



Pain Prevention and Treatment in Children and Young People with Cerebral Palsy

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Case Study

- Your son John has CP and is 5 years old. John uses a wheelchair for mobility. You are seeing a specialist at a rehab center.
- Your main concern is John's pain
- John has daily bouts of pain that occur several times– John cries when he experiences the episodes and you are worried about the impact on his quality of life
- You don't understand why John is in pain and don't want to "mask" it by using medications –You would prefer to "cure" it
- You are exhausted and feel discouraged

Objectives: In children and young people with CP...

1. Understand the need to assess for pain
2. Be able to understand common potential causes of pain
3. Have knowledge of tools to identify pain with a focus on the 'body diagram'
4. Have a working knowledge of the '**ADOPT FRAMEWORK**' to approach pain management

The Problem of “Pain” in CP!



- Children with CP and pain are less likely to participate in life situations (*Fauconnier et al. 2009*) and have a lower quality of life (*Dickenson et al. 2007*)
- Colver in SPARCLE study identified pain in CP as the most important factor impacting negatively on quality of life

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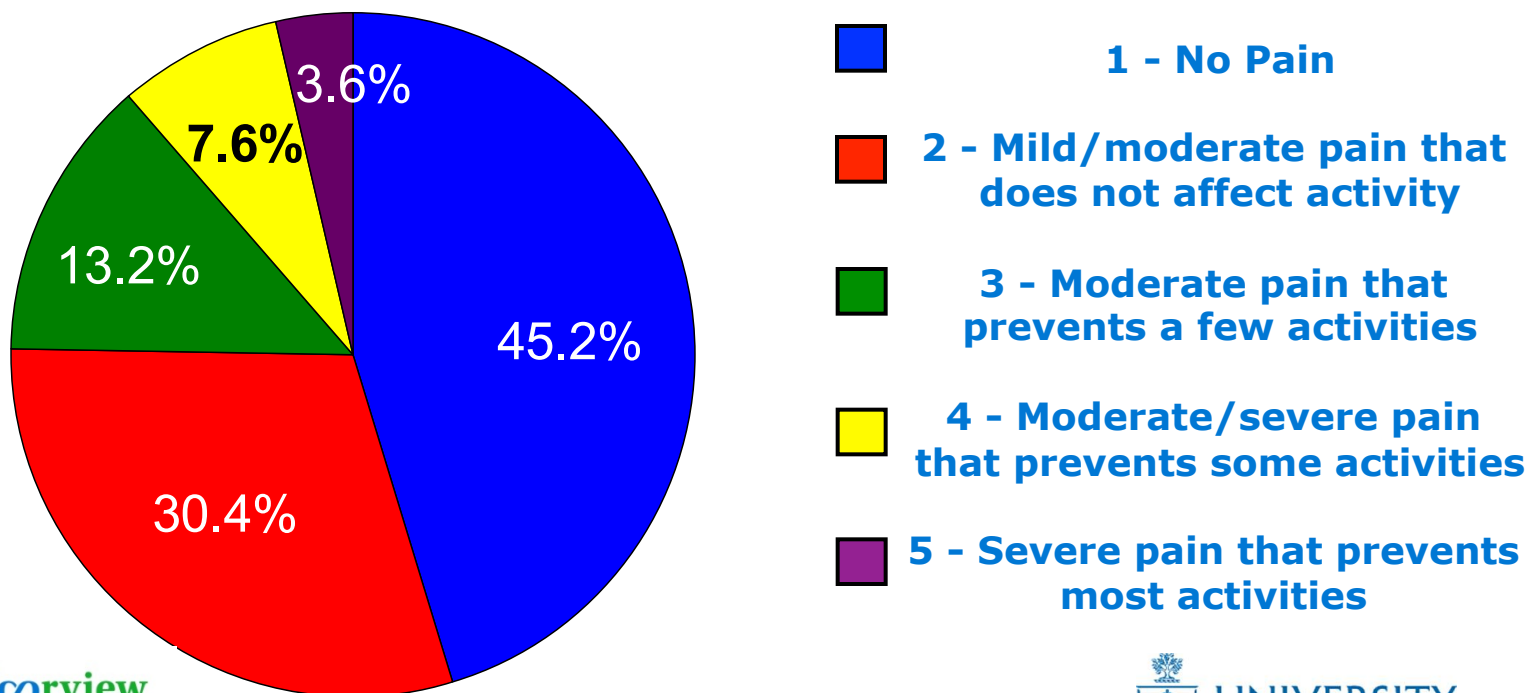
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

