

"When the Words Just Won't Come Out" Understanding Selective Mutism

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What Is Selective Mutism?

Selective Mutism is a complex <u>childhood anxiety disorder</u> characterized by a child's *inability* to speak in select social settings, such as school. These children are able to talk normally in settings where they are comfortable, secure and relaxed. Although the exact etiology of Selective Mutism is unclear at this time, the majority of cases are believed to be due to severe behavioral inhibition and a heightened sensitivity to anxiety and/or fear.

Why does a child develop Selective Mutism?

The <u>majority</u> of children have a genetic predisposition to anxiety. Recent research by the Selective Mutism Group Childhood Anxiety Network indicates that the majority of these children have distinctive behavioral characteristics that can be explained by the studied hypothesis that children with inhibited temperaments have a decreased threshold of excitability in the limbic system within the brain, specifically, the amygdala. Research is now underway to prove this theory with Selectively Mute children.

Studies indicate that severely inhibited children often meet the diagnostic criteria for social phobia. Interestingly enough, studies indicate that over 90% of Selectively Mute Children meet the DSM-IV diagnostic criteria for social phobia.

Rare causes of Selective Mutism are due to:

- (1) Bilingual children that have spoken one language for the majority of their life and are exposed to another language during their preschool or early elementary years. A perfectionist attitude as well as an Insecurity over their ability to understand and speak this 'new' language causes increased internal stress levels.
- (2) Approximately 20-30% of Selectively Mute children have expressive language disorders. An unproven theory is that these anxiety-prone children have an insecurity and fear of embarrassment predispose these children to anxiety over their spoken voice
- (3) Very rare causes, less than 2-5% of cases: Environmental influences that cause a child severe internal stress, such as history of mental or physical abuse, family dysfunction A very rare cause of SM. Less than 2% of the cases.

What characteristics does a Selectively Mute child portray in social settings?

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. Because most of these children have a persistent fear of performance or social interaction,

they manifest symptoms, such as freezing, lack of smiling, expressionless face and mutism as a direct response to fear and anxiety.

The following are various personality characteristics of Selectively Mute children:

- MUTISM
- Blank Facial expressions (when anxious)
- Lack of smiling (when anxious)
- Staring into space (when anxious)
- Difficulty with eye contact (when anxious)
- Frozen appearance (when anxious)
- Awkward and stiff body language (when anxious)
- 'Bashful Bladder Syndrome' or Paruresis; children are 'afraid' and have great difficulty, or cannot urinate outside the home, such as in public bathrooms, friends homes, school, etc.
- Difficulty 'initiating' play/(saying or indicating thank-you, hello, goodbye are incredibly difficult for these children)
- 'Slowness to respond' (i.e., when asked a question, will take longer than the average child to respond either nonverbally or verbally. This is one reason why standardized testing is often difficult and yields inaccurate results)
- Sensory Integration disorder (DSI) symptoms. I.e., heightened sensitivity to surroundings/noise/crowds/touch/foods.
- Excessive tendency to worry and have fears (often manifested in children older than 6 years of age)
- Behavioral manifestations at home, such as: moodiness, assertiveness, inflexibility, procrastination, cries easily, need for control, bossy, domineering, extremely talkative and expressive.
- Intelligent, perceptive and inquisitive
- Increased concentration level
- Introspective and sensitive/ (seems to understand the world around them more thoroughly than other children the same age and portrays an increased sensitivity to feelings and thoughts.... although often have difficulty 'expressing' feelings)
- Manifests Artistic Talents (artwork is very detailed. Symmetry and geometry are an interesting aspect to children's work)
- Tendency to be visual spatial learners (learn via hands-on and experience rather than rote memory)

 Verbal abilities greater than mathematical abilities (tends to enjoy and be more skilled at language arts (reading/writing compared to mathematics)

It is so important to realize that these children are as normal and appropriate as any other child when in a comfortable environment. Parents will often comment how boisterous, social, funny, inquisitive, extremely verbal and even bossy these children are at home! However, what differentiates SM children is their severe behavioral inhibition and inability to speak in most social settings. These children feel as though they are 'on stage' every minute of the day! This can be quite heart wrenching for both the child and parents involved.

