

Recognizing and Managing Pain in SMA

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Make today a breakthrough.



The Speakers have no relevant financial interests to disclose.

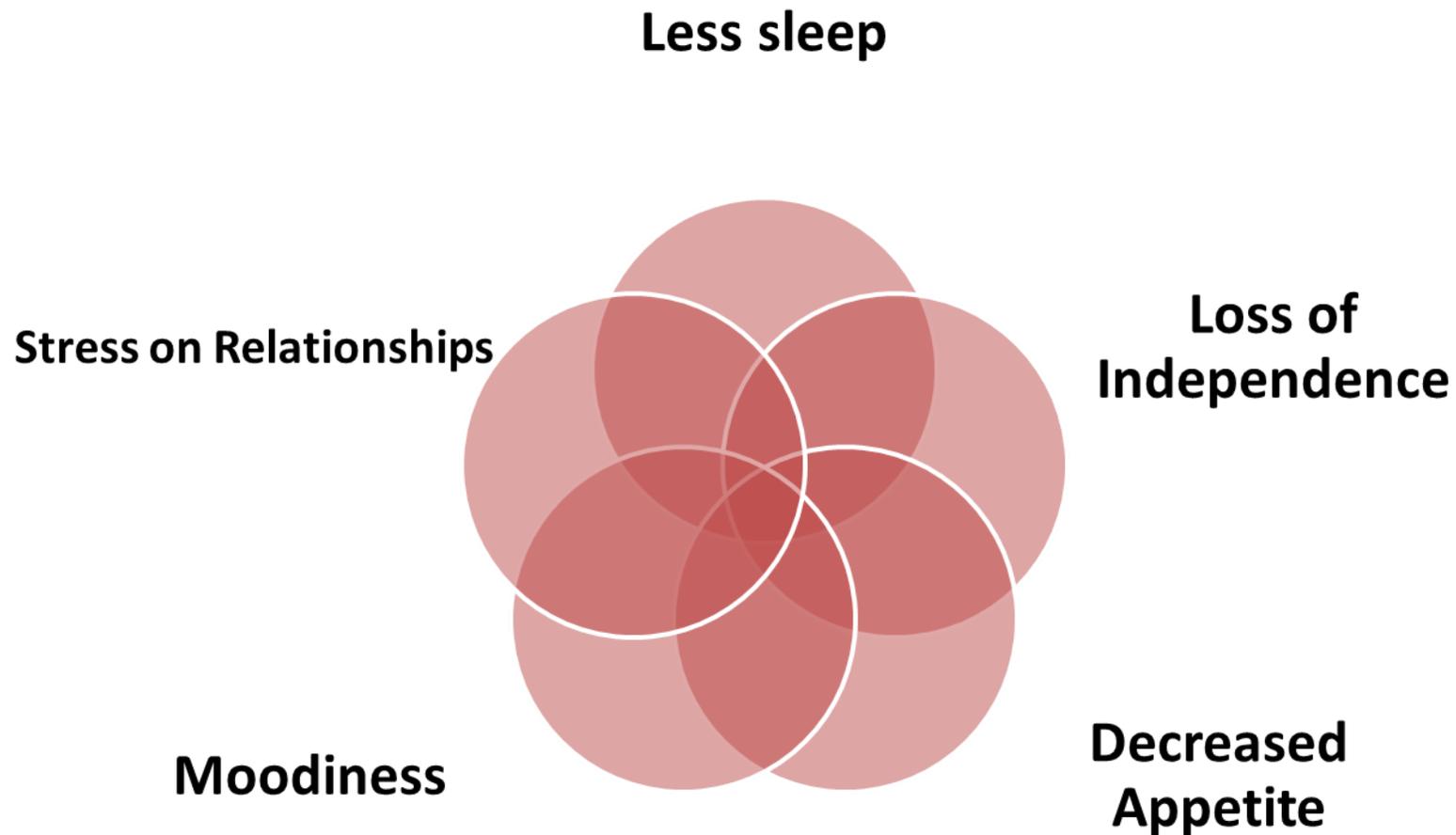
Objectives

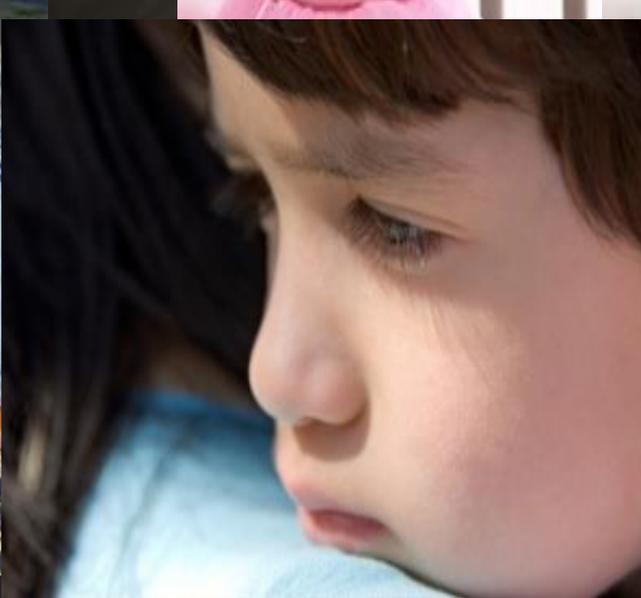
- Define Pain
- Discuss Potential Causes of Pain
- Review Pain Management Modalities
- Answer Questions

A Few Caveats on Pain

- Affects all aspects of life
- Multi-factorial (physical, psychological and emotional)
- Finding the source can be difficult and complicated
- Untreated pain can cause damage, affecting function and quality of life
- Learning skills to cope with chronic pain is essential
- Children may not have the words/language skills or ability to adequately describe pain, and thus their pain is often under treated

Untreated Pain Directly Affects Quality of Life





General Concepts about Pain

Myths Regarding Pain in Children (false beliefs)

- If you can distract a child, s/he does not have real pain
- Sleeping children are not in pain
- Behavior is directly related to pain intensity
- Pain builds character
- Infants have a higher threshold for pain
- Children will tell you when they are in pain
- Medications are always the best solution
- Medications are never the best solution

