



I'm Special Too! Siblings of Special Needs Children

By Judy Winter

Being the sibling of a child with special needs may be challenging. With the support of a loving family, this experience can result in rich life lessons that serve children well. So take time to let your children know they are all special.

It's not easy being the brother or sister of a child with special needs. These siblings may believe their parents' time and energy must go to meet the demands of their brother or sister with a disability, leaving little time for them. Research shows that siblings of children with special needs are at greater risk for depression. They also tend to be over-achievers to make up for the shortcomings of their brothers or sisters. Plus, they sometimes bury their needs to avoid adding conflict to already stressed-out families.

Many parents of children with special needs function on too little sleep, visit lots of hospital emergency rooms, and are primary caregivers 24/7. So it's easy to see how the needs of other children in the family may go unmet. That is especially true if these children appear to be doing well in other important areas of their lives, including school.

It's not easy trying to be the perfect child.

Being the one without a disability can be a pretty heavy load to carry, too. Through no fault of their own, these kids are asked to cope with the loss of a simpler and more normal family life, and give up regular family outings.

They may be afraid their siblings will embarrass them in front of their peers. They may wonder how special needs in the family will affect their own social life, future plans and responsibilities. Add to this mix powerful emotions like anger, grief, fear, and the protectiveness siblings often feel toward the child with a disability, and it's easy to see why these kids need to understand where they fit in a challenged family.

Seek a regular life in spite of special needs.

From the beginning of our special needs parenting adventure, we promised our oldest child, Jenna, that her brother's special needs would not short-change her life dreams. During the past 12 years, it hasn't been easy to keep that promise. But now we are enjoying the fruits of our commitment and spending time with two well-adjusted and happy children. Jenna, now 18, is following her long-held dreams of becoming a

photojournalist. She has high self esteem and a wisdom beyond her years. And she's a wonderful big sister and role model for others.

Here are six tips to meeting the needs of siblings without disabilities.

1. Make one-on-one time with the child without a disability a priority. If that means getting a sitter, do it. Siblings deserve time away so they can have your full attention. Such efforts may also help your child make it through those days when special needs demands more of your time and attention.
2. Encourage your child to express honest feelings about having a brother or sister with special needs. Siblings may hold back emotions to avoid adding stress to the family, or because they feel guilty about having negative feelings. Let them know these feelings are normal.
3. If despite your best efforts, your child still has a hard time coping with her role, seek professional help. This can challenge even the most well adjusted child. It's OK, and sometimes necessary, to ask for help.
4. See your family's special challenges as a chance to

model positive problem-solving behavior for your children. Kids with brothers and sisters with special needs often display a maturity and sensitivity beyond their years, which can serve them well in other challenging situations.

5. Encourage your children to keep journals, then honor their privacy.
6. Try hard to avoid using siblings as caregivers. There are community agencies designed to help with these needs. Access them.

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What Is Smith-Magenis Syndrome?



Smith-Magenis syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2. The first group of children with SMS was described in the 1980's by Ann CM Smith, MA, a genetic counselor, and Ellen Magenis, MD, a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 25,000 births. SMS is underdiagnosed, but as awareness of it increases, the number of people identified grows every year.