Often, these children show signs of anxiety before and during most social events. Tummy aches; nausea, vomiting, diarrhea, headaches and an array of other <u>physical complaints</u> are common before school or social outings.

When in school most SM children stand motionless and expressionless, turn their heads, chew or twirl their hair, avoid eye contact, or withdrawal into a corner. Over time, these children learn to cope and participate in certain social settings; only they perform nonverbally. Social relationships are very difficult for these children. This can be quite frustrating to the child as time goes by. A SM child's nonverbal existence in various social settings can go on for many years, unless parents have their child properly diagnosed and treated.

When are most children diagnosed as having Selective Mutism?

Beginning as young as one or two years of age, these children often stand motionless with fear as they are confronted with specific social settings. This can be quite heart wrenching to watch. These children are so anxious they literally freeze; are expressionless, unemotional and often, socially isolated. Parents often describe these children as excessively shy/socially withdrawn clingy, manifest separation anxiety, etc; However, In the majority of cases, it is when the children start school, and are away from their parents, that the diagnosis of Selective Mutism is made. When children enter school, and there is an expectation to perform, interact and speak that Selective Mutism becomes blatantly obvious. Because most children meet the DSM-IV diagnostic criteria for social phobia, it should not be surprising that many children feel a tremendous amount of inner anxiety in social settings, such as school.

Typically, teachers will tell parents that the child is not talking or interacting with other children. In other situations, parents will notice early on that their child is not speaking to most individuals outside the home. If these symptoms persist for more than a month, a physician should be alerted to the possibility of Selective Mutism.

Unfortunately, few people truly understand Selective Mutism and professionals and teachers will often tell a parent, 'your child is just shy', or' they will outgrow it.' For the true Selectively Mute child this is completely wrong and inappropriate! In many circumstances, parents will wait, and hope their child outgrows their mutism. But, without proper recognition and treatment, most of these children do NOT outgrow SM and end up going through years without speaking, interacting normally or developing proper social skills.

Why is it so important to have my child diagnosed when he/she is so young? Studies clearly indicate the earlier a child is treated for an anxiety disorder, 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!

Anxiety disorders are the #1 mental illness among children and adolescents.

The US surgeon general recently stated that our country is in a state of emergency as far as children's mental health is concerned. Evidently 10% of children suffer from mental disorders, but less than 5% of these children are actually receiving treatment. When anxiety disorders go untreated, consequences are worsening anxiety symptoms, depression, low self-esteem, and social isolation throughout childhood, adolescence and into adulthood. In addition, studies indicate that persistent untreated anxiety leads to school dropout, self-medication with drugs and alcohol as well as suicide.

Therefore, the main objective should be to diagnose anxious children earlier so they can receive proper treatment at an early age, develop proper coping skills and overcome anxiety.

If a physician suspects a child has Selective Mutism, what should they do?

Inform the parents of your suspicion and indicate that with proper treatment the prognosis is good that the child will overcome their anxiety and mutism. Refer the child to a specialist that understands Selective Mutism. This could be a social worker, school psychologist, family and child psychologist, psychiatrist or another primary care physician. In addition, direct the parents to the the Selective Mutism Group Childhood Anxiety Network (www.selectivemutism.org/) for further information,

How is a child 'evaluated' for Selective Mutism?

A trained professional familiar with Selective Mutism will have a parental interview. Emphasis will be on social interaction and developmental history as well as behavioral characteristics. (Including any delays, hearing, speech and language) family history (history of family members with anxiety/depression is common), behavioral characteristics (shy temperament?), home life description (family stress, divorce, death etc) and medical history. From the results of the initial interview, the professional will often see the child. Although most SM children do not speak to the diagnosing professional, at least the professional can spend time with the child and attempt to build trust. Because 20-30 % of Selectively Mute children have a subtle abnormality with speech and language, a thorough speech and language evaluation is often ordered. In addition, a complete physical exam (including hearing) standardized testing, psychological assessments as well as a thorough developmental screen are often recommended if the diagnosis is not clear.

What are the DSM-IV diagnostic criteria for Selective Mutism?

