

MY CHILD HAS PRADER-WILLI SYNDROME

Now What?

You've learned that your child has this strange sounding "syndrome", a word that just means a group of signs and symptoms which together identify a condition, and you have so many questions...

What Is Prader-Willi Syndrome?

Prader-Willi syndrome (PWS) is a birth defect of unknown cause. Infants, because of weak limb muscles (hypotonia), usually nurse or suck poorly and often must be fed with special nipples or tubes. They sit up, crawl and walk later than the average child.

Around two to four, most children develop an insatiable appetite which can result in life-threatening obesity if not carefully controlled. This appetite, accompanied by easy weight gain, and behavior problems such as stubbornness and temper tantrums are major problems associated with Prader-Willi syndrome.

Small hands and feet, short adult stature, poor balance and coordination, and lack of puberty are characteristics, too. Not every child has every characteristic, and there are degrees of severity.

Keep in mind that this list does not include all the positive qualities that children with Prader-Willi syndrome also have!

Will My Child Be Retarded?

IQs are usually in the 70s but vary in Prader-Willi syndrome from as low as 40 to as high as 100 (above 90 is normal). Normal IQs, even in the 90-100 range, are accompanied by learning disabilities. Almost all children require some form of special education.

Can PWS Be Outgrown?

No, it is a lifelong condition. But most children with PWS learn to feed themselves, are toilet trained, walk, talk, swim, play, go to school, work and enjoy many pleasures of life.

Take pride in your child's accomplishments and own special individual developing personality. ENJOY TODAY!

Then Why Do I Feel So Bad?

In a very real sense, you lost the beautiful normal baby you dreamed about for nine months. And you've lost the hope that the problem was temporary or curable. You're going through a grieving process, mourning the loss.

My husband/wife doesn't seem to feel about it as I do. Often the father may withdraw into his work, respond with anger, refuse to talk about it, or act practical with comments like "We have to accept it since we can't change it", while the mother may be tearful and emotional and see him as unfeeling. Sometimes these roles are reversed. It is vital that each understand that both are grieving but men and women as individuals do it at different rates and in different ways.

Seek help if it starts to undermine your relationship.

What Can I Do To Help My Child?

- First of all, take care of yourself and your marriage. Don't let this child take over every minute; allow relatives and friends to help. Keep balance with other children, friends and extended family.
- Find a doctor who knows PWS or is willing to learn. Don't be afraid to ask questions - and insist on answers, even if it is "I don't know".
- Seek early intervention services. Physical therapy helps strengthen weak muscles; many need speech therapy. . Keep a careful, detailed baby book. It has proven to be
- invaluable for obtaining services later. . Provide lots of stimulation - colors, sounds, activities, talking to your child. . Set limits. Don't do for him what he can do for himself or treat him as if he is handicapped or helpless.
- When eating begins to improve, don't reinforce it with food or praise. Start food security when the child becomes mobile, e.g., clear the table immediately after a meal, keep food off the counters, no more candy dishes on the coffee table. Locking up food when the child gets older can lower stress on all.
- Learn all you can about nutrition.
- Incorporate exercise in your growing child's daily life.

You can prevent your child from becoming obese by learning to say "NO", even when your child gets upset and begs for more food. The younger you start appropriate food management (and exercise), the easier it will be.

Where Can I Find Support? No One Seems To Understand.

Generally, a young child with PWS who is not obese looks normal, so family and friends often do not understand either the need for food security or the parents' grieving. The best source of support is other parents going through similar circumstances. Confidentiality rules bar professionals from giving you names, but you can give them permission to give out your name. The Prader-Willi Syndrome Association (USA) can put you in contact with others in your area or elsewhere.

Advances in the use of psychotropic medications to improve behavior and mood, growth hormone to improve short stature and lean body mass - plus all the general research on obesity - offer much hope for a vastly improved future for today's child with PWS.