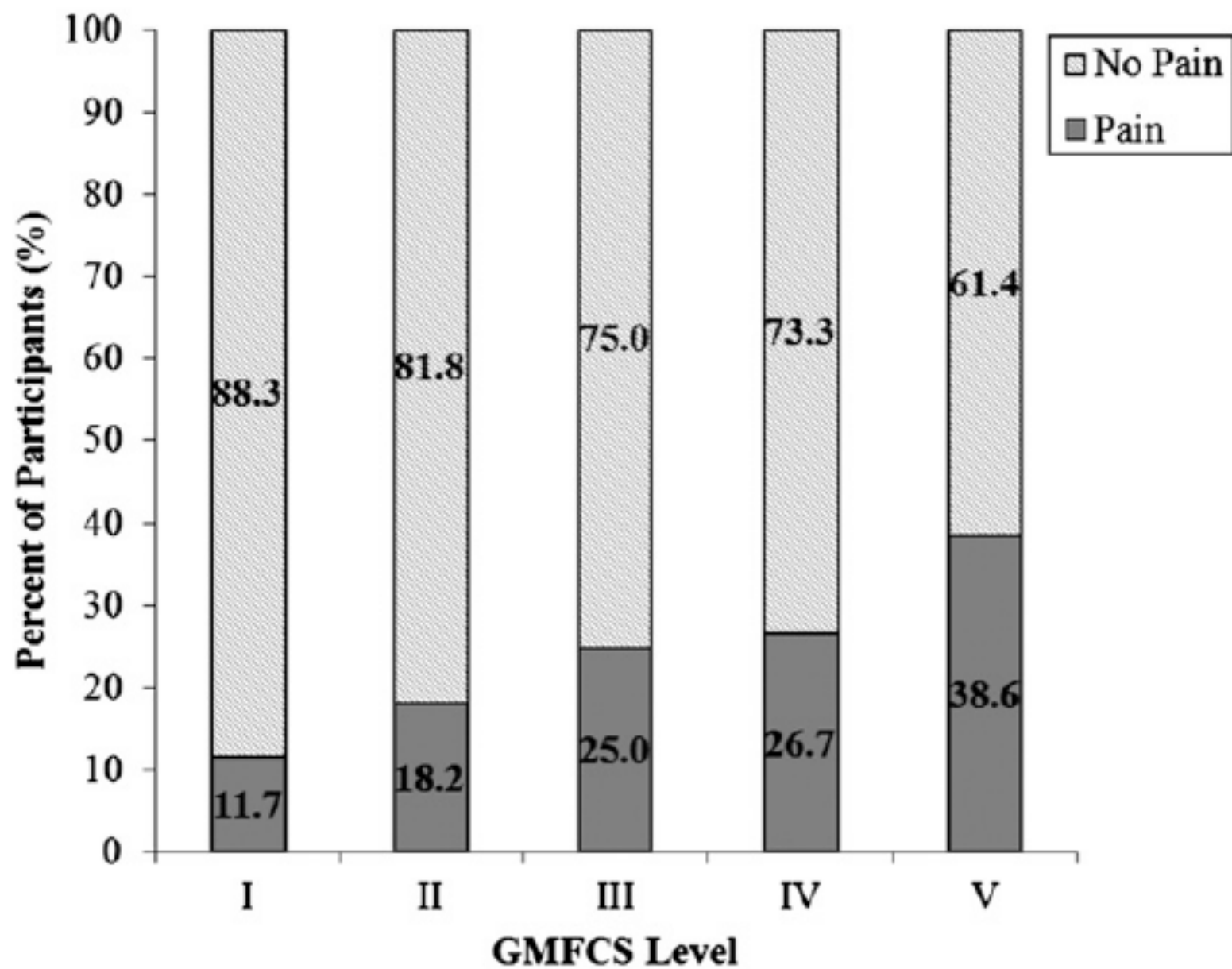
Characteristics of Pain in Children and Youth With Cerebral Palsy

Melanie Penner, Wen Yan Xie, Navneet Binopal, Lauren Switzer and Darcy Fehlings

Pediatrics 2013;132:e407; originally published online July 15, 2013;

DOI: 10.1542/peds.2013-0224





Investigating the impact of pain, age, Gross Motor Function Classification System, and sex on health-related quality of life in children with cerebral palsy

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Figure 1. HRQOL for children based on age with and without pain. Trendlines show the linear line of best fit.

