

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, teen, or young adult who is mute or barely whispers to few others in school or other social settings, but is able to speak where they're comfortable such as at home?

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



What is Selective Mutism?

Selective Mutism (SM) 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.

To meet the diagnostic criteria for SM, the individual must be able to speak and communicate in at least one setting (typically in which they are comfortable, secured, and relaxed, such as at home) and be mute in at least one other setting (such as in school).

More than 90% of individuals with Selective Mutism also have social anxiety, a debilitating and painful disorder. Those with SM have a fear of social interactions where there is an expectation to speak.

What does Selective Mutism look like?

The typical presentation is a “timid” child who can speak and act socially appropriate with family members, close peers, or very familiar relatives yet is mute or barely whispers to a few others in school or when addressed in public settings such as in restaurants or stores.

Not everyone diagnosed with SM manifests their anxiety the same way. Some may be completely mute and unable to speak or communicate to anyone in a social setting; may speak or whisper to select individuals; may find it difficult to respond or initiate communication nonverbally; may stand motionless and expressionless with fear when they are confronted in certain settings. Less severely affected individuals with Selective Mutism may look relaxed and will socialize with one or a few others but cannot speak and or effectively communicate to teachers or in large groups of peers.



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

Most children with Selective Mutism have a genetic predisposition to anxiety. They frequently show signs of severe anxiety, e.g. separation anxiety, excessive tantrums and crying, moodiness and inflexibility, problems sleeping, and extreme shyness from infancy on.

Children with SM often have severely inhibited temperaments.

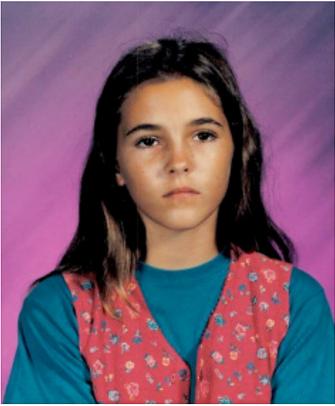
Studies show that individuals with inhibited temperaments are more prone to anxiety than those without. As a result, symptoms of Selective Mutism are most prevalent in social settings, e.g. birthday parties, school, family gatherings, routine errands, etc.

Approximately 30% of children with SM have subtle speech and/or language abnormalities such as language delays. Our research shows that as children age and remain mute or minimally verbal, their ability to express themselves is compromised. This leads to an acquired expressive language disorder, primarily in narrative speech, because they aren't participating in the typical responding-and-initiating of a conversation in social environments or where the use of more complex language is expected such as in school.

Some children with Selevtive Mutism may have subtle learning disabilities including auditory processing disorders. Many come from bi- or multilingual families, have spent time in a foreign country, and/or have been exposed to another language during their formative language development years (2-4-years old). These children are usually innately temperamentally inhibited but the additional stress and insecurity of having to learn another language can cause an increased anxiety level and ultimately mutism.

Selective Mutism and Sensory Processing Disorder

Research from the Selective Mutism Research Institute (SMRI) indicates **many children who present with Selective Mutism also have sensory sensitivities and meet the criteria for Sensory Processing Disorder (SPD)**. Thus, SPD can be an underlying reason for mute behavior.



In larger, more crowded environments where multiple stimuli are present (e.g. the classroom setting), a child may have difficulty processing sensory input. As a result, anxiety is produced. As anxiety increases, the child may actually feel fear. In these situations, children with Selective Mutism tend to “shut down,” avoid interacting, freeze, and become mute. They may appear like a “deer-in-headlights.”

