

OUR HEALTHY SIBLINGS --THE NEGLECTED POPULATION

By Janalee Heinemann—Prader-Willi Syndrome Association (USA)

(Writers note: The following was written sixteen years ago, but sibling issues have remained the same; Recently, the following article was read by a couple of young mother's who did not know we had this information on siblings. They requested we reprint this article and also inform our readers of the sibling booklet Sarah and I wrote for younger siblings, **Sometimes I'm Mad – Sometimes I'm Glad**. It is primarily for ages 4-14.)

Last week, while going through old mementos, I came across a Christmas card from our daughter, Sarah, written when she was in third grade. She is now 12 years old and a sibling to 13-year-old Matt, who has Prader-Willi syndrome. Included in the card was a list of jobs she would perform as a gift to us. Between the usual (1) I will clean my room and (4) I will take Lambi for a walk daily, was (2) I will help when Matt has a tantrum and (3) I will help keep food away from Matt. What seemed like a normal life to Sarah at age 8, was far from normal for the average 8-year-old.

Now that Sarah is 12, she is much more aware and sensitive to what her peers view as OK and not-OK, plus there is nothing more important to a 12-year-old than to be just like the other kids. When your cupboards and refrigerator are locked, and your brother's behavior is "weird" and embarrassing at times, it is hard to be comfortable in these situations with your peers. Sarah recently told me of an incident on the bus, where a Special-Ed school bus went past theirs. The boys on her bus began making fun of the children on the Special-Ed bus and mocking them. Sarah said, "*I was mad at them and wanted to say, 'Stop it! How would you feel if someone did that to you!' But, I didn't because I was afraid they would turn on me and make fun of me because of Matt.*"

As a professional, I worked with families of children with cancer. Their sibling dilemmas and problems are very similar to our PWS siblings and most siblings of children with developmental disabilities. The unique issues to our PWS siblings are the weight and behavior issues. Since Sarah and I wrote the PWS sibling book, *Sometimes I'm Mad and Sometimes I'm Glad*, five years ago and geared it as reading for younger siblings, I would like to focus here on the commonalities of siblings of all ages in situations of disabilities.

I find that there are a myriad of feelings for siblings: resentment, guilt, love, jealousy, anger, a desire to protect, being left out and isolated, a fear of the disability being contagious or inherited, embarrassment, compassion, and loneliness. Other issues I hear from siblings are that the parents love the disabled sibling more, seeing the siblings disability as a stigma on themselves, and a desire to be "sick" themselves to

get attention; (I asked Sarah if I missed any feelings and she said, "Sometimes you just feel downright miserable.") There is frequently a mixture of all of these feelings, with some surfacing stronger at times. The strength of the feelings and how your child will overtly act or react is often age related.

YOUNGER CHILDREN may be at risk because:

1. They have a limited understanding of what is wrong.
2. They are egocentric and wonder "*Will I catch it?*" "*What will happen to me?*"
3. They believe in magical thinking i.e. "*It's all my fault because I said...*" "*Did I cause it?*" "*Will God make it happen to me if I'm bad?*".
4. Their parents are the most important people in their world, and their parent's attention is often diverted to the disable child.
5. In their great desire to please their parents, they may willingly take on too much responsibility.

PRE-TEENS AND EARLY TEENS are more focused on the following:

1. They are much more aware of their siblings differences and much less willing to be different themselves, thus they are more likely to be embarrassed or ashamed of how their disabled sibling looks or acts.
2. They feel guilty for various reasons E.g. because they are healthy and their sibling isn't; because they resent their sibling; because sometimes they wish their sibling was dead.
3. They feel isolated i.e. "*My parents don't understand me.*" "*My friends don't understand what I have to go through.*"
4. They are acutely aware of their parent's double standard for their sibling on discipline, chores, achievements, and tolerated behavior.
5. They now may resent having to "take care" of their disabled sibling. I find that during this age period, they are the least sympathetic and understanding of their disabled sibling -- but that's true in "normal" family situations also.

This is an all-too-long phase when you pray your kids will grow out of it before they kill each other! Even at this "worst

OUR HEALTHY SIBLINGS - -THE NEGLECTED POPULATION

of ages" though, siblings have a strong bond. The same 12-year-old brother who, over a minor issue such as which TV program to watch, will shout, "I hate him. I wish he were dead!"-- will also be the first to hotly defend his brother if a group of peers pick a fight or make fun of him.

OLDER TEENS often begin to feel more comfortable with themselves and their situation but a parent needs to be aware that:

1. If the disabled sibling's problems cause too much home disruption and alienation from parents, this is the age when the sibling will "escape" by being away from home a lot.
2. Or, it's an age when parents themselves see a way to "escape" and expect the teen to become overly responsible.
3. Sometimes they feel need to "make up" for their disabled sibling by being an overachiever.
4. They may question more the justice of why God let this happen.
5. They feel a need to protect their sibling from the world.
6. They begin to become concerned about who will take care of their disabled sibling if something happens to their parents.

I don't list all of the above issues to add more guilt to a population of parents who are already over burdened and guilt ridden. I only mention these potential problems to let parents know they are not alone and remind parents of the impact on siblings. As parents, we do the best we can, but often look back and feel that it wasn't good enough--that we made mistakes. Some of the pitfalls we parents fall into are that we:

- Abdicate some of the parenting role to our healthy sibling. This may not be all bad as long as the burden is not on just one person. Spread the responsibility out. We don't have to apologize to our children for helping them turn into responsible, caring people. The problem comes when one sibling is taken advantage of. As overwhelmed parents, it is tempting to use the siblings to ease our own burdens.

- Say things we wish later we hadn't said because we knew they weren't helpful. What parent can honestly say they haven't made one of the following remarks: "*You should be thankful you don't have...!*"; "*How would you feel if you had...?*", "*Why can't you be more understanding of...?*" "*You shouldn't feel that way about...!*".
- Give in frequently to our disabled child to avoid problems or to appease your guilt over the situation - -and expect the siblings to give in also.

Besides forgiving ourselves for being human, and our siblings also, other steps we parents can take after realizing we have done or said something inappropriate are:

1. Acknowledge to your child that you made a mistake
2. Let your child vent his/her feelings and admit you also have some of the same feelings regarding your disabled child- -or to the situation the disability creates i.e. We don't hate Matt for the problems of living with locked cupboards and refrigerator, but we do hate the syndrome at times.
3. Do some problem solving with your child regarding how you can both deal with the situation, i.e. We decided that although it wouldn't be fair to Matt to allow Sarah to eat in front of him, the compromise is to allow her to snack after he is in bed.
4. Find some special time away from all your children, so you can come back feeling more refreshed and less sorry for yourself. Kids do not look kindly on parents who are martyrs.

Although it may be hard to believe at this point in your life, when it is all said and done and the siblings are grown, they will most likely become more loving, responsible, and compassionate than the average adult. Although Sarah is still struggling with the ethical dilemmas of all 12 -year-olds, I trust the day will come when she has the personal integrity and sensitivity that her grown brothers and sisters have. Our healthy sibling's lives will be partly enriched and partly damaged by their situation. We can nurture the enriched part and minimize the damaged part by accepting them and ourselves with all of the normal faults and feeling that accompany the family of any child with a disability.