



WHAT is Selective Mutism?

A GUIDE to Helping Parents, Educators and Treatment professionals

Understand Selective Mutism as a Social Communication Anxiety Disorder

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Do you know a child who is mute, barely whispers to few others in school or other social settings, but is able to speak when comfortable such as at home?

If so, this child may be suffering from Selective Mutism.



Selective Mutism is a complex ***childhood anxiety disorder*** characterized by a child's inability to speak and communicate in a socially appropriate manner in select social settings, such as school. These children are able to speak and communicate in settings where they are comfortable, secure and relaxed, such as at home.

To meet the diagnostic criteria for Selective Mutism (SM) a child has to be able to speak in at least one setting and be mute in at least one other setting. The typical presentation is the 'timid' child who can speak and act socially appropriate with family members, close peers and very familiar relatives, yet is mute or barely whispers to a few others in school or perhaps when addressed in public settings such as restaurants or stores

More than 90% of children with Selective Mutism also have social anxiety. This disorder is quite debilitating and painful to the child. Children and adolescents with Selective Mutism have an actual FEAR of speaking and of

social interactions where there is an expectation to speak and communicate.

Many children with Selective Mutism have great difficulty responding or initiating communication in a nonverbal manner. Therefore, social engagement may be compromised in many children when confronted by others or when in a setting that is overwhelming and comes with a feeling of expectation.

Not all children manifest their anxiety in the same way. Some may be completely mute and unable to speak or communicate to anyone in a social setting, others may be able to speak to a select few or perhaps whisper. Some children may stand motionless with fear when they are confronted in specific social settings. They may freeze, be expressionless, unemotional and may be socially isolated. Less severely affected children may 'look' relaxed, carefree and socialize with one or a few children but cannot speak and effectively communicate to teachers or peers.

Why does a child develop Selective Mutism and what are their presenting symptoms?

The majority of children with Selective Mutism have a **genetic predisposition** to anxiety. In other words, they have inherited a tendency to be anxious from one or more family members. Very often, these children show signs of severe anxiety, such as separation anxiety, frequent tantrums and crying, moodiness, inflexibility, sleep problems, and extreme shyness from infancy on.

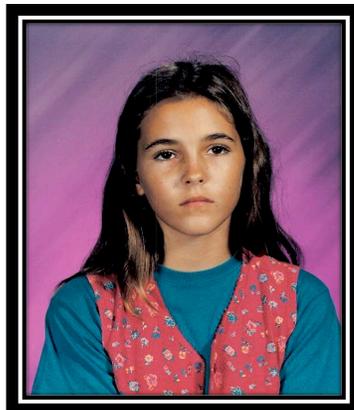
Children with Selective Mutism often have **severely inhibited temperaments**. Studies show that individuals with inhibited temperaments are more prone to anxiety than those without 'shy' temperament. As a result, symptoms of SM are most prevalent in **social settings** such as birthday parties, school, family gatherings, routine errands, etc.

Approximately 30% of children with Selective Mutism have subtle **speech and/or language abnormalities** such as receptive and/or expressive language abnormalities and language delays. Interestingly enough, our research has found that as children age, and remain mute or minimally verbal, their ability to express themselves is compromised; hence leading to an acquired expressive language disorder, primarily in the area of narrative speech. WHY? Children with SM lack the typical give/take of a conversation in social environments (playing with friends, responding and initiating conversation with relatives) or where more complex language is

expected (such as in school and having to explain or initiate a thought or idea).

Some may have subtle learning disabilities including auditory processing disorders. Some children with SM come from **bilingual/multilingual families, have spent time in a foreign country, and/or have been exposed to another language during their formative language development (ages 2 –4 years old.)** These children are usually innately temperamentally inhibited but the additional stress of ‘speaking another language’ and being insecure with their skills is enough to cause an increased anxiety level and mutism.

Research at the SMart Center indicates that many children who present with Selective Mutism have Sensory sensitivities any many meet the criteria for Sensory Processing disorder (DSI). Thus, DSI can be an underlying reason for ‘shut down’ and mute behavior. In larger, more crowded environments where multiple stimuli are present (the classroom setting), a child may have difficulty processing sensory input. As a result, anxiety is created. As anxiety increases, the child may actually feel fear. Children with SM tend to avoid, ‘shut down,’ freeze and become mute. They may appear, as seen in the picture below, similar to a ‘deer in headlights.’



