

Hyperphagia and How it Affects Learning

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Prader-Willi syndrome is a rare neurodevelopmental genetic disorder that affects multiple systems in the body. There are many symptoms of PWS, including hyperphagia, behavioral challenges, hypotonia, incomplete sexual development, cognitive deficits, metabolic dysregulation, and several more. Hyperphagia is often a misunderstood symptom of PWS by the school system.

Hyperphagia is defined as an “intense persistent sensation of hunger accompanied by food preoccupations, an extreme drive to consume food, food-related behavior problems, and a lack of normal satiety” by the International Clinical Trial Consortium consensus paper *Behavioral Features in Prader-Willi Syndrome (2021)*. As with all symptoms of PWS, hyperphagia severity varies from person to person. The Hyperphagia Questionnaire developed by Dykens et. al (2007) separated hyperphagia into three distinct categories hyperphagic behaviors, hyperphagic drive and hyperphagic severity. This highlights that hyperphagia is not only actively food-seeking or eating as often believed. Hyperphagia is one of the effects of impaired development of the hypothalamus and the brain pathways that control eating behavior. What is critical to understand is that this is not the student’s fault that they are unable to consistently regulate their food intake or thoughts about food without ongoing support; despite some of the believable proclamations that they can.

Hyperphagic behaviors include being preoccupied or distracted by the thought, smell, or presence of food, perseverative talking about food, increased anxiety symptoms when food is present, or food related schedules change and bargaining to obtain more or different food. In the classroom it can be difficult to know when distracted or off-task behavior is related to hyperphagia or the function of something else. Therefore, implementing and maintaining a food secure environment is necessary. Creating and maintaining a food secure environment is an essential part for achieving academic goals.

What is food security in the classroom? All lunches and snacks are stored securely in cubbies or out of sight. Snacks and lunch are planned and occur at the same time every day. If participating in a school lunch program, picking out menu items that are part of their prescribed meal plan in advance, may avoid some hyperphagic behaviors. For example, some schools will hand out the lunch menu several weeks ahead of time. Having the parent or guardian circle acceptable choices for the upcoming weeks may be helpful. Avoid reading books that are food focused or using word math problems with food (six apples etc.). Avoid field trips that are solely food focused or adding special food treats at the end of a field trip. If there are celebrations or food activities, attempt to use nonfood related treats/activities. If food related activities are unavoidable, communication with the parent/guardian to plan the amount and type of food the student can safely have, may avoid conflict. It is recognized food related school functions are typically are a time for socialization with peers and building meaningful relationships. Awareness of developmental, social, health and educational needs should be given careful consideration when providing support for the student with PWS. For some students, a 1:1

helper/Para may be needed to maintain safety and food security both during times of food consumption and activities that may invoke feelings of food insecurity. Celebrate holidays and special occasions with cultural crafts and stories rather than food. Refrain from using lunch boxes or food containers to develop fine motor skills in therapy sessions. Practicing opening these things will most certainly increase anxiety and increase hyperphagic behaviors.

As educators and therapists, you may not observe overt food seeking behavior when food security is not in place. You may observe the student with PWS refusing to complete work, become agitated or aggressive, disengage from the task, put their head down or “daydream” instead. When these other hyperphagic behaviors occur, immediately examine the environment. Was there a change in the schedule or food in the curriculum? Is there food present right now? An additional complication is that the student may be able to maintain their composure until they get home and feel “safe enough” to fall apart. Continuous, open and honest communication with parents is necessary for the student’s safety and success in school. Structure, consistency in approach and food security are the keys to success for those with PWS.

To learn more about educating and supporting students with PWS, go to pwsausa.org/schoolsuccess/.