Considerations for Non-Verbal Children

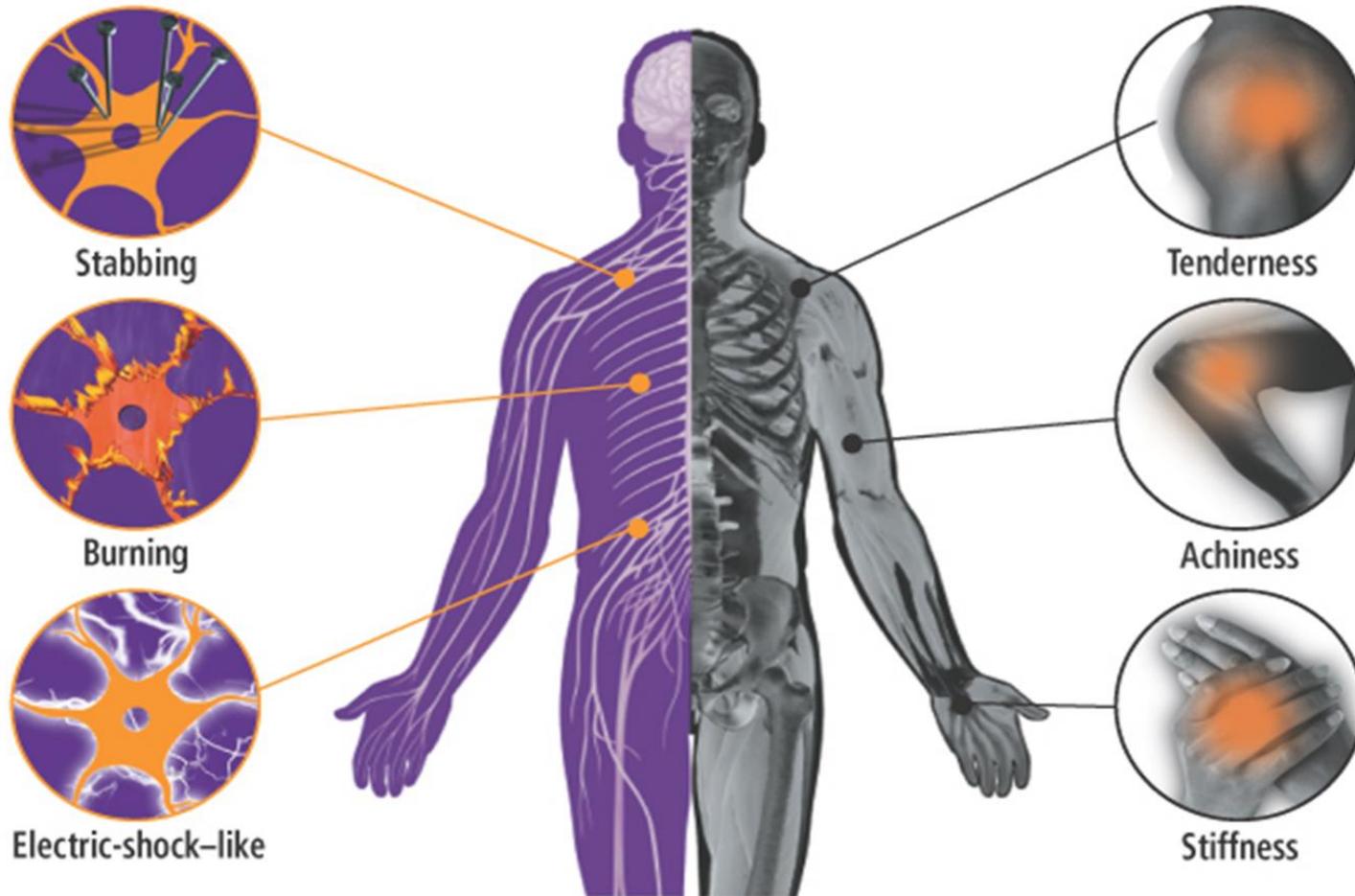
- ***Always*** consider other common sources of pain:
 - Constipation
 - Corneal abrasion
 - Dental pain
 - Ear infections
 - Fractures
 - Gastrointestinal reflux
 - Skin breakdown
 - Urinary tract infections (UTI's)

Common Types of Pain

	Acute (usu MSK)	Chronic (persistent)	Neuropathic	Procedural (episodic)	Referred
	Normal pain reaction to injury that gets better	Injury heals but pain continues. Pain lasts beyond expected recovery time	Pain caused by damage to the nerves	Pain from procedures	Originates in one part of the body but is felt in another
Time-frame	Short lived, < 3 months	Generally, > 3 months	Can be acute or chronic	Short lived	
Changes we see	<p>↑HR</p> <p>↑BP</p> <p>↑Perspiration</p>	<p>Appetite changes</p> <p>Sadness, Fatigue</p> <p>Moodiness</p>	<p>Tingling,</p> <p>Burning</p> <p>“pins and needles”</p>	<p>Fear, Anxiety</p>	

Neuropathic Pain (chronic)

Muscle/Skeletal Pain (acute)



What is Neuropathic Pain?

- Pain caused by injury or disease
- Difficult to treat and responds best using a multi-modal approach
- Can result in severe disability
- Medicines used to treat other types of pain don't seem to work for neuropathic pain



▪ American Chronic Pain Association . www.theacpa.org

Possible Causes of Pain in SMA

- Musculoskeletal
 - Joint pain
 - Scoliosis
 - Hip subluxation
(top of leg bone=ball of joint is partly out of socket)
 - Contractures – all joints but often knees/hips
(shortening of muscles, tendons or ligaments)
 - Muscle cramping / muscle spasm
- Fractures
- Positional
- Equipment (braces, wheelchairs, respiratory equipment, etc.)
- Immobility
- Pressure sores
- Pain after procedures (G-tube, scoliosis surgery, etc.)

