Using tone-reducing medications in children and youth with Cerebral Palsy

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Dr Matt Hicks
Oct 28, 2014 on behalf of SCP

Objectives

- review the motor patterns likely to be encountered in children with Cerebral Palsy
- features that distinguish spasticity and dystonia
- goals of medical interventions
- oral medications used to manage spasticity
- oral medications used to manage dystonia
- medication algorithms

Definition 2005

- Cerebral Palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occur in the developing fetal or infant brain.
- The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.

Cerebral Palsy

- CP is not an etiologic diagnosis, but a clinical descriptive term
- the diagnosis relies essentially on clinical aspects, based on phenomenology

Cerebral Palsy

- ‘group’ – the singular Cerebral Palsy is preferred even though it may describe several groupings that serve different purposes, but may overlap
- ‘developmental’ nature of CP almost always implies impacts on the developmental trajectories of people who have CP
- ‘movement and posture’ abnormalities are core features

Implications of Diagnosis

- caused by abnormal development of, or damage to, motor control centers of the brain
- caused by events before, during, or after birth
  - origins may start as early as brain formation and early development but may extend to acquired brain injury in children and youth

Implications of Diagnosis

- abnormalities of muscle control that define CP are often accompanied by other neurological and physical abnormalities

- the presence of other abnormalities should be considered the “norm” for CP, so must always be borne in mind

CP types

- CP is often defined based on topography of involved limbs, or type of motor disorder (or both)

Topography

- Hemiplegia (generally spastic but rare forms of hemiplegic dystonia exist)
- Diplegia
- Quadriplegia (Tetraplegia)

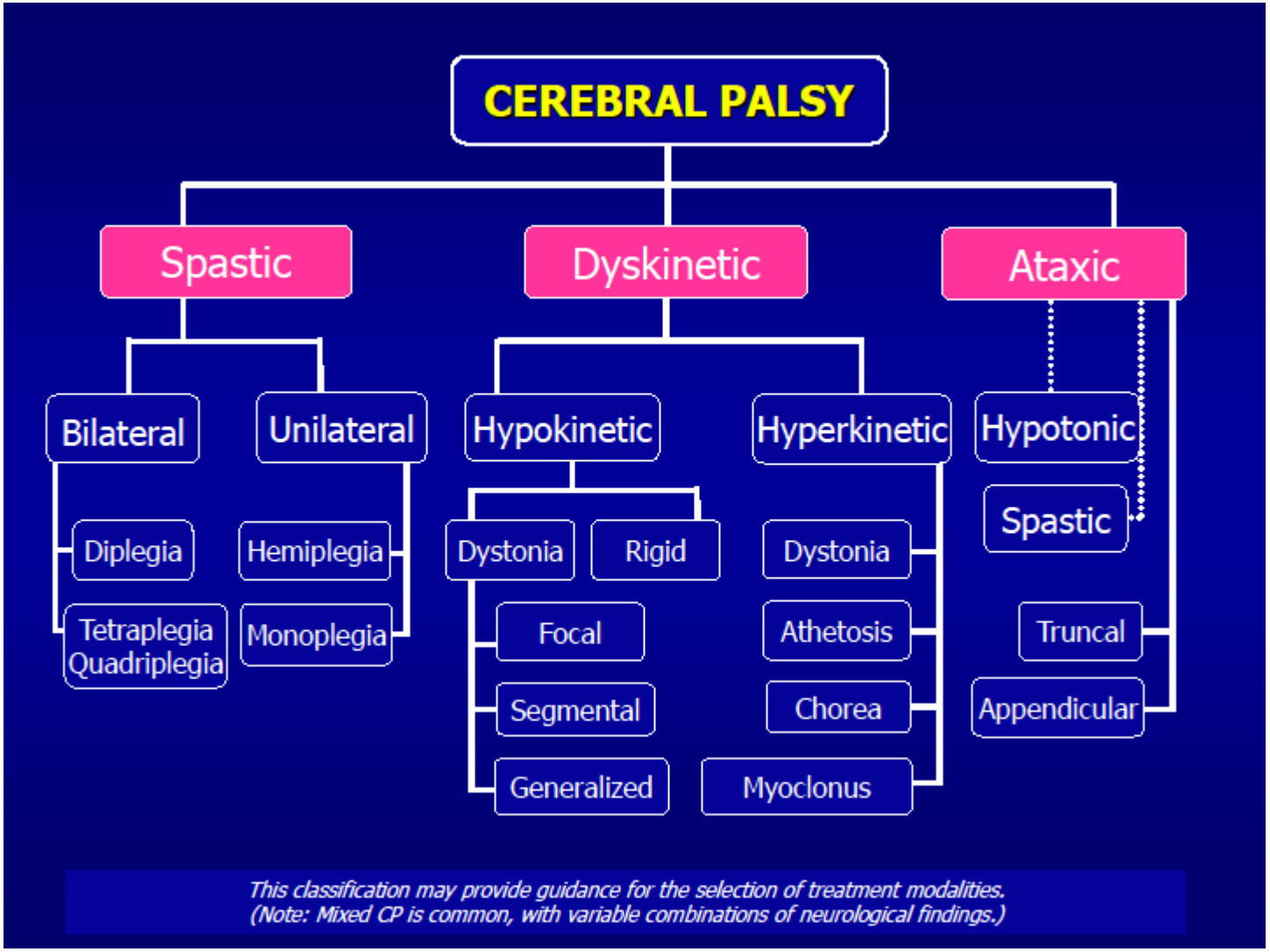
Descriptive terms

- spastic 75-80%, (upper motor neuron lesions)
  - hemiplegia 20-30%
  - diplegia 30-40%
  - quadriplegia 10-15%

- "non-spastic" - 15-20%,
  - dyskinetic - 10-15% (basal ganglia)
    - ataxic - <5%, (cerebellar lesions)
    - Hypotonic - <5%

Motor Control System

- Cerebral motor cortex
  - –initiates the “command to move”
- Basal ganglia
  - – starts and stops movement: “accelerator and “brake”;
  - organizes collaboration between agonist/antagonist muscles, especially for postural control
- Cerebellum
  - – coordinates movement: the “steering wheel”

