

Behavior Management in SMS

By Mary Beall, SMS Parent, M.ED

What are the common behavior problems for Smith-Magenis Syndrome?

- Attention Deficit With or Without Hyperactivity
- Frequent Outbursts/Temper Tantrums
- Seeking Attention
- Attention Deficit With or Without Hyperactivity
- Impulsivity
- Distractibility
- Disobedience/defiance
- Aggression and Destruction
- Self-Injury: biting or hitting self , head-banging, and skin picking
- Nail-Yanking and Insertion of foreign objects into body
- SMS Stereotypic behaviors: self-hugging in excitement, hand clapping

There are also other problems commonly mentioned by parents, but not yet documented. These may be a result of other symptoms, for example, children with sensory integration problems may cut the tags out of all of their clothes, or refuse to wear sweaters. Some behaviors relate to modulation. They don't know when enough is enough, or else they don't have the skills to use just enough. They squeeze way too much toothpaste, pour way too much drink, spread way too much butter, use too much toilet paper, squeeze way too hard when they hug a person or an animal, and run instead of walking. They can keep a household in upheaval when they take the batteries out of everything, get into the toothpaste and shampoo (sometimes smearing it all over), raid the refrigerator and dump the food, or rip up the film in your camera bag. And they are loud! They enjoy yelling or singing loudly, which is particularly annoying at 4:00 a.m. While it is possible that a person with SMS could never show significant behavioral problems, some degree of self-injurious behavior and sleep disturbance occurs in most SMS individuals. Despite their very difficult behaviors, children and adults with SMS are very affectionate and have engaging personalities and much untapped potential.

Why do they behave this way?

It is unclear exactly what causes these behaviors, however past research in the study of behavioral aspects of the syndrome (Dyken and Smith, 1998) show that sleep (or lack thereof) is the most significant factor predicting the difficult behaviors that occur in SMS. Other factors are probably multi-faceted. There may be an internal drive to do these things, sort of a "short-circuit" that makes them react without a filter to stop them. They seem to have an immediate "fight or flight", adrenaline-driven response to many situations.

Other possible causes include:

- Anxiety: Young adults who have SMS (finally at an age where they can talk about their emotions) mention that they worry and feel anxious a lot.
- Frustration: At themselves, others, their lack of skills, their communication problems, (and because they don't get to be in charge!)
- Speech/Language Problems: their speech is delayed, and when/if they can speak, it is difficult to understand them . They also have delays in understanding what others say to them, and in the ability to follow verbal directions.
- Delayed Development: they can't do things others their age can do, and if they are in a situation with others their age, they are often expected to
- Delayed Emotional Development: their ability to control and understand their own emotions is similar to that of a child much younger than they are.
- Sensory-integration problems
- Sleep-deprivation: their sleep disorder and inverted circadian rhythm makes them “up and at em” at a time when the rest of the family is asleep, and very sleepy and sometimes irritable when others are wide awake.
- Medical Problems: ear infections, frequent colds, toilet-training issues, and constipation are common, some have hearing impairment, seizures, scoliosis, and renal abnormalities.

So What's a Parent to Do?

You have an extremely difficult job. You have to cope with all of the problems that SMS brings while slowly working for positive change. This job is constant. There are times when all you can do is take each problem as it comes, and do the best that you can.

Here are some common misunderstandings :

- Our children are choosing to act badly.
- Inconsistent or poor parenting causes the behaviors.
- More consistent applications of rewards and punishments would cure them.
- They are misbehaving to get back at you for something.
- We should be able to control our child's behaviors.
- The child needs to understand “who is boss” and then they will comply.

The problem behaviors are a documented symptom of SMS. Of course, some of the behaviors they display are just naughty, just as the behaviors of any child can be. It can be really hard to tell what is caused by the SMS, and what is not. It is better to err on the side of assuming that the SMS is causing , or contributing to it, because the symptoms of SMS have such an overwhelming affect on their lives. And how can it hurt if you first think about how the SMS may be contributing before you decide they are just “choosing to be bad”.

