# **NHS** choices Your health, your choices Selective Mutism – Advice Sheet for Parents

# http://www.nhs.uk/conditions/selective-mutism/pages/introduction.aspx adapted for Sussex Community NHS Trust:

Selective mutism (SM) is an anxiety disorder that prevents children speaking in certain social situations, such as school lessons or in public. However, they're able to speak freely to close family and friends when nobody else is listening – for example, when they're at home. It's important to understand that when the mutism happens, the child is not voluntarily refusing to speak but is literally unable to speak, feeling frozen. In time, they learn to anticipate the situations that provoke mutism and do all they can to avoid them. Experts believe SM is a phobia of talking. Most children will work their way through SM with sympathetic support, although they may remain reserved and anxious in social situations.

This page covers the following information and advice for professionals and parents of children with SM:

- Which children are affected?
- When does it start?
- What are the signs?
- What causes selective mutism?
- What can parents do?
- How is it treated?
- Where can I get support and advice?

### Which children are affected?

SM is relatively rare, affecting one in 150 children. Most primary schools will know of at least one child with SM. It's more common in girls and children of ethnic minority populations, or in those who have recently migrated from their country of birth.

#### When does it start?

SM usually occurs in early childhood and is first noticed when the child begins to interact outside the family circle – for example, when they start nursery or school. It can last a few months but, if left untreated, can continue into adulthood.

### What are the signs?

Children with SM often have other fears and social anxieties and may have additional speech and language difficulties. They may not be able to give you eye contact and may seem:

• nervous

- uneasy and socially awkward
- clingy
- excessively shy and withdrawn, dreading that they will be expected to speak
- serious
- stubborn or aggressive, having temper tantrums when they get home from school
- frozen and expressionless during periods they cannot talk

Children with SM may communicate using gestures – for example, nodding or shaking their head to get their message across. They may manage to respond with a word or two, or speak in an altered voice, such as a whisper. Some children with SM also have a fear of using public toilets – perhaps because they fear making sounds while urinating that others may hear.

#### What causes selective mutism?

It's not always clear what causes some children to develop SM, although it is thought to occur as the result of anxiety. The child will usually have inherited a tendency to experience anxiety from a family member. Some children have trouble processing sensory information such as loud noise and jostling from crowds – a condition known as sensory integration dysfunction. This makes them "shut down" and unable to speak.

Many children become very distressed when separated from their parents and transfer this anxiety to the adults who try to settle them into a new setting. If they have a speech and language disorder or hearing problem, this only makes speaking even more stressful. There is no evidence to suggest that children with SM are more likely to have suffered abuse, neglect or trauma than any other child. When mutism occurs as a symptom of <u>post-traumatic stress</u> it follows a very different pattern and the child suddenly stops talking in environments where they previously had no difficulty. However, this type of speech withdrawal may lead to SM if the triggers are not addressed and the child develops a more general anxiety about communication. Another common misconception is that a selectively mute child is controlling or manipulative, or that the child has <u>autism</u>. There is no relationship between SM and autism, although the two conditions can occur in the same child.

#### What can parents do?

If left untreated, SM can lead to isolation, low self-esteem and social anxiety disorder. It can persist into adolescence and even adulthood if not tackled. With diagnosis at a young age and appropriate management, children can successfully overcome this disorder. SM needs to be recognised early by families and schools so that they can work together to reduce the child's anxiety. Staff in early years settings and schools are increasingly seeking training so they are ready to provide appropriate support.

## Getting a diagnosis

If you suspect your child has SM and help is not available, or if there are additional concerns, for example if your child struggles to understand instructions or follow routines speak to your nursery/school SENCO, health visitor or GP, who can refer you to a CAMHS clinician and the speech and language therapist (SLT, see below). The clinician may initially wish to talk to you without your child present, so you can speak freely about any anxieties you have about your child's development or behaviour. The clinician will want to find out if anxiety disorders are present in your family, and if there is anything in your child's life causing them significant distress, such as divorce or difficulty learning a second language. They will look at your child's behavioural characteristics and take their full medical history. Your child may not be able to speak during their assessment, but the clinician will be prepared for this and try to find another medium of communication. For example, children may be encouraged to communicate through parents, or older children may be invited to write down responses or use a computer.

