



Therapeutic Interventions

for the Child the
Prader Willi-Syndrome



Written by:
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THERAPEUTIC INTERVENTIONS FOR THE CHILD THE PRADER WILLI-SYNDROME

*Working Together
To Change Lives!*

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Janice Agarwal, PT, CNDT

Chapter 1: What is a Pediatric Physical Therapist?

A pediatric physical therapist specializes in the examination, evaluation, treatment, and management of infants, children, and adolescents with developmental, neuromuscular, and skeletal disorders. Physical therapists collaborate with patients' families and other medical, educational, developmental, and rehabilitation specialists to promote the participation of children in daily activities and routines in the home, school and community. Physical therapy treatments improve gross and fine motor skills, balance and coordination, and strength and endurance. In addition, physical therapy treatments enhance learning opportunities and sensory processing/integration.²

All physical therapists currently must earn a graduate degree (either a master's degree or a clinical doctorate) from an accredited physical therapy program before taking a national licensure examination. A physical therapist must also be licensed in each state in which the therapist practices. Physical therapists are trusted health care professionals with extensive clinical experience who complete a thorough examination and then prevent or treat conditions that limit the body's ability to move and function in daily life.

Chapter 2: What is Early Intervention?

Early Intervention (EI) is a systematic program of therapy, exercises, and activities designed to address developmental delays that may be experienced by children with Prader-Willi syndrome or other disabilities. These services are mandated by a federal law called the Individuals with Disabilities Education Act (IDEA). The law requires that states provide EI services for all children who qualify, with the goal of enhancing the development of infants and toddlers and helping families understand and meet the needs of their children. The most common EI services for infants with Prader-Willi syndrome are physical therapy, speech and language therapy, occupational therapy, and social services.

Private and public health insurance programs cover payment for physical therapy, but the services and reimbursement may vary and families should be familiar with the benefits provided by the policy or program. In addition, provision of pediatric physical therapy is required legislatively by the following acts of congress:

The Individuals with Disabilities Education Act (PL 105-17, IDEA)

IDEA is a federal law that supports the provision of public education for all children regardless of the nature or severity of their disability. Part C of IDEA is an optional federal program that supports Early Intervention for infants and toddlers (birth to three years). All states currently participate in Part C.

IDEA includes provisions for pediatric physical therapy for children from birth to twenty-one years of age who are eligible for Early Intervention (Part C) or special education and related services (Part B) programs. IDEA interacts with other legislative mandates, such as the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and the Technology-Related Assistance for Individuals with Disabilities Act.

The Americans with Disabilities Act

ADA protects the rights of all individuals with disabilities.²⁵

Section 504 of the Rehabilitation Act

Section 504 requires the provision of reasonable accommodations, including physical therapy, for persons with disabilities.

When Should Early Intervention Start?

Early Intervention (EI) should begin any time shortly after birth, and should usually continue until the child reaches age three. An amendment to IDEA in 2004 allows states to have EI programs that may continue until the child enters, or is eligible to enter, preschool. Although it's never too late to start, the sooner EI begins, the better.

How Does Early Intervention Benefit Infants?

The first years of life are a critical time in a child's development. All young children go through the most rapid and developmentally significant changes during this time. During these early years, they achieve the basic physical, cognitive, language, social, and self-help skills that lay the foundation for future progress. These abilities are usually attained according to predictable developmental patterns. Because children with Prader-Willi syndrome face delays in all areas of motor development, EI is highly recommended.

Development is a continuous process that begins at conception and proceeds stage by stage in an orderly sequence. There are specific milestones in each of the five areas of development (gross and fine motor abilities, language skills, cognitive development, social development, and self-help skills) that serve as prerequisites for the stages that follow. Most children are expected to achieve each milestone at a designated time, also referred to as a "key age," which can be calculated in terms of weeks, months or years. Primarily due to hypotonicity (see Chapter 4, "Basic Issues for All Children with PWS"), infants with Prader-Willi syndrome will likely experience delays in certain areas of development. On their own timetable, however, infants with Prader-Willi syndrome will achieve each of the same milestones in the same order as other children. Remember, in monitoring the development of a child with Prader-Willi syndrome, it is more useful to look at the sequence of milestones achieved, rather than the age at which the milestones are reached.

Each service type provided in Early Intervention (EI) addresses specific aspects of an infant's development.

Physical Therapy

Physical therapy (PT) focuses on motor development. For example, during the first three to four months of life, an infant is expected to gain head control and the ability to pull up to sitting position with no head lag and enough strength

in the upper torso to maintain an erect posture. Obtaining this milestone and others will be delayed in infants with Prader-Willi syndrome, but with appropriate physical therapy these milestones will eventually be achieved.

Speech and Language Therapy

Speech and language therapy (ST, SPT, or SLP) focuses on the many pre-speech and pre-language skills that must be acquired before an infant says his or her first words. These skills include the ability to imitate and echo sounds; turn taking skills (learned through games like “peek-a-boo”); visual skills (looking at the speaker and objects); auditory skills (listening to music and speech for lengthening periods of time, or listening to speech sounds); tactile skills (learning about touch, exploring objects in the mouth); oral motor skills (using the tongue, moving the lips); and cognitive skills (understanding object permanence and cause and effect relationships).

As infants with Prader-Willi syndrome may not say their first words until two or three years of age, speech and language therapy during this early time period is crucial to help infants with Prader-Willi syndrome develop the skills needed to say their first words. While many children may have delays with speech they often have normal receptive skills for understanding speech.

For more information, see the American Speech-Language-Hearing Association at www.asha.org.

Occupational Therapy

Occupational therapy (OT) focuses on fine motor skills, activities of daily living (ADL's), and sensory development. These skills include opening and closing things, picking up and releasing toys of various sizes and shapes, stacking and building, manipulating knobs and buttons, experimenting with crayons, etc. As infants with Prader-Willi syndrome will need to learn to feed and dress themselves and learn skills for playing and interacting with other children, occupational therapy during early development is crucial.

For more information, see the American Occupational Therapy Association, Inc. at www.aota.org.

How Does Early Intervention Benefit Parents?

Programs for Early Intervention (EI) offer parents support, encouragement and information. Therapists teach parents how to interact with their infant and toddler while meeting their child's specific needs and enhancing development.

Parents and families have the primary role in their child's development. EI therapists collaborate with the family to implement an individualized program for the child. Families are supported through coordination of services, advocacy, and assistance to enhance the development of their child. For example, pediatric physical therapists help parents with:

- *Positioning* during daily routines and activities
- *Adapting toys for play*
- *Expanding mobility* (movement) options
- *Using equipment effectively*
- *Teaching safety for the home and community*
- *Providing information* on the child's physical and health care needs
- *Easing transitions* from early childhood to school and into adult life
- *Safe movement* throughout the home

Who Pays for Early Intervention?

The evaluation to determine whether your child is eligible for EI is free of charge if performed by a state-authorized entity. No child deemed eligible can be denied services based on ability to pay, but insurance companies may be billed and/or a sliding scale payment may be required, depending on the state in which you reside. Check with your state's EI center for information about authorized service providers and financial obligations. Frequently, there is little or no cost to parents for these services.²⁰

How Do I Sign Up for Early Intervention Services?

Parents can refer their own child. They can also get a referral for Early Intervention (EI) from their pediatrician, or find a local agency by visiting the website of the National Early Childhood Technical Assistance Center (www.nectac.org). Each state has its own set of laws governing EI services. Once a referral has been made, the program staff must schedule and complete an initial evaluation within a specified time.

Once the assessment is completed, a caseworker is assigned to coordinate the various services for which the infant and family qualify. EI services are individualized to meet the specific needs of each infant. The caseworker, therapists, and family will determine the duration, frequency, and location of services and will set goals based on developmental

milestones.

These will be recorded in a document called the **Individualized Family Service Plan (IFSP)**. The IFSP describes the process of planning, decision-making, and implementation of EI services for children and their families. This IFSP is periodically reviewed so that goals can be re-assessed by the whole team as the child progresses.

What Happens After Age Three?