Typical symptoms of children with SM who have sensory challenges present with:

- Oversensitivity to being touched by fabrics, hair washing and brushing, hugging, handholding, etc. They often pull out tags from their clothes and prefer elastic band pants compared to buttoned pants.
- Tendency to misinterpret touch in the classroom. For example, they will indicate another child pushed them when they were only gently nudged.
- Oversensitivity to sounds, lights and/or smells (sounds are the most common sensitivity)
- Picky eating tendencies

Within the classroom, a child with sensory difficulties may demonstrate one or more of the following symptoms:

- Social withdrawal/playing alone or not at all
- Physical discontent sitting close to or near others

- Group activity avoidance
- Hesitation in responding (including nonverbally)
- ADHD-like symptoms may manifest when in school and in group settings but not in a quieter, calmer and more predictable environment such as at home

Sensory Processing Disorder may cause a 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. Modulating sensory input tends to affect the child's emotional responses. As a result, many sweet-natured children can also seem quiet, stubborn, or inflexible.

Children with SM who also have sensory processing difficulties often have emotional regulation challenges as well.

Challenging behavioral patterns can manifest such as:

- Inflexibility
- Procrastination
- Stubbornness
- Impatience
- Crying spells and tantrums

Experience at the **Selective Mutism Anxiety and Related Disorders Research and Treatment Center (SMart Center)** indicates sensory processing disorder may or may not lead to learning or academic difficulties. Many children, especially highly intelligent children, can compensate academically and perform 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.

So, it is not atypical for a child with SM to be timid, have sensory sensitivities, emotional regulation challenges, and/or a subtle speech and language disorder. What is crucial to



understand is that many of these symptoms may *not* exist in a comfortable and predictable setting, such as at home.

Children are rarely “just mute.” Emphasis needs to be put on the causes and propagating factors of mutism. You cannot simply treat to speak. Understanding the causes as to why a child developed SM is needed to develop an appropriate treatment plan and school based accommodations and interventions.

There is *no* evidence to prove the cause of Selective Mutism is related to abuse, neglect or trauma.

When are most children diagnosed with Selective Mutism?

Most children are diagnosed between three and eight 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.

Oftentimes, it is not until children enter school (where there is an expectation to perform, interact and speak) that Selective Mutism becomes more obvious. Teachers commonly initiate the discovery and make the parents aware of the child’s failure to communicate and interact.

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 surrounding Selective Mutism are scarce. Most research results are based on subjective findings from studies with a limited number of children. Additionally, textbook descriptions of SM are often nonexistent or 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, 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 children who seem oppositional in nature may have been pressured to speak for months or perhaps years by parents, teachers, and/or treating professionals. No only does SM persist in these children, but it is negatively reinforced. These children may develop oppositional behaviors out of frustration, pressure, and their own inability to make sense of their mutism.



Because of the scarcity and oftentimes inaccurate information in published literature, many children with SM are misdiagnosed and mismanaged. Some parents will wait and hope their child outgrows their mutism. Instead, the child ends up going through years without speaking, interacting normally, or developing appropriate social skills. Without proper recognition and an understanding of what’s causing the disorder, these children do not outgrow it. We must understand the cause to establish an effective treatment plan.

Although mutism is the most obvious, it is not the only struggle children endure. Determining if the child has cooccurring symptoms is critical. A child with a sensory disorder requires a workup and diet and treatment plan with a sharper focus on sensory, while a child with speech and language challenges will need therapy addressing their specific speech and language needs.

Many individuals who suffer from Selective Mutism and social anxiety who do not receive proper treatment are at risk of developing the consequences of untreated anxiety.

Why is an early diagnosis so important?

Our findings indicate the earlier a child is evaluated and treated for Selective Mutism, the quicker the response to treatment which leads to a better overall prognosis. If a child remains mute for many years, his or her behavior can become a conditioned response where the child literally gets used to non-verbalizing.

If left untreated, SM can have negative consequences throughout the child's life and pave the way for an array of academic, social and emotional repercussions as an adult:

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

The SMart Center's our main objective is to diagnose children early so they can receive proper treatment and develop proper coping skills to prevent the above.