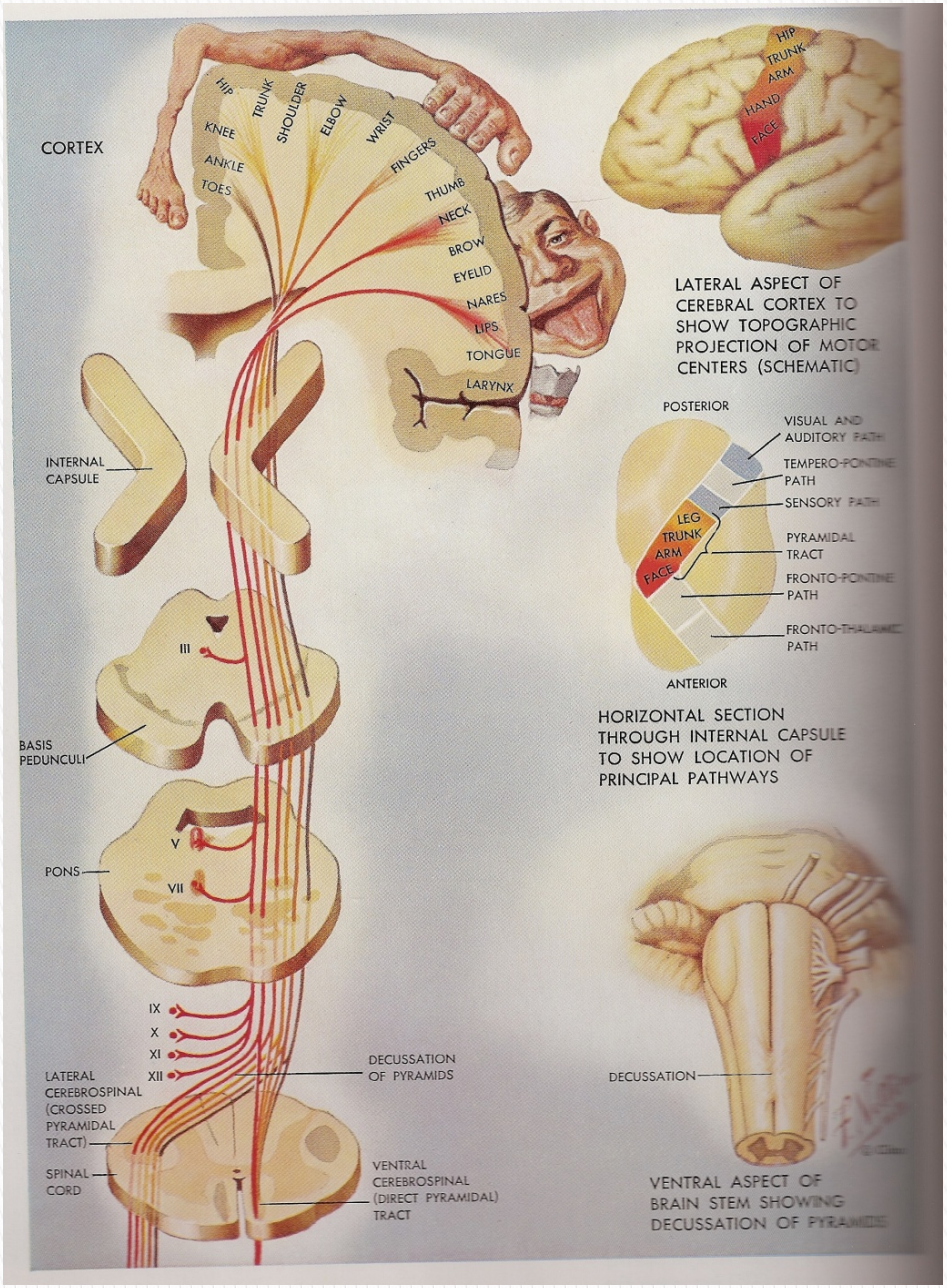

CEREBRAL PALSY
Spastic
Dyskinetic
Ataxic
Bilateral
Unilateral
Hypokinetic
Hyperkinetic
Hypotonic
Diplegia
Hemiplegia
Dystonia
Rigid
Dystonia
Spastic
Tetraplegia
Quadriplegia
Monoplegia
Focal
Athetosis
Truncal
Segmental
Chorea
Appendicular
Generalized
Myoclonus
This classification may provide guidance for the selection of treatment modalities.
(Note: Mixed CP is common, with variable combinations of neurological findings.)

Examination – Imaging Correlations

Spasticity:	White matter lesions
Rigidity:	Diffuse cortical lesions
Dyskinesia:	Basal ganglia/thalamic lesions
Ataxia:	Cerebellar lesions

Pyramidal system

Lesions to the pyramidal system may present as spasticity



Spasticity

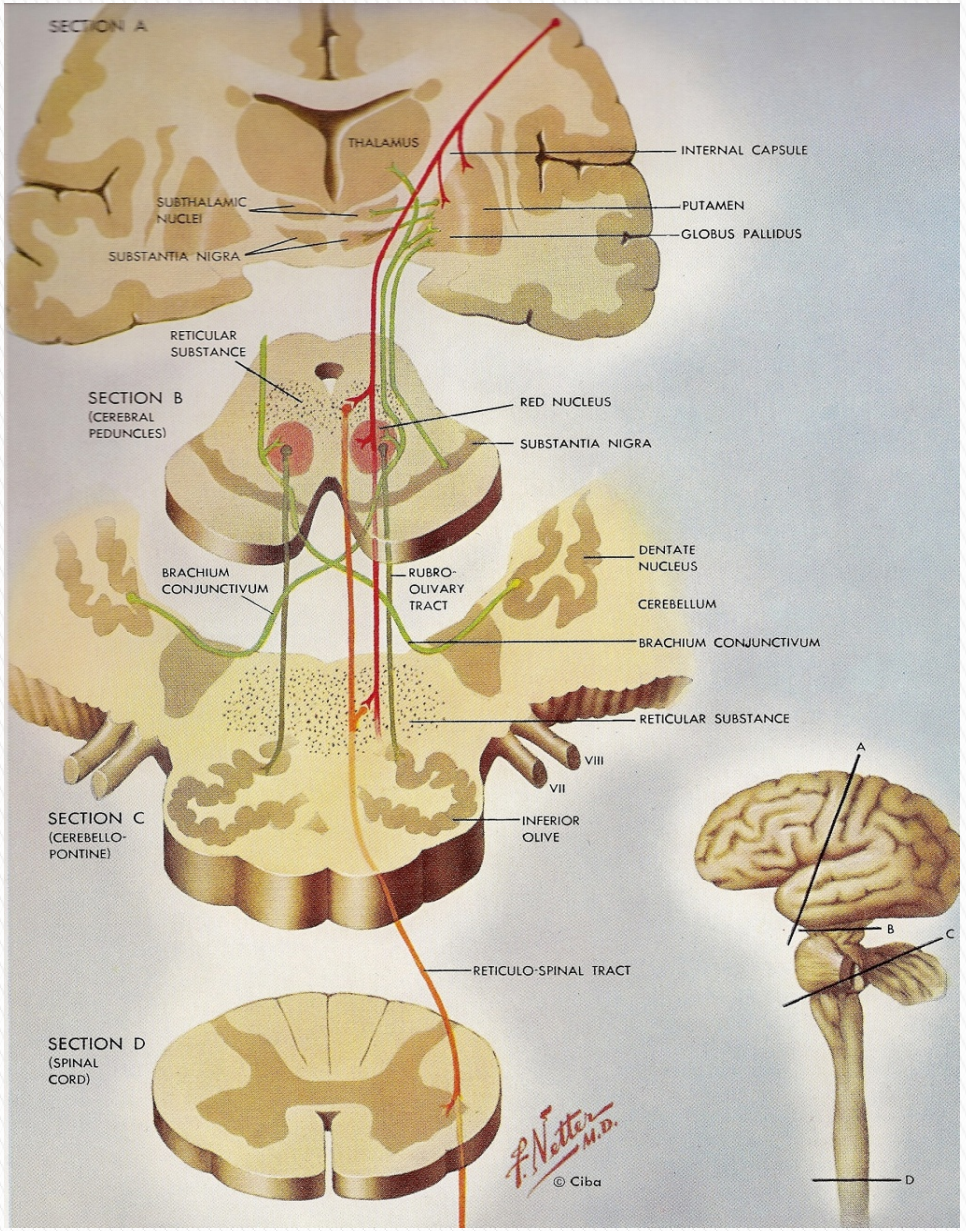
- velocity-dependent increased resistance to passive stretch
- rapid increase in movement leads to ‘catch’ with subsequent release
- continuous and passive partial muscle contraction
- clonus (a series of rapid muscle contractions)
- exaggerated deep tendon reflexes,
- muscle spasms,

Spasticity

- ranges from mild muscle stiffness to severe, painful, and uncontrollable muscle spasms
- postural changes include scissoring (involuntary crossing of the legs), equinus posturing, fisting, and loss of wrist supination
- fixed joints (contractures = fixed high resistance to passive stretch of a muscle due to fibrosis)

Extra-pyramidal System

Lesions to the extra-pyramidal system may present as ‘dyskinesia’