A child meets the criteria for Selective Mutism if the following are true:

- 1- Child does not speak in 'select' places, such as school or other social events.
- 2- But, they can speak normally in settings where the child is comfortable, such as at home. (Although some SM children can be mute at home)
- 3- the child's inability to speak interferes with their ability to function in educational and/or social settings.
- 4- Mutism has persisted for at least one month.
- 5- Mutism is not caused by a communication disorder (such as stuttering) and does not occur as part of other mental disorders (such as autism).

What is the differential diagnosis of Selective Mutism?

Because of the scarcity of research and literature on SM, physicians and other professional often misdiagnose or mismanage SM. The common disorders that professionals confuse with SM are:

(1) Pervasive Developmental disorders, such as Autism and Aspergers Syndrome: Children with these disorders often have social and communication impairments and a tendency for anxiety. HOWEVER, what clearly differentiates these children from SM

- children is that PPD children manifest these same symptoms in ALL aspects of their life. On the contrary, SM children only manifest social and communicative impairments when severely anxious and when confronted with select social settings. SM children are very aware and interactive when comfortable and do not, in the least, manifest PPD symptomotology when they are not anxious.
- (2) Oppositional Defiant Disorder: Individuals often misinterpret mutism as a means of defiance. This is incorrect and completely counterproductive! Children with SM literally cannot speak due severe anxiety. Studies on temperamentally inhibited children indicate that the skeletal muscles of the larynx contract during extreme anxiety (X). This does not mean that children with SM cannot have concomitant ODD, but their mutism is not a result of ODD
- (3) Extreme shyness. This is probably the number one misinterpretation of mutism among professionals. Extreme shyness usually does not cause significant impairment in social, communicative and academic performance, as does SM. When a child is mute for more than one month, shyness is usually not the cause.
- (4) Severely learning disabled and emotionally disturbed: Anxious children, such as Selectively Mute children are notorious for their inability to 'initiate' and 'hesitancy in responsiveness'. As a result of severe anxiety. Teachers often misinterpret the SM child's abilities and behavioral characteristics. As a result, too many SM children are shuffled through the educational system without having their emotional and academic needs met. Teachers, similar to physicians, are uninformed of SM. As a result, misinterpretation of symptomotology is not surprising.

How is Selective Mutism Treated?

The main goal with treatment is to <u>lower anxiety</u>, <u>increase self-esteem</u> and <u>increase confidence in social settings</u>. A professional should devise an 'individualized treatment plan' for each child.

Treatment usually focuses on a combination of:

- (1) **Behavioral approach**: For example, *Positive Reinforcement* is used for verbal behavior (stickers are given for verbalization!). Another tactic is *desensitizing* the child to school. Parents take the child into school, when few people are around, to get the child to 'practice speaking.' After the child is speaking quite normally, the teacher, and then the students are gradually introduced into the classroom.
- (2) Play Therapy. Trained therapists use the art of 'play therapy' to help children relax and open up.
- (3) Cognitive Behavioral Therapy: CBT Trained therapists help the child modify their behavior by helping them redirect their anxious fears and worries into positive thoughts.
- (4) Medication: Studies clearly indicate that the best approach to therapy is a combination of behavioral techniques and medication. Since most parents are reluctant to start medication immediately, we often use behavioral techniques for an indeterminate amount of time. If children are not making enough progress with behavioral therapy alone, we often recommend medication. Medication in the form of serotonin reuptake inhibitors (SSRI's), such as Prozac, Paxil, Celexa, Luvox, and Zoloft are very successful in the treatment of anxiety disorders. Similar to the SSRI's there are other drugs that affect one or more neurotransmitters, such as serotonin, norepinephrine, GABA and dopamine, etc..... are also proving to be affective. Examples are Effexor XR, Serzone, Neurontin, Buspar and Remeron. These classes of drugs work well in children that have a true biochemical imbalance. This seems to be the case in the majority of SM children. Very often, we have seen positive effects in as little as a week. Medication is used as a 'jump start.' Our hope is that as we lower anxiety (by doing low and titrating upwards

gradually) via medication we can implement behavioral techniques more easily and successfully!