Children age out of Early Intervention at age three. Children are re-evaluated by their school district to be approved for special education and continued speech, physical, and occupational therapy services administered through a preschool. The Individualized Education Program (IEP) is mandated by the Individuals for Disabilities Act to meet the needs of any individual with disabilities or special needs.

For more detailed information, visit this IEP guide on the Department of Education's website: www2.ed.gov/parents/needs/speced/iepguide/index.html

Chapter 3: APTA and IDEA Fact Sheet

APTA, American Physical Therapy Association
1111 North Fairfax Street
Alexandria, VA 22314-1488

Phone: 800-999-2782, ext 3254

Fax: 703-706-8575

Email: pediatrics@apta.org

Website: www.pediatricapta.org

IDEA, the Individuals with Disabilities Education Act

Implementation of IDEA Part C is the responsibility of each state through a lead agency appointed from education, health, human services, public health, or another related state agency.

Part C requires that multiple agencies work together and collaborate on meeting the needs of infants and toddlers and their families in their states and communities.

Eligible children have a developmental delay or a medical diagnosis that has a high probability of a developmental delay.

States define the eligibility criteria for developmental delay by addressing the child's development in cognitive, physical, communicative, social/emotional, and adaptive (self-help) domains.

Eligible infants and toddlers are entitled to Early Intervention (EI) services in natural environments where children live, learn, and play (their own homes).

EI services are provided, as necessary, to meet the developmental needs of the child and needs of the child's family related to the family's ability to enhance the child's development.

IFSP, the Individualized Family Service Plan

Parents are an integral part of the process and development of the IFSP and must be notified of their rights, including the right to due process.

Under IDEA, Early Intervention Child Find mandates evaluation and assessment, service coordination and development of an IFSP that must be provided free of charge. *EI services are free except when federal or state law provides for a system of payments by families, including a schedule of sliding fees.*

With parental consent, local agencies may access other funding sources, such as the state's Medicaid program. Additional rules and requirements pertaining to funding may be determined by the state.

The inability of parents to pay or utilize personal insurance must never prevent the delivery of EI services.

Chapter 4: Physical Therapy

Physical therapists use their knowledge and skills specifically related to motor and self-care function, assistive technology, and medical/ health care science to provide a unique contribution to the IFSP team.² Physical Therapists provide service by collaborating with the team, exchanging information with the family, and integrating interventions into everyday routines, activities, and locations.

How to Start Pediatric Physical Therapy

The process begins with an interview to identify the child's needs, usually while a newborn is still in the hospital, and continues with a physical and developmental evaluation of the child. This evaluation may include assessment of muscle and joint function, mobility, strength and endurance, cardiopulmonary status, posture and balance, and sensory motor and neuromotor development.

Basic Issues for All Children with PWS

Children with Prader-Willi syndrome exhibit low tone (hypotonicity), decreased muscle strength, delayed motor planning, dyspraxia, delayed gross motor skills, scoliosis, and decreased sensory awareness (such as oral motor deficits).

Hypotonicity

Hypotonicity (low muscular tone) is seen as excessive floppiness and inactivity. The child feels more flexible and difficult to handle. This is noticeable because considerable support may be necessary to stabilize the head and trunk during feeding, dressing, bathing, and carrying the child. This will often lead to difficulty in exploring their environment or bringing their hands or objects to their mouth. Movement is how children learn. If a child loses even a few months of this movement and exploration their cognitive and physical development can be adversely affected.

Hip subluxation may occur when the child's thigh and pelvic muscles are hypotonic. Legs are abducted (like doing the splits) and externally rotated (pigeon-toed). If you or your therapist are concerned about hip subluxation, speak with your pediatrician. An x-ray may be warranted.

Muscle Strength

Muscle strength is the amount of force a muscle can produce with a single maximal effort.¹⁶ Building muscle strength helps with body alignment and makes performing everyday actions easier. *Children with low muscle tone have the potential to strengthen their muscles.*

Motor Planning

Motor planning is the brain-body communication that allows one's brain to make a plan of action and have one's body carry it out.

Dyspraxia

Dyspraxia is difficulty in planning, sequencing, and carrying out unfamiliar actions in a skillful manner. Dyspraxia leads to poor motor planning.

Praxia is the ability to interact successfully with the physical environment to plan, organize, and carry out a sequence of unfamiliar actions, and to do what one intends, wants, and needs to do in an efficient, satisfying manner.¹⁴

Gross Motor Skills

Gross motor skills are movements that involve large muscle groups for crawling, walking, running, and other activities. Motor skills involve the movements of muscles in the body. Fine motor skills are movements of smaller muscles for actions such as grasping objects. Gross and fine motor skills usually develop together since most activities use both large and small muscle groups.

Scoliosis

Scoliosis is an abnormal lateral (sideways) curve of the spine. Scoliosis may be noted with infants who are encouraged to sit before their back muscles can properly sustain an upright posture symmetrically using muscles on both sides of the back. For many children with Prader-Willi syndrome, however, scoliosis occurs before they come up to sit. This type of infantile scoliosis will often resolve when parents, working with therapists, are able to aggressively strengthen their children's back and trunk (core) muscles. Physical therapists should strongly recommend that infants with scoliosis be placed in a functional compression bracing suit to assist with sensory-motor, neuro-motor, or musculoskeletal deficits.

These suits help a child develop and use postural control and movement mechanisms to perform daily activities in the most efficient and least energy consuming manner, and build a symmetrical and stable foundation for strengthening the core muscle

groups. The suits are often made of a Lycra material to provide a steady stretch tension while also guiding the internal soft tissue structures with compression. This compression provides deep pressure sensory information to the proprioceptive feedback system (see “Sensory Awareness” below), resulting in improved limb and body awareness, improved core muscle and joint stabilization, and increased activation and use of muscles.

If your child has scoliosis, work with your physical therapist to learn about the best type of compression brace for your child.

Sensory Awareness

As described by A. Jean Ayers, OT, in *Sensory Integration and the Child*: Sensory experiences include touch, movement, body awareness, sight, sound, and the pull of gravity. The process of the brain organizing and interpreting this information is called Sensory Integration (SI). Sensory Integration provides a crucial foundation for later, more complex learning and behavior.

For most children, Sensory Integration develops in the course of ordinary childhood activities. Motor planning ability is a natural outcome of the process, as is the ability to adapt to incoming sensations. But for some children, Sensory Integration does not develop as efficiently as it should. When the process is disordered, a number of problems in learning, development, or behavior may become evident.⁴

All children with Prader-Willi syndrome have Sensory Integration deficiencies. These weaknesses are manifested through poor motor skills, poor sucking, poor vocalization, poor body awareness, behavioral issues and cognitive development. Basic treatment strategies are described later in this book.

Work with your OT, PT, and SPT to address sensory awareness and develop a plan for the early years. Update the plan as children enter school to provide strategies to help them develop and be successful at all ages and in any environment.

PWSA | USA’s website (<http://www.pwsausa.org>) has several articles on sensory integration deficiencies and strategies.



Young children with PWS often have infantile scoliosis, which can usually be resolved with therapy and bracing. As a child’s trunk strength increases, the muscles can correct the curve. This child had a thirty-three degree scoliosis that decreased to seven degrees with one year of therapy and bracing.

Chapter 5: Physical Therapy Intervention

The goal of physical therapy is to facilitate normal development of gross motor skills, not to artificially accelerate the rate of gross motor development. It's important not to put too much emphasis on *when* our infants achieve their milestones, and to focus instead on *how well* our infants achieve each stage of development. These stages need to be achieved in the correct sequence, so that each subsequent stage can be built on the solid foundation of the prior stage. Although almost all of our infants will eventually obtain motor skills (regardless of the speed or order in which they are acquired), developing motor skills in the proper order ultimately translates into better strength and coordination.

Unfortunately, many parents, physical therapists, and insurance companies assume that the value of physical therapy is only measured by the speed with which a child achieves motor skills. Nothing can be further from the truth. How quickly a child goes from lying to sitting, and later to standing, does not address the underlying issues of hypotonia, lax ligaments, decreased strength and endurance, and decreased sensory motor awareness. If pushed too quickly, children with Prader-Willi syndrome will learn inefficient compensatory muscle movement patterns because they do not have a solid foundation in strength and coordination. If these compensatory patterns are not addressed properly, they will develop into significant orthopedic and functional problems.