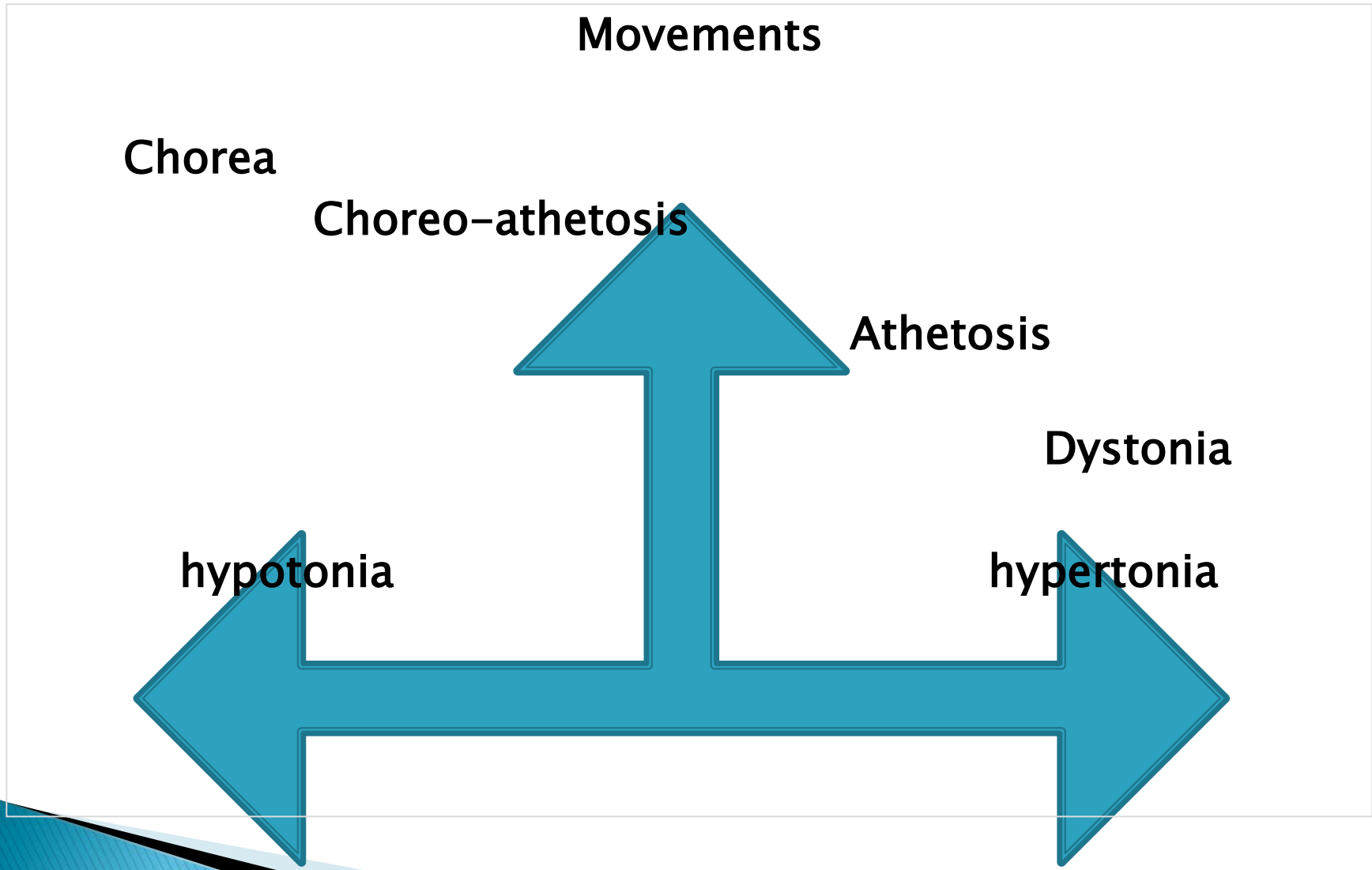


Dyskinetic

- Dyskinetic or Extra-pyramidal

- athetosis
- chorea
- choreoathetosis
- ataxia
- Hypotonia
- dystonia

Dyskinesia


Movements
Chorea
Choreo-athetosis
Athetosis
Dystonia
hypotonia
hypertonia

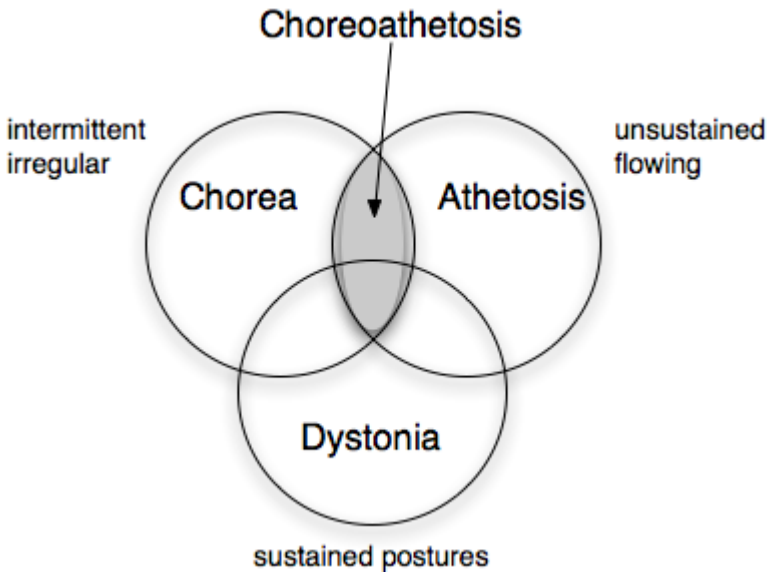
Chorea

- from the Latin word choreia – dance
- ceaseless occurrence of a variety of jerky, but well coordinated involuntary movements
- movements may involve the limbs, trunk, or facial muscles

Athetosis

- continuous stream of slow, sinuous, writhing movements, typically of the hands and feet.
- movements typical to athetosis are sometimes called athetoid movements.
- often caused by damage to the corpus striatum of the brain, but can also be caused by a lesion of the motor thalamus.

Choreoathetosis



Dystonia

- sustained unwanted muscle contractions
- repetitive twisting movements
- abnormal postures of trunk, neck, face, limbs
- involuntary concomitant contraction of agonist and antagonist muscles
- overflow of unwanted muscle contractions to adjacent muscles
- tremor may be present

Primitive Reflexes

- Moro
  - evident at birth and disapears by 4-5 months
- Positive supporting reaction
  - generally disappears by 4 months
- Asymmetrical tonic neck
  - usually evident by1 mo, and disappears by 4-6 months
- Parachute reflex
  - begins to emerge at 7-9 months

Mixed CP

- It is increasingly recognized that a number of individuals with cerebral palsy have a “mixed” disorder (including both spastic and non-spastic features)

Hypotonic

- Hypotonic CP is thought to be rare
- truncal and extremity hypotonia with hyperreflexia and persistent primitive reflexes

Ataxia

- ataxia = meaning "lack of order"
- signs and symptoms consisting of gross in-coordination of muscle movements
- ataxia can be nonspecific; but implies dysfunction of areas such as the cerebellum

Spastic vs Dystonic CP

- Spasticity
  - –More consistent
  - –Seen with upper motor neuron signs
- Dystonia
  - –Resolves with sleep
  - –Increases with agitation or excitement
  - –Can be triggered by attempts at voluntary movement or a specific body position

Spastic vs Dystonic CP

	Spasticity	Dystonia
	clasp-knife tone	'rigid' tone
head -	flexed	torticollis
elbows -	flexed	extended
fingers -	flexed	extended
hips -	scissored	asymmetric
knees -	flexed	often flexed
feet -	equino-varus	often plano-valgus

HAT Tool

- **Hypertonia Assessment Tool (HAT)**

- Authors: Fehlings, D., Switzer, L., Jethwa, A., Mink, J., Macarthur, C., Knights, S., & Fehlings, T. (Bloorview Kids Rehab, Toronto)