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 receiving treatment. Anxiety disorders are the most common mental illnesses among children and adolescents. Social anxiety disorder is the most common anxiety disorder that children with SM suffer from. Generalized anxiety, specific phobias and OCD are also seen accompanying SM.

How is Selective Mutism treated?

SMart Center clinicians, Selective Mutism specialists, treat their patients using **Social Communication Anxiety Therapy® (S-CAT®)**, the world-renowned, “holistic” or “whole-child” treatment approach developed by Dr. Elisa-Shipon-Blum. Based on the understanding that SM is a social communication anxiety disorder and is deeper than just not speaking, S-CAT® has been used to successfully treat more than 5,000 patients world-wide.

Through an **Individual Intensive One or Multi-Day Program**, or **CommuniCamp Intensive Group Treatment Program** (www.CommuniCamp.org), S-CAT® requires understanding the answers to three key questions:

1. Why did the child develop SM?
2. What are the maintaining and reinforcing factors (reasons why SM continues to exist, i.e. co-morbidities parenting styles)
3. What Stage or Stages of Social Communication™ is the child in across a variety of settings?

The **Selective Mutism Stages of Social Communication®**, determines the child’s baseline level of comfort and communication and developing individualized step-by step-strategies to help the child progress into speech in all aspects of life. **The Selective Mutism Stages of Social Communication Comfort Scale®** describes the various stages of social communication that are possible for children suffering from SM (opposite page).

The Social Communication Bridge® illustrates the Selective Mutism Stages of Social Communication in a visual format and can be used to determine the stage of social communication from setting to setting (next page).

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. , simple message switch, multiple voice message device ,tape recorder, video, etc)

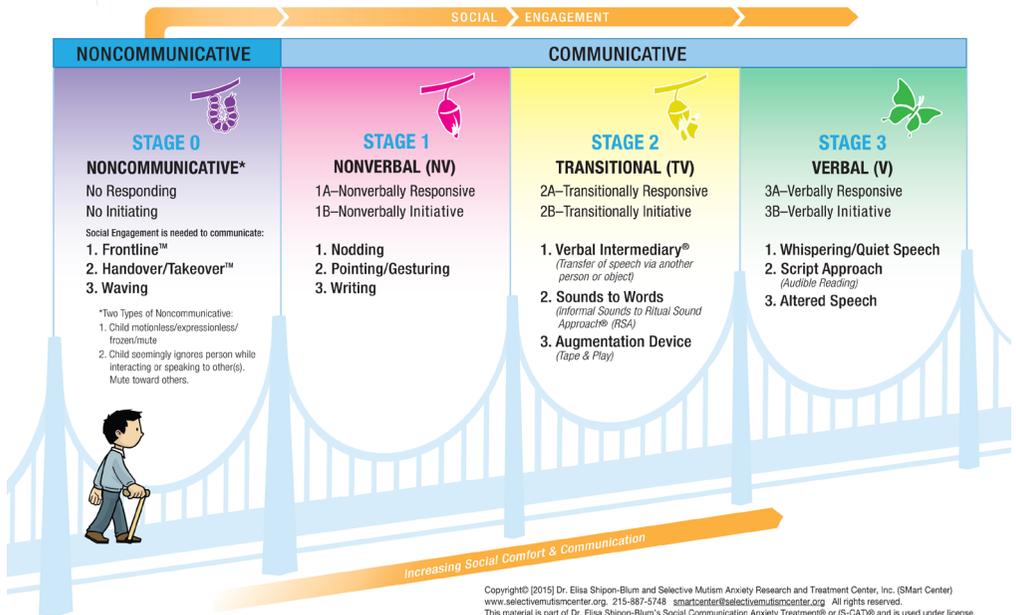
STAGE 3 - Verbal Communication (VC)

3A Responding – Approximate speech/direct speech (e.g. altered or made-up language, baby talk, reading/rehearsing script, soft whispering, speaking)

3B Initiating - Approximate speech/direct speech (e.g. altered or made-up language, baby talk, reading/rehearsing script, soft whispering, speaking)

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Children suffering from Selective Mutism change their level of communication based on setting and expectations from others. A child may have difficulty communicating nonverbally and may not communicate at all when feeling anxious or uncomfortable. Some children are able to engage and have excellent nonverbal skills (professional mimes). They are stuck in the nonverbal stage of communication and suffer from a subtype of SM called *Speech Phobia*. Although mutism is the most noted symptom, it merely touches the surface of our children.