One example would be how an infant learns to sit up independently, widely considered an important “milestone.” An infant who develops trunk muscles and sits before developing neck, chest, and shoulder muscles will be able to sit up, but once up, will not be able to hold his head upright, will not be able breathe efficiently (limiting lung expansion), and will not be able to rotate his trunk to help look around. This will lead to further difficulty when the infant learns to stand. Physical therapists help infants develop neck, chest, and shoulder muscle strength before working on trunk strength. Physical therapists will first work with a prone (on his stomach) infant to build muscles to support

lifting his neck so he can look around, then on chest wall muscles to help support his shoulder blades and shoulder joints, then shoulder and arm muscles to allow him to prop up, then finally on trunk, waist, and pelvic muscles. Developing support level-by-level keeps a child's spine and pelvis in proper alignment as he incrementally builds strength to hold each spine segment in place before he moves upright. If weak when upright, a child will not be able to use his arms and shoulders for support and protection when he falls. If weak when upright, a child will try to develop the muscles he needs for neck and chest strength, but these muscles will develop poorly (with compensatory movements). Appropriate physical therapy can minimize problems with trunk posture and facilitate correct muscle development. More advanced motor skills can then be built upon a proper foundation.

Treating injury is different from facilitating normal development. After an injury, children with PWS have difficulty maintaining correct motor development. If treatment of an arm or leg fracture requires immobilization or causes any decrease in activity level, it is imperative that therapy be started as soon as medically allowable to let the child relearn how to use the limb and correct the compensatory movements that will have developed due to the immobilization. Although normal tone children will almost automatically resume normal activity after an injury, children with PWS may not.

Instead, our children will take the easy way out and continue to use the compensatory movements learned during recovery. It is difficult but important to revert back to previously learned "normal" ways of movement. Children with PWS need to move through each stage of the developmental sequence in proper order without skipping ahead: rolling, pivoting, sitting, crawling, and so forth. Children develop postural control in stages, using sight as the dominant sense to achieve and maintain an upright position. The following are some of the milestones that our children need to master and the order in which they should be achieved. Parents and caregivers are encouraged to attend physical therapy sessions to learn exercises and techniques that can be carried over at home to help infants and children reach their milestones.



lex loves to ski. Instructors that have the necessary knowledge and equipment can provide amazing results. A family ski trip that includes a child with PWS is now a reality.

Normal Development in the First Year

Infants without delays follow a developmental progression that starts at birth. As the infant grows and his neurological system matures, gross motor skills will develop.⁶

First Three Months

The infant becomes increasingly alert and wants to look around and hold his head up to watch you talk or look at lights and movement. He begins to develop strength and coordination in his neck and upper back muscles.⁶

When prone (on his belly), he is able to move his head more efficiently. His upper extremity control increases and he is able to prop up on his forearms. While watching activities around him, he will start to shift weight side to side.

Around Four Months

As the infant gains control of his head, he will *roll over accidentally* as he reaches for a toy.⁶

Early movement at this age may start as “creeping” (pushing his body around on his stomach), scooting or crawling on one leg while dragging the other, or a combination of rolling and squirming on his stomach, back, or bottom. Shortly after this form of locomotion, most infants progress to hands-and-knees crawling. Most don’t start crawling until around eight months, when they are more independent with sitting.

Around Six Months

The infant has good control of his head and displays strong control against gravity. When placed into a seated position, the infant will balance himself by *propping up* on both arms.⁶

Shortly after this, infants will *move into and out of sitting without help* using both hands to move and then *sit independently* while mouthing or playing with a toy.

Around One Year

This is the time when an infant/toddler tries to pull himself up to a stand, then *cruise along furniture*, then *take a few steps*. This is the age when nothing is safe because kids get into everything!⁶

Infants with PWS: Year 1 (Before Walking)

Our children with Prader-Willi syndrome are often delayed in comparison to the normal pattern of development. Without interference their gross motor skills do develop in sequence, but not with the strength, balance, coordination, and motor planning control required to allow them to learn higher skills successfully. We must encourage their natural curiosity to reach out, explore objects, and interact with the environment.

Development takes effort, so we might as well make it fun.

The following are just ideas; your PT will establish an individualized program to treat your infant's strengths and weaknesses based on a detailed professional assessment. In accordance with the prescribed program, your PT will give you very specific instructions on wonderful ways to work with your child — however, this section provides a few general ways in which you can interact with your infant at home to encourage proper development at each stage of the process. Each developmental milestone will build on a previously developed skill as your infant learns many new movements and prepares himself for higher activities. Playing with your infant at home will make it possible for your infant to explore his surroundings and develop gross motor and cognitive skills.



A child lying prone on a stable pillow or boppy will raise his head to view objects and reach for toys while strengthening his neck, shoulders, and back.

Head Control

Head control is the first movement that an infant achieves and is necessary for sitting, crawling, and walking. Head control requires strength and coordination of neck muscles to allow the infant to flex (bend) forward, backwards, and side-to-side. An infant will first develop head control and good postural tone on the ground while prone (on his stomach), then while supine (on his back), and later in sitting.⁶

Intervention: Start in Prone

Due to the risks of SIDS (sudden infant death syndrome), all work done in prone needs to be monitored carefully.

Staying prone means staying on one's belly. Infants first develop head control and postural tone while on the ground, mostly when they are prone. An infant develops very strong shoulders when learning to prop up and look around. Infants should be allowed to slowly work to lift their heads up, to come up on their shoulders, and later, to come up on all fours and crawl. Strong shoulders mean:

- **Easier future development of fine motor skills** such as writing, playing with small toys, and developing soft and strong grips.
- **Better development of protective “righting reactions,”** or catching themselves with their extended arms, needed to protect heads when infants fall forward, sideways or backwards. Without proper strength in their shoulders

and trunks, they may walk but will have difficulty with advanced movements involving balance coordination.

- **A strong stable shoulder girdle**, which is required later for accurate speech sounds.

Infants with hypotonia often abduct their arms and legs from the trunk to increase their stability. Try placing a hypotonic child on his stomach over a small pillow, leg, or boppy and bringing his arms over the pillow. Place their hands on the ground to provide some weight bearing and give your child a chance to work on his spinal muscles and neck by encouraging him to look up at interesting objects or towards sounds.

Children that don't have proper strength in their shoulders and trunk may walk but will have difficulty with more advanced movements due to fear of falling and hurting themselves, otherwise known as postural instability.

One of the other issues that is improved with infants spending time on their bellies is a stronger pulmonary system. The rib cages of babies are set very high. As they develop strong trunks and abdomens, we see their rib cages start to drop and elongate, and breathing becomes deeper and more oxygen rich. Many of our children have unanticipated problems because of their pulmonary limitations. We want to give them every chance to increase their pulmonary function.



Pull to Sit:

Place the infant on your lap and gently, with hands on his shoulders, raise him to sit upright. Do not let their head drop back. This is a fun way to sit with your child and play.

Intervention: Pull-to-Sit

Another important way to develop head control is in the pull-to-sit position. Place the infant on his back (either on the floor or on your lap). Place both of your hands behind his shoulders, providing as much support as required so that the baby's head does not drop back. If the neck is very weak, place a hand behind his head rather than his shoulders. Slowly raise the child from the ground towards you. As the infant's neck gets stronger, you can do this by holding his hands and gently pulling the infant up to sit. This should only be done when the infant shows that he can bring his own head forward.



Pull to Sit (advanced):

When your child has more head control, you grab his elbows and slowly pull to sit. This requires strength in neck, shoulders, and core.

As you place your child back onto the ground, realize that this is a wonderful time to encourage him to look from side to side. If he

cannot move his own head from side to side, you can gently place your fingertips on his head and help him while he follows a toy with his eyes. You can also help your child bring his hands and feet to his mouth so he can start exploring his own body. This also encourages the strengthening of the abdominal muscles (belly).