There is a difference between annoying behaviors and behaviors that are dangerous and destructive. They aren't going to be cured of SMS, and so will probably always act somewhat differently than you would expect. Decide what you can live with. Choose your worst or most irritating problems and make a plan. What needs to change? It may be the space they are in, or the way people deal with them, or even the time of day that you try to do something. You can arrange your house, yard, and car so that some things won't be a behavioral issue at all. If you can solve the problem with an environmental change, do it.

So What Can We Do?

Do What Works! Don't worry about what someone else says, or what the current parent magazines say, or whether your methods are "fair" to other children. (is it fair to expect your child with SMS to behave exactly like typical children when she has so many more problems?) You may have to try several methods, and you may have to use them in conjunction with each other. There is no perfect answer, and no program that will give 100 % compliance, or that will guarantee that the child won't explode. The good news, however, is that there are some SMS parent-tested strategies that can make it *more likely* that your child can control himself and improve his behavior.

Thoughts to consider

1. **Try to get some sleep.** Work on finding a sleep solution first-because sleep deprivation increases their behaviors, and decreases our ability to cope.
2. **Children with SMS shouldn't be expected to be able control their own behavior without assistance.** The behaviors are a documented symptom of SMS, in other words, you could say they have a "behavioral control" disability. If a child has vision impairment, people don't just expect them to work out a way to see, and then punish them if they don't. They are given tools and instruction and encouragement to overcome their disability. In the same way, our children need our help, our coaching, our encouragement to accomplish what is for them a very difficult task.
3. **If you want them to control and change their behavior, you may first have to control and change your own behavior.** (as explained by Dr. Ross Greene, in **The Explosive Child**) We can't expect them to conform to our methods and our standards. We have to find ways to change our approach to make it more likely for them to succeed.
4. **Use of force and authoritative commands as your primary discipline technique can make it more likely that the undesirable behaviors will increase.** These children react strongly to a strident tone of voice and lots of authoritative commands. They get into power struggles and get "locked in". At that point, no threat of punishment or offer of reward is big enough to stop them. You can actually see a change in their demeanor, and from that point on, they will be acting controlling, menacing, and threatening. This looks very much like defiance, but you can tell the difference because they only do it when they get locked into a power struggle.

5. **Many behaviors can be minimized by creating a relaxed, supportive, flexible atmosphere.** When you can, let them control something,...anything. Try not to be rigid or demanding. That doesn't mean you don't set boundaries, just that you try to keep from having to constantly say NO! or overpower them. Try to stay calm, or at least act calm when they are "losing it". They need to "borrow your calm."

Set Up An "SMS-Friendly" Environment

- **Caregivers are kind, and flexible.** When a child begins to get defiant, the adult makes sure that their own tone of voice and body language are very neutral-not negative, you don't want to set them off worse!
- **Lots of the "house rules" are handled by the environment so the adults aren't always having to say no.** SMS-proof similarly to baby-proofing. Try locks on cabinets and refrigerators, locking up remote controls...
- **Plan rules/expectations around the child's developmental and emotional age.** For example, if their developmental age is 4, then you can't expect them to be able to stay on task much longer than a 4 year old would.
- **Respect their attention span.** Don't expect them to sit still for very long. Many of them can't even sit still to watch more than a few minutes of their very favorite video, how can we expect them to sit and be quiet for long periods of time?
- **Consider their Language Level.** If they have auditory processing problems, they will have trouble following directions, and long conversations. They have a hard time "holding their thoughts in their head", and so may be constantly interrupting before they forget what they wanted to say. They don't know "turn-taking" in conversation. They may be at a language stage where they can only talk about something happening right now, that they can see. At this stage they can't talk about what happened at school, or particularly "why" it happened. They will be very literal. They may not be able to use "self-talk" inside their head to help them control themselves.
(and remember that language levels decrease when we are upset, resulting in even more communication problems and behaviors...think of times you have been very angry and couldn't be rational)
- **Use Visuals.** Use notes, drawings, photos, gestures, and even your facial expressions to help them get more information. A daily schedule with photos can reduce anxiety about transitions. Since many can read, written reminders and lists can help them take care of themselves.
- **Act as a narrator for their feelings and teach them words to use for emotions.** "Your face is scrunched up and your legs are kicking, You are so MAD!" (at first, the emotions may have to shown in sign language)

But what can we do to make him behave?