A complete understanding of the individual is necessary to develop an appropriate treatment plan and school-based accommodations and/or interventions. After a comprehensive evaluation consisting of various assessment forms completed by a parent and teacher, the three key questions come into play. As a reminder, they are:

1. Why did the child develop SM?
2. Why does Selective Mutism persist in the child?
3. What Stage is the child in, and what can be done at home, in the real world, and at school to help build the coping skills and overcome their social communication challenges?

Treatment is then developed via the *holistic* or *whole child* approach under the direction of a Selective Mutism expert, the outside treatment professional, parents, and school personnel.

Dr. Shipon-Blum's S-CAT® treatment program incorporates anxiety-lowering techniques, methods to build self-esteem, and strategies to help with social comfort and communication progression. Examples include *bridging* from “shut-down” (Stage 0) to Nonverbal Communication, transitioning into spoken communication via Verbal Intermediaries®, ritual sound shaping known as Ritual Sound Approach®, and possibly the use of augmentative devices.

The missing link in most treatment plans is referred to as the Transitional Stage of Communication (Stage 2). Once there is some comfort in social engagement and nonverbal communication, emphasis should be put on helping a child progress from the Nonverbal Stage (Stage 1) to the Verbal Stage (Stage 3) of communication via the Transitional Stage (Stage 2).

Time in the therapy office is simply not enough. The office environment is used to help develop strategies and prepare the child for the real world. Strategies and interventions are developed based on where the child is on the Social Communication Bridge® and are meant to be desensitizing as well as a vehicle to unlearn conditioned behavior.

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®—providing choices to the child, which helps transfer his or her need for control into the strategies.



Games and goals via 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 (based on choice and control) are used in S-CAT®.

By lowering anxiety and increasing self-esteem, the child suffering in silence will develop necessary coping skills to enable proper social, emotional, and academic functioning.



What makes S-CAT[®] different that other treatment approaches?

1. Dr. Shipon-Blum's S-CAT[®] program focuses on the treatment of the child as a whole, not just their SM diagnosis.
2. It's been proven to work quickly. Within three visits (or less), children make substantially significant improvement in their ability to speak in all settings—at home, at school, and in the real world.
3. Patients are seen monthly, not weekly.
4. Step-by-step evidence-based success strategies and goal charts are provided to children, parents, and school staff.
5. Results are quick and children are seen less often (avg. 3-7 sessions) leading to significantly less overall cost for treatment.
6. S-CAT[®] has been used successfully for over 5,000 children from around the world.

The SMart Center and the 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 SMRI who studied the efficacy of S-CAT[®]. By tracking the progress of eligible patients from 5-12 years old, the researchers analyzed the changes in social communication in the home, real world, and school settings.

The results*?

Within three visits, patients showed statistically significant improvements in social communication within school (teachers/peers), strangers within the real world (waiters and store clerks), and at home with guests and peers.

The study also indicated **implementation by parents and school staff is needed to see the most progress**. This implies therapy in the office, without follow through, is not as effective as child goals/games, parenting changes/goals, and individually developed accommodations/interventions within the school setting.



*To read the full study and to see a summary of the results with statistics and graphs, visit www.SelectiveMutismCenter.org

S-CAT® integrates components of behavioral-therapy, CBT, and an insight-oriented approach to increase social communication and promote social confidence in a fun and safe environment.