HAT ITEM	SCORING GUIDELINES (0=negative or 1=positive)	SCORE 0=negative 1=positive *(circle score)*	TYPE OF HYPERTONIA
1. Increased involuntary movements/postures of the designated limb with tactile stimulus of a distal body part	0= No involuntary movements or postures observed	0	DYSTONIA
	1= Involuntary movements or postures observed	1	
2. Increased involuntary movements/postures with purposeful movements of a distal body part	0= No involuntary movements or postures observed	0	DYSTONIA
	1= Involuntary movements or postures observed	1	
3. Velocity dependent resistance to stretch	0= No increased resistance noticed during fast stretch compared to slow stretch	0	SPASTICITY
	1= Increased resistance noticed during fast stretch compared to slow stretch	1	
4. Presence of a spastic catch	0= No spastic catch noted	0	SPASTICITY
	1= Spastic catch noted	1	
5. Equal resistance to passive stretch during bi-directional movement of a joint	0= Equal resistance not noted with bi-directional movement	0	RIGIDITY
	1= Equal resistance noted with bi-directional movement	1	
6. Increased tone with movement of a distal body part	0= No increased tone noted with purposeful movement	0	DYSTONIA
	1= Greater tone noted with purposeful movement	1	
7. Maintenance of limb position after passive movement	0= Limb returns (partially or fully) to original position	0	RIGIDITY
	1= Limb remains in final position of stretch	1	

Differential Diagnosis

History	Exam	Neuroimaging	Workup
Prematurity	Spastic Diplegia	PWMI/PVL	None
Neonatal encephalopathy	Dystonia	HI putamen, VL thalamus	Maternal/fetal risk factors
Severe developmental delays, no risk factors	Choreo-athetosis, hypotonia	Semi-lobar Holoprosencephaly	SNP array, HPE gene sequencing
Motor delay / abnormal gait	Dystonia	Normal	Trial of Sinemet, CSF Neurotransmitters
Normal development then CP	Dystonia	HI Globus Pallidus	Metabolic disorders, including mitochondrial

Treating Hypertonia

- Spasticity
- Dystonia
- (Rigidity)

Goals of Treatment

Individualize medical-rehabilitative interventions based on goals of treatment:

- Improve/preserve function
- Improve ease of care/comfort
- Decrease pain/discomfort
- Decrease orthopedic deformities
- Promote general health and well-being
- Promote integration in school and community life
- Consider secondary morbidities
- Plan for long-term outcome

Systematic Approach

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY REVIEW

A systematic review of interventions for children with cerebral palsy: state of the evidence

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This article is commented on by Msall on pages 877–878 of this issue.

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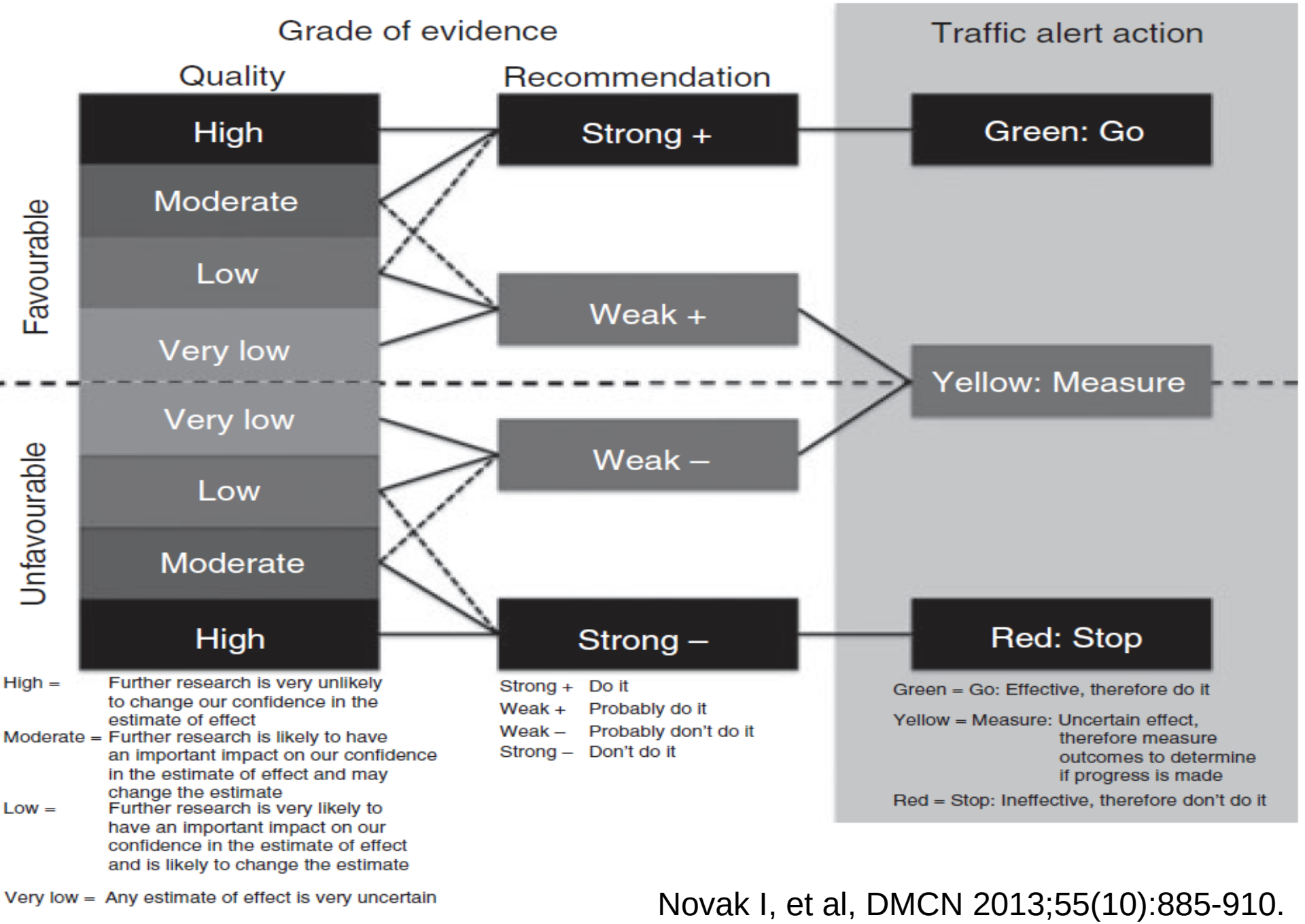

