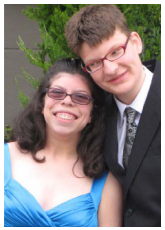
Social Skills Therapy



The foundations of social relationships begin in infancy, therefore parents and care providers should focus upon building social skills as early as possible with the help of a professional, such as an Infant Stimulation Therapist, who can facilitate the social exchange between infant and care provider.

For many reasons including speech problems, processing delays, physical limitations, neurocognitive impairment, learning disorders and sensory integration issues, children with Prader-Willi syndrome often need extra help learning appropriate social skills. Social Skills Therapy often begins from age three years, and sometimes as early as two years, to help the child develop and strengthen social and play skills necessary to initiate, develop and maintain genuine, fulfilling and long-lasting friendships. Social Skills Therapy is often provided by a Speech & Language Pathologist in a group setting.

Behavior Therapy and Psychiatric Intervention

Behavior management is a crucial component to reduce behavior problems and ensure a safe, high quality life for everyone impacted by PWS. It is critical to establish and maintain daily routines and structure, set firm limits, discuss ahead of time any known deviations from the schedule, and anticipate and prepare for potential problems. It is also critical to adhere to the Principles of Food Security[1] and incorporate Collaborative Problem Solving[2] techniques. A Functional Behavioral Analysis should be conducted prior to creating a Behavior Therapy Plan in order to determine the antecedent events and/or secondary gain motivators of any behavior problem.

For some persons with PWS, the body's biochemistry overwhelms all environmental attempts to reduce anxiety and necessitates the use of psychotropic medications. Such medications can be helpful to reduce the often high levels of anxiety, depression, obsessive-compulsive symptoms, and sometimes psychotic symptoms that can occur with PWS. A physician who specializes in Psychiatry can diagnose and prescribe appropriate psychotropic medications.

[1]Developed by Linda Gourash, MD and Janice Forster, MD of *Pittsburgh Partnership*

[2]Developed by Ross Greene, PhD of the *Center for Collaborative Problem Solving*

Prader-Willi California Foundation and the national Prader-Willi Syndrome Association have an extensive amount of materials available for parents, physicians, therapists, caseworkers, and school staff. Please contact PWCF or PWSA (USA) so that we may provide more detailed information, support and advocacy services for you, your child, your patient, your client, your consumer, or your student.

The outlook for a person with Prader-Willi syndrome is more hopeful today than ever before. Today, with strict food control, the person with PWS may have a normal life expectancy and can accomplish many of the things their "typical" peers do — attend school, enjoy community activities, work, even move away from home to an appropriate, supervised and structured residential setting. Research offers hope for new medications and treatments to better manage the multitude of symptoms caused by this complex disorder. To learn more about Prader-Willi syndrome and how you can help, call us or visit our website.

Prader-Willi California Foundation is a non-profit 501(c)(3) corporation established in 1979. An affiliate of Prader-Willi Syndrome Association (USA), PWCF is dedicated to supporting persons with Prader-Willi syndrome, their families and the professionals who serve them.

pwcf.org Prader-Willi California Foundation
Supporting People with Prader-Willi Syndrome

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Core Therapeutic Interventions

for the Child with Prader-Willi Syndrome

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Prader-Willi Syndrome

Prader-Willi Syndrome (PWS) is a non-inherited genetic disorder that affects multiple systems in the body and causes many different and complex symptoms. PWS is the most common genetic cause of obesity identified in children. There is no cure, but there are successful therapeutic interventions. And there is hope.

"Failure to Thrive" symptoms begins in utero and continue though infancy and sometimes into early childhood. The major symptom is severe low muscle tone, called hypotonia, which results in delayed developmental milestones, impaired sensory integration problems and often causes feeding difficulties and respiratory problems.