SM must be diagnosed according to specific guidelines. These include observations lasting for more than one month that:

- your child does not speak in specific situations, such as school lessons or when they can be overheard in public
- your child can speak normally in situations in which they feel comfortable, such as being alone with you at home or in an empty classroom
- their inability to speak interferes with their ability to function in that setting
- their inability to speak has lasted for at least two months
- their inability to speak is not better explained by another behavioural, mental or communication disorder

## Speech and Language Therapy Assessment

SM can sometimes mask an underlying speech and language difficulty. For this reason the speech and language therapist will also need to carry out an assessment of your child's speech and language development. If there are any areas of difficulty the SLT will become involved in the care plan for your child and will advise on ways to support speech and language development at home and school.

#### How is it treated?

The effectiveness of treatment depends on:

- how long your child has had selective mutism
- whether or not they have additional communication or learning difficulties or anxieties
- the co-operation of everyone involved with the child

With appropriate handling and treatment, most children overcome selective mutism – but the older they are, the longer it takes. They should gradually progress from relaxing in their

school or nursery, to saying single words and sentences to one person, before eventually being able to speak freely to all people in all settings.

Treatment does not focus on the speaking itself, but focuses on reducing the anxiety that your child has for speaking to and being overheard by people outside their immediate circle of family and friends. The need for individual treatment can be avoided if family and staff in early years settings work together to reduce this anxiety by creating a positive environment for the child. This means:

- not letting the child know you are anxious
- reassuring them that they'll be able to speak when they're ready
- concentrating on having fun
- praising all efforts the child makes to join in and interact with others (such as passing and taking toys, nodding, pointing)
- showing no surprise when the child speaks, but responding warmly as you would to any other child

As well as these environmental changes, older children may need individual support to overcome their anxiety. The most effective forms of treatment are behavioural therapy and cognitive behavioural therapy. These are briefly described below, along with some commonly used techniques to help your child overcome their anxiety.

#### **Behavioural therapy**

Behavioural therapy is designed to reinforce desired behaviours and eliminate undesired behaviours. Rather than examining your child's past or their thoughts, it concentrates on helping your child combat their difficulty in a practical way, using a step-by-step approach to help them conquer their fears. Several of the following techniques can be used at the same time by family members and school staff under a speech and language therapist's or psychologist's guidance:

- Stimulus fading the child communicates at ease with someone such as their parent when nobody else is present. Gradually, another person is introduced into the situation and once they are included in talking, the parent can withdraw. The new person can introduce more people in the same way.
- Positive and negative reinforcement being positive about all forms of communication and not rewarding avoidance and silence. If the child is under pressure to talk, they will experience great relief when the moment passes. This not only makes being silent far more enjoyable than trying to speak, but also strengthens the child's belief that talking is a negative experience.
- Desensitisation reducing the child's sensitivity to the sound of their voice in public, and encouraging them to communicate using voice or video recordings. Older children may build contacts using email, instant messaging

or online chat, and then leave voicemail messages. They can build up relationships this way until they feel ready to try more direct communication.

- Shaping a technique that encourages the child to interact without speaking before being slowly coaxed into trying sounds such as clicks and hums, then whispering quiet sounds such as 's', and gradually trying a word or two.
- Graded exposure an older child is encouraged to work out how much anxiety different situations cause (such as answering the phone or asking a stranger the time). Situations causing the least anxiety are tackled first. With realistic targets and repeated exposure, the anxiety associated with these situations decreases to a manageable level.

#### Cognitive behavioural therapy

Cognitive behavioural therapy (CBT) works by helping individuals focus on how they think about themselves, the world and other people and how their perception of these things affects their thoughts and feelings. This is carried out by mental health professionals and is more appropriate for older children and adolescents, particularly those experiencing social anxiety disorder, and adults who have grown up with SM. CBT also challenges fears and preconceptions through graded exposure.

#### Medication

Medication is only really appropriate for older children and teenagers whose anxiety has led to depression and other problems. Medication should never be prescribed as an alternative to the environmental changes and behavioural approaches described above. However, <u>antidepressants</u> may be prescribed alongside a treatment programme to decrease anxiety levels and speed the process of therapy, especially if previous attempts to engage the child in treatment have failed.

## **Advice for parents**

- Don't use pressure or bribes with a child to encourage speaking.
- Let your child know you understand they are scared to speak and have difficulty speaking at times.
- Don't praise your child publicly for speaking, as this can cause embarrassment. Wait until you are alone with them and consider a special treat for their achievement.
- Stop putting your child in situations where they have to talk, and reassure them that nonverbal communication (such as smiling and waving) is fine until they feel better about talking.
- Don't avoid parties or family visits, but consider what environmental changes are necessary to make the situation more comfortable for the child.
- Give them love, support and patience as well as verbal encouragement.