These children may have trouble processing specific sensory information. Typical symptoms of children with SM who have sensory challenges present with:

- Over sensitivity to feel of fabrics, hair brushing/washing and hugging, handholding and being touched. They often pull out tags from their clothes and prefer elastic band pants compared to buttoned pants.
- Picky eating tendencies
- Overly sensitive to sounds, lights and/or smells...with sounds being the most common sensitivity.
- Emotional regulation challenges

- Socially withdrawn and tend to misinterpret touch in the classroom. Will indicate kids 'pushed them' when in reality they were gently nudged.

Modulating sensory input tends to affect the child's emotional responses when he or she has sensory challenges. Hence, many children with SM have emotional regulation difficulties. As a result, many sweet natured children can also seem quiet stubborn or inflexible, and may tend to procrastinate or tantrum easily if they do not agree with or expect something.

DSI may cause the child with SM to misinterpret environmental and social cues. This can lead to inappropriate social responses, frustration and anxiety. Their inability to effectively communicate reinforces this. The anxiety experienced may cause a child to shut down, avoid and withdraw from a situation, or it may cause him/her to act out, have tantrums and manifest negative behaviors.

Within the classroom, a child with sensory difficulties may demonstrate one or more of the following symptoms; withdrawal, playing alone or not playing at all, hesitation in responding (even nonverbally, with pointing a finger or shaking their head), distractibility, difficulty following a series of directions or staying on task, or difficulty completing tasks. Experience at the Smart Center dictates that sensory processing difficulties may or may not cause 'learning' or academic difficulties. Many children, especially, highly intelligent children can compensate academically and actually do quite well. Many focus on their academic skills, often leaving behind 'the social interaction' within school. This tends to be more obvious as the child ages.

What is crucial to understand is that many of these symptoms may NOT exist in a comfortable and predictable setting, such as at home.

In some children, there are processing problems, such as auditory processing disorder, that cause learning issues as well as heightened stress.

Selective Mutism is therefore a symptom. Children are rarely 'just mute.'

Emphasis needs to be on CAUSES and propagating factors of mutism. Often, children with SM have one or more reasons, as mentioned above, as to why they developed social communication difficulties and SM. So, it is not atypical for a child with SM to be timid, have sensory sensitivities and/or perhaps a subtle speech and language disorder while another child may be bilingual and timid by nature.

When evaluating a child with SM it is critical to determine the cause as to why the child developed Selective Mutism in order to develop an appropriate treatment plan and school based accommodations/interventions.

Studies have shown NO evidence that the cause of Selective Mutism is related to abuse, neglect or trauma.

When are most children diagnosed as having Selective Mutism?

Most children are diagnosed between 3 and 8 years old. In retrospect, it is often noted that these children were temperamentally inhibited and severely anxious in social settings as infants and toddlers, but adults thought they were just 'very shy.' Most children have a history of separation anxiety and being 'slow to warm up.' Often it is not until children enter school and there is an expectation to perform, interact and speak, that Selective Mutism becomes more obvious. What often happens is teachers tell parents the child is not talking or interacting with the other children. In other situations, parents will notice, early on, that their child is not speaking to most individuals outside the home.

If mutism persists for more than a month, a parent should bring this to the attention of their child's physician.

Why do so few teachers, therapists and physicians understand Selective Mutism?

Studies of Selective Mutism are scarce. Most research results are based on subjective findings based on a limited number of children. In addition, textbook descriptions are often nonexistent or information is limited, and in many situations, the information is inaccurate and misleading. As a result, few people truly understand Selective Mutism. Professionals and teachers will often tell a parent, 'the child is just shy,' or 'they will outgrow their silence.' Others interpret the mutism as a means of being oppositional and defiant, manipulative or controlling. Some professionals erroneously view Selective Mutism as a variant of autism or an indication of severe learning disabilities. For most children who are truly affected by Selective Mutism, this is completely wrong and inappropriate!

Research at the SMart Center indicates that children who seem 'oppositional' in nature often have parents, teachers, and/or treating

professionals who have pressured them to speak for months, perhaps years. Mutism not only persists in these children, but also is negatively reinforced. These children may develop oppositional behaviors out of a combination of frustration, their own inability to 'make sense' of their mutism, and other people pressuring them to speak.

As a result of the scarcity and, often, inaccuracy of information in the published literature, children with Selective Mutism may be misdiagnosed and mismanaged. In many circumstances, parents will wait and hope their child outgrows their mutism. However, without proper recognition and understanding of the SM causes, most of these children do not outgrow Selective Mutism. Instead, they end up going through years without speaking, interacting normally, or developing appropriate social skills.