- Psychotherapy addresses the anxiety that underlies the person's inability to speak in certain situations
- Adjunctive treatment to address coexisting conditions (factors into the development and maintenance of SM) including Speech and Language therapy, occupational therapy, sensory-integration therapy, and other interventions that may be recommended by the treatment provider(s).
- Medication* primarily antianxiety, e.g. Selective Serotonin Reuptake Inhibitors (SSRI's), Selective Norepinephrine Reuptake Inhibitors (SNRI's). *Not all children need medication. Never to be used alone without psychotherapy.
- Balanced diet/nutrition: complex carbs, proteins, Vitamin B (B6), Magnesium, Zinc, Calcium, Omega 3 FA's (EPA version)
- Exercise (at least 30 minutes per day, 5 days per week) and good sleeping habits. Avoid electronics 1 hour prior to bed.
- Treatment to foster self expression, develop emotional maturity, self-esteem and confidence building such as music, art, animal therapy.



Dr. Elisa Shipon-Blum is the President and Director of the S^Mart Center (Selective Mutism, Anxiety, & Related Disorders Treatment Center) located in Jenkintown, Pennsylvania. She founded the Selective Mutism Association (SMA) and the Selective Mutism Research Institute (SMRI), a foundation established to study Dr. Shipon-Blum's theories and treatment methodologies on Selective Mutism. In addition, Dr Shipon-Blum is a Clinical Assistant Professor of Psychology and Family Medicine at the Philadelphia College of Osteopathic Medicine. She is a board certified family physician who specializes in Selective Mutism.

Dr. Shipon-Blum developed the evidence-based treatment, Social Communication Anxiety Treatment[®] (S-CAT[®]) from her years studying and researching individuals with Selective Mutism. She consults with families, treating professionals, and educators, and has successfully treated over 5,000 selectively mute children, teens, and young adults from around the world. Dr. Shipon-Blum also created CommuniCamp[™], an intensive group treatment program modeled after S-CAT[®] concepts and strategies.

Dr. Shipon-Blum lectures throughout the country and performs school evaluations and trainings for treating professionals, educators, and parents. She is considered one of the world's leading experts in the treatment and understanding of Selective Mutism and has been featured on national television programs such as *20/20*, *CNN*, *Inside Edition*, and *Good Morning America*, as well as other local, national, and international television and radio broadcasts. Dr. Shipon-Blum has also been featured in *TIME Magazine*, *People Magazine* and newspapers such as the *New York Times*, *Chicago Tribune*, *Boston Globe*, *San Diego Tribune*, *Philadelphia Inquirer*, and *Palm Beach Post*.

Dr. Shipon-Blum is presently involved in multiple collaborative research projects and has written numerous articles and books on Selective Mutism. She has also produced numerous DVDs on the topics of treatment and assessment of Selective Mutism, and the development of school accommodations and interventions for mute children, teens, and young adults.



Fortunately, individuals with Selective Mutism can (with proper treatment) develop the necessary coping skills to combat their anxiety and overcome their silence, finally allowing the rest of the world to see what their parents tend to see within the confines of their comfortable home environment: a chatty, confident and assertive child.

To schedule an appointment or learn more about our treatment services, contact us today:
(t) 215-887-5748 | (e) smartcenter@selectivemutismcenter.org
www.selectivemutismcenter.org

Assessments, Testing, & Evaluations

Our specialists can help uncover the underlining contributing factors to your child's social communication challenges, so we can tackle them together.

Individualized Intensive Treatment

S-CAT®, our evidence-based treatment approach, has been used to successfully treat over 5,000 children, teens, and young adults world-wide.

CommuniCamp™ Group Treatment

A 3-day intensive program for children ages 3-15 who struggle to respond and/or initiate speech in school and other social settings. Parent training included.

General Education, School Training, and Case Management

For parents, teachers, and treating professionals. Interventions such as IEPs and 504s, can be discussed.



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*"Butterflies are caterpillars that struggle
and come out with flying colors."*



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