

## ***My Child Has Selective Mutism, What Do I Do Now?***

**Written by Christine Stanley and Teresa Cardulla**

### **Evaluate your child.**

Once you suspect selective mutism (SM), you should confirm that diagnosis. In doing so, be sure you are not misdiagnosing the symptoms. Other similar conditions can be autism, Asperger's (a high functioning form of autism), Pervasive Development Disorder (PDD), Oppositional Defiance Disorder (ODD), social anxiety and separation anxiety. Many parents find that once they see the criteria for SM, they are quite certain their child's symptoms match that diagnosis, but be sure to have a complete evaluation to include every detail of your child's situation.

Other contributing factors that can add to or complicate the SM are sensory processing challenges, delayed speech and language development, auditory processing issues and articulation problems. Sometimes it is difficult to sort through them all when children encounter multiple issues. Is the SM causing my child to melt down when there are fireworks, or is it the sensory issues? Is SM causing the articulation problem or speech delay? These are very common types of questions and ones that are very unique to your child. Sometimes it takes a long time to sort through them and truly figure that out.

### **Find a professional to diagnose and treat your child.**

In evaluating your child, it is extremely important to evaluate the whole child, not just the SM characteristics. Be careful not to view SM as the sole challenge your child faces if there are others. As mentioned above, be aware of the concurrent conditions that often occur, including social anxiety, separation anxiety, sensory processing issues, speech delays and articulation problems and auditory processing challenges.

Because there can be multiple issues, diagnosis can be tricky but it is very important! You will need an official evaluation and diagnosis so you can treat all conditions, not just one. Find a clinical therapist to conduct the evaluation. This can include a psychologist, psychiatrist, clinical social worker, counselor or speech and language pathologist. Sometimes a preschool screening might catch it. Then your pediatrician, psychologist, psychiatrist or social worker may make the official diagnosis.

One of the most common questions received through the Selective Mutism Group-Childhood Anxiety Network (SMG-CAN) is how do I find a therapist. SMG-CAN has

created guidelines on how to find a treating professional. Find that information at (provide link.)

Don't be afraid to interview professionals that might be working with your child. It is important to find the right fit for your child and someone who understands anxious children and the proper approach with them. Questions for that interview can also be found in the guidelines just mentioned.

### **Research and learn about SM.**

Educating yourself about SM and understanding your child's world is critical to successful treatment. One of the most crucial points in that is using a non-threatening manner. There should be no pressure to speak. It can actually reinforce mutism. Children should be gently guided in social settings. It is so easy to want to provide incentives or bribe children "to speak." Yelling, threats of punishment and irrational statements can bring severe negative attention to SM making the child more anxious and unable to make progress. This is very common, especially at first or before you know the root cause of SM, but when you educate yourself and understand that your child is really so anxious that no bribe will "make them speak," you'll be on your way to understanding your child and helping them to begin progressing.

Some days are easier than others and often there are various factors, like new situations, different people, new or different circumstances related to a situation. It can make a seemingly simple situation very complicated but it requires a lot of patience! For example, Natalie is able to speak in restaurants to order her food. This has become very easy for her and she even makes eye contact and smiles. Typically it is her immediate family (parents and two sisters) with her when they go to a certain restaurant. Recently another family member joined her family at the same restaurant. When her mother asked her to order she shook her head "no" and began to close off. It was obvious she was shutting down and was feeling very uncomfortable. Although she can normally order her food at that restaurant, having grandma there changed the scenario and made it impossible for her to share her order. This was not grandma's fault! The change in the dynamics created stress that kept her from ordering that time. It is common to think, "Will she ever speak in a restaurant again?" or "Have I set her back?" This was a minor setback due to changing circumstances. The more you can become in tune to every situation and how seemingly minor changes can affect SM children, the better equipped you'll be able to "roll with it", move on and understand in the future. Many parents of SM children feel a constant "one step forward, two steps back" feeling. However, those steps forward are huge and we need to provide caring, encouragement and support for their accomplishments! This does require an incredible amount of patience and realistic expectations, at least related to speaking. Try not to let the SM become a

power struggle with you and your child, but try to meet them where they are verbally or non-verbally and work together. That requires parents to come to terms with the SM in order to help the child. That can be difficult! Any time your child experiences something that makes them "different," even temporarily, it can increase stress on the family. Let go of the guilt and use that energy to learn about SM, understand your child and help them overcome SM.

### **Educate others**

Your child must feel understood and accepted by extended family, friends, teachers and others they encounter regularly socially. All have a role in helping the SM child feel comfortable and this can eventually help the child overcome mutism. Many parents have found that creating the proper environment for their child, at home, in family settings and in the school, is one of the foremost things in creating success for their child. It can have a huge impact! Allowing the child to feel safe and accepted relieves a lot of their anxiety!

