

**All children with Prader-Willi Syndrome are born with abnormal tone and have physical and sensory deficiencies. The consequences of these dysfunctions may include:**

- Trunk/upper and lower extremity weakness
- Sensory integration deficiencies
- Skeletal abnormality (scoliosis and hip dysplasia)
- Oral-motor dyspraxia

### **BRUSHING AND JOINT COMPRESSION**

- Provide DEEP PRESSURE input to skin
- Should feel like a heavy massage
- Brush perpendicular to limb
- Imagine brushing the bone – bristles should bend
- Start with palm of hand, go up the arm (imagine painting a wall up and down)
- Move by turning the arm to match the brush
- Go to the back. You can brush up and down, side to side, or diagonally
- Continue to the other arm, then the palm of the other hand
- Follow this with deep proprioception to the joints
- Move to the foot and legs

What type of brush?

- Bristles should be soft

Do not brush:

- Face
- Neck
- Stomach
- Chest
- Genital regions

How to implement:

- Start with a 2 week trial
- Look for specific behaviors that will be affected
- Implement procedure 4-5/day
- If you see changes, continue for 1 month, then reduce
- This is an intense, specific treatment for a limited time - this is not forever!
- Child may need periodic 2 week “tune ups” around times of stress (after illness, after growth spurts, during holidays, etc.)

### **ROLLING:**

- Use a simple wooden rolling tool
- Roll up and down back from neck to bottom
- Implement procedure 4-5/day
- If you see changes, continue for 1 month, then reduce
- This is a treatment that should be maintained daily

**Your child has sensory integration problems if you see the following:**

- Inability to use eyes and hands together in a coordinated effort (eye-hand coordination)
- Poor balance
- Difficulty paying attention
- Doing the same thing over and over again (distractibility, perseveration)
- Avoiding movement or touch
- Low muscle tone (hypotonia)
- Difficulty maintaining alertness-frequent need to rest
- Unpredictable emotions (outbursts for no apparent reason)
- Difficulty adjusting to change in routine/transitions
- Difficulty organizing self and using self control
- Difficulty concentrating and using reasoning skills
- Poor understanding of relationships to objects in space (visual-spatial relationships)
- Poor understanding of what is being said to them (auditory processing)
- Gets upset at seemingly small changes in their environment (temper tantrums)
- Difficulty sleeping

**VESTIBULAR**

- Many balance problems can be tracked to the vestibular system
- Provides information about movement, gravity and changing head positions
- Helps us stabilize our eyes when we are moving and tells us if objects around us are moving or remaining still
- Need to accurately process vestibular (movement, gravity, head position) information to see, maintain posture, maintain balance, plan actions, move, calm down and regulate behavior
- A child needs to understand these spatial concepts in order to be able to translate information into the two-dimensional world of paper and pencil

**VESTIBULAR - what we see:**

- Falls frequently
- Hypotonic
- Clumsiness
- Unpredictable behavior
- Tantrums
- Overly impulsive
- Flicks fingers
- Decrease sense of safety
- Poor attention – vestibular input helps get the brain ready to act, think and participate
- Appears lost in space – vestibular system helps with telling where you are in time and space
- No handedness, delayed emergence of dominance, left/right confusion
- Tend to use longer periods of time to accomplish age-appropriate task
- Decrease in safety awareness

**VESTIBULAR - what we do:**

- Amusement park rides
- Bouncing on large balls, old mattress
- Games such as hop scotch, ball catch, soccer, baseball, hockey, tag
- Riding on trikes, bikes, scooters.
- Rocking on rocking horse or rocking chair
- Rolling and sledding down hills
- Roughhousing or wrestling
- Sliding down a slide
- Somersaulting
- Spinning on swivel chair, Sit & Spin, scooter board, tire swing
- Walking, running, hiking, swimming

**Calming vestibular** is slow, rhythmic, linear swinging or rocking, gentle, slow spinning in one direction, gentle bouncing

**PROPRIOCEPTION**

- Proprioceptive input provides unconscious awareness of body position and tells us about the position of our body parts, their relation to each other, and their relation to other people and objects
- It communicates how much force is needed for muscle contraction and allows us to grade our movements
- This system feeds back information about position, movement and balance from other systems, including the peripheral and central nervous system
- Receptors for the proprioceptive system are located in all of our joints
- Proprioceptive input can have a powerful calming and organizing effect on the nervous system

