

Tricks Up Our Sleeves: Helping Our Children Manage Their Behavior

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As parents and caregivers of children with Smith-Magenis Syndrome, we face so very many challenges every day—medical issues, lack of sleep, educational concerns, and dealing with our child's behavior. On the SMS listserv started by Steve and Lisa Thomas, the issue of behavior is a recurring theme. I asked parents to send me their most successful hints in dealing with the special challenges our children's behavior present.

PREVENTION - is a common theme repeated many times by parents. Preventing a full-blown outburst before it occurs is always preferable to intervening when the child is already out of control. With time, we become experts at reading our child's signals and attempting to ward off an outburst. Sharon Bourbonnie, mother of Kelly, age 9, has learned that "positive feedback is a must. Some behaviors just have to be ignored. I pick my battles." Many children with SMS thrive on routine, so keeping a predictable schedule is a priority for many parents. If your child has problems processing the spoken word, you may want to draw simple pictures or use a written schedule to show the course of events during the day. When the child starts to "lose it," remaining low-key and non-confrontational is important. Yelling seems to typically escalate the child's tantrum. Bonnie and Bill Spear, parents of Ben, age 10, write about Ben's wonderful aide in school. "His current aide is always one step ahead of Ben. If he drops his crayons, she knows if she makes him pick them up immediately he won't. So she keeps right on going. A minute later, she'll say, 'I wish I had a crayon; I wonder where they're hiding.' And then Ben will be the hero by dropping on the floor to find all the missing crayons." She has avoided a confrontation as well as keeping Ben in a positive frame of mind because he is helping solve a problem by picking up the crayons. Keeping busy also seems to be important to many children with SMS. Redirecting our child to a video or computer game is often helpful. Some children like to be on the go all the time. Carla Osburn, mother of 6-year-old Kelsey, writes, "She is always interested in going somewhere (any place but home). Our son, Craig, who is 13, is the same way. The first thing he wants to know in the morning is where he will be going that day. When Laurie Bellet, mother of Ariel, age 13, has no respite in sight, she always plans a trip to the mall with Ariel to keep her busy and happy.

REDIRECTION - means helping the child to focus on something other than what is upsetting him. The most important point mentioned by many parents is that the redirection needs to occur before the behavior has escalated into a full-blown meltdown. Many parents find humor useful. Jan Reeder, mother of Emily, age 10, writes "... when Emily is getting mad, we can grin real big and say 'Here comes that silly Grumpy Gus face!' or 'I can see that you're getting mad, so I BETTER NOT see you smile! No smiling or laughing when you're mad!' Lots of times those things make her laugh, and then we redirect into a game of trying not to make each other smile."

I also try to help Craig laugh instead of "lose it." I can tell when he's getting testy because he starts talking about things that he has thrown across the room in the past during fits of anger. He'll often spell these things to me... "k-e-y-c-h-a-i-n"... "b-a-l-l-o- o-n"... and I know he's ready to lose his temper. So

when he starts spelling, I'll clap for him and say, "good spelling!" in my most enthusiastic voice. That's often enough to start him laughing and stop being so mad. I also try to "talk" Craig out of a mood by asking him many questions... "What did you have for lunch? Did you go to art class today? Was Mrs. Birch in school today?" He'll start to concentrate on answering me and will sometime snap out of his foul mood. Using praise is another way to redirect your child. Beth Kurtz's 22-month old daughter Lauren loves watching her mom load and unload the dishwasher. When Beth would close the door, Lauren would have a fit. Beth turned this negative experience into a positive one. When she's done with the dishes and ready to close the door, she asks Lauren for her help in closing the door and then lavishly praises her for helping. Lauren becomes excited and starts clapping her hands. She responds to the same type of praise when turning the TV off and on, changing channels, and other daily routines. Karen Innes-Walker, mother of Emily, age 4, has a good way to help avoid Emily's tantrums. She says, "If we are somewhere I know has potential to lead to a tantrum (e.g. finishing a speech or music therapy session), I will quickly say 'Let's do some fast walking or stomping' - anything to distract her."