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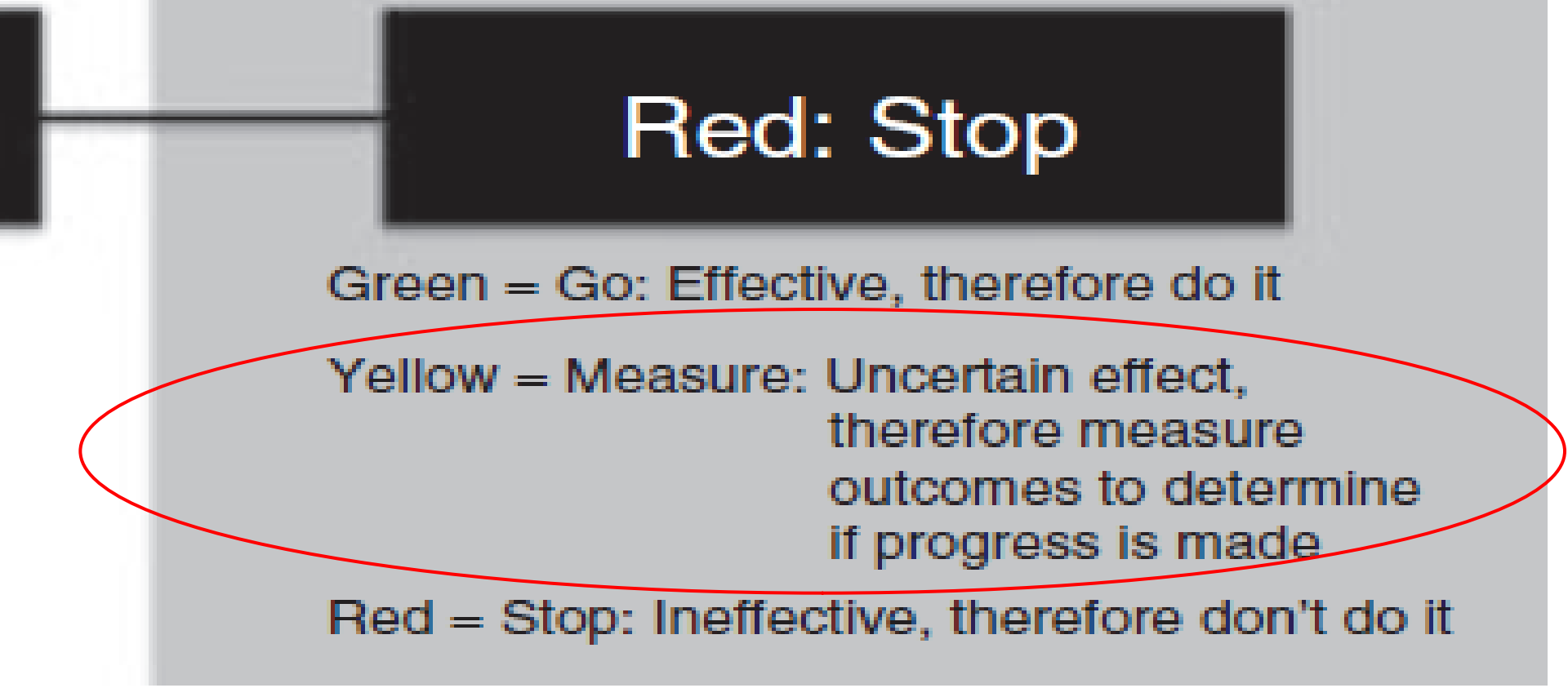

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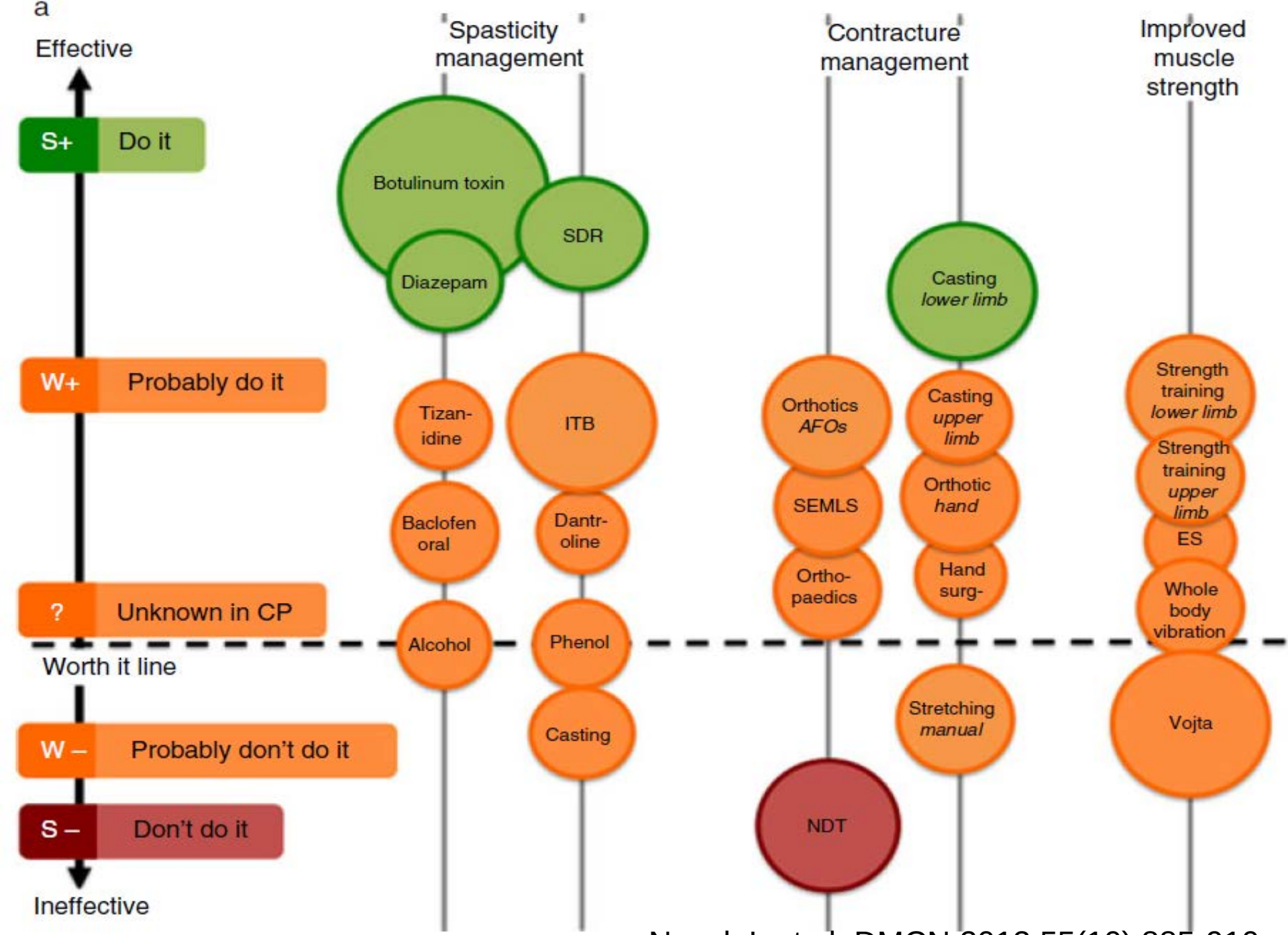

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Treatment

- Oral medications to address hypertonia
  - Systematic Review of CP Rx, Novak et al DMCN 2013, Vol 55:10, 885-910
- After assessing for spasticity vs dystonia, considerations in choosing a medication

Recommendations

- Standardized and validated spasticity scales and clinically relevant measures should be used.
- Need for safety, efficacy and pharmokinetic data for oral medications.
- “There is an urgent need for studies to establish the efficacy of current therapies and find additional safe and effective treatments to help children affected by generalized spasticity due to CP.”
- The effects of both spasticity and the treatment of spasticity on activity and participation as defined by the ICF need to be studied in children with CP