Investigating the impact of pain, age, Gross Motor Function Classification System, and sex on health-related quality of life in children with cerebral palsy

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Table III: Frequency of physician-identified causes of pain in children with pain (HUI3 ≥ 3)

Pain causes and sub-categories	<i>n</i> (%)
No pain identified by the physician	18 (27)
Musculoskeletal deformity	16 (24)
Hip dislocation/subluxation	6 (9)
Contracture	7 (11)
Spine deformity	2 (3)
Foot deformity	1 (2)
Hypertonia	12 (18)
Focal muscle spasm	3 (5)
Spasticity	6 (9)
Dystonia	3 (5)
Post-surgical pain	9 (14)
Other ^a	6 (9)
Overuse ^b	4 (6)
Missing physician report	1 (2)

“ADOPT” Framework for Pain Management in Children with CP

- **A**SSESSMENT of health issues linked to chronic pain
- **D**EMYSTIFICATION of “Chronic” Pain
- **O**PTIMIZE health management (include a prevention focus)
- **P**ROMOTE
 - Physical Wellness (fitness, activities, participation)
 - Psychosocial Wellness (individual with CP/caregivers)
- **T**reat PAIN

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ADOPT: ASSESSMENT

- Pain is very common in children with CP
- Health Professionals are frequently missing the presence of pain

THEREFORE

- In every child/youth/adult we see with CP Clinicians need to systematically ask about pain
- Caregivers should be encouraged to bring up 'pain' in the clinical visit

ASSESSMENT: ICF framework

- Assess health issues (detailed review of systems)
- Assess impact on “Activities/Participation”
- Assess Fitness/Activity Level
- Assess Psychosocial Well-being of Individual/Caregivers

ASSESSMENT: Common approaches

- How pain is experienced is very subjective or personal
- There are 3 common approaches:
 1. Self-report tools: used by a child to tell you about their pain experience
 2. Observer or proxy tools: can be used by a parent, a well-known caregiver, or sometimes a clinician who does not know the child to assess pain
 3. Physiological tools: assesses changes in how the body reacts

ASSESSMENT: Challenges



- No single approach is perfect
- Children may not have the right words to describe their pain
- Other children may not be able to self-report
- Pain may affect a child in different ways at different times
- Observers may not 'see' pain cues or recognize that pain is the issue

Chronic Pain Assessment Tools for Cerebral Palsy: A Systematic Review

Shauna Kingsnorth, Taryn Orava, Christine Provvidenza, Ellie Adler, Noam Ami, Tessa Gresley-Jones, Deepali Mankad, Naomi Slonim, Linda Fay, Nick Joachimides, Andrea Hoffman, Ryan Hung, Darcy Fehlings

[Article](#)[Figures & Data](#)[Supplemental](#)[Info & Metrics](#)[Comments](#)

- Chronic pain tools assess:
 - presence of pain;
 - interference with a child's functioning or activities;
 - pain intensity; and
 - pain presence over a period of time
- Examples:
 - Paediatric Pain profile (PPP) (*proxy*)
 - Child Activity Limitations Interview (CALI) (*proxy & self report*)
 - PROMIS Pain Scale (*proxy & self report*)

ASSESSMENT: Pain presence

- Pain tools can help you think about pain in different ways:
 - Are there activities that are difficult or bothersome to do because of pain? For example:
 - *Going to school or doing school work*
 - *Reading*
 - *Sports*
 - *Doing things with friends*
 - Does your child have trouble:
 - *Sleeping*
 - *Feeling angry*
 - *Can't have fun*
 - *Trouble paying attention*
 - How important are these activities?



ASSESSMENT: Pain presence

- If a child is non-verbal, you can look for physical cues such as:
 - Changes in responsiveness or sociability
 - Appearing withdrawn or depressed
 - Cried /moaned/groaned
 - Hard to console or comfort
 - Restless/agitated or distressed
 - Resists being moved
 - Grinds teeth or mouthing movements

Hunt, et al. (2004). *Developmental Medicine & Child Neurology*, 46, 10.

ASSESSMENT: Body diagram

Have you talked about pain today?



What is chronic pain?

Chronic pain is pain that lasts longer than 3 months or beyond the expected healing time.

Where can I have chronic pain?