Hyperphagia marks the next stage of PWS and begins some time during early childhood and continues throughout the individual's lifespan. For reasons not yet understood, no matter how much food is eaten the brain does not recognize a feeling of satiety or fullness. Instead, persons with Prader-Willi syndrome experience hyperphagia—an overwhelming, unrelenting, physiological drive to eat. At the same time, the metabolic system slows to almost half the normal rate. If caloric intake is not significantly reduced and strictly controlled, persons with PWS will quickly gain an enormous amount of weight leading to complications caused by morbid obesity. Persons with PWS are vulnerable to sudden death due to choking, stomach rupture or stomach necrosis.

Second only to hyperphagia on the list of serious challenges that PWS presents is the brain's difficulty managing emotional states. Anxiety, frustration, disappointment and anger are emotions that are often exceedingly difficult for persons with PWS to manage behaviorally.

There are currently no known medications that eliminate or even reduce the insatiable appetite symptom that is the hallmark symptom of PWS. There are, however, other medical, therapeutic, and familial interventions that not only save lives but also significantly improve the quality of life of persons impacted by PWS.

THE "CORE" THERAPEUTIC INTERVENTIONS

Early identification and early intervention are critical to ensuring a high quality of life for persons with Prader-Willi syndrome. This brochure provides a brief overview of the therapeutic interventions that are considered "core" therapies for the child with PWS.

Growth Hormone Therapy

Synthetic human growth hormone (hGH) medication is considered standard treatment protocol for children with PWS. In addition to increased height, hand and foot size, other benefits of hGH include more normalized craniofacial structure, decrease in body fat, decrease in body mass index, increase in muscle development, improved respiratory function, improved physical performance, increase in resting energy expenditure, improvement in cholesterol levels, and increase in bone mineral density.

Physical Therapy

Physical therapy should begin in infancy or as early in life as possible to help strengthen large muscle groups important for the acquisition of gross motor skills, strength, endurance and the management or reduction of orthopedic issues including foot pronation and scoliosis. Therapy should support not only the acquisition of gross motor skills but also work to improve the quality of gross motor movements.

PWS causes abnormal muscle tone which results in deficiencies in sensory integration. The Physical Therapist should be trained in Sensory Integration Therapy to improve the ability of the child's brain to process the input it receives from the body's senses of sight, sound, touch and taste, as well as from the vestibular system which involves body awareness, movement, balance and the pull of gravity upon the body; and the proprioceptive system which informs the brain about the body from the input received from joints and muscles.

Children with PWS often have global praxis problems defined as difficulty with motor planning, sequencing and organizing the body to perform fine and gross motor activities.

Growth hormone treatment does not replace physical therapy.

Occupational Therapy

Occupational Therapy should begin as early as possible in infancy and continue throughout childhood.

The focus of Occupational Therapy during infancy is on acquiring and refining fine motor skills such as hand-eye coordination, batting, grasping, and pinching. Some Occupational Therapists are trained feeding specialists and can help teach parents special feeding techniques to help babies who, by virtue of weak muscles and problems coordinating the suck-swallow-breathe skills, have difficulty bottle feeding.

In childhood, Occupational Therapy will focus upon hand and finger strength and dexterity, motor planning and coordination to help the child master such skills as coloring, cutting, tracing and writing. Therapy must also help the child master self-care skills such as buttoning, zipping, snapping, toileting, opening and closing containers.

It is important that the Occupational Therapist be trained to assess for and treat Sensory Integration deficits.

Oral Motor Therapy

Oral-motor therapy is an important intervention beginning in infancy to help build oral muscles and lay down neural pathways necessary to help the baby learn to babble, a precursor skill to the development of clear speech.

Speech & Language Therapy

Speech and Language Therapy is important throughout childhood. Hypotonia frequently causes a diagnosis of Dysarthria, which refers to weak oral-motor muscles, and contributes to poor articulation. Apraxia of Speech, also called Speech Dyspraxia, is also frequently diagnosed in children with PWS. Dyspraxia is a neurological disorder that interferes with the brain's ability to sequence and coordinate data in ways necessary to produce clear, smooth speech as well as organized pragmatic language. Speech Apraxia requires specialized treatment by a Speech and Language Pathologist who is trained in the treatment of this disorder.