Important for the child with SM, as mentioned, is understanding the causes. Mutism is merely the most obvious. Determining if the child has sensory processing difficulties, speech and language difficulties as well as timidity are critical because a child with sensory difficulties will need a more thorough sensory workup and a sensory diet and aggressive treatment, while a child with S/L challenges will need therapy addressing their speech and language needs. Specific treatment to address social communication anxiety is needed, such as Social Communication Anxiety Treatment (S-CAT)®, which is implemented at the Smart Center.

In fact, many individuals who suffer from Selective Mutism and social anxiety who do not get proper treatment to develop necessary coping skills may develop the negative ramifications of untreated anxiety. (See below).

Why is it so important to have my child diagnosed when he/she is so young?

Our findings indicate that the earlier a child is evaluated and treated for Selective Mutism, the quicker the response to treatment, and the better the overall prognosis. If a child remains mute for many years, his/her behavior can become a conditioned response where the child literally gets used to non-verbalizing. In other words, Selective Mutism can become a difficult habit to break!

Because Selective Mutism is an anxiety disorder, if left untreated, it **can have negative consequences throughout the child's life and, unfortunately, pave the way for an array of academic, social and emotional repercussions such as:**

- **Worsening anxiety**
- **Depression and manifestations of other anxiety disorders**
- **Social isolation and withdrawal**
- **Poor self-esteem and self-confidence**
- **School refusal, poor academic performance, and the possibility of quitting school**
- **Underachievement academically and in the work place**
- **Self-medication with drugs and/or alcohol**
- **Teen or unplanned pregnancy**
- **Suicidal thoughts and possible suicide**

At the SMart Center, our main objective is to diagnose children early so they can receive proper treatment at an early age, develop proper coping skills, and overcome their anxiety.

According to the US Surgeon General, our country is in a state of emergency as far as children's mental health is concerned. 10% of children suffer from mental disorders, but less than 5% of these children are actually receiving treatment.

Anxiety disorders are the most common mental illnesses among children and adolescents.

How is Selective Mutism treated?

Social Communication Anxiety Therapy (S-CAT)[®] is the philosophy of treatment by **Dr. Elisa Shipon-Blum** and implemented at the Selective Mutism Anxiety Research and Treatment Center (SMart Center) www.selectivemutismenter.org.

S-CAT[®] is based on the concept that Selective Mutism is a **social communication anxiety disorder** that is more than just not speaking.

Dr. Shipon-Blum has created the **Selective Mutism Stages of Social Communication Comfort Scale™** that describes the various stages of social communication that are possible for children suffering from SM.

The **Social Communication Bridge®** illustrates the Selective Mutism Stages of Social Communication in a visual format.

SELECTIVE MUTISM-STAGES OF SOCIAL COMMUNICATION COMFORT **SCALE ©**

NON-COMMUNICATIVE -neither non-verbal nor verbal. NO social engagement.

STAGE 0 - NO Responding, NO initiating

Child stands motionless (stiff body language), expressionless, averts eye gaze, appears 'frozen,' **MUTE**
OR

Seemingly **IGNORES** person while interacting or speaking to other(s). **MUTE towards others**

For communication to occur, **Social Engagement** must occur

COMMUNICATIVE (Nonverbal and/or Verbal*)

*TO ADVANCE FROM ONE STAGE OF COMMUNICATION TO THE NEXT, INCREASING SOCIAL COMFORT NEEDS TO OCCUR.

STAGE 1 - Nonverbal Communication: (NV)

1A Responding -pointing, nodding, writing, sign language, gesturing, use of 'objects' (e.g. whistles, bells, Non-voice augmentative device (e.g. communication boards/cards, symbols, photos)

1B Initiating -getting someone's attention via pointing, gesturing, writing, use of 'objects' to get attention (e.g. whistles, bells, Non-voice augmentative device (e.g. communication boards/cards, symbols, photos)

STAGE 2 - Transition into Verbal Communication (TV)

2A Responding -Via any sounds, (e.g. grunts, animal sounds, letter sounds, moans, etc.): Verbal Intermediary or Whisper Buddy; Augmentative Device with sound, (e.g. simple message switch, multiple voice message device, tape recorder, video, etc.)

2B Initiating -Getting someone's attention via any sounds, (e.g. grunts, animal sounds, letter sounds, moans., etc.): Verbal Intermediary or Whisper Buddy; Augmentative Device with sound, (e.g.,

Children suffering from Selective Mutism (SM) change their level of social communication based on the setting and expectations from others within a setting.

Therefore, a child may have difficulty socially engaging, communicating nonverbally and perhaps cannot communicate at all when feeling anxious or uncomfortable.