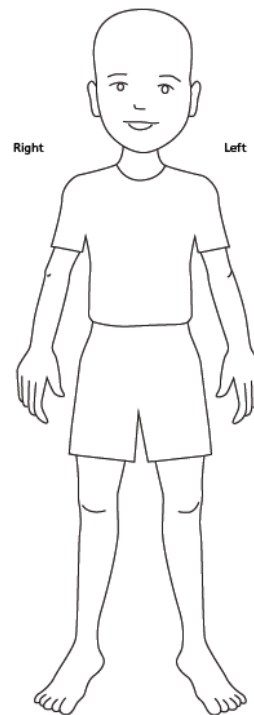
Chronic pain can occur anywhere in the body. Use the diagram on the back of this card to mark where you have pain.



How do I know if my child has chronic pain?

Share this card with your health care provider to start a conversation about pain.

Circle where you have pain:



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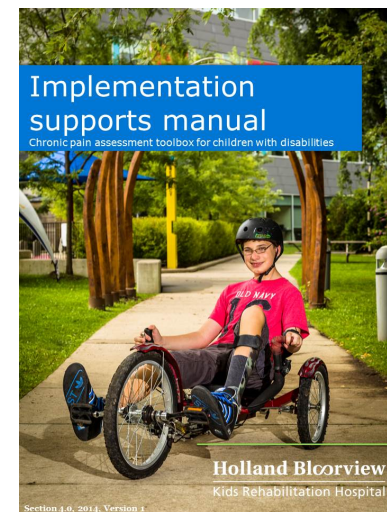
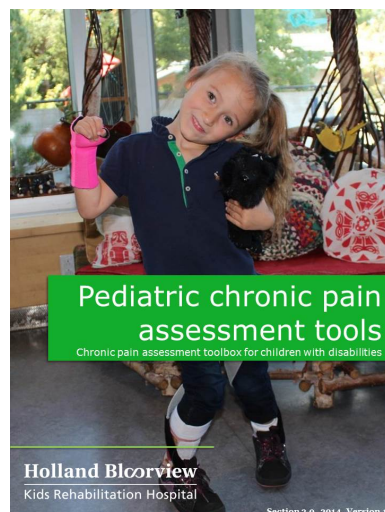
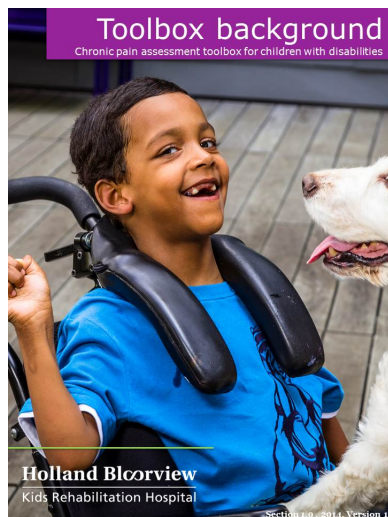
Share with your health
care provider at your
next appointment