PHYSICAL ATTENTION - is extremely important to the child with SMS. We all know that our child's need for hugs is a strong one! I try to spend some time alone with Craig every day, squeezing his arms, tickling and hugging him, giving him my undivided attention. "Brushing therapy" has been useful for Jan's daughter, Emily. This involves brushing her body in a very specific manner with a scrub brush that doctors use. Your child's Occupational Therapist would be the best person to advise you how often and in what manner to brush your child. Warm baths calm many children. Patty Saunders' son, Joe, who is almost 4, enjoys being held on her lap and snuggling while reading books. He also loves going for a walk in a backpack carrier. Roughhousing seems to be greatly enjoyed by many children with SMS. Spinning on an office chair or swing really helps Craig to calm down. Spinning should be avoided, however, if your child has seizures.

THE GREAT PARENT SWITCH - is helpful when possible. On the e-mail list, we have noticed that the child with SMS often responds more favorably to one parent than another. When possible, the parents can switch being in charge, to relieve each other and help alleviate an outburst. Of course, when both parents have a break in the form of a respite worker or outside help, this is even more helpful! Laurie Bellet often saves Ariel's least favorite chores to be completed with the respite caregiver. Ariel is much less likely to put up a fuss for the caregiver than she is for her parents. We have noticed that Craig prefers Mom at some times and Dad at other very specific times. If it's homework time, only Mom can help. But when Craig wants to work out in the woodshop, he becomes upset if I invade his "space" with his dad. I've learned to just stay away and avoid a confrontation. Of course, a much-needed (and well-deserved!) break is not always an option. Connie Bessette, mother of Jon, 28, has learned to walk away and get busy with something else when Jon becomes oppositional. She has found that a break helps Jon to "regroup" as much as it helps her.

VISUAL CUES - are another way to help our children. People with SMS are often very strong visual learners, and we can build on this strength to help our children manage their behavior. Whenever Craig and I go somewhere, I am sure to bring along several index cards and a pen. If we are in church and he is becoming agitated or loud, I write a note on a card for him: "You need to be quiet in church. We will ride the elevator in one hour." I use this trick at home as well. When I can see Craig's anxiety level rising, I'll write something down like "No throwing the keys. We will go to the mall in a half hour." Craig typically feels compelled to read whatever I've written, and that can be enough to break the cycle. It also helps me to remove myself from the situation. I deal with Craig's verbal perseveration in the same way. I'll write down an answer to his question on a card, and if he keeps asking me the same question, I tell him to read the card and I walk away. We also use Craig's interest in reading in situations that involve a lot of

waiting, such as doctor offices or restaurants. We might make lists of his classmates, favorite toys, or the foods he's ordering. Barbara Haas-Givler is an Education Specialist with the Genetic Department of Elwyn Inc. She shared with me a great idea to cut down on Craig's loud noises while he's watching TV. On the left side of a card I drew a happy face and wrote, "No yelling, the TV is on." Then I wrote the numbers 1-5 across the card, and ended with a sad face on the right side of the card that said, "Too much yelling, the TV is off." Each time Craig yelled or made loud noises, I crossed off a number, bringing him closer to the sad face. This has really reduced the frequency of his loud outbursts. I must admit, however, that sometimes I don't even have the energy for this and will yell at him to "stop yelling!" I'm sure other SMS parents understand...

VERBALIZING & ACKNOWLEDGING - the child's distress can sometimes relieve the child of some anxiety. When having a fan or dishwasher running bothers Karen's daughter, Emily,, Karen asks Emily "What is mummy doing?" and answering this question helps keep Emily calm. Connie's son, Jon, is also helped by this tactic. If he's upset, she will say something like "Measuring is hard for you." Jon seems more willing to solve a problem after Connie validates his feelings.

TIME-OUT - gets mixed reviews from parents. Patty Saunders' son, Joe, does not do well in time-out; instead of calming down, he becomes more agitated and self-abusive. This is also the case with Craig. Sharon uses time-out rarely and only as a last resort with Kelly. Time-out works for Jeanie Singleton's 9-year old daughter, Katie, especially if Katie is sitting where she can't see her mom. This seems to be an important facet of time-out-the child should be completely removed from adult attention, because even negative attention can be rewarding to our children. The Singleton's have another interesting slant on time out; because they live in the country they are able to send Katie outside when she throws a fit-regardless of the temperature or time of day. She needs to finish crying outside and pull herself together before coming back in the house. They aren't sure how they would handle time- out if they ever moved to the city!