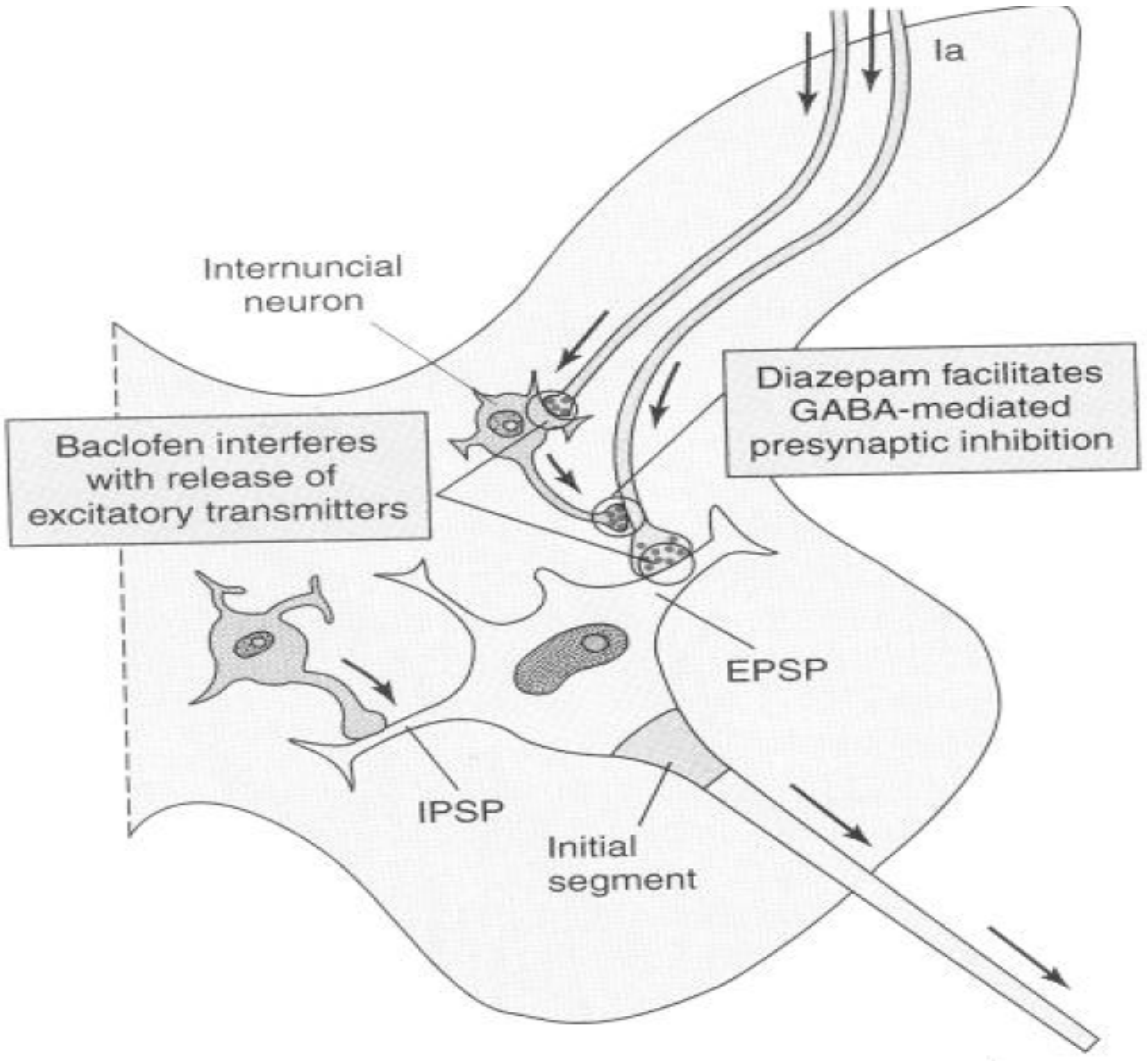
Goals of therapy

- Goal of therapy 3 fold
- Ease burden of care due to abnormal tone/postures
- Ease discomfort associated with daily stretches
- Reduce painful muscle spasms
- Patients selected in our clinic are generally been more compromised (GMCS 4 and 5)
- Parents are informed of the limited role that medications play

Medication	Mechanism of action	Dosing	Evidence	Side effects
Diazepam (Valium)	GABA-A	1-2 mg/day up to 12 mg/day	Probably effective in short term	Ataxia, daytime somnolence, withdrawal
Oral Baclofen	GABA-B	10 – 60 mg/day	Conflicting evidence, insufficient evidence	Drowsiness, sedation, withdrawal
Dantrolene	Blocks Ca release from SR	0.5 – 12 mg/kg/day	Conflicting evidence	Weakness, drowsiness, irritability
Tizanidine	alpha2-noradrenergic agonist	0.05 mg/kg/day	Possibly effective	Hypotension, sedation, dry mouth, dizziness
Trihexyphenidyl (Artane)	Muscarinic receptor, ?Dopaminergic	0.1 to 0.75 mg/kg/day	No RCTs, observational studies	Anti-cholinergic
Levodopa / Carbidopa	Increases CNS dopamine	1-6 mg/kg/day	No RCTs, observations	Nausea, vomiting

Medication choices

- Spasticity:
  - Baclofen
  - Benzodiazepines
  - Dantrolene sodium
  - Tizanidine/Clonidine
  - Others
- Dystonia
  - Trihexyphenidyl
  - Levo-Dopa


Ia
Internuncial neuron
Baclofen interferes with release of excitatory transmitters
Diazepam facilitates GABA-mediated presynaptic inhibition
EPSP
IPSP
Initial segment

Baclofen

- GABA-b agonist
- GABA and Glycine are principal inhibitory neurotransmitters in CNS) majority of GABA neurons are interneurons and constitute 30-40% of CNS neurons
- Mediates presynaptic inhibition of dorsal horn interneurons in spinal cord
- Decreases excitability of Ia afferent neurons, reducing output to motoneuron

Baclofen

- Adverse effects
- Sedation
- Respiratory (bronchoconstriction)
- Reduced seizure thresholds
- Withdrawal syndrome
- Memory impairment
- Constipation
- Ataxia/Weakness/Fatigue
- Insomnia
  - Nausea/Constipation/Urinary frequency
  - Excessive sweating
  - Rash/Itch

Baclofen Adverse Effects

- **Cardiovascular**: Hypotension
- **Gastrointestinal**: Constipation, Nausea, Vomiting
- **Musculoskeletal**: Poor muscle tone
- **Neurologic**: Asthenia Dizziness, Headache, Somnolence
- **Renal**: Urinary complication
- **Other**: Fatigue Shivering

Baclofen Dosing

- <2 years: 10-20 mg daily ÷ tid; titrate dose every 3 days in increments of 5-15 mg/day to a maximum of 40 mg daily
- 2-7 years: 20-30 mg daily ÷ tid; titrate dose every 3 days in increments of 5-15 mg/day to a maximum of 60 mg daily
- ≥8 years: 30-40 mg daily ÷ tid; titrate dosage as above to a maximum of 120 mg daily

Benzodiazepines

- Diazepam (Nitrazepam/Clonazepam)
  - Diazepam Dosing: (minimal literature guidance)
    - 0.12-0.8 mg/kg/day ÷ tid
  - Nitrazepam Dosing:
    - 0.3 to 1.5 mg/kg/day ÷ bid (based on anti-epileptic dosing)

Diazepam Adverse Effects

- **Cardiovascular**: Hypotension
- **Dermatologic**: Rash
- **Gastrointestinal**: Diarrhea
- **Musculoskeletal**: Muscle weakness
- **Neurologic**: Ataxia, Incoordination, Somnolence
- **Psychiatric**: Euphoria
- **Respiratory**: Respiratory depression
- **Other**: Fatigue

Tizanidine

- Alpha2-adrenergic agonist, (monoamine)
- Prevents release of excitatory neurotransmitters (glutamate/aspartate),
- may facilitate action of glycine,

  - Dosing in children 'not established'
    - 0.05 mg/kg/day ÷ bid
    - (adult max = 36 mg/d)

Tizanidine Adverse Effects

- Hypotension (less with tizanidine)
- Sedation (more common than baclofen)
- Weakness/dizziness
- Hallucinations/insomnia
- Elevated liver enzymes (tizanidine)

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DRAFT - Medications for Spasticity Management

Exclusions / Considerations

- *If seizures are not well controlled then Baclofen contraindicated (relative)*
- *Medications likely of greatest benefit in quadriplegia rather then diplegia or monoplegia given systemic effects*
- *Use benzodiazepines with caution in children with respiratory/OSA symptoms*

Preparations

Baclofen
- *10 and 20 mg regular release tablets; reliable recipe available to make into liquid*

Nitrazepam (Mogadon)
- *5 and 10 mg regular release tablets & 1mg/mL liquid*

Diazepam (Valium)
- *2, 5, 10 mg regular release tablets & 1 mg/mL liquid*

Tizanidine (Zanaflex)
- *4 mg regular release tablets*

Side Effects/Adverse Drug Reactions (ADRs)

Baclofen
- *Seizure exacerbation,*

Nitrazepam/ Diazepam
- *Somnolence, dizziness, cognitive effects, hypersalivation & swallowing difficulties*