Intervention: Sitting

Place the infant in an upright sitting position on your lap, facing you. With your hands behind his shoulders and his head initially supported by your knees (until he can hold it up himself), move him from side to side.



Encourage a child on his back to explore his feet and bring his hands to his mouth to strengthen his arms, legs, and core. This facilitates good sensory and body awareness.

Rolling

Rolling an infant from back to belly or belly to back requires some head control and the ability to rotate the body from hips to shoulders. Rolling is one of the first abilities that allows an infant to move around.⁶ Often, infants with PWS have difficulty initiating this movement.



Intervention: Place the infant on his back on the floor. Show the infant a bright toy. As he focuses on the toy, move the toy to one side. As the infant follows the object with his eyes, he will be encouraged to roll. If he cannot roll independently, gently hold onto his opposite leg and help him roll onto his side, and then over onto his stomach. Repeat for each side. This can become a fun game to play with your child!

Rolling Side-to-Side:

To roll an infant to the left, gently grasp his right leg and draw it across his body to encourage him to twist and roll over his left side to his belly. Reverse the motion to return him to his back, and do the same with the other leg. This can become a fun game with your child and it dramatically improves his vestibular system.

Sitting

The ability to maintain a sitting position requires an infant to have developed equilibrium reactions and protective reactions forward, side-to-side, and backwards.⁹

Equilibrium and righting reactions: Righting reactions can be broken into several different reflexes that serve to keep the head in a normal position, right the body to a normal position, and adjust the body parts in relation to the head and vice versa. The majority of the righting responses should be built into the nervous system before three years of age. The equilibrium reactions develop in childhood as well and are for



Propping Up

the purpose of maintaining or regaining control over the body's center of gravity.²¹

Intervention: If an infant has difficulty maintaining his balance, his equilibrium reactions can be improved by playing in sitting and challenging his balance in all directions. This should be done in a very safe environment with pillows all around, and the adult must be careful not to let the infant fall and hurt himself. If the infant falls to the side while in sitting, you need to try to teach him to use his hands for balance. Start by placing one of his hands out to the side. Gently shift him off balance to that side so that he needs to use that arm to maintain sitting balance. Try the same procedure on the other side.

Initially an infant sits by propping himself up with both hands in front. As his balance and upright posture improve, he maintains the sitting position by placing a hand to one side or the other as needed to keep upright. Eventually, the infant will be able to hold himself in a good sitting position without the use of hands for balance.⁶

Creeping and Crawling

Creeping is moving around on one's stomach. Some define it as squirming on one's stomach or rolling to obtain objects.

Some people prefer to call this "commando-crawling."

Crawling is raising one's stomach off the ground and moving around on arms and knees. Initially, it may start as scooting. This is when the child brings both arms forward simultaneously, followed by both legs. Eventually, this will progress to use of alternating arms and legs, usually once the infant sits well without support. He will also learn to rotate from a sitting position to his hands and knees. Their arms, legs, and back muscles need to be strong enough to keep him from falling on the floor as he does this.

It is vital that infants and toddlers not be placed too frequently in car seats, infant walkers, bouncy seats or other positions that limit their time on the floor on their stomachs. Belly time and experience bearing weight on the palms of their hands is vital to correct fine motor development, pencil grasp for writing, and attainment of fine motor skills to button and zip while dressing later in life.



Alex is just learning to move from prone to a sit. He has propped himself up on both hands for posture.



Alex is transitioning from creeping on his belly to crawling. His legs are abducted to provide increased stability.

Babies that are left on their backs for long periods of time often become bottom shufflers and do not go through the normal developmental stage of crawling. They transition into walking without having attained the necessary strength that they should have developed in their shoulders and back during crawling, nor all of the strength of their arms and hands as well as the sensory motor experience that are crucial to fine motor development in their adolescent years.



Work with your therapist to place tape on your child to encourage correct posture and provide shoulder stability to allow him to be more active.

Intervention

Up until this time, infants have been working on head, neck, shoulder, and back control while on their stomachs by propping up on a rolled up towel to allow placement of weight on their arms. As strength increases, their ability to look around and to reach out and touch objects becomes easier. Placing toys outside their reach and then putting your hands under their stomachs gives them just enough support to move toward the toy. Once the toy has been retrieved, you can gently remove your hand from their abdomen to allow them to fall back down to the ground. When infants are ready to do this on their own, they will become more vocal and will start pushing objects away. This is an important time — this is when infants develop the neural connections to learn how to push up on all fours. A parent or therapist coming to their infant's "rescue" to help them do what they need to learn to do by themselves robs infants of this needed opportunity. Postural control, balance, locomotion, and manipulation all come together in crawling.

Pull to Stand

Once an infant has developed the strength, coordination, and balance to move freely on the floor by crawling, he will begin to pull up to stand.

Intervention

Initially this will start with your child coming into a high kneel position on both knees, facing a sturdy piece of furniture, such as a coffee table. If your child is unable to assume this position, you can place him in this position yourself. Then position yourself behind them with your hands on his hips to keep him upright and gently shift him to one side, placing all of his weight on one knee, so that you can pick up the non-weight-bearing leg to assist him up into a standing position. You may need to keep your hands on his hips to guide him as he pulls himself up to the standing position.



High Kneel Position

As infants pull up to stand, they gain further strength and control in their trunk and leg muscles. Soon they develop enough strength and balance to cruise

along furniture, and nothing is safely out of their reach! This is a great time to work with your therapist to see if your child will need foot orthotics to correct any weaknesses that will lead to future problems in standing and walking.

If your infant has difficulty moving, you can help him improve his standing balance by gently shifting his weight from side to side and encouraging him to learn to balance weight on each leg. Place your hands at his hips as you shift his weight from one leg to the other.

Encourage cruising along furniture by placing a toy just out of reach along the edge of a couch or coffee table. With both of your hands on your child's hips as he supports himself while facing the piece of furniture, allow him to shift his weight to the leg farthest from the toy so that he can move his front leg closer to his intended goal. Once he places that foot down, shift his weight to his front leg and allow him to bring his trailing leg up to meet it. Once your infant has perfected this sidewise shuffling movement, he will soon be able to move around the furniture independently.



Alex is learning to pull up to stand. His therapist is using both hands on his hips to encourage weight shifting from one foot to the other to he can start cruising along furniture. The straps will help him move with less support.

Walking

As your child begins to walk, confirm with your therapists whether orthotics are required at this point. Children with PWS typically learn to walk with their feet wide apart, their knees stiff, and their feet turned out. Locking their knees, widening their base, and rotating their feet are strategies they will naturally use to increase stability. This very inefficient pattern will eventually develop into problems with the knees and feet. Infants will also find it difficult to move up to a narrow base of support, which is required to run and jump and play with their peers. Orthotics are sometimes recommended to eliminate this inefficient walking pattern.

Intervention

Place your child in a standing position behind a small push toy (with handles) that is very stable. Stand behind the infant with your hands on his hips for support. Move the object several inches forward and allow him time to shift his weight to one side, pick up a foot, and take a step forward. Repeat this as he continues to move the object forward. As his balance and posture improve, offer him less support. Try to make walking a fun and purposeful activity. Allowing an infant to hold a large ball or object will give him some confidence in walking around the room.

Children with PWS: Year 1-3 (After Walking)

Once your child is walking, you may find that your therapists decrease his physical therapy to one session per week. They may also increase his occupational therapy to two or three sessions per week as he starts to refine motor movements. This is a great time to make sure that your therapists are all communicating with each other to get the best carryover.

For example, your physical therapist should work with your occupational and speech therapists as to determine which sitting device will provide the greatest stability for your child's trunk when he is working on fine motor or oral motor activities.

Once children begin to walk, we want to refine how they walk and expand their gross motor skills. This process can involve lots of fun activities and exercises. For example:

- **Walking up and down stairs**, first with both feet meeting on each step, and then with alternating feet
- **Jumping down from a two-inch platform**, slowly increasing the height
- **Jumping on a trampoline** while you are holding both of their hands
- **Catching large balls** and throwing them back at you (this challenges their balance)
- **Starting to run**
- **Standing on one foot**
- **Kicking a ball**
- **Walking obstacle courses**
- **Walking on thick mats**
- **Balance beams** or walking on painted lines

Children will need good balance control for daily functional activities such as dressing, picking up objects, moving from indoors to outdoors, navigating uneven surfaces like grass or sand, and walking up and down hills.