REASONING & BEHAVIOR MODIFICATION - also works well for some children, but not for others. For many children, the reward must be very concrete and immediate to have value to the child. We use quarters to help motivate Craig with behaviors such as "wash hair by myself" and "stay at the table during dinner." He puts quarters on his chart for each task completed, and he knows that when he fills the chart, he earns a new Viewmaster reel. When we started using this method, I kept a supply of reels at home so his reward would be immediate. Now he has learned to wait until we can get to the store to buy new reels. We also use peanut butter chips (the type using for baking cookies) on occasion. Craig has a hard time turning off the TV to get on the bus in the morning, but if we bribe him with a few peanut butter chips, he's able to turn the TV off and get out the door. Sharon writes, "Kelly loves cookies and swiss rolls, so each day at school she earns a treat to be given at the end of the day. She must receive 4 check marks in each of the class areas - regular classroom, special ed. classroom and 'other' like PE/Music/Speech/OT, etc, before she can earn her treat." The consistency Sharon uses with this reward helps make it more effective.

MUSIC - is a favorite of many children with SMS. The types of music most enjoyed varies widely, and includes Barney, Sesame Street, popular children's songs, Christmas songs, church and gospel music, and classical music. Sing- along songs seem to be especially favored. Some children, such as Karen's daughter Emily, enjoy keyboards with pre-programmed melodies. The Saunders often use some of Joe's tapes at dinnertime to help Joe stay longer at the table. Beth's daughter, Lauren, has had difficulty when visiting in an unfamiliar place. She sometimes keeps crying until they leave and Lauren can listen to Barney in

the car. Perhaps a small cassette player with headphones would help Lauren to handle the extra activity and stimulation of a visit a little longer. Lisa Downs is a teacher of a 9-year old student who loves listening to music on headphones. Lisa writes, "One of the more successful strategies I have found in order to keep him on task is to list what he needs to do before he can go into his 'time out' room which he loves, and listen to his tape." Lisa is combining her student's strength in visual skills and his love of music to help him learn.

THE ULTIMATE GOAL - for behavior management is for the child to be in charge of their own behavior. Although this may not be attainable for all children with SMS, it is important to keep it in mind when using various behavior strategies. If we know that spinning helps calm Craig down, we might first say "You're getting too upset...go spin on your swing." After a few weeks (or months...) we will say, "You're upset...what do you need to do?" and without words, lead him to the swing. The goal is for Craig to learn to go to the swing without our direction. Jan has a great way of helping Emily deal with her own anger. Jan writes, "We talk about Emily's anger barometer in terms of her 'engine running high (mad) and engine running low (calm). So when she's starting to escalate, we can say, 'Can you feel your engine starting to run high? It sounds like you need to go hide.' And we would redirect her to her hiding place, which was a square table in a corner that had a thick blanket over it like a tent. It was like retreating into a little cave; it was dim (not too dark) and secluded. It removed her from external stimuli and she felt secure in there. Often she would go hide and end up falling asleep, and would be fine when she came out. The engine analogy is a real good self awareness tool that she can use to gauge her own level of self-control and take action on her own when she feels it getting out of hand." When time-out is necessary for Emily, she is in charge of being her own timer. Emily can only come out of her room (which has nothing in it except for her mattress and a few stuffed animals) after she counts to 100 in a calm voice with no bad words. Jan says, "Once she could count without using an angry voice or profanity, we knew that she was able to control herself. Sometimes it would take five minutes, sometimes it would take five hours, but the 'key' to coming out (counting) was always there for her when she was ready to use it, and it was a punishment technique that was relatively non-disruptive for the rest of the family because we weren't having to focus all of our attention on her while she was being punished."

Children with SMS, regardless of age or developmental level, are notoriously clever. They quickly learn how to manipulate others and "push our buttons." As parents, teachers, and caregivers, we need to be just as clever and be prepared with our own tricks. We are so very fortunate to have each other and to be able to share our tips and strategies. Here's hoping for reasonable peaceful days (and nights!) for all of us!