Holland Bloorview
Kids Rehabilitation Hospital

Chronic Pain Toolbox for Children with Disabilities



www.hollandbloorview.ca/toolbox



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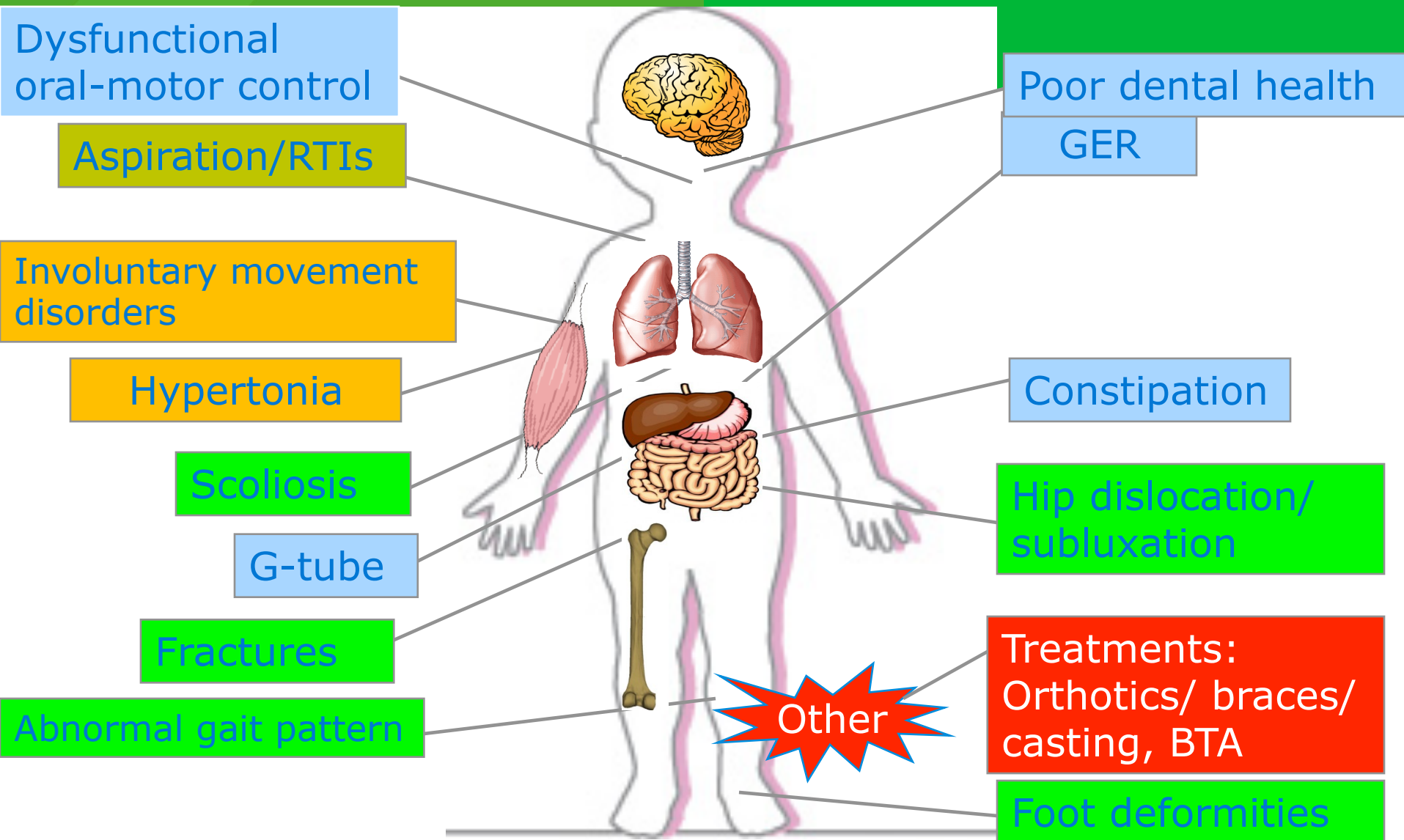
DEMYSTIFICATION

- Clinician Family Interaction
- Explain your “diagnosis” (es) for the cause of the pain
- Provide context for ‘pain’ in CP
- Discuss concept of:
 - “Breaking the Cycle of Chronic Pain” by
 - “Moving on with Activities”

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Differential Diagnosis of Pain in Children with CP



OPTIMIZING HEALTH: Commonly Missed or Under-diagnosed Causes of Pain in CP

- Dystonia
- Gastro-intestinal
 - Posterior Drooling (choking on saliva)
 - Constipation
 - GE Reflux
- Hip Dislocation (prevention)
- MSK – Gait Patterns
- Osteoporosis (Fragility Fractures) - prevention

Optimize Health: Hip Subluxation

- Prevention of pain

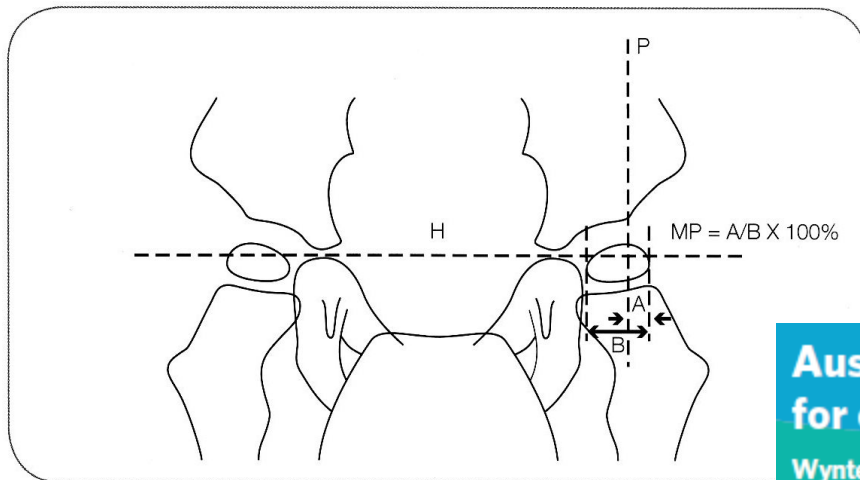


Figure 3: Migration percentage

Consensus Statement
on Hip Surveillance
for Children with
Cerebral Palsy:
Australian Standards of Care
2008