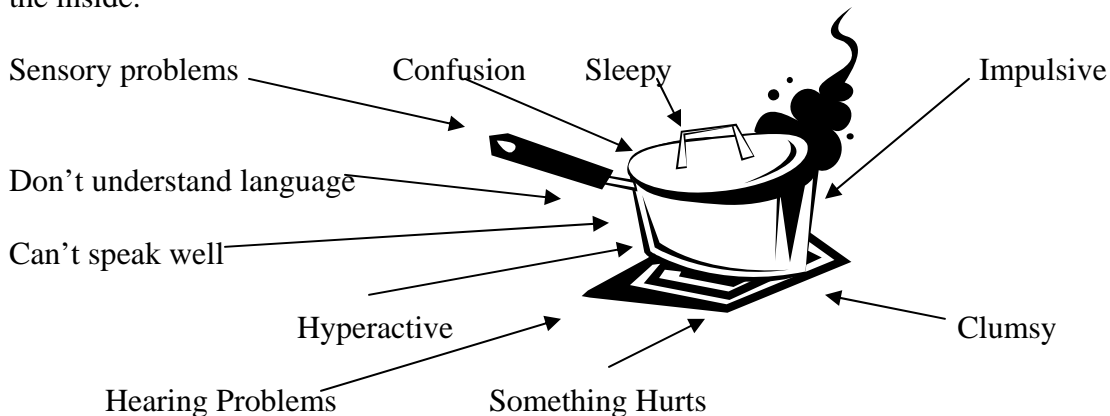
- When you can, use the same good parenting skills you would use on any child.
- Speak at the child's level, one command at a time
- Have a plan, and a backup plan, especially for high risk situations
- Be as consistent as you can (no one is 100%!)
- Help the child understand that you are the authority (not harshly)
- Give reasonable choices.
- Distract them.

But...

Sometimes, particularly in the early years, all you can do for most of the behaviors is :

Keep a Lid on It !-Preventing the SMS Explosion

Children with SMS have so many problems, that they are often keyed up or “boiling” on the inside.



Sometimes they boil over just from their own internal struggles. Things that happen to stress them are just added flames . Each thing that happens makes the flames higher, and makes the child that much closer to boiling over into an explosion.

Examples of Flames:



Someone tells them “No”, or “Hurry”
Someone yells
Teasing
Change/Transition

Attention is on someone else
They are hurried
Asked to sit still for a long time

Biggest flames: Being forced to do
Power struggles
A parent/teacher's attitude that they have to "win"



something

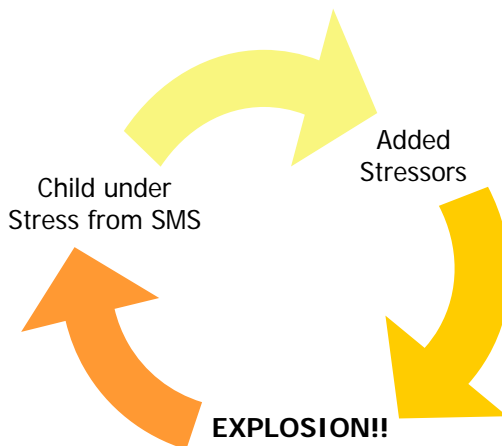
We can't change their SMS, and their tendency to "boil". Our job is to keep the flames as controlled as we can. It's a balancing act, trying to recognize their mood and ability to stay in control. We don't want to add "fuel to the flame".

