

NTSAD Care Tips



Motion & Massage

The first of a series of videos to help families understand different topics that may arise in caring for their child.

This series is meant for informational purposes only. It is not medical advice. Please consult your physician.

Massage

- Incorporate into activities when you're with your child from dedicated time for massage to working on different parts while they're on your lap, or at the beach, a park or a friend's or family member's house.
- Purpose is to keep their muscles moving and flexible
- Great cuddle time activity while being in tune with their responses
- Connecting all the senses – auditory and physical – while making the connections for them

When do you start massage?

- Do it now.
- Prevent contractions.
- Pre-emptive.
- Prolong the time between more extreme interventions like surgery.

Work all parts of the body

- Work in one direction – from head to toes or reverse
- Note breathing changes when working the muscles – that can tell you if they're uncomfortable or if they're relaxed
- Be gently firm and keep talking or singing to them. Explain what you're doing too.

Hips & Hamstrings

- Loosen and increase flexibility
- Work massage motions into diaper changes
- Use jojoba or cocoa butter for massage
- Crossed ankle position, butterfly rocking motions, pigeon poses

Hands

- Can be sensitive due to lack of sensory input of touching and exploring the world as other children do
- Lymphatic massage can help with puffiness in hands – working from fingers up arm to shoulder
- Spend time opening hands, move fingers

Back

- Massage alongside the spine with thumb the space between the spine and scapula (shoulder blades)
- Releases the tension and can help with "tummy time"

ILY (I love you) Massage & Digestion

- Use cocoa butter or oil
- Help digestion and encouraging healthy peristalsis (the movement of food from stomach through the digestive system) which is in a clockwise pattern
- I – massage on left side of stomach from bottom of rib down to hip in one direction
- L – massage from under right rib, across stomach and down the left side of belly button to above left hip
- Y – massage from above right hip up to underneath ribs, across top of stomach and down left side from left ribs to left hip
- When massaging abdomen, you can take the opportunity to help them stretch their torso, opening up the stomach, their chest and airways.

Tone

- Can fluctuate depending on disease progression and/or seizures
- Hypertonia
 - Limbs, joints and muscles are tight and contracted
 - Can cause extra calories to be burned
- Hypotonia
 - Opposite of hypertonia
 - Low tone
 - “Floppy”
 - Can be state after seizure activity
- Excess tone can lead to contracture where one set of muscles remain tight

Orthotics

- Use of orthotics can prevent contracture
- AFOs (Ankle Foot Orthotics) – support the ankle, can be used in combination with stander
- Wrist splints – keeps in hands in neutral position
- Watch skin irritation and weigh the benefit versus risk ratio
- Stander
 - Allows multiple avenues to interact with peers and environment around them
 - Allows body to be more open, allowing gravity’s benefits to work with digestion, bones, joints, respiration



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