Tizanidine
- Hypotension, sedation, dry mouth, dizziness

Medication Options

Oral Baclofen
- <2 years: 10-20 mg daily ÷ tid; titrate dose every 3 days in increments of 5-15 mg/day to a maximum of 40 mg daily
- 2-7 years: 20-30 mg daily ÷ tid; titrate dose every 3 days in increments of 5-15 mg/day to a maximum of 60 mg daily
- ≥8 years: 30-40 mg daily ÷ tid; titrate dosage as above to a maximum of 120 mg daily

Benzodiazepines: Diazepam or Nitrazepam
- Diazepam: 0.12-0.8 mg/kg/day ÷ tid
- Nitrazepam: 0.3 to 1.5 mg/kg/day ÷ bid

Tizanidine
- 0.05 mg/kg/day ÷ bid

Baseline Assessment
- HAT
- CCQ
- COPM
- Adapted Tardieu
- Physical Exam

Reassessment in clinic at **6 weeks**

6 Week Assessment
- HAT
- Screen for ADRs
- Physical Exam

Reassessment in clinic every 3 months for first year of trial then Reassess in clinic every 6 months with a repeat Baseline Assessment annually

Follow up Assessment
- HAT
- CCQ
- Screen for ADRs
- Physical Exam

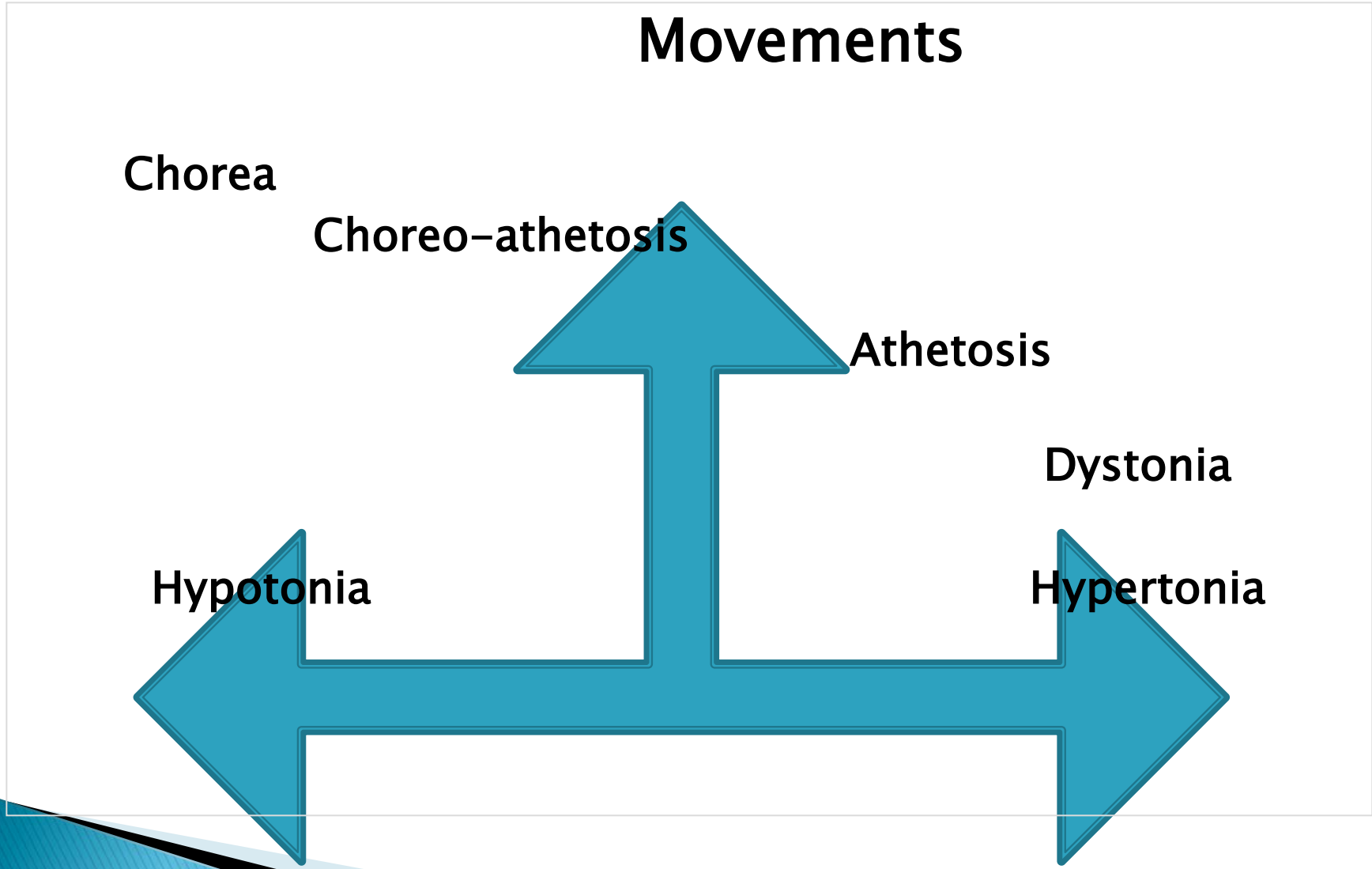
For suboptimal response or serious ADRs taper medication as follows:

Oral Baclofen
- Wean 10% per week

Benzodiazepines: Diazepam or Nitrazepam
- Wean 10% per week

2014-01-13

Dyskinesia


Movements
Chorea
Choreo-athetosis
Athetosis
Dystonia
Hypotonia
Hypertonia

Medications for Treatment of Dyskinetic CP

Medications for	Dystonia	Chorea
Dopamine agonists: levodopa/carbidopa, amantadine, bromocriptine, pergolide	✓	
Dopamine antagonists: pimozide, haloperidol		✓
Monoamine depleters & blockers: tetrabenazine	✓	✓
Monamine depleter: reserpine		✓
Anticholinergics: trihexyphenidyl, benztropine	✓	
Benzodiazepines: clonazepam, diazepam, lorazepam	✓	✓
Other muscle relaxants: baclofen, cyclobenzaprine	✓	
Antiepileptic drugs: primidone, carbamazepine	✓	
Antiepileptic drugs: levetiracetam, valproic acid		✓

Trihexyphnidyl

- Anticholinergic
  - Dose

- Week 1 & 2: 0.1 mg/kg bid
- Week 3 & 4: 0.1 mg/kg tid
- Week 5 & 6: 0.15 mg/kg tid
- Week 7 & 8: 0.20 mg/kg tid
- Consider increase to 0.25 mg/kg tid if suboptimal response
- Expected optimal response at 3 to 4 months post-medication initiation

Trihexyphenidyl

- Dosing:
  - one study found that younger children tolerated higher doses, and suggested the folllowing
    - mean dose/age
    - 0-3yr - 0.76 mg/k/d
    - 4-6yr - 0.72 mg/k/d
    - 7-9yr - 0.51 mg/k/d
    - 10-12yr - 0.33 mg/k/d
    - 13-15yr - 0.4 mg/k/d
    - 16-18yr - 0.2 mg/k/d

Trihexyphenidyl

- Adverse effects reported in 6 articles:
  - agitation
  - dry mouth
  - blurred vision
  - urinary difficulty
  - drowsiness
  - forgetful, hallucinations
  - decreased seizure control
  - treatment emergent chorea

Trihexyphenidyl

- Side effects per Micromedex ®
- common
  - **Gastrointestinal:** Nausea (30% to 50% .), Xerostomia (30% to 50%)
  - **Neurologic:** Dizziness (30% to 50%)
  - **Ophthalmic:** Blurred vision (30% to 50%)
  - **Psychiatric:** Feeling nervous (30% to 50%)
- severe
  - **Gastrointestinal:** Paralytic ileus
  - **Neurologic:** Confusion
  - **Ophthalmic:** Angle-closure glaucoma, Raised intraocular pressure
  - **Psychiatric:** Disorientated

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Trihexyphenidyl (Artane) Guideline for Dystonia Management

