

LISTENING BEYOND THE TANTRUM

By: Janalee Heinemann

Dear Mom, I'am very very very real Sorry what going on! Rose are Red and heart are pink and truely I love you very very much, But thing not going very well for me! My body don't seem right at all for me. I wish you and everbody make every thing feel happy for me. The bad part is in side my body. The good part is out side my body. I just wish all bad part going away from me. I just dont like bad part, It make me very sad to me I have to go trow it, but it not right for me! The bad thing about me real hard for ever body to understand! tell ever body I am very sorry! The End

Love, Matt

I just wish can fix, But I can fix for me.

The previous page is an apology note Matt wrote to me yesterday after a "major" tantrum (we rate them major, minor, and crying spell). During the tantrum, he said he hated me for "studying about Prader-Willi". He swore, tore the heads off flowers in the yard, then cried and hollered in his bedroom for two hours, then fell asleep. Today he is contrite, quiet, has played patiently with our 4-year-old grandson for hours and thoroughly enjoyed playing in the pool with his 20-year-old brother, Tad. The Prader-Willi "demon" has passed and hopefully will stay out of Matt's soul for a while.

When a child with Prader-Willi is screaming, crying, swearing, and swinging their arms and telling you they hate you, it is hard to listen and to feel anything but contempt and anger. Add to that the difficulty in understanding the speech of a child with PWS and the fact that once the child is out of control, he/she repeats the same thing over... and over. It is like they have their foot stuck on the accelerator (of their rage control) at 100 mph and can not let go until they crash.

At that point, who wants to listen to what they are saying! Al has said that during those first moments of a tantrum, if we had a type of mace-like spray to squirt in Matt's face which would make him fall instantly asleep, it would save us all a lot of grief.

Perhaps we also don't want to hear "beyond the tantrum" because of the pain we would see. In a recent "crying spell" (lowest rating on the tantrum scale) we worked real hard on hearing what Matt had to say. After finding an article on PWS, Matt said when he sees something written about Prader-Willi syndrome, it reminded him he has it, and "...it (the anger) goes over and over and over in my brain!" He said, "You know I more intelligent than other (Prader-Willi kids) and I can't help read about it because I curious. It say I always

be short and I never have sex... it say I never be normal. It hurt in my heart and in my head... It say about what between my legs (small penis and undescended testicles.) I never have a girlfriend. I be embarrassed she see me. It say I die before I get old... I think about food all the time (When) I see food I can't have, I feel anxious. I want it real bad and it make me mad... You don't know what it's like. You don't know how I feel!"

Matt gets fixated on an issue for awhile, then changes topics, but mostly his issues deal with the injustice Prader-Willi syndrome. How much of the rage is a chemical/neurological dysfunction and how much is justified anger at the world? Looking at Matt's tortured mind is sometimes more than we (or he) can bear.

You're right, Matt; we don't know what it's like. If we let ourselves feel what you feel, we wouldn't be strong enough to lift you up when it was over, give you a hug, and say, "Let's go on from here."

Michael Parker

We all have Prader Willi Syndrome
we feel that we arent Human.
Humans have fredome.
We don't have fredome

We arent Human Because we cant
have Children.
But how can Aliens have children?

If we arent Human we are Aliens
If we arent Human, were oh were is
our ufo?

We want to go Home.