Possible causes of Pain in SMA cont'd

	Pain Considerations	Treatment	Medication
Scoliosis	<p>-Severe curvature can cause irritation of nerves</p> <p>-Can lead to leg pain and affect breathing</p>	<p>PT/OT</p> <p>Bracing</p> <p>Surgery</p>	<p>Non-Steroidal Anti-Inflammatory</p> <p>Gabapentin</p>
Contractures	<p>Muscle imbalance</p> <p>Muscle weakness</p> <p>+/- Spasticity</p>	<p>Orthotics</p> <p>PT/OT PROM</p> <p>Repositioning</p> <p>Moist heat</p>	<p>Non-Steroidal Anti-Inflammatory</p> <p>Gabapentin</p>
Hip Dislocation		<p>Most recommend observation instead of surgery due to high reoccurrence rate</p>	

TIPS for Parents: Keep a Pain History

- Quality or nature of pain (what was happening when it started)
- Mode of onset and location (sudden, gradual, ongoing)
- Duration and chronicity (how long and how often)
- What makes it worse or better
- Description (throbbing, burning, dull, sharp, radiates)
- Timing of pain (does it happen at set times)

Tips for Parents: Pain Medication

- Don't wait for pain to be severe before treating
- Give at regular intervals to prevent pain before the next dose
- No single medication or dose will work for all children
- Weigh risk of, and treat, potential side effects

Integrative Therapies for Pain



Non-Medication Pain Treatments

Age	Pain Behavior	Intervention
Infant	<ul style="list-style-type: none"> •High pitch cry •Grimacing •Difficulty sucking •Avoiding eye contact •Inconsolability 	<ul style="list-style-type: none"> •Swaddling •Position changes •Gentle massage •Pacifier dipped in sugar water solution
Toddler	<ul style="list-style-type: none"> •Sleep difficulties •Protect area of discomfort •□ play/appetite •Irritable 	<ul style="list-style-type: none"> •Distraction •Art/Music Therapy •Guided Imagery •Massage •Aqua therapy
School-age and Adolescent	<ul style="list-style-type: none"> •Guarding •Insomnia •Mismatched cues •Quiet or Subdued •Irritable or Anger 	<ul style="list-style-type: none"> •Breathing techniques •Guided Imagery •Acupuncture (>8 years) •Hypnosis •Art/Music Therapy

Transcutaneous Electric Stimulator (TENS)

- TENS machines are thought to work in two ways:
 - Set on a high pulse it is thought to block a pain nerve pathway to the brain.
 - Set on a low pulse rate it stimulates the body to make its own pain easing chemicals called endorphins. These act a bit like opioids to block pain signals
- Pros:
 - Decrease need for pain mediation
 - Non-invasive
 - Can help relieve pain from muscle spasms
 - You are in control
- Cons:
 - Cannot be used if there is a loss of skin sensation
 - Cannot be used if patient has a pacemaker



Hot / Cold Therapy

Cold Compress	Decreases blood flow , decreases inflammation and pain	Injury, bruise, swelling	Can make tension and spasms worse 10-15 minutes on/off
Warm Moist Heat	Increases blood flow, relaxes sore muscles, decreases spasms	Chronic muscle pain, stress	Can make inflammation worse 10- 15 minutes on/off

Integrative Therapies

Use of conventional therapy, as well as complementary therapies, together in an individualized plan of care.

Guided Imagery

The deliberate use of the imagination to help the mind and body heal, stay well, or perform well.

Therapeutic Touch and Massage

“Therapeutic Touch is an intentionally directed process of energy exchange during which the practitioner uses the hands as a focus to facilitate the healing process.”