Things parents can do to make these activities more fun:

- **Visit playgrounds** so they can play on the slides, climb the ladders, and swing!
- **Take them to mommy and me classes** or gym classes
- **Hippotherapy** – therapy on a horse

Children with PWS: Year 3-5 (Preschool)

Most children with PWS walk independently by the time they are in preschool. During the preschool years, normally-developing children continue to build gross motor skills such as running a bit faster while swinging their arms, jumping off small steps, climbing, skipping, catching and throwing, hopping (first on two feet, then on one foot), and riding a tricycle. Children with PWS, however, continue to have difficulty with these skills due to their hypotonicity and obstacles related to muscle strength, motor planning, sensory awareness, and the delayed development of earlier gross motor skills.



Alex is climbing a rope ladder. Climbing adds shoulder and arm strength to existing back muscles and builds legs. Climbing also encourages alternating arm and leg movements, builds confidence, and can be fun! Placing small toys at the top can be a fun reward.

Children with PWS: Year 6-12 (Grade School)

At this age, injuries become more common. Please remember that any injury should be followed with therapy as soon as is medically allowable. The period after an injury is also a great time to reassess a child for scoliosis and determine if orthotics will be of benefit.

Children with PWS can receive therapy services in school; however, be aware that due to the cutbacks in state funding of local schools, this has become more and more difficult to obtain in recent years. Still, if your child is having difficulty with balance and walking to and from classes, he should be eligible for continued help. In-school therapy is a great opportunity for your child's professionals to continue to help him refine gross motor skills such as running, hopping, and throwing and catching balls. It is also an excellent time to continue to work on the vestibular system (balance), the proprioceptive system (body awareness), and some more advanced movements.



Hippotherapy (therapy on a horse) stimulates muscles, mobilizes joints, increases sensory motor interpretation, and develops balance and equilibrium reactions. It also improves cardiopulmonary function, which may lead to improved speech production.

Even if your child is unable to obtain services in school, you should be able to find other ways to help him become more active through weekend and after-school programs. Many communities have clubs that may offer adapted team sports and other individual and group activities dedicated to children with disabilities. These sorts of activities can not only help your child continue to develop physically and learn discipline, but can also provide a great opportunity for you to meet other parents and find out what other community resources are available. Many organizations

work with a sliding fee scale to accommodate families with financial constraints. When your child has developed sufficient skills and confidence, he or she might also enjoy participating in the Special Olympics. (Registration for the Special Olympics begins at age eight.) And of course, there are many activities that can be done right at home as well. Here are just a few of the age appropriate activities you may be able to find near you:

- **Adapted team sports** (football, basketball, baseball, soccer, bowling, etc.)
- **Swimming**
- **Karate or tae kwon do**
- **Dance**
- **Tennis**
- **Running or walking programs**
- **Exercise, yoga, or Pilates**
- **Horse riding**
- **Special Olympics** (begins at age eight)
- **Backyard games** (tag, capture the flag, leaf-pile jumping)
- **Playing on play sets**
- **Video game fitness programs** for Wii, Playstation, or Xbox



Alex playing soccer. He started playing on our town teams. He was never the best, but he always tried the hardest!



Although riding a horse is great, any animal will do! We are an active family and include Alex in everything.



As our children grow older we need to encourage them to be active with our families. Hiking, biking, and swimming are just a few activities. While some adjustments may be required, the more we ask from our children the more they will give (all of our children).

Adolescents with PWS

As with younger children, if an adolescent with PWS sustains an injury, you should be sure to follow recovery with therapy as soon as possible — and remember to continue to screen periodically for scoliosis. If your child is heavy, it may be necessary to have them x-rayed in order to properly identify any signs of scoliosis.

Some adolescents do well in both group and individual activities such as those listed in the prior section, as well as in more specialized group classes like low impact aerobics or Zumba. The primary goals in choosing activities are for the kids to have fun while working to maintain core strength, build strong lungs and hearts, and manage weight.

Encouraging active lifestyles in general will also help control weight. The release of endorphins induced by exercise is an additional benefit; this can allow an adolescent to relax following a period of activity, and may help moderate poor behavior, promote healthy sleep habits, and ultimately lead to a better mood and more positive self-image.

Adults with PWS

Adults have similar needs to adolescents, but may have additional issues following the transition from a family home to a group home.

Ideally, group homes should provide regular, organized exercise time that is fun and motivational. If funding allows, bring in an exercise instructor to add variety and to assess the exercises led by group home coordinators. Local health clubs or colleges may be able to provide volunteer or low cost instructors.

Other ideas include:

- **DVD's for yoga, Pilates, or dance.** Kids and adults alike love to dance to jazz, swing, hip hop, and Zumba (Latin dancing).
- **Wii-Fit, Xbox Kinect, and other physically interactive video games.** Both Wii and Xbox offer a variety of fun activities. Some programs allow players to store weight and body mass information, then track weight loss as added motivation. It's also fun to design your own Wii avatar and watch it move as you move.
- **Swim classes at a local YMCA or school.** Supervised swimming is fun for all ages and is a treat of an activity.
- **Exercise equipment.** For overweight adults, machines that offer lower impact on joint, such as ellipticals and stationary bikes are preferred.

Chapter 6: Sensory Integration

Sensory integration is “the organization of sensory input for use.”⁴ This system enables the body to synthesize, organize, and process incoming sensory information received from the body and the environment to produce purposeful, goal-directed responses.

Sensory dysfunction is the ineffective neurological processing of information received through the senses, causing problems with learning, development, coordination, and behavior.⁴

Sensory integration theory is based on the understanding that neural plasticity (the ability to change) and sensory integration occur in a specific developmental order and that brain functions integrate the sensory and motor experiences.

Four main sensory systems play a role in the growth and development of the child: vestibular, proprioceptive, tactile, and oral motor.

Vestibular System

Vestibular receptors are in the semicircular canals of the inner ear. Improvements in vestibular function are often associated with improvements in hearing. Vestibular receptors provide information about movement, gravity, and changing of the head position, which helps us to stabilize our eyes when we are moving and tell us if objects around us are moving or remaining still. These skills affect balance, posture, righting reactions, muscle tone, seeing, attention, and regulation of behavior.¹¹

The vestibular system is one of the first sensory systems to develop in utero and is functional at birth. Children born with abnormal tone (decreased fetal movement) will have vestibular dysfunction and should start vestibular intervention as soon as possible to stimulate vestibular development (to catch up). Initially, that is as simple as rocking our babies over and over again. Placing your child in a mechanical rocking chair with

padding on both sides to support their head is a lovely way to start.¹⁷

What We see when the vestibular system is weak¹⁴

- **Hypotonia.** Because of low muscle tone, many of our children feel squishy when we squeeze their bodies and arms. If you shake their arms or legs, you will see their hands or feet flopping in an uncontrolled manner. They also don't help you when you are picking them up — it's like picking up a sack of flour.
- **Clumsiness.** We all know these children. Almost anything they touch falls, anything that can be broken will be broken, and any opportunity to spill or drop something will lead to a mess. They are also incredibly messy with feeding, get food all over their mouth and face, and really don't know they are doing this. They are the proverbial "bull in a china shop."
- **Difficulty learning new activities.**
 - Frequent falls. These are the children that seem to fall over their feet. They don't have the protective reactions to extend their arms in front of them to prevent their heads from hitting the ground when they fall. We need to be vigilant with this because the fear of falling will prevent our children from attempting new tasks or refining very simple milestones such as running, climbing stairs or hills, jumping, etc.
 - **Unpredictable behavior.** This starts to declare itself as our children reach the toddler stages and older. They can get upset at the simplest of things. They are easily distracted and taken off tasks. They have frequent tantrums.
 - **Overly impulsive.**
 - **Poor attention.** Vestibular input gets the brain ready to act, think, and participate. Without a vestibular system to help our children understand where they are in time and space, they often appear lost.
 - **No handedness,** delayed emergence of dominance, right/left confusion.
 - **Tends to take longer periods of time** to accomplish age-appropriate tasks.