Fire Prevention: "Only You Can Prevent Forest Fires", Your Child Can't!
Three ways to control the "flames".



1. *Put them out.* Change what is bothering them, or reduce the stressors.
2. *Stop, Breathe, Get Control* (If you can control your own reactions, and keep your own adrenaline from flowing, they have a better chance to control theirs)
3. *Do something to slow down or eliminate the "fight or flight" adrenaline .*

Another way to look at it is that they get in a vicious cycle:



They are stressed already, just by the problems that come with SMS. Then they get extra stressors, or "triggers" that set them off. At this point, their natural reaction is to "lose it" and explode or self-abuse. Their own reaction (and our reactions to theirs) then stresses them more, and the cycle starts all over again. We have to find some Cycle Interrupters, or some Flame Reducers.



Vicious Cycle Interruption (Flame Reducers)

Definition: Anything that you can do to interrupt the cycle-also called "Redirection" or "Distractors"

- Whisper
- Surprise them in some way-blow a bubble, laugh, pull out a flashlight

- Sing your instructions instead of saying them in a demanding way
- Use an excited voice and change the subject
- Request their help with something totally unrelated to the problem causing the stress
- Provide coaching, a second person (whoever they are not angry with at the time) can sometimes give advice on what to do, or get them to go for a walk
- Send them on an errand
- Appeal to their natural sense of empathy-show them a cut on your finger
- Ignore or “pretend not to notice a behavior they are doing just to engage you
- Physically moving them, or better yet, enticing them to go somewhere else
- Changing the person they are dealing with-move them away from who they are mad at
- Think about the positive. If you are thinking , “what a brat!” it will show up in your tone of voice and body language.
- Point at something out the window
- Use routines for bedtime, morning, etc, always doing things in the same order
- Write or draw whatever you want to communicate to them
- Use humor or drama (i.e., they say “No!” and you say in a southern drawl, “well I declare, Miss Scarlet, you do say that well!”)
- Find a way to give them some freedom and a sense of control
- Make them think something is their idea
- Refuse to React to their Provocations
- Keep Yourself as Calm as You Can
- Use exaggerated, excited praise for any tiny step your child makes towards controlling himself (You are really furious, but your only hit me once!) see book by Glasser.
- Wait-sometimes just waiting a moment and being silent can calm them down.

(Note: There are many more suggestions in the behavior management article by Bev Frey, 1999. It can be read on www.prisms.org under managing behavior.)

Special note about being forceful with them: Sometimes it works, but watch out!

Yelling at them and being forceful (this is more than assertive) sometimes controls them very well. I believe that the reason is because it is just another one of the distractors/vicious cycle interruptors. Using a threatening tone of voice, or yelling can surprise or shock them enough to break the cycle. This is particularly true if they are “revving themselves up” by perseverating on something.

However, use it very cautiously and as seldom as you can because:

1. You are their model, and you will probably hear whatever you said come out of their mouths later.
2. They learn that “force” is the way to get what you want and you may see them try to become more forceful.
3. A pattern of force can send them into a pattern of rages, and can increase the problems you are hoping to decrease.

4. Trying to control them with force brings out our own “fight or flight, adrenaline-driven responses. That just makes things worse, plus there is a danger of hurting them if we let our anger take control of us.

In The Explosive Child, Dr. Greene presents this formula:
(Inflexible Child + Inflexible Adult = Meltdown!)

Tips For a full-blown melt-down

- child is now shouting, hitting, threatening
- child taunts and defies authority
- may be injuring herself
- destroying property
- strength seems superhuman

Goal: stop the tantrum, or give child tools to get himself out

Goal is not: trying to teach a lesson, trying to show who is boss

(That enhances a power struggle, and these children get locked into their own power struggles and will not/cannot give in!)