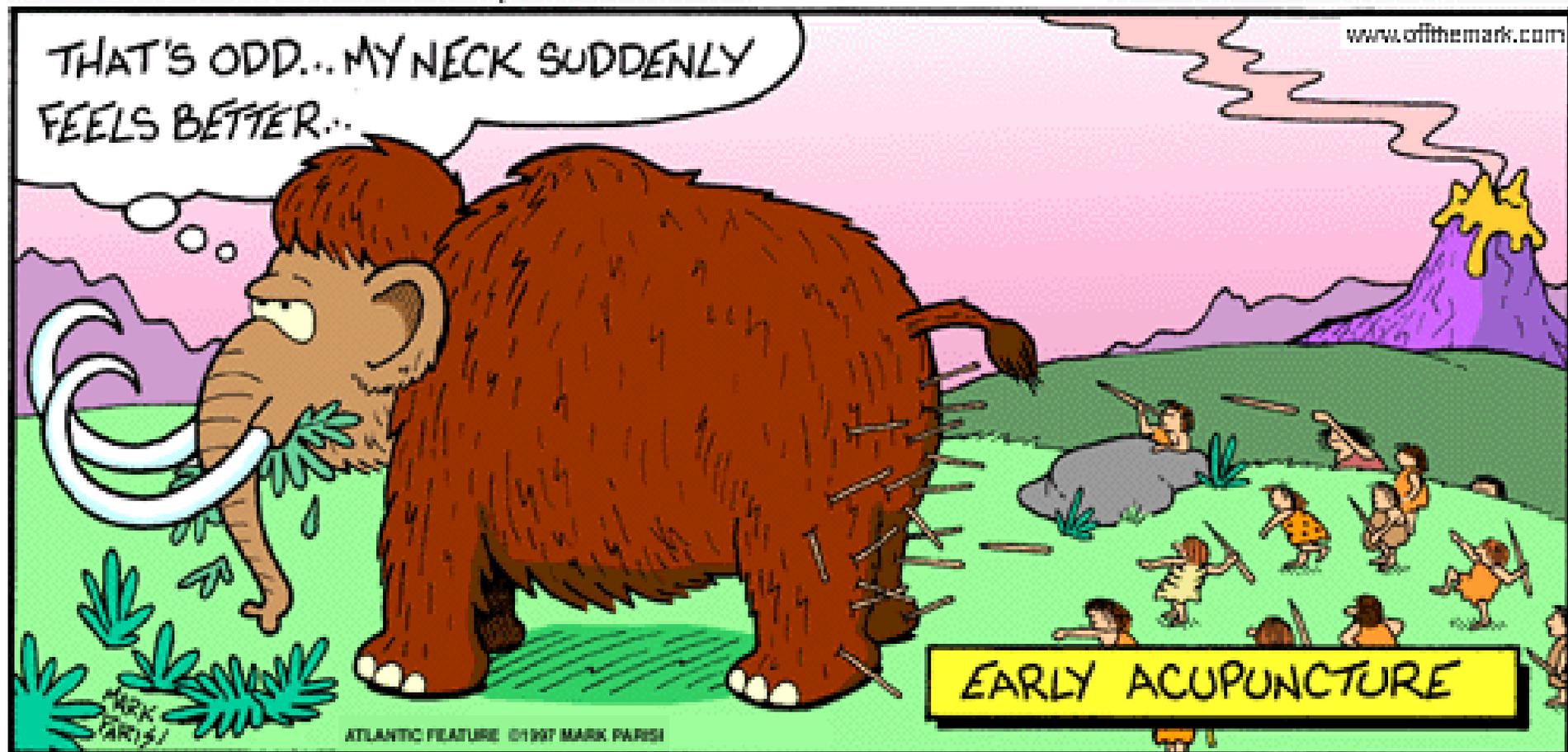
Nurse Healers-Professional Association

Acupuncture

off the mark

by Mark Parisi

www.offthemark.com



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Tips for Parents re: Procedures

1. Cuddle your child
2. If old enough, describe what will happen and how it will feel
3. Do not tell a child “it won’t hurt”. Instead say: “the pain will last a short time and feels like a “sting”, “poke” or “squeeze.”
4. Have items that are interesting or comforting
5. Consider using medications to numb skin
6. Stay calm: children sense parents fear/worry and this can increase their own fear/worry, which can increase pain
7. Use normal voice, smile, relax
8. AVOID words that focus on the procedure or increase fear: don’t say “It’ll be over soon” or “You’ll be okay” or “I’m sorry” or “I know it hurts”
9. Focus child’s attention elsewhere (activities, singing, toys, etc.)
10. Praise and reward
11. Pain medications afterward as needed

Questions?
Comments...

THANK YOU!!!

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<https://www.surveymonkey.com/s/2016AnnualSMAConference>

Or fill out the paper survey in your conference folder.

- All participants who complete a survey by 10:30 am on Sunday June 19th, will have their name entered into a raffle for a brand new iPad!
- The winners will be drawn and announced on Sunday, June 19th at the Closing General Session/It's a Wonderful Life.