**PROPRIOCEPTION - what we see:**

- Bites and chews objects, hands and nails
- Clumsiness
- Exerts too much or not enough pressure when handling objects
- Grinds teeth
- Mushy speech
- Walks next to walls or gently touches them
- Tantrum and throws self on the ground
- Seeks heavy work activities, jumping, crashing, pushing, pulling
- Poor writing, difficulty with coloring between lines, stopping on time, letter formation, staying in or on line, works hard at writing-pressing to give input to hands
- Affectionate, hugs tightly, sits on lap
- Seeks enclosed/tight spaces for boundaries

**PROPRIOCEPTION - what we do:**

- Brushing, rolling, deep massage
- Digging in the garden
- Carrying heavy books, watering flowers, carrying luggage
- Catching and throwing heavy weight balls, beanbags, cushions
- Crawling through tunnels or boxes on the floor
- Gross motor activities - walking with backpack, biking uphill, obstacle course, toning exercises
- Hammering nails into logs or tees into styrofoam
- Hanging from monkey bars
- Jumping on a trampoline, old mattress or air mattress
- Karate
- Pillow fights or squishing between pillows
- Pounding and rolling play-doh or clay
- Pouring beans, sand or water from one container to another
- Pushing or pulling heavy laundry baskets, light furniture, wheelbarrow or weighted wagon
- Silly animal walks or wheelbarrow walking
- Swimming or extra bath time
- Tug of war with blankets or ropes
- Tumbling on the ground
- Weighted
- Weight lifting

**TACTILE**

- Tactile input provides us with information about light touch, pressure, vibration, temperature, and pain
- Feedback from this system contributes to the development of body awareness and motor planning abilities
- The tactile system has complementary protective and discriminative abilities
- Gives concrete feelings of body and environment, primary protective system
- Tends to detect sensory dysfunction easily because it is exposed to the most abuse

**TACTILE - what we see:**

- Desensitized to cuts and bruises, pain and temperature
- Does not like having hair or teeth brushed
- Drops objects frequently
- Flicks or shakes hands, rub face, or lick or chew on lips
- Needs extra personal space
- Picks at skin
- Sloppy eaters and dressers
- Sloppy hand writing, dropping the pen frequently
- Touching objects constantly

- Won't allow band-aids

**TACTILE - what we do:**

- Brushing, rolling and deep massage
- Deep pressure and joint compression
- Deep touch can calm and alert children.
- Dress up box with gloves, shoes, hats etc.
- Hand massages
- Painting with water, paint roller, soap crayons
- Pet care - brushing, grooming, petting
- Rubber gloves (doubled) filled with corn, rice, flour etc.
- Scavenger hunts, look for toys in objects like play-doh or sensory play materials
- Sensory toys to fidget with; Koosh balls, relaxable balls, slinkys, colorful paperclips, plastic pop beads, therapy tubing or bands to pull on
- Sensory buckets filled with pinto beans, rice etc and hide objects or game cards to find
- Sitting in padded or bean bag filled seat or air cushion
- Play musical instruments, piano, bells, drums, rhythm sticks
- Temperature variables discuss the differences between cool and cold, warm and hot
- Warm beds before going to sleep

**WARNING ABOUT LIGHT TOUCH:**

- Light touch is alerting (lightly move your hand over the hair on your opposite arm – this should feel slight uncomfortable)
- Using light touch alerts the protective system and can make the child feel threatened
- Activities involving light touch are difficult for many of our children -- for them, new clothes may be intolerable
- An insect bite can make some children crazy and they scratch until bleeding and deep
- Some children don't like finger-painting, glue, etc
- This really becomes an issue in social situations, in school, when someone touches your child in line, or while they are moving around
- Petting, tickling. Some children experience light touch as painful, uncomfortable or disconcerting

**ORAL-MOTOR**

- Eating is the most sensory intensive activity.
- Oral motor input (sucking) induces a calming and self-regulating state to allow an infant to learn about sensory input.
- Oral motor control supports head, neck and trunk development.
- Oral motor can help a child calm or alert themselves so that they can play and interact with their peers.
- What food do you choose to eat can be influenced by your calming or alerting qualities. Oatmeal or cereal?
- We can self-regulate with our mouth using food and non-food items.