- **Give them physical space if they are aggressive-**don't crowd them in a threatening manner
- **Active ignoring:** you are close by, preventing as much danger and destruction as you can, but you don't give them eye contact, even if you have to pick them up, you just act like they are a “sack of potatoes”
- **Move them:** if you can, safely, the goal is to help them calm down by getting them away from the place where they were “set off”, (their visual trigger) ; try to choose a place that has few things they can destroy (this is most effective when they are really small, and of course gets much harder later)
- **Control yourself-**voice and body language, show no emotion except possibly boredom
- **Don't react!** To their words or deeds trying to “get to you”
- **Don't interact:** don't argue back, don't answer questions, don't repeat instructions
- **If you have to overpower them** to help them get control, (watch out, sometimes this one backfires!), then try to find a neutral way-one that doesn't involve excessive force by an adult: put them in an empty room, use a therapeutic hold (but you must get trained first!), *A therapist taught us how to roll our daughter up in a sheet like a hot dog-head out of course, it seemed to really help her.*
- **Don't expect them to be able to talk about it or make restitution yet.** (**some can't do that for many years!**) They get control of themselves in stages. As they begin to calm down, their ability to stay that way is still very precarious. If something happens to stress them, they escalate quickly back to the tantrum.
- **Provide recovery time** Let them eat something, or rest, or play on the computer.
- **Forgive, and make each day new.**



Think of Yourself as Their Behavior Coach

How to Be a Behavior Coach

*This technique is very powerful and is much better explained in Transforming the Difficult Child, by Howard Glasser.

-Set the bar low to ensure success. (Set your expectations for how he should behave not by what a “typical child” is doing, but by his own abilities-by what he is showing you right now... The first goal should be to do a little bit better, which probably won’t be anywhere near what you really want

-Celebrate and praise even the most basic good behavior-they should get more attention from us for the things they do right, then for the things they do wrong.

-Prioritize and work on only a few skills at a time

A good coach knows that you can’t learn it all in a day.

-A good coach teaches skills, and doesn’t expect them to already have them.

Explain, draw, and demonstrate what you want, and help him to practice.

-Reward effort, not just success.

The coach knows that the hardest work may be in the beginning, while the most learning is happening. “You look very angry right now, but so far you are staying in control, keep it up! “Or “that must have been hard, I can see you were trying your best”

-Encourage the discouraged. “You almost did it!”

Tools that may make it easier for them to learn control

- Occupational and Physical therapy to help them with motor skills and sensory integration issues
- Sign language-to help them communicate while speech is developing
- Medication-can give them enough control of themselves that they can then respond to behavioral techniques
- Some people have had luck with special diets and vitamins

Final thoughts...

When my daughter, Laura (age 20, has SMS) saw that I was writing about how to manage children with SMS, she said, “ Well, Mom, just tell them Matthew 7:12, from the Bible! “ (knowing Bible verses is one of her quirky strengths) When I went to look it up, I realized it said, “ Do unto others as you would have them do unto you”! I guess in that short sentence, she said most of what I have been trying to say.

Start each day new. They do...they need a new clean slate. Don't keep score...on them or on yourself. You WILL make mistakes. Some days you'll be too exhausted to do anything but survive. I've been watching March Madness, because for once in a lifetime, my college team made the playoffs. These players are good...amazing even, but the funny thing is, they only get it in the basket about 50 % of the time...and they keep on shooting. They have been facing that free throw line all of their basketball careers, you would think they would be able to do it blindfolded by now. But they can't, because it is such a hard task, and so is parenting the child with SMS.

If you feel like you have to walk on eggshells...

Well, maybe you do...

The eggshell protects the chick until it is developed enough to be ok on it's own. If the egg is cracked too early, and the chick is exposed before it is ready for the pressure, it will not survive.

In the same way, our SMS children need us to protect them and give them time to develop. Their emotional/behavioral control is very slow to develop. They need coaching, patience, encouragement, acceptance, and flexible boundaries until they can develop enough control on their own to begin to break free of their frustrations and let their sweet natures dominate.