What we do to strengthen the vestibular system

To lessen the fear of movement or positional change, start at very slow, tolerable speeds. A child will become upset due to sensory overload if over stimulated. Before, during, and after vestibular stimulation, the child should be assessed for overstimulation. Please work with your therapists closely as you start this therapy.

- **Swinging.** In a well-supported seat that provides head control. Linear activities strengthen motor development and will help with balance and extensor muscle tone.
- **Rocking.** Linear (back and forth) activities in a chair or on a rocking horse without head support. The sooner we start this the better, for newborn and up, even adults. Rocking chairs, rocking horses, or other rocking animals are great

ways to build vestibular function and help to calm a child who is upset. Many amusement parks have animals or cars that allow the child to rock forward and back.

- **Bouncing.** On large balls, air mattresses, or old spring mattresses. This is a wonderful way to work on the vestibular system and will immediately result in a more upright posture with better head control. With bouncing, as with other activities, we see a cascade of overlapping effects on several sensory systems.

Bouncing stimulates the proprioceptive system by compressing joints and developing better posture, which allows more appropriate swallowing and better control of fine motor activities. Blow up mattresses are wonderful tools for all children, allowing jumping, falling, and walking with balance. If you prop the mattress up against a wall, a child will have fun running and bouncing off of it. These are great ways to challenge your children in a safe environment.

- **Games.** Such as hop scotch, ball catch, soccer, baseball, hockey, and tag. All of these will depend on the balance system, and learning them early will help to refine it. These games cause our children to learn to shift their weight onto one leg to kick a ball, learn hand-eye coordination to play catch, and learn to control a stick held in their hands to play baseball or hockey. Physical games also force children to learn to maintain their balance while rotating their bodies and shifting their weight to accommodate for the movements of weighted objects.

- **Scooter boards.** Scooters — small square flat boards with four wheels — are an excellent tool to begin learning the balance required to ride wheeled vehicles. A child can lie or sit on the scooter and be pushed in multiple directions, travelling by spinning or in straight lines. These scooters help children to learn to maintain trunk and head control while using arms and legs to move about. With a group of kids, it's fun to set up mini scooter races. Kids should become familiar with linear travel (back and forward, or side to side) before working on spinning.



Vestibular therapy starts at birth! Swings and rockers will dramatically improve balance, posture, righting reactions, muscle tone, vision, speech, attention span, and behavior. Encourage all family members and therapists to engage in fun vestibular activities.



Children love to be pushed and pulled. We raised and taped the flaps to provide shoulder and trunk support. He loved to be scooted all over the floor and progressed to a laundry basket.

- **Trikes and bikes.** Significantly more advanced. A trike allows us to see if our children can maintain balance and look forward while their hands and feet are steering and pedaling (dissociate head and extremity movements). For many of our children, the greatest problem here is distractibility. Parents need to be reminded that getting a child with vestibular issues to ride a bike is fantastic, but not to fret if it cannot be done safely. Not all kids will ride bikes. If finances permit, a tandem bicycle can allow parents and caregivers to actively provide the benefits of biking with a safety net for moments of distraction. On a tandem, the child in back can talk to the person in front and let us know what is happening around us. Wonderful compromise!

- **Rolling and sledding down hills.** Initially, parents may have to deal with the sensory issue of our children not liking the feel of grass. Please start early with brushing and playing in sand and grass to overcome this issue. Rolling sideways down hills is a fun activity for any kid. Although many hypotonic children find it difficult to engage the stomach and back muscles needed to keep rolling down the hill, it's worth the dirt and grass stains on clothing to encourage vestibular strength and balance and build awesome memories. On snow this becomes even more fun, and it's faster!



Sledding down a hill after a big snowstorm!

- **Roughhousing or wrestling.** Many fathers love the idea of wrestling with their kids, but are scared to roughhouse because they feel children with disabilities are too fragile. Our kids love roughhousing and wrestling! They are not too delicate, and they will actually benefit from rough but careful play. Touch stimulates proprioception, rolling stimulates vestibular, giggling stimulates oral motor, and so on. I remember telling this to an audience of Dads. Many of them agreed they would love to play on the floor with their kids but that they were afraid to hurt them. Well, several years later, one of these Dads, a lawyer, came up to me to thank me. He told me how his 15-year-old son now waits at the door for them every day to come home from work so that they can wrestle together. Both look forward to this everyday and both are doing extremely well! So, getting on the floor or on a mattress and wrestling can be a safe and positive developmental activity, as well as a fun event for our kids.

- **Sliding down a slide.** Slides are a wonderful way to learn protective reactions. Our kids need to develop strong protective reactions to protect their heads if they fall. Always be there to hold your child so that they are not afraid to slide, then let them go down faster and faster with their arms in front of them. It will be fantastic training.

- **Somersaulting.** Our kids come into this world with such poor head control that we wince at the thought of somersaulting. Once children can walk and have good head control, placing them in a gym class with thick mats and someone to help them control the complete motion is great for the vestibular system and for confidence. This is safe if done in moderation with control and supervision.

- **Spinning.** On a swivel chair, Sit-and-Spin, scooter board, or tire swing. Spinning is initially very scary for many of our kids. Going around just once or twice and stopping to give them a cuddle will allow them to slowly accept spinning. Our goal is to get our children to ask for more and more. Once they get over the initial fear of something that feels different, hypotonic children crave spinning. I love watching kids spin themselves and then try to walk a straight line before falling. Once children get used to spinning, higher-level activities are obtained more easily as children have fewer and fewer fears.

- **Walking, running, hiking, and swimming.**

- **Aerobic, dance, or Zumba classes.** Kids love to dance. They love to feel the rhythm and the music. It really doesn't matter if they can keep the proper steps — just that they have fun. With repetition, the steps may actually come!

- **Wii-Fit and Xbox Kinect** provide a variety of fun activities. Both now have a number of games/programs that track names, ages, fitness levels, and calories burned. They are fun and can be played in all types of weather with minimal space.

- **Amusement park rides** — The more the merrier! Amusement rides challenge our kids while providing so much fun. You can use these rides to see how developed their vestibular system has become. If your child can handle the tea cup rides and asks for more, you've done a great job training their vestibular system. Try these rides only if you know your child has great head and trunk control.

Calming Vestibular

Calming vestibular movements involve slow, rhythmic, linear swinging or rocking, or very gentle bouncing motions. Begin by rocking your child in a chair or placing him (with adequate props for alignment and support) in mechanical rockers/swings. This should be started as soon as an infant is born, and I highly encourage it forever! Rocking will become a favorite activity to calm a child who feels stressed, needs to relax, or for other reasons needs to calm himself down. In a classroom where rockers may not be available, a child can



Rocking is Forever! Rocking has a very calming affect and should be encouraged daily.

bounce lightly on a large therapy ball when learning difficult or tedious material without disturbing the rest of the classroom.¹⁴

Proprioceptive System

The proprioceptive system receives sensory stimuli from receptors in all muscles, joints and connective tissue and sends it to our central and peripheral nervous systems (our brains and spinal cords). Without our needing to think about it, this system processes information about our body's position in space, the position of our body parts, their relation to each other, our balance, and our position relative to other people and objects (body awareness). It tells us how much force we need to contract our muscles and allows us to grade our movements. By reassuring us that we are where we think we are, proprioceptive input can have a powerful calming and organizing effect.¹⁴

What we see when the proprioceptive system is weak

- **Biting and chewing objects, fingers, or nails.** Often this is done out of boredom or during highly stressful times when children are trying to cope with their surroundings. It is a way of selfstimulating as an effort to not act out.
- **Exerting too much or not enough pressure when handling objects.** This can be seen when petting or holding a small animal. With incorrect proprioceptive input, children are not able to tell the difference between soft and hard touch and may pet or hold too hard. This can also be seen when holding a pencil or utensil. Objects are held so hard that a child's hand fatigues.
- **Grinding teeth.** This is often noted in the evening. Please discuss this with your dentist. A night guard to prevent significant damage to teeth and prevent temporomandibular joint syndrome (TMJ) may be recommended.
- **Mushy speech.** A child needs to be aware of the position of tongue and jaw to make controlled sounds and speech. Without this awareness, speech may not be intelligible.
- **Walking next to or gently touching walls.** Children have to be touching something all the time! With poor body awareness, continuing to touch walls after balance should be well developed is a crutch to add security when walking. It also gives them a better awareness of what is around them and how close objects are, and can calm anxieties due to poor balance or protective reactions.
- **Seeking activities involving weights.** Heavy work, jumping, crashing, pushing, and pulling. All of these activities put stress on the joints and give children more proprioceptive awareness, which makes them feel better, so of course, children will crave these activities.