Exclusions / Considerations
- *Use with caution in hepatic impairment, glaucoma, GI obstruction and post-NEC/short gut*
- *Consider a Sinemet trial for patients with prominent choreiform movements as these may be exacerbated by Artane*

Anticipated Responders
- *Preterm*
- *Upper limb dystonia*
- *Younger age at treatment initiation*
- *Normal cognitive ability*

Preparation
- *Available as 2 and 5 mg regular release tablets*
- *Suspension prepared as 0.4mg/mL*

Side Effects/Adverse Drug Reactions (ADRs)
- *Dry mouth*
- *Constipation*
- *Blurred vision*
- *Drowsiness*
- *Forgetfulness*
- *Behaviour changes*
- *Transient irritability*
- *Rarely, worsening of dystonia*
- *Hallucinations*

Titrate medication as follows
Week 1 & 2: 0.1 mg/kg bid
Week 3 & 4: 0.1 mg/kg tid

Baseline Assessment
- HAT
- CCQ
- COPM
- Adapted Tardieu
- Physical Exam

RN Assessment
- Screen for ADRs

Reassessment in clinic at **4-6 weeks**

4-6 Wk Assessment
- HAT
- Screen for ADRs
- Physical Exam

Continue medication titration as follows
Week 5 & 6: 0.15 mg/kg tid
Week 7 & 8: 0.20 mg/kg tid
Continue at 0.20 mg/kg tid until reassessment at 3 months

RN Assessment
- Screen for ADRs

Reassessment in clinic at 3 months
Expected optimal response at 3 to 4 months post-medication initiation
Consider increase to 0.25 mg/kg tid if suboptimal response

Follow up Assessment
- HAT
- CCQ
- Screen for ADRs
- Physical Exam

Reassess in clinic every 3 months for first year of trial then
Reassess in clinic every **6 months** with a repeat Baseline Assessment annually

RN Assessment
- Screen for ADRs

For suboptimal response or serious ADRs taper medication slowly over 4 weeks

2014-01-13

Carbi-Levo Dopa

- Dosing:
  - There are no guidelines for treating CP with carbi-levo dopa, so we have been using the guidelines developed for Dopa Responsive Dystonia

- Week 1 & 2: 1 mg/kg/day of L-dopa ÷bid
- Week 3 & 4: 2 mg/kg/day of L-dopa ÷bid
- Week 5 & 6: 3 mg/kg/day of L-dopa ÷bid
- Week 7 & 8: 4 mg/kg/day of L-dopa ÷bid
- Week 9 & 10: 5 mg/kg/day of L-dopa ÷bid
- Week 11 & 12: 6 mg/kg/day of L-dopa ÷bid

Carbi-Levo Dopa

- Dopamine does not cross the blood-brain barrier, but levodopa does
- A peripheral decarboxylase inhibitor such as carbidopa is combined with levodopa to reduce the incidence of nausea and vomiting by inhibiting the peripheral conversion of levodopa to dopamine

Carbi-Levo Dopa

- Adverse effects
- **Common**
  - **Gastrointestinal**: Nausea (5.5% to 5.7%)
  - **Neurologic**: Confusion (2.3% to 3.7%), Dizziness (2.3% to 2.9%), Headache (1.9% to 2%)
- **Serious**
  - **Cardiovascular**: Myocardial infarction
  - **Dermatologic**: Malignant melanoma
  - **Neurologic**: Dyskinesia (12.2% to 16.5%)
  - **Psychiatric**: Depression (1.3% to 2.2%), Hallucinations (3.2% to 3.9%), Suicidal thoughts
  - **Other**: Neuroleptic malignant syndrome

Alberta Children's Hospital

DRAFT
Levodopa (L-dopa)/carbidopa (Sinemet) Guideline for Dystonia Management

Exclusions / Considerations
- *1st line if patient has prominent choreiform movements*
- *Consider if diagnosis or etiology unclear to rule out Dopa-responsive dystonia*
- *History of psychosis, hypertension and melanoma are contraindications*

Anticipated Responders
- *Upper limb dystonia*

Preparation
- Preferred tablets for kid available as Levodopa 100mg/ Carbidopa 25mg regular release tablets
- Liquid preparation made as 5mg/1.25mg per mL

Side Effects/Adverse Drug Reactions (ADRs)
- *Nausea and vomiting*
- *Somnolence*
- *Dyskinesia*

Titrate medication as follows
Week 1 & 2: 1 mg/kg/day of L-dopa ÷bid
Week 3 & 4: 2 mg/kg/day of L-dopa ÷bid
Week 5 & 6: 3 mg/kg/day of L-dopa ÷bid

→ **Baseline Assessment**
- HAT
- CCQ
- COPM
- Adapted Tardieu
- Physical Exam

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Reassessment in clinic at **6 weeks**

→ **6 Wk Assessment**
- HAT
- Screen for ADRs
- Physical Exam

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Continue medication titration as follows
Week 7 & 8: 4 mg/kg/day of L-dopa ÷bid
Week 9 & 10: 5 mg/kg/day of L-dopa ÷bid
Week 11 & 12: 6 mg/kg/day of L-dopa ÷bid
Continue 6 mg/kg/day of L-dopa ÷bid until reassessment at 3 months

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Reassessment in clinic every 3 months for first year of trial then Reassess in clinic every 6 months with a repeat Baseline Assessment annually

→ **Follow up Assessment**
- HAT
- CCQ
- Screen for ADRs
- Physical Exam

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For suboptimal response or serious ADRs taper medication slowly over 4 weeks

Treatment Planning Summary

- Standardized baseline and follow up assessments
- Standardized timing of assessments
- Standardized dose titration
- Ongoing contact with Nurse Clinician for Adverse Drug Reactions

Care and Comfort Questionnaire

- **Please rate how easy or difficult it is for you or your child in the last two weeks to perform the following tasks relative to a cooperative**
- **individual without a disability (try to distinguish between motor control and abnormal tone as the explanation for the problem):**

- **Personal Care**
- 1. Putting on pants (trousers)? Very easy 1 2 3 4 5 6 7 Impossible N/A
- 2. Taking off pants (trousers)? Very easy 1 2 3 4 5 6 7 Impossible N/A
- 3. Putting on a shirt? Very easy 1 2 3 4 5 6 7 Impossible N/A
- 4. Changing diapers? Very easy 1 2 3 4 5 6 7 Impossible N/A
- 5. Ease of sitting on a toilet seat? Very easy 1 2 3 4 5 6 7 Impossible N/A
- 6. Ease of sitting in a bathtub, with or without adaptive equipment?
  - Very easy 1 2 3 4 5 6 7 Impossible N/A

Assessing the impact of therapy using an adapted questionnaire

Care and Comfort Caregiver Questionnaire (CareQ)

Patient's name: _____ Date of birth: __/__/__ Date of visit: __/__/__

Name of person completing form: _____

Relationship to patient: Mom Dad Other relative Other nonrelative

For the sections on personal care and positioning, please rate how easy or difficult it is *for you* (the caregiver) to perform the following tasks. In the right-hand column, please indicate how much of the task you would say your child is able to do himself or herself, for example, 20%, 50%, 80%, or some other percent that you believe is appropriate.

Thank you very much for taking the time to complete this questionnaire.

	Personal Care	Very Easy				Impossible	Child Is Able To Do:
1.	Performing oral-facial hygiene (eg, brushing teeth, washing face, combing hair)	1	2	3	4	5	___ %
2.	Putting on shirts	1	2	3	4	5	___ %
3.	Taking off shirts	1	2	3	4	5	___ %
4.	Putting on pants	1	2	3	4	5	___ %
5.	Taking off pants	1	2	3	4	5	___ %
6.	Changing incontinence pads or briefs (underwear)	1	2	3	4	5	___ %
7.	Cleaning buttocks or perineum with toileting	1	2	3	4	5	___ %
8.	Washing upper body	1	2	3	4	5	___ %
9.	Washing lower body	1	2	3	4	5	___ %

- Questions???