

Words of Wisdom for the Newly Diagnosed

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Well, it's happened to you. That which you thought only happened to "other people". You have a "special needs" child. You have a child who has Prader-Willi syndrome (PWS).

Maybe it is the baby you've been waiting for and dreaming about for nine months, or a toddler for whom you have finally gotten a diagnosis. It may even be an older child. But whatever the age, you will no doubt find yourself grieving for the child you didn't have, that beautiful, normal child of your dreams.

What comes first is denial: "No! It can't be. It can't be happening to me and my child and my family." And maybe you're angry because it is happening to you and your child and your family. Maybe you find yourself hating the doctor who gave you the bad news, or hating other parents whose kids are just fine, or even hating your baby or child. You may feel despair and fear as you try to face reality, and there's a long, long road ahead to the destination of acceptance.

It's important that you don't deny your feelings. They are there; they exist; and they are real. If you discover that you are hating the child you love so much, then the next step may be hating yourself. The anger and fear and despair that threatens to overwhelm you needs a safe place to be expressed, no matter how negative those feelings are. Often when a person confronts, expresses and deals with such feelings, that person may be more able to cope, not only with the feelings but also with the demands that inevitably come with a child with PWS.

So who for you can provide that safe place? It should be a person whom you can trust to listen without judgment, to hear you out when you need to talk, and to keep in confidence that which you are saying. For you, would that be a member of the family? A beloved friend? A minister, priest or rabbi? Parent support groups also can provide that kind of support, plus the assurance that you are not alone. Even the Internet with its email discussion lists can be helpful. In some cases, you might want to seek counseling professional.

Now there's more to consider in this situation than just you and your little one. There's your marriage. Your husband or wife is just as important as he or she was before this happened. A marriage is like a green plant – watered regularly, it will thrive and grown, but without attention it will wither and die, or at the very least, wilt. Have dates; express your affection; comfort each other; do things together separate from the child or children.

This is often a time of great stress for marriages, especially when the spouses do their grieving differently and at different rates. Sometimes the husband will bury himself in his work and be unavailable both emotionally and physically to his wife who want to talk about it all the time. Or the wife may be so focused on the child's needs that she no longer had any time for her husband. So if you find that your

marriage is drooping, make haste to get some counseling. You're already unhappy – don't increase it.

There are also your other children, if you have them. Life shouldn't revolve around the child with PWS. Yes there will be demands on our time, your strength and your spirit, but they need you too. And they can be a source of comfort and joy, if you let them. Yes, even in the midst of sibling squabbles, broken toys and runny noses!

Take some time out to enjoy the rest of your family and other facets of your life. Do you like play bridge or tennis? Do you want to sing in the church choir? How about the book review group you've been invited to join? Or a get-away weekend with your spouse? Do it! Fit that interest in somewhere so you don't lose yourself as a person. Don't be afraid to use respite care, be it babysitters, professionals, grandparents, or other relatives or friends. Teach them (what is needed), try them (to be sure they can meet those needs) and then trust them (to do it).

As your child grows, be sure to provide discipline. Remember that the word "discipline" does not mean punishment but teaching – teaching your child what is appropriate and what is not appropriate; teaching your child what is expected of him or her. Because your child has PWS doesn't mean that he or she should be pitied and not given the discipline you would give any other child. You want your son or daughter to have self-esteem and to become as acceptable part of society as possible and consistent discipline with realistic expectations is a route to those highly desirable ends.

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Be sure too, to notice your child's strengths – what he or she can do. After all, there are individuals with PWS who have made Eagle Scout, been bar mitzvahed, won awards for horseback riding, performed in dance recitals, been in movies, participated in community service, spoke at training sessions for agencies serving persons with PWS, won bowling tournaments, made the Honor Society, fasted to raise awareness of hunger in poor countries ...who have brought not just problems but joy to their parents. Granted, no one with this syndrome has been signed to a professional football team but elected to public office or written a best-seller but who knows what can happen?

Last but not least is laughter. Sometimes if we don't laugh, we cry. You may not feel it right now, but you going to be able to laugh again. Cultivate that ability! Your child is going to say and do some funny things as he or she grows. Enjoy these moments, write them down and get a good chuckle out of the humor. After all, being the parent of a child with PWS means trying to figure out how to lock up the apple tree!