- **Poor writing.** Working hard at writing, or difficulty with coloring between or within lines, stopping writing on target, forming letters, or staying on lines. Children will press down very hard to get more input into their hands.

What we do to strengthen the proprioceptive system

-Gross motor activities.

- **Brushing, rolling, deep massage.** In the shower or tub, use a cloth or sponge to rub arms and legs vigorously. Hand massagers are great to use on your child as well, or the child can feel and benefit from the vibration by using the hand massager to massage you! You may also want to learn the Wilbarger Brushing Protocol, a technique used in occupational therapy to address issues such as sensory seeking or defensiveness. It helps provide internal organization with tactile and proprioceptive stimuli. The program needs to be taught and supervised by an experienced OT — please speak with your OT for more information.¹⁶



Encourage your therapist to utilize weighted vests. The benefits include increased body awareness, balance, and orientation, and decreased impulsivity.

- **Digging in the garden.** This is especially fun if you dig for treasures that have been previously buried in the ground.

- **Carrying heavy items.** Books or luggage, or watering flowers with heavy watering cans. Weight lifting. Sleeping under blankets or quilts that have pennies or washers sewn in to add weight.

- **Pushing or pulling heavy objects.** Laundry baskets, light furniture, wheelbarrows, or weighted wagons.

- **Make a human burrito or sandwich.** Firmly press on your child's arms, legs, and back with pillows, or make a "burrito" by rolling him up in a blanket.

- **Tug of war** with blankets or ropes.

- **Catching and throwing** weighted balls, beanbags, and cushions.

- **Crawling** through tunnels or boxes on the floor.



Climbing increases overall body awareness and encourages strengthening, and is also fun.

- **Animal walks.** Crab, bear, penguin, or other silly animals. Wheelbarrow walking (the adult holds the child's legs like wheelbarrow handles while the child walks on his hands while facing the ground).

- **Walking, biking uphill, running obstacle courses,** or toning exercises with a backpack filled with a small amount of weight.

- **Hammering** nails into logs or tees into Styrofoam. Pounding and rolling Play-Doh or clay.

- **Hanging** from monkey bars with supervision.

- **Jumping** on a trampoline, old mattress, or air mattress. Start by holding a child's hands while he jumps.

- **Karate.** This is also great for balance and strength and can be fun for the entire family.

- **Pillow fights** or squishing between pillows.

- **Pouring** beans, sand, or water from one container to another. With simple bowls, spoons, or buckets and small items to bury and dig back out, sand boxes can provide endless therapy and amusement for a young child. If you are planning this activity outdoors, you can use bird seed so if it spills, it will be eaten!

- **Swimming or extra bath time.** Swimming is an activity your child can enjoy lifelong. Many communities and schools offer swim lessons and have swim teams.

- **Tumbling** on the floor or in the grass.

Tactile System

The tactile system provides information about the environment by the sense of touch. Stimulation of the tactile system is received by receptors in the skin, which is the largest organ of the body. The system has two components. The first is the protective system which senses if touch is harmful due to pressure, temperature and pain; the other is the discriminative system which senses the difference between harmful and beneficial touch.¹⁵

What we see when the tactile system is weak

- **Desensitization** to cuts and bruises, pain, and temperature. It is very important that we be vigilant to injuries or changes and the possibility of heat stroke or frostbite.

- **Does not like having hair or teeth brushed.**

Gingivitis and damage to the roots of teeth are frequent complaints. Work carefully with your dentist. Quarterly visits for cleaning are recommended.

- **Flicks or shakes hands**, rubs face.

- **Licks or chews** on lips.

- **Picks at skin** or hangnails.

- **Sloppy handwriting**, eating, and dressing.

What we do to strenghten the tactile system

- **Brushing, rolling, deep massage.** In the shower or tub, use a cloth or sponge to rub arms and legs vigorously. Hand massagers are great to use on your child as well, or the child can feel and benefit from the vibration by using the hand massager to massage you!

You may also want to learn the Wilbarger Brushing Protocol, a technique used in occupational therapy to address issues such as sensory seeking or defensiveness. It helps provide internal organization with tactile and proprioceptive stimuli. The program needs to be taught and supervised by an experienced OT — please speak with your OT for more information.¹⁶

- **Deep pressure and joint compression.** Deep massages, tight clothing. Work with your therapists to learn different techniques to help you.

- **Dress up boxes** with gloves, shoes, hats etc.

- **Massage hands.** This is also an excellent technique to calm a fidgety child when you need for him to relax. We often use this during shows, long plays, or movies. Adding a massage of the feet is also encouraged.

- **Painting, finger painting or with brushes.** Sitting or standing both encourage sensory activities, posture stabilization, and fun!

- **Pet care** — brushing, grooming, petting.

- **Rubber or latex gloves** (doubled) filled with corn, rice, flour, etc. Children love to play with these. Use them when you need your child to be quiet or attentive during school, at a play, or at events that require long sitting.



Jumping on a trampoline provides excellent joint and muscle stimulation and encourages balance and cardiopulmonary function, but it needs to be CLOSELY supervised.

- **Scavenger hunts.** Look for toys in objects like Play-Doh or sensory play materials.
- **Sensory toys.** Let kids fidget with Koosh balls, slinkies, colorful paperclips, plastic pop beads, therapy tubing, or elastic bands. Have several so that they can be rotated.
- **Sensory buckets** filled with pinto beans, rice, etc. Hide objects or cards in the buckets for treasure hunts.
- **Sitting on padded seats,** beanbag chairs, or air cushions.
- **Playing musical instruments,** piano, bells, drums, rhythm sticks.
- **Temperature variation.** Discuss the difference between cool and cold, warm and hot.
- **Warm beds** before going to sleep.
- **Sew washers or pennies into bedding** to create weighted blankets. Initially, infants will need to learn to accommodate to this new weight, but once they adjust, they will find it easier to sleep.

Oral-Motor System

Eating is the most sensory-intensive activity. Oral-motor issues such as sucking and chewing difficulties are due to weak lip, cheek, and tongue muscles and lack of jaw stability. A child's lack of early hand-to-mouth and toy-to-mouth play also contributes to increased sensory deficits.¹⁵

Oral-motor input plays a large part in maintaining a child's/individual's level of sensory arousal:

- **Oral function** is connected to posture and respiration.
- **Oral-motor control relies on proper stabilization** of the head, neck, and trunk.
- **Suck-swallow-breath synchrony plays an important role in a child's arousal levels.**
- **Oral-motor input (sucking) induces a calming and self-regulating state** to allow an infant to learn about sensory input.
- **Oral-motor input can help a child calm or alert themselves** so that they can

play and interact with their peers.

- **Eating is the most sensory intensive activity.** Oral diets will consist of a variety of tastes, textures, and temperatures and will encourage sucking, blowing, biting, crunching, chewing, and licking.

Parents can work with speech and occupational therapists to devise plans to stimulate oral-motor activity. PWSA | USA's website (<http://www.pwsausa.org>) has updated articles on sensory integration and treatment ideas for oral motor deficiencies.

Oral-motor treatment will aid in increased oral-motor and gross motor function in the following ways:

- **Sucking can promote increased trunk flexion.**
- **Blowing can promote trunk extension.**
- **Biting can promote jaw, neck and shoulder, and pelvic stability.**
- **Crunching and chewing can promote balance/stability** and mobility in the jaw, neck, shoulder, and pelvis.