**ORAL-MOTOR - what we see:**

- Difficult sucking or blowing through a straw
- Grinds teeth
- Inappropriate use of tongue and lips
- Poor suck and swallow
- Prefers to eat only sour, pungent, salty or bland

**ORAL-MOTOR - what we do:**

- Blowing bubbles, whistles
- Cold or frozen grapes, popsicles, frozen peas or carrots, flavored ice cubes crushed into ice chips
- Chewy bagels, dried fruit, fruit rollup, end of a straw
- Crunchy pretzels, vegetables, popcorn, apples, rice cakes
- Sour/tart – cranberries, tart lemon/lime wedges, war heads or sour candies, sour sprays
- Spicy – hot salsa, red cinnamon jellybeans, gum or Altoids
- Sucking – hard candy, citrus fruit wedges, lollipops, using a straw to suck up applesauce or jello
- Tugging, biting, pulling – licorice, beef jerky, fruit leather, a straw, or soft rubber tubing
- Warm – warm soup, oatmeal, warm tea

**CALMING TECHNIQUES**

**These help relax the nervous system and can reduce exaggerated responses to sensory input:**

- Warm or tepid bath
- Deep-pressure massage, back rub, deep brushing or roller
- Snuggling in a sleeping bag, beanbag chair or large pillow
- Firm pressure or skin to skin contact, bear hugs
- Swinging back and forth
- Slow rocking in a rocking chair, in an adult's lap
- Hideout, fort, or quiet corner
- Neoprene vest, Lycra/spandex clothing, weighted vest
- Lap snake or pillow made from dried beans
- Lavender, vanilla or soothing smells
- Sucking
- Fidget toys
- Hugging a teddy bear, self hug or adult hug
- Reduced noise and light levels (turn off the TV, radio and lights)
- Stretches

**ORGANIZING TECHNIQUES**

- Sucking (hard candy, long curly straws)
- Vibration (wiggle pen, toy massager, vibrating toys or pillows)
- Proprioceptive activities
- Chewing such as gum, hard licorice

- Swimming

### **SCHOOL AND CHILDCARE STRATEGIES**

- Visual information is easier to organize than verbal
- Minimize visual clutter
- Define their space - Are they in the middle of a class where the distractions are the highest or near a door?
- Encourage the child to be in the front or back of lines
- Build sensory activities into the day so that the child's system can stay in a calm state
- Allow self-soothing behaviors
- Use weight vests, hats, lap snakes
- Build movement into the schedule
- Allow time to switch from one activity to another
- Use color coded folders to keep order
- Use the strongest sensory systems to teach new activities
- Provide a quiet corner, room or place for child to go and relax (bean bag chair to read quietly)
- Have a rocking chair available for calming

### **SLEEPING STRATEGIES**

- Warm bath or shower
- Massage or joint compression prior to bed
- Weighted blankets (blanket with weights sewn into them, horse blankets)
- Body pillows, sleeping bags
- Swaddle an infant
- Try different types of pajamas, tight or loose, silky or cotton, determine which your child prefers
- Bed tent to block out distractions
- Neutral color on the walls
- Dark blinds to cut down on the light
- Back rubs and brushing
- Predictable bed routines
- Organized room, clean and uncluttered

**REFERENCES - CATALOGUES**

- Abilitations ..... 800-850-8602
- Sammons Presston ..... 800-323-5547
- Sensory Resources ..... 888-357-5867
- Oriental Trading Company Inc ..... 800-228-2269
- Beyond Play Early Intervention Products ..... 877-428-1244
- Super Duper Publications ..... 800-277-8737
- The Learning Shop ..... 800-236-7467
- Therapy Skill Builders ..... 800-228-0752
- Flaghouse Special Populations and Rehabilitations ..... 800-743-7900

**REFERENCES - BOOKS**

- The Out-of-Sync Child: Recognizing and Coping with Sensory Integration Dysfunction.  
Carol Kranowitz
- The Out-of-Sync Child has Fun.  
Carol Kranowitz
- How Does Your Engine Run? A Leader's Guide to the Alert Program for Self-Regulation.  
MS Williams and Sherry Shellenberger
- Smart Moves: Why Learning is Not All in Your Head.  
Carol Hannaford