. et al. The FLACC: A Behavioural Scale for Scoring Postoperative Pain in Young Children, Pediatric Nurse 23(3): 293-297, 1997. Copyright: Jannetti Co. University of Michigan Medical Centre. | | | |
| Malviya, S., Vopel-Lewis, T. Burke, Merkel, S., Tait, A.R. (2006). The revised FLACC Observational Pain Tool: Improved Reliability and Validity for Pain Assessment in Children with Cognitive Impairment. (Pediatric Anesthesia 16: 258-265). | | | |

Paediatric Pain Profile



https://ppprofile.org/wp-content/uploads/2018/11/full_ppp_document.pdf

The pain history

This part of the profile asks about your child's history of pain. It provides space to write about your child's experience with pain as an infant, during surgery or from injuries, or pains that have occurred due to your child's illness or disability. Knowing how your child has coped with pain and injury in the past can help to guide how pain is managed in the present.

Baseline assessments

In this section we ask you to describe on the pain profile your child's behaviour when they are 1) at their best or 'on a good day' and 2) if your child has any current or recurring pains. Using the pain profiles you just circle the number that best describes how much your child is like the item in the left hand column. There are sheets to describe your child's most troublesome pain (Pain A) and up to two other pains (Pains B and C). Then transfer the numbers you have circled to the right hand column of each profile and add up the totals. The total scores can then be plotted by placing a cross in the shaded area on the Summary Graph.

Summary Graph

The baseline assessments provide a comparison for any further assessments you need to make in the future.

Ongoing pain assessments

You can use the Pain Profile – ongoing pain assessments sheets to make assessments at any time that suits you, for instance if you need to record your child's behaviour or if you are monitoring your child's response to a treatment. The scores can be transferred to the Summary Graph and/or the Assessments, actions and outcomes page.

Assessments, actions and outcomes

Using this sheet you can describe the actions that have been taken to relieve your child's pain and your child's response. It is often a good idea to use the profile again after the intervention to see and record if the action has been effective in relieving the pain.

Talking to professionals about your child's pain

Some pains can be quite troublesome and difficult to relieve. You might like to talk to your doctor or another health professional about your child's pain. It might be helpful to show them your child's Profile. Ask them if they would like to write something on the professional's page about your child's pain problem.

Non-Communicating Child's Pain Checklist - Revised (NCCPC- R)

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 |

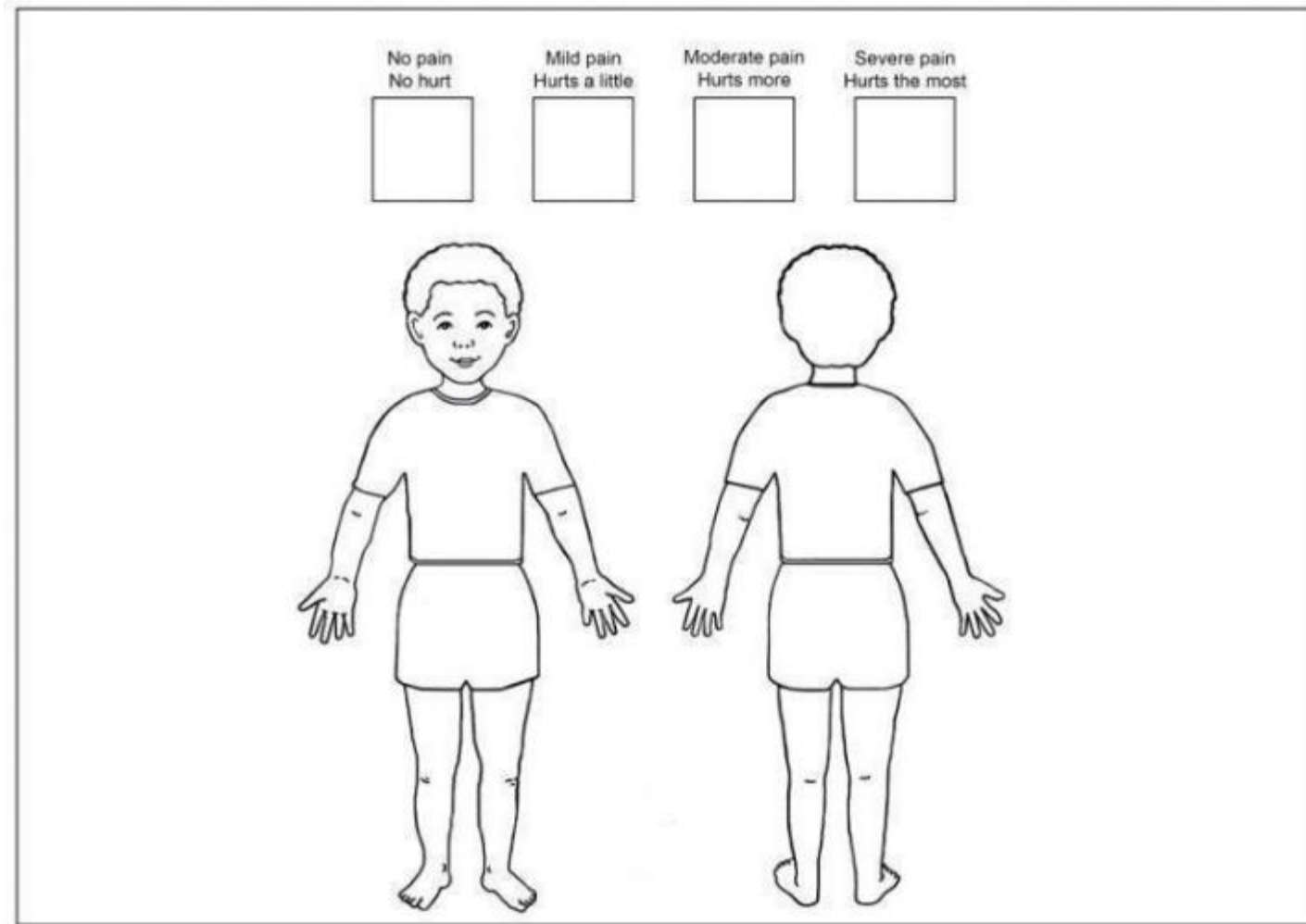
VII. Eating/Sleeping

| | | | | | |
|--|---|---|---|---|----|
| 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: | | | | | | | | |

PatchSA Colour Tool for Assessing and Locating Pain in Children



https://patchsa.org/pain_symptom_management_resources/





The Chronic Pain Assessment Toolbox for Children with Disabilities

This Chronic Pain Assessment Toolbox for Children with Disabilities is a compendium of resources based upon high quality research evidence. The Toolbox is intended to support the assessment of chronic pain in pediatric disability clinical practice.

