

Thinking Ahead: The Power of Early Interventions

There is a wide consensus that early interventions for children with developmental disabilities can result in significant improvements in cognitive, academic and social outcomes. This is certainly true for children with PWS. The PWSA (USA) publication, “Therapeutic Interventions for the Child with PWS,” states:

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, Early Intervention is highly recommended (p.6).

For children with PWS, basic early intervention services include: physical therapy, speech and language therapy, and occupational therapy. As a parent of a young child with PWS, we highly recommend connecting with professionals who can help you implement – at home and school – these critical early intervention services.

We also encourage implementing early practices and strategies in the home to help manage the challenges of weight and behavioral issues which we often see in children with PWS. These practices will help you build a strong foundation of support for your child as they grow and mature. Here are some tips to get you started:

Healthy Eating Habits

Caring for a child with PWS is more than simply about counting calories. It is also about making sure your child is consuming healthy calories that will contribute to more healthy development. Fortunately, earlier diagnosis and education can make it easier for children:

- To adapt to a specialized diet at a younger age.
- To accept that food is available only at certain times.
- To learn about making healthier food choices.
- To help with age-appropriate cooking activities to learn about calories, portion sizes, and preparation of food. Note: Depending on a child’s food drive, this might not be an option for every child.

This can all be an important part of the strategy to prepare a family – including siblings – for what may need to be done to keep a child with PWS safe as they grow into adulthood.

Although it may be necessary or helpful to lock food in the future, early education and behavioral management are critical components of early intervention for a child with PWS.

Professionals like Dr. Jennifer Miller and others are constantly enhancing and advancing our understanding of what healthy eating habits look like for a child with PWS. So, with the support of your child's medical team, keep informed about the latest recommendations for how to implement healthy eating habits for everyone in your home. Over the long run, this will help your child to appreciate healthy eating and optimize their ability to be part of their own well-being. It will also better prepare a child for food related modifications (such as locking a refrigerator, cabinets, etc.) should those be necessary in the future.

Behavior Management

Children with PWS are most successful behaviorally when a positive behavioral strategy is developed and consistently employed. This is a tried and true strategy that is effective for people with PWS of all ages. A positive behavioral strategy uses incentives and rewards to move a person successfully through the day by mixing preferred and non-preferred activities. For example:

If Tommy, who has had a problem getting up and ready for school in the morning, is able to accomplish this task in the designated half hour time period he will receive a sticker. If he earns 10 stickers during the week, he will be able to pick a movie he wants to watch.

In this example, Tommy's desire to watch a movie of his choice is used to motivate him to successfully accomplish a non-preferred activity – getting ready for school on time. You can find many helpful resources on positive behavioral strategies by searching online. If you are working with a counselor, social worker, or school professional they also might be able to assist you with ideas. And don't forget to contact PWSA (USA) for helpful behavioral resources (video and written) for supporting people with PWS. The more you know the better your plan will be! Implementing the concept of home positive behavioral support early in your child's life will prepare them for similar support programs at school and other settings. It will also help you to be a resource to help other professionals understand what kind of behavioral support works best for your child.

The Good News: It Works for Everyone!

Remember, healthy eating habits and positive behavioral supports can work for everyone in the house – including parents and other children. So you have nothing to lose by doing some research and experimenting with what works best for your home in these crucial areas. In the long run we believe it will help you to create a healthier and happy family!

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