Wynter M
Gibson N
Kentish M
Love SC
Thomason P
Graham HK

Document 1 of 3

**Australian Hip Surveillance Guidelines
for children with Cerebral Palsy 2014**

Wynter M, Gibson N, Kentish M, Love SC, Thomason P, Willoughby K, Graham HK

Download available from: www.ausacpdm.org.au/professionals/hip-surveillance

Hip Dislocation



Hypertonia Intervention

SPECIAL ARTICLE



Practice Parameter: Pharmacologic treatment of spasticity in children and adolescents with cerebral palsy (an evidence-based review)

Report of the Quality Standards Subcommittee of the American Academy of Neurology and the Practice Committee of the Child Neurology Society



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ABSTRACT

Objective: To evaluate published evidence of efficacy and safety of pharmacologic treatments for childhood spasticity due to cerebral palsy.

Methods: A multidisciplinary panel systematically reviewed relevant literature from 1966 to July 2008.

Results: For localized/segmental spasticity, botulinum toxin type A is established as an effective treatment to reduce spasticity in the upper and lower extremities. There is conflicting evidence regarding functional improvement. Botulinum toxin type A was found to be generally safe in children with cerebral palsy; however, the Food and Drug Administration is presently investigating isolated cases of generalized weakness resulting in poor outcomes. No studies that met criteria are available on the use of phenol, alcohol, or botulinum toxin type B injections. For generalized spasticity, diazepam is probably effective in reducing spasticity, but there are insufficient data on its effect on motor function and its side-effect profile. Tizanidine is possibly effective, but there are insufficient data on its effect on function and its side-effect profile. There were insufficient data on the use of dantrolene, oral baclofen, and intrathecal baclofen, and toxicity was frequently reported.

Botulinum toxin type A injections can be an effective treatment for pain in children with hip spasms and cerebral palsy

Developmental Medicine & Child Neurology 2009, 51: 705–710

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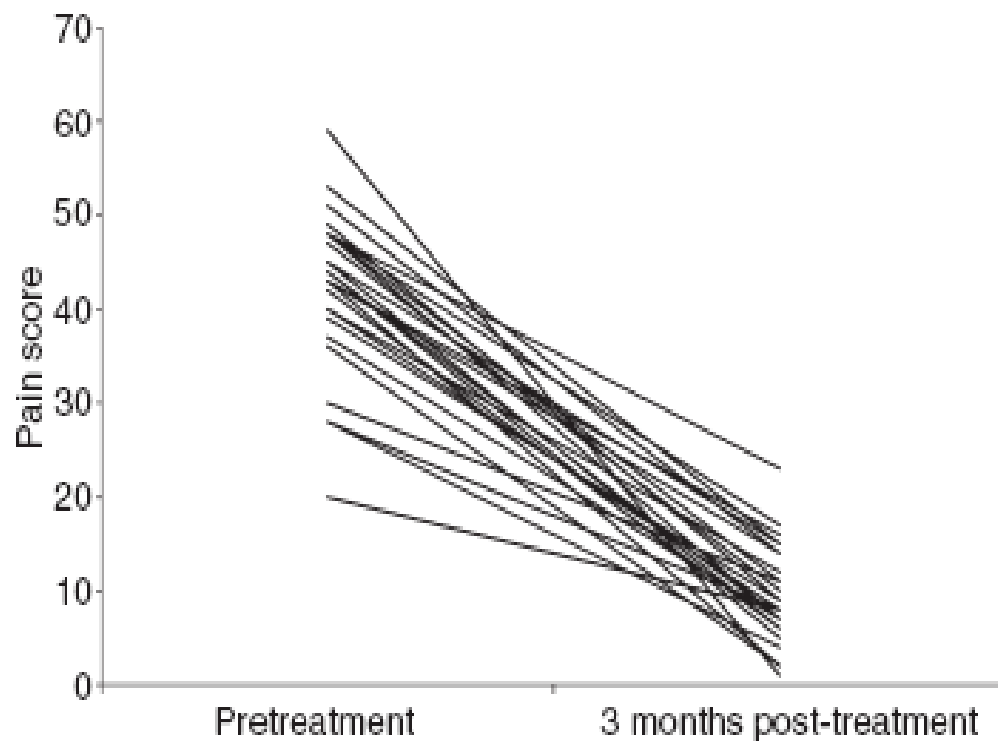