(5) Self-esteem boosters: Parents should emphasize their child's positive attributes. For example, if your child is artistic, then by all means, show off their artwork! Have a special wall to display your child's masterpieces; perhaps they can even have a special exhibit! Have them 'explain' their artwork to family members and close friends.... this promotes more verbalization practice as well as helps with confidence!

(6) Frequent socialization: Encourage as much socialization as possible without 'pushing' your child. I recommend frequent play dates with classmates. Your goal is for your child to feel comfortable enough with their classmates so that verbalization will occur. Most SM children will talk to friends in their own home. As the child gets increasingly comfortable speaking to one child, invite another child over, and then have two or three children at a time! As a child gets more comfortable with friends, they will hopefully speak to them at school!

(7) School involvement: Physicians need to educate parents that the teachers and school personnel is of utmost importance in the treatment process of Selective Mutism.

Teachers must be educated to SM. Nonverbal communication is acceptable in the beginning. As the child progresses with treatment, the teacher should be involved in the treatment plan as well, with verbalization being encourage in subtle, nonthreatening ways.

(8) Family involvement and parental acceptance: Family members must be involved in the entire treatment process of the SM child! Very often changes in parenting styles and expectations are necessary to accommodate the initial needs of the SM child. Remember, never pressure or force your child to speak, this will only cause more anxiety. Convey to your child that you are there for them. Spend one on one time, especially at night, when all pressure is off, and engage your child in discussions about their feelings. Allowing your child to 'open up' helps release stress. A parent's acceptance and understanding is crucial for the child!

--It is important to realize that with proper diagnosis and treatment, the prognosis for overcoming Selective Mutism is excellent!

Please visit the Selective Mutism Group Childhood Anxiety Network (SMG~CAN) for further information about Selective Mutism and related childhood anxiety disorders. www.selectivemutism.org.

The SMG~CAN is a division of the 501©3 nonprofit organization, the Childhood Anxiety Network, Inc (CAN) www.childhoodanxietydisorders.org, which is dedicated to the education, promotion of public awareness and the early identification and treatment of childhood anxiety disorders.

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SELECTIVE MUTISM: INFORMATION FOR PARENTS, MEDICAL, MENTAL HEALTH AND EDUCATIONAL PROFESSIONALS

by Bruce Black, M.D.

What is selective mutism? Selective mutism is a psychiatric disorder of childhood characterized by persistent failure to speak in one or more major social situations, including school, despite ability to comprehend spoken language and to speak. The disorder was first described in 1934, and there have been many case reports and small case series published in the psychiatric literature since then. Prior to the initiation of our research program in 1990 (initially at The National Institutes of Health in Bethesda, Maryland, and subsequently at New England Medical Center in Boston), the disorder had never been studied systematically.

Children manifesting the disorder characteristically refuse or are very reluctant to talk in school and to strangers. The severity of the disorder varies, from children who have never been heard to speak in school to those who do speak in school but are markedly reluctant to do so. The term "speech reluctance" also has been used to describe this condition. All children affected with this disorder speak normally with individuals with whom they are very familiar and comfortable, such as immediate family or very familiar peers. Some affected children speak more freely with peers than with adults. Although symptoms may be apparent from the preschool years, the disorder generally does not come to clinical attention until the child starts school. Transient manifestations of speech reluctance after starting school are not uncommon. Persistent forms of the disorder are less common.

What causes selective mutism? At the present time, we cannot say with certainty what causes selective mutism. There may be different causes for different individuals. Our research to date indicates that most children with this disorder are very shy and anxious when interacting with unfamiliar persons, or in any situation where they feel that they are the center of attention or are being observed or evaluated. As they become more accustomed to and comfortable in a particular social situation, they are more likely to talk. It seems likely that this extreme shyness or self-consciousness (or "social anxiety" as it is referred to by psychiatrists) is the central cause of the disorder. In fact, it seems likely that in many cases selective mutism is no more than an extreme shyness, or an early childhood form of "public speaking anxiety." Many of the children we have studied have parents or siblings who have suffered from selective mutism or from extreme shyness. This observation, as well as what we know about the hereditary basis of extreme shyness, suggests that a vulnerability or tendency to develop the disorder is passed on genetically, just as a tendency to develop diabetes or heart disease may be passed on.