For some children, they are able to engage and have excellent nonverbal skills (professional mimes). These children are stuck in the nonverbal stage of communication and suffer from a subtype of SM called: Speech Phobia.

Therefore, although mutism is the most noted symptom, it merely touches on the surface of our children. A complete understanding of the child is necessary to develop an appropriate treatment plan and school-based accommodations and/or interventions.

According to Dr. Shipon-Blum's work, after a complete evaluation (consisting of various assessment forms-parent/teacher; parent and child interview), treatment needs to address three key questions.

- **WHY did a child develop SM? (Influencing, precipitating and maintaining factors)**
- **WHY does Selective Mutism persist despite being in active treatment and parent/teacher awareness?**
- **WHAT can be done at home, the real world and within school to help the child build the coping skills and overcome their social communication challenges?**

The **Social Communication Bridge®** can be used to determine the stage of social communication from setting to setting.

Treatment is then developed via the whole child approach. Under the direction of the outside treatment professional, the child, parents, and school personnel work together.

Dr. Shipon-Blum emphasizes that although lowering a child's anxiety level is key, it is often not enough, especially as children age. Over time, many children with Selective Mutism no longer feel anxious, but mutism and lack of proper social engagement continues to exist in select settings.

Children with SM need strategies and/or interventions to progress from nonverbal to spoken communication. This is the Transitional Stage of communication, and this aspect is often missing from most treatment plans. In other words, how do you help a child progress from Nonverbal to Verbal communication?

Quite frankly, time in the therapy office is simply not enough. The office setting is used to help prepare the child for the outside world. To develop the strategies to help the child unlearn their conditioned behavior. Then, in the Real World and within the school setting, the strategies/interventions are implemented.

Strategies and interventions are developed based on where the child is on the Social Communication Bridge® and are meant to be a desensitizing method as well as a vehicle to unlearn conditioned behavior.

S-CAT® incorporates anxiety-lowering techniques, methods to build self-esteem, and strategies/interventions to help with social comfort and communication progression. This may include “Bridging” from shut own to nonverbal communication and then transitioning into spoken communication via verbal intermediaries, ritual sound shaping, and possibly the use of augmentative devices.

The key concept is that children with SM need to understand, feel in control, of and have choice in their treatment (age dependent). This is a critical component of S-CAT®.

S-CAT® provides choice to the child and helps to transfer the child’s need for control into the strategies and interventions! Therefore games and goals (based on age) via the use of ritualistic and controlled methods (e.g., use of strategy charts) are used to help develop social comfort and ultimately progress into speech

Silent goals (environmental changes) and active goals (directed goals based on choice and control) are used within the S-CAT® program.

Every child is different and therefore an individualized treatment plan needs to be developed that incorporates home (parent education, environmental changes), the child’s unique needs and school (teacher education, accommodations/interventions).

Therefore, by lowering anxiety, increasing self-esteem, as well as increasing communication and social confidence within a variety of real world settings, the child suffering in silence will develop necessary coping skills to enable proper social, emotional and academic functioning.

The Selective Mutism Anxiety Research and Treatment Center (SMart Center) and Selective Mutism Research Institute (SMRI) are committed to performing and disseminating information on Selective Mutism treatment options, new scientific advances, and research studies.

Dr. Evelyn Klein and Dr. Sharon Armstrong are the primary investigators at the Selective Mutism Research Institute (SMRI) studying the efficacy of Dr. Shipon-Blum's Social Communication Anxiety Therapy (S-CAT®). By tracking the progress of eligible patients in the 5-12 age range, the researchers are able to analyze the changes in social communication in the home, real world, and school settings.

Within just three visits to the SMart Center results of the S-CAT® efficacy study show **statistically significant improvements** in social communication in the school with

teachers/peers, with strangers within the real world (i.e. waiters and store clerks) and at home with guests and peers. Results show that Children with Selective Mutism are becoming verbal directly to others in all settings.

Findings of the S-CAT® efficacy study indicate implementation by parents and school staff is needed to see the most progress. This implies therapy in the office, without follow thru, is not as effective as child goals/games, parenting changes/goals and individually developed accommodations/interventions within the school setting.

Fortunately, with proper treatment, children with SM can develop the needed coping skills to combat their anxiety and overcome their silence...allowing for the rest of the world to 'see' what parents of children with SM tend to see only within the confines of their comfortable home environment; chatty, confident and assertive children!

“Butterflies are caterpillars that struggle and come out with flying colors.”

For more information, please contact the Selective Mutism Anxiety Research and Treatment Center (SMart Center):

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