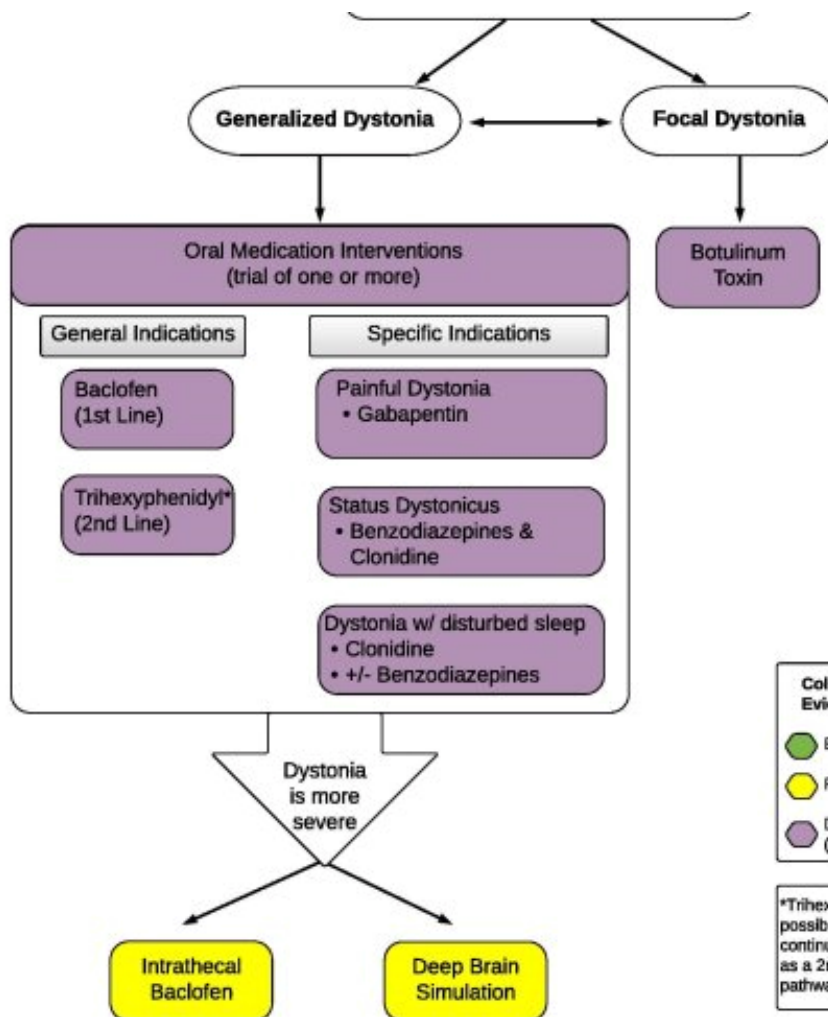
Figure 1: Individual pain profile scores before and 3 months after treatment with botulinum toxin type A.

OPTIMIZE HEALTH: Treatment of Pain associated with Dystonia

- Oral Medications: Baclofen, Gabapentin
- Focal Dystonia: Botulinum toxins
- Intrathecal Baclofen Pump
- Deep Brain Stimulation

Dystonia Care Pathway

<http://www.aacpdm.org/resources/care-pathways>



Care
Pathways



Color Legend for Level of Treatment Evidence

- Effective
- Probably or Possibly Effective
- Data Inadequate (recommendation based on expert opinion)

*Trihexyphenidyl had level 'C' evidence of being possibly ineffective for dystonia however, continues to be recommended for consideration as a 2nd line oral medication by the care pathway expert team.

OPTIMIZE HEALTH: GI Tract Posterior Drooling



- Posterior drooling describes the situation in which saliva, sometimes mixed with food components, is spilled through the faucial isthmus creating a risk of aspiration
- Associated with discomfort, coughing, night awakenings, aspiration pneumonias
- Tx options include Botulinum toxin injections, surgical ligation procedures

Care
Pathways



OPTIMIZE HEALTH: GI-Tract: Constipation

Macrogol (polyethylene glycol) laxatives in children with functional constipation and faecal impaction: a systematic review

D Candy,¹ J Belsey²

Arch Dis Child 2009;**94**:156–160. doi:10.1136/adc.2007.128769

publication of well designed randomised trials now permits a more evidence-based approach, with PEG-based treatments having been proven to be effective and well-tolerated first-line treatment.