What we see when the oral-motor system is weak

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



Alex kissing a giraffe. Actually, the giraffe is very gently retrieving a very small piece of food on Alex's lips.

What we do to strengthen the oral-motor system

- **Blowing.** Bubbles or whistles, playing musical instruments, making tooting sounds.
- **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.
- **Sour/tart.** Cranberries, tart lemon/lime wedges, Warheads® or sour candies, sour sprays/powders.
- **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.
- **Spicy.** Hot salsa, red cinnamon jellybeans, gum or Altoids®.
- **Warm.** Soup, oatmeal, tea, cider.

Blowing, sucking, and chewing activities can significantly improve a child's ability to calm himself, attend to difficult tasks, keep control of body movements, and support his airflow for speech. Sucking and blowing activities in particular help develop breathing and the support posture needed to sit upright. The longer the straw and the thicker the liquid, the more work it takes to suck the liquid. Sucking also helps calm a child down, and deep breathing helps relaxation. Blowing or sucking through a straw or other tool also requires watching, so these activities can also strengthen the eye muscles used to focus sight.

Chapter 7: Calming Techniques

Many activities can be calming, help relax the nervous system, and reduce exaggerated responses to sensory input. Calming activities and techniques include¹⁵:

- **Warm or tepid bath.**
- **Deep-pressure massage**, back rub, deep brushing or roller; massaging a child's hands or feet during activities that require him to sit for long periods of time.
- **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 adults lap or a hammock.
- **Neoprene vest**, Lycra/spandex clothing, weighted vest.
- **Tube socks or pillows filled with dried beans.**
- **Lavender, vanilla, or soothing smells.**
- **Sucking hard candies or lollipops.**
- **Fidget** toys.
- **Hugging** a teddy bear, self hug, or adult hug.
- **Stretches.**
- **Hideout**, fort, or quiet corner.
- **Reduced noise and light levels** (turn off the TV, radio, and lights).



"Sucking and blowing activities in particular help develop breathing and the support posture needed to sit upright."¹⁴

Chapter 8: Organizing Techniques

Organizing techniques provide sensory input that satisfies a child's immediate needs so that he can focus on tasks or activities. These may include:

- **Sucking.** Hard candy, long curly straws, lollipops, pacifiers, or chew toys. Please discourage sucking on shirts or fingers by providing a replacement object.
- **Chewing.** Gum, hard licorice, gummy bears, or similar sugar-free candies, bagels, or firm bread.
- **Vibration.** Wiggle pen, toy massager, vibrating toys or pillows.



Deep-Pressure Massage

- **Proprioceptive activities** can be both calming and organizing. Placing a weighted toy or vest on a child's lap can help HIM calm down and listen to a teacher. Placing your hands on HIS shoulders and firmly pushing downwards will also relax and calm down a child. A big long hug will also relax. If you see a child start to become disorganized or upset, starting with a hug may prevent a tantrum.
- **Carrying a weighted ball or heavy object** from room to room or pushing a heavy object will also help a child calm down and stay focused.

Chapter 9: School and Childcare Strategies

Both calming and organizing activities need to be utilized as part of an Individualized Education Program (IEP). Teachers, aides, and care providers need to know how to take advantage of sensory input to help a child learn.

- **Visual information is easier to organize** than verbal information. Make a picture chart for daily activities.
- **Use the sensory systems to teach new activities.** Including visual and tactile (and taste if appropriate) input with new activities will increase the chances or greater learning potential.
- **Minimizing visual clutter decreases distractions** and allows better focus.
- **Defined workspace.** Children should be near the front of the classroom where it's easier to maintain focus on the teacher, rather than near a door or in the middle or back of a class where the distractions are greatest.
- **Encourage the child to be in the front of lines.** If the line leader position is rotated among students, then the back of the line is a good second choice, as it will have fewer distractions than the middle.
- **Allow time to switch from one activity to another.** As much as possible, keep to a routine and announce transitions well before they need to occur.
- **Building movement and sensory activities into the day** helps a child remain in a calm state.
- **Allow time for self-soothing behaviors.** Have a rocking chair available for calming time.
- **Provide a quiet corner,** room, or place for child to go and relax (for instance, a bean bag chair to read quietly).
- **Use weighted vests, hats, bean-filled socks to help calm a child down.** If you know that a child will be placed into a new situation or needs to really focus on a task, placing a weighted object on his lap will set them up to successfully

stay calm and learn.

- **Use color-coded folders** to keep order.

Chapter 10: Sleep Strategies

Calming strategies help a child get to sleep:

- **Warm bath or shower.**
- **Predictable bedtime routines.** Predictable bedtime routines. Bedtime should be the exact same time every night. Children prefer the routine and will develop a better sleeping pattern.
- **Massage or joint compression** prior to bed. Back rubs and brushing.
- **Weighted blankets.** Blankets with weights sewn into them, heavy quilts, horse blankets.
- **Body pillows, sleeping bags.**
- **Swaddle an infant.**
- **Different types of pajamas.** Try tight or loose, cotton or silky, to determine what your child prefers.
- **Bed tent to block out distractions.** Dark blinds to cut down on the light.
- **Neutral color on the walls.**
- **Organized room,** clean and uncluttered.

Conclusion: Sensory Diets -- A Daily Plan for Sensory Stimulation

People of all ages, with or without Prader-Willi syndrome, rely on various types of sensory stimulation to stay alert, focused, and organized. Many of these sensory activities take place unconsciously or unintentionally, such as chewing gum during a meeting or a class, doodling during a telephone call, or tapping a pen against the table while working out a difficult crossword puzzle.

A sensory diet is an activity plan that provides this kind of sensory input in a regimented and intentional fashion to help individuals (like those with Prader-Willi syndrome) who may have particular difficulty with tasks that the rest of us take for granted to stay focused and organized. Such a plan will draw upon a variety of the activities discussed throughout this book in order to stimulate the individual's various sensory systems on a regular and consistent basis. A trained physical and occupational therapist will be able to help you develop the right plan for your child, and to adjust it as his needs and abilities develop.

The effects of a sensory diet are both immediate and cumulative. In the short term, certain sensory activities can help a child to perk up or calm down within a given situation; however, in the long term these same activities can actually help to restructure your child's nervous system over time so that he will be able to integrate more appropriately to activities, develop a longer attention span, and handle transitions more easily.

As with other aspects of a child's education and development, a sensory diet should be based on the observations of the child's various caregivers and developed in collaboration with his treatment team — including parents, teachers, additional caregivers, and therapists. Sensory diets are a lifelong commitment requiring the correct recipe and consistent application, and they will often change over time. It's important therefore to make sure that all involved are kept up to date with any changes, and that the advice and observations of all parents and professionals are taken into account. Applied properly, the right sensory diet will have an important positive impact on your child's life and relationships.

On the following page is an example of a home sensory diet designed for an eight-year-old child in elementary school. A separate program would be devised for when the child was at school (including such activities as taking “movement breaks,” or providing crunch/chewing oral comfort while doing handwriting or listening to stories). Remember that every child develops differently, and should have his own unique program — you should always consult your therapists when developing a sensory diet for your own child.

Sample Sensory Diet

In the Morning:

- **Massage feet and back** to help wake up.
- **Use vibrating toothbrush** or hairbrush.
- **Eat crunchy cereal** with milk.
- **Jump on mini trampoline.**

After School:

- **Go outside and play** on playground equipment.
- **Push grocery cart** or weighted laundry baskets (help with laundry or household chores).
- **Spinning** as directed.
- **Massage feet** to “reorganize,” use therapy putty, make body sandwiches.
- **Oral-motor** — use thick liquids through a straw, eat crunchy or chewy snacks or chew gum before table activities such as handwriting or coloring.

Dinnertime:

- **Help set table.**
- **Provide crunchy or chewy foods**, or add a bit of spice or tartness.

Bedtime:

- **Warm bath** with bubbles and calming essential oil.
- **Massage** during reading time.
- **Lights out** at same time every night.

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