*Who do you tell?* Everyone! It is extremely important, especially with younger children, to inform each person that comes in contact with your child, at school, at family gatherings and in other social settings. Gauge the situation as far as how in-depth you go (how much time will your child spend in each setting?) but some parents have found great success in educating those around their child. Give handouts to teachers and school staff. Purchase books on SM and loan them to teachers, care providers, family and friends. Purchase the cards provided by SMG-CAN and available on the website. They are business card-sized with a brief explanation of SM on one side and how to relate to an SM child on the other side. These are very effective to give to people that provide swimming lessons, dance lessons, coaches, parents that work in your child's classroom, etc. They don't need to know your child's entire history like a teacher might, but they need the condition at least outlined because they will be working closely with your child for a time. Having them understanding the condition can make a huge impact on how they interact with your child.

If your child is older, you may have to tread a little more lightly. It is important to talk this over with the child and emphasize that you telling others is simply to help them. However, you may limit the number of people you tell, compared to the younger child. You may need to ask them how much they want to reveal and how they want this very personal information communicated. An older child should be highly engaged in their treatment and this is something you can address together, as a team.

Unfortunately, there are people who just don't get it or don't want to get it. Sometimes it is necessary to limit contact with those people as it can really slow

progress. Continue to try to educate them and as your child progresses, it may become easier for the child to interact with them.

### **Advocate for your child.**

We need to do everything possible to make school a positive experience for your child. The more comfortable your child feels, in general, the greater their success at school. Advocate for your child and start discussing the need for an educational plan. This might be an IEP if he or she qualifies for special education services or a 504 plan if not. This is the legal document that outlines accommodations for your child. It is the law that your child receives a fair and equal education. If that means your child needs accommodations to receive that fair and equal education, they need to have that plan in place! It could include receiving speech or occupational services or could be as simple as having goals like being placed by a child he or she knows, or being provided warning if there will be a fire drill, substitute or field trip. It is their right to get their needs met! Speak with your child's teacher or school counselor to get that process started.

### **Deal with SM daily.**

Convey understanding that it is hard to get the words out. Gain their trust by letting them know you are going to help. Reassure them that they are not alone and that other kids suffer from SM! These can all be important steps in "rebuilding" if past well-intentioned efforts to get a child to communicate have failed! An apology for misunderstanding can go a long way! So can letting them know that there are others like them and that many kids have fears of various degrees and ranges.

Sometimes siblings can get frustrated with SM because they don't understand it or it affects their life. Explain to them what SM is, encourage their assistance and support, but also reiterate their role in SM and that they can't do everything for them! Gain participation by siblings, even if it requires some incentive as well. They are an important piece of the puzzle and the stress of SM can affect them too. Work hard to not make them feel left out. Dealing with SM can be so time-consuming and you may be spending extra time with your SM child, even if it is for meetings and evaluations! Try to keep a balance and at least be cognizant of potential sibling issues.

### **Lead by example. Be a social role model!**

Let your child see you socialize with others in your community. This can have a huge impact! Use opportunities at church, the grocery store, school, with family or in public to teach them basic social skills, which they may very likely lack! You're the best teacher!

Many parents of SM children have social anxiety themselves. Some may first come to realize this as they deal with their child's situation. They may find it difficult to deal with the emotions of all this, as well as advocating for their child. If a parent has anxiety, set goals, let your child see YOU working on goals and talk about your feelings. This is very powerful! Your child will be comforted to know he or she is not alone and will be inspired by watching you reach your goals!

You can increase social interactions by scheduling play dates. You can have specific goals in mind but practicing social interactions, having fun and increasing comfort are likely to come faster and more naturally by using play. Try different activities and situations. Some like structured and others struggle with too much structure. It is often better to keep the group small. Let the child dictate your involvement. After a certain point, if something isn't working, try something else! Push the comfort level slowly and be mindful not to overstimulate by over-scheduling. Often SM children get overwhelmed more easily than normal and don't need as much social activity. School can be enough! There is a fine line and that's one you'll learn as a parent.

### **Encourage strengths.**

It is very important to encourage your child's strengths. If they are good at art, encourage art classes. If martial arts gives them a boost, try it! Don't let your hopes and dreams for your child interfere with the reality of the situation. Do what works for them.

### **Take care of you.**

The SM diagnosis can be stressful and all-consuming. Try hard to manage your stress by finding time away, practicing healthy habits, finding others who understand and leaving the guilt behind! People who haven't experienced SM don't always understand. Although often well-intentioned, sometimes friends, family and others just don't quite "get it!" WE understand. It is important to get support from people who have been there. SMG-CAN is a great resource and joining can be a powerful part of getting through your journey with SM.

Sometimes people don't see a child not speaking as a major disability. You'll probably hear "he's just shy" or "she'll grow out of it." It is easy to make light of SM, but in fact, it is a severely debilitating condition that is best served by addressing it early! If there are concerns or your gut tells you something is not right, trust it. Do some research, ask around and have your child evaluated if necessary just to make sure. Just know you are not alone in your journey! For more information and resources, check the SMG-CAN website at [www.selectivemutism.org](http://www.selectivemutism.org).