What this study adds

- ▶ Children with constipation treated with polyethylene glycol (PEG)-based laxatives have demonstrated consistently good outcomes.
- ▶ The efficacy of PEG is as good as or better than lactulose or milk of magnesia over a wide range of ages and treatment durations.
- ▶ PEG has the added advantage of being an effective disimpacting agent.



Prevention of Pain from Fragility Fractures: Osteoporosis Clinical Practice Guidelines

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

REVIEW

Informing evidence-based clinical practice guidelines for children with cerebral palsy at risk of osteoporosis: a systematic review

DARCY FEHLINGS¹ | LAUREN SWITZER¹ | PAYAL AGARWAL¹ | CHARLES WONG¹ | ETIENNE SOCHETT² |
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PROMOTE PHYSICAL WELLNESS

- Promotion of maintenance of flexibility
- Cardiovascular Fitness, Good Nutritional and Dental Health
- Participation in Physical Activities

PROMOTE PSYCHOSOCIAL WELLNESS

- Participation and engagement
(some research to support this as an approach to shift attention to positive activity focus and away from negative cycle of pain)
- Support/Relief for Primary Caregivers

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TREAT PAIN

- Use of Pain Medications
 - Consider if pain continues to restrict activities despite optimizing “health management”
 - Try to avoid opioids
- Other Pain Relief Techniques (e.g. Biofeedback)

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Case Study

- Your son John has CP and is 5 years old. John uses a wheelchair for mobility. You are seeing a specialist at a rehab center.
- Your main concern is John's pain
- John has daily bouts of pain that occur several times– John cries when he experiences the episodes and you are worried about the impact on his quality of life
- You don't understand why John is in pain and don't want to "mask" it by using medications –You would prefer to "cure" it
- You are exhausted and feel discouraged

ASSESSMENT

- Neonatal history: born at term after an emergency C-Section for cord prolapse
- Past Medical History: aspiration pneumonias
- Review of Systems:
 - chokes on saliva (including triggering of night awakenings)
 - spits up food on a daily basis (improved on “reflux” meds)
 - hard infrequent bowel movement
 - wheezes post feeding

ASSESSMENT

- Development: good RL, no EL, MACSV, GMFCS V
- Rehab Supports:
 - wheelchair with custom inserts and tray, no standing frame, Rigid AFOs
 - full day school program with therapy consultation to school
 - no communication system in place
 - no extracurricular activities
- Family – two parent family, minimal extended family support, only child

ASSESSMENT

- Tone – significant variability in tone by history, triggered by “emotions”, or out of the blue, better at night-time
- Physical Exam: height and weight < 3 % with decreased weight velocity, neuro exam reveals severe generalized dystonia, MSK – good passive range of motion
- Investigations: hip x-ray normal

ASSESSMENT: “Cause” of Pain

- Dystonia
- Posterior Drooling
- Constipation
- Reflux
- Malnutrition/Osteopenia
- Aspiration: Oral Feeding Safety

ASSESSMENT: ICF framework

- Assess health issues (detailed review of systems)
- Assess impact on “Activities/Participation”
- Assess Fitness/Activity Level
- Assess Psychosocial Well-being of Individual/Caregivers

DEMYSTIFICATION

- Focus of initial discussion was on DYSTONIA
- Complexity of Causes of Pain (with examples for John)
- Discussed the impact of pain on Parent Stress

Optimizing Health

- G-tube placement booked
- Dietician part of the G-tube team (osteopenia prevention with improvement in nutrition, calcium intake and vit D 1000 iu; improved fluid intake will link to improved bowel movements)
- Dystonia: oral artane started
- Saliva management consult: exploring botulinum toxin salivary gland injections
- Connection with local paediatrician
- 3 month follow-up organized – link to Augmentative Communication Services

PROMOTE WELL-BEING

- Parents reported feeling significantly better now that they understood why John's pain was episodic (demystification of dystonia)
- Social Worker – referral initiated to investigate local support services, respite support outlined

TREAT Pain

- Did not institute pain medications at this time as optimizing health was prioritized

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DISCUSSION

- Common sources of “Missed” Pain in Children/Young People with CP
- Thoughts on the “FRAMEWORK”
 - missing components?
 - different perspectives?
- Ideas for “STRUCTURING” THE PAIN QUESTION into regular clinical practice?
- Thoughts on using “pain” medications
- Thoughts on biofeedback/mindfulness approaches to pain management

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THANK YOU!

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