There is no substantial evidence to support any other cause. For example, physical or sexual abuse, neglect, or other types of psychological trauma, and dysfunctional family relationships have all been proposed in the past as possible causes of selective mutism. However, our research has found no evidence of past abuse unless there is some other reason to believe that it has occurred. Parents or teachers sometimes express the opinion that, "The child is just being stubborn! He (or she) can talk if he (she) wants to." In our experience, this does not seem to be

an adequate explanation. Indeed, most children with selective mutism do not seem to be any more stubborn or oppositional than the average child. However, in some cases, it seems that the child and those around the child are so accustomed to the child not speaking, that it becomes difficult for the child to "break out of the mold." As some children have told us, "I can't talk now. Everyone will look and say 'He talked! He talked!" Of course, this *fear* of speaking is not at all the same as willful stubbornness.

How and when should selective mutism be treated professionally? Many children seem to improve over time without any specific treatment. The younger the child and the shorter the interval of time that the child has been in school without talking, the more likely it seems to be that the child will start talking without any treatment. However, some children may continue to have significant problems with extreme shyness, even after they start talking in school.

Although individual psychotherapy, play therapy, psychoanalysis, and family therapy have frequently been recommended for children with selective mutism, there is no evidence to date that these types of treatment are likely to be of substantial benefit. Our experience suggests that these treatments are not helpful in most cases, and may occasionally actually be harmful. Treatment with certain medications has been shown to be safe and very helpful for some children. A specific type of psychotherapy known as cognitive-behavioral therapy (or CBT) is often helpful, when provided by a therapist who has had intensive training and experience in using this method of treatment. The CBT therapist works with the child and his or her teacher and parents to develop a plan to assist the child in very slowly increasing his or her vocalization, with frequent praise and encouragement, and working at a pace that the child is comfortable with.

The process of deciding when and how to treat a child with selective mutism is a complex one. Multiple factors must be considered including: How severe is the selective mutism, and how much is it interfering with the child's academic and social development? Does the child seem to be improving without treatment? What are the relative risks and side effects of different types of treatment? Do the child and his or her family have access to a skilled CBT therapist or pediatric psychopharmacologist (a physician with special expertise in the use of medication to treat psychiatric conditions in children)? How do the parents and the child feel about treatment, including treatment with medication?

For children who have been in school for less than three to four months, we usually do not recommend any treatment, unless there are other significant problems in addition to the selective mutism and shyness. In these cases, watching and waiting is usually the wisest course. However, even when no specific treatment is indicated, we can sometimes be helpful to parents and schools by providing recommendations on how they might best deal with the child's reluctance to speak. For children who have been in school more than three to four months, we do usually recommend a trial of CBT with an experienced therapist. For more severe or persistent cases, we also usually recommend a trial of treatment with a medication called fluoxetine (Prozac).

How can parents, teachers, and school counselors help the child with selective mutism? It is important to understand that the child with selective mutism is genuinely frightened of or uncomfortable with speaking in school. He or she is not "just being stubborn." Gentle and consistent encouragement, support and reassurance is the approach that is most likely to be helpful. Any progress in verbal or non-verbal communication should be praised and encouraged even if it is merely progress from complete silence to barely audible whispers. Because many children with selective mutism are very uncomfortable being made the center of attention, it is sometimes best to offer the praise and encouragement privately, rather than, for example, praising them loudly in front of the whole class or another teacher. Struggles between the child and adults, particularly regarding speaking, should be avoided as much as possible. Attempts to pressure, demand, or force the child to speak, to trick the child into speaking, or to punish or shame the child for not speaking are most often counter-productive.

Finally, unless there are other specific indications, we recommend that the child with selective mutism remain in regular classes, rather than in classes for children with emotional disabilities or speech and language impairments. This may require some flexibility on the part of teachers and school administrators. We believe a willingness to find ways to help the child communicate and learn in a regular classroom setting is usually in the best interest of the child.

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