

Episode 3 – Selective Mutism and the Use of Medication

Hello and welcome to the Selective Mutism HELP, Home Educational Learning Program, Podcast, my name is Kelly, and I will be your host. This podcast aims to give you the help you need to support the person in your life affected by selective mutism.

In this episode I'll be talking about a potentially controversial topic which is the use of medication in those affected by Selective Mutism. I'll be discussing various studies done about medication and I'll be talking about our journey and how our thoughts on medication has changed during the last few years. Let's get started.

Welcome to episode 3 of the Selective Mutism HELP Home Educational Learning Program podcast. My name is Kelly, and I am a parent of a child with Selective Mutism. Being that I am a parent and not a medical professional, this podcast is for informational purposes only. I wanted to talk about medication early in my podcast series because I think it is a topic that comes up quite often when trying to figure out what is best for your SM child. After interviewing various SM professionals from around the world, I've learned that different countries have different regulations about offering medication to children. I'm in the US and, well, let's just say that using medications for various ailments is very common here. At the end of this podcast, I'll introduce a potentially effective alternative to medication that could be just as effective.

Let's start by talking about which types of medications are most commonly used for treating selective mutism. As you recall, Selective Mutism is an anxiety disorder, so many of the medications used are the same that are used for disorders such as anxiety and depression. Selective serotonin reuptake inhibitors (SSRIs) are the most commonly prescribed type of medication for anxiety and depression. According to the Mayo Clinic, they work by increasing the levels of serotonin in the brain. Serotonin is one of the neurotransmitters or messengers in the brain that carry signals between nerve cells within the brain. They increase the level of serotonin by blocking the reabsorption, or reuptake, of serotonin back into neurons. There are other neurotransmitters in the brain other than serotonin, but SSRIs only affect the serotonin transmitters which is why they are called selective serotonin reuptake inhibitors. The two most common SSRIs prescribed for those with SM are Prozac, or fluoxetine, and Zoloft, or sertraline. There is no specific data to choose one over the other, but Prozac is the default because it is the most commonly used. Zoloft can be used for those as young as 6, with Prozac being used for those a little older. With that being said, many are used off label because there haven't been any studies conducted for younger kids.

Speaking of studies, I wanted to share a few studies with you about the use of medication for those with SM. I'll have links in the episode notes if you want to learn more about these studies. The first is a study done in 1994 by Black and Uhde. They had 16 children diagnosed with SM that were either treated with a placebo or a dose of fluoxetine at a dose of 0.6 mg/kg/day for 3 months. They interviewed parents, teachers, and clinicians before and after the trial. For those on fluoxetine, the parents rated their child as significantly more improved, but the clinicians and teachers did not reveal significant differences. They concluded that fluoxetine may be beneficial and safe with longer treatment being necessary, but further research needs to be done.

A study in 1996 by Summit et al studied 21 children between the ages of 8-14. They were prescribed between 10-60 mg fluoxetine for 9 weeks and 76% showed diminished anxiety and increased speech in public settings which included schools.

A study in 2008 by Manassis and Tannock studied 17 children who had been mute for at least one full school year. Eight of them were on fluoxetine, 2 of them were on sertraline, and the others were not on medication. All of the students were receiving SM support at school during the study which lasted 6-8 months. Again, the mothers and clinicians gave reports at the beginning and end of the study. Per the mother's report, those on an SSRI showed improvement and reduced mutism outside the home. The clinicians rated those on medication to be functioning at a higher level than those not on medication. However, since all students were receiving school consultation, they can't be sure that medication alone caused the improvement.

The final study I wanted to talk about is the Child/Adolescent Anxiety Multimodal Study by Compton et al. In this study they examined the relative efficacy of using only Cognitive Behavior Therapy, or CBT which I discussed in my last episode, Sertraline alone, combination of CBT and sertraline, and a placebo. They studied 448 kids that were between 7-17 years old that were diagnosed with separation anxiety disorder, general anxiety disorder, and or social phobia. Since there hasn't been a study like this specifically for those with SM, this is the closest study to use. The results of their study showed that after 4 months 23% were doing better with the placebo, 55% did better with only sertraline, 60% did better with CBT only, and 81% did better with a combination of sertraline and CBT.

Although there have been some studies, including the few that I mentioned, according to the book *Psychiatric Drugs in Children and Adolescents*, the evaluation of the effects of using an SSRI for those with SM is still largely based on the reports and opinions of expert panels, consensus conferences, and clinical experience. In other words, there just isn't enough research to definitively say yes, using an SSRI needs to be in the treatment protocol for an SM child. It really depends on the clinician's experience with using these types of meds and finding a psychiatrist or pediatrician that is comfortable prescribing these types of medications, especially if the child is young. The American Academy of Child and Adolescent Psychiatry does recommend to first consider using CBT, then use an SSRI. Or if the child is more severe, has a high number of comorbidities, and/or a strong family history, adding an SSRI may be beneficial.

Now, let me share with you our personal experience with medication. Our daughter was officially diagnosed at age 4.5. We met with a psychologist who specialized in SM. During our first visit, she drew a Venn diagram which showcased the study about 55% did better with meds, 60% did better with CBT, but 81% did better with the combination of the two. She asked if we would be interested in starting our daughter on meds. My husband and I were both quick to answer "absolutely not." At that time we couldn't imagine starting our little 4.5 year old on anxiety medication. Neither of us and any experience with these types of medications and there is a lot of stigma around medicating, so we weren't on board with starting her on meds, but we were on board with starting cognitive behavior therapy. So, a few weeks after our first meeting, we started our daughter in weekly sessions. I was in the room with my daughter for every session and I could not believe just how bad her SM was. She was unable to talk to me if the psychologist was anywhere in the room, she was unable to make eye contact with the psychologist, she couldn't hand anything to the psychologist, and she threw a tantrum every

time we had to leave. Being that our psychologist was an SM specialist, she knew a lot of strategies to try to facilitate communication with our daughter, but after about 5-6 weeks we weren't seeing any improvement. So, the topic of medication came up again. Since I was with my daughter during every weekly session and I could see just how hard it was for her to try to communicate, we decided to give medication a try. I wanted to give her brain a break from being overly protective so she could have an opportunity to participate in trying to be brave. I was nervous about side effects, so we talked about what to expect. We were told she may get an upset stomach or headaches. There was also the possibility of hyperactivity and being disinhibited meaning she may try to do more daring things. The side effects generally only last a couple weeks, but we were told that if the side effects were concerning, if we stop the medication, the side effects would go away. We were given a handout explaining that the medications would be used off label since she was only 4.5 years old. We opted for sertraline since that was labeled for 6 year olds and had shown to have success in those as young as 4. We met with our daughter's pediatrician and he was hesitant to start her on an SSRI at such a young age. I gave him the handouts from our psychologist and after speaking to a few of his colleagues he agreed to start our daughter on a very low dose of sertraline.

Start low and go slow is the motto when using an SSRI. We started very low at only 5 mg or 0.25 mL. Since it was a liquid, and very concentrated, we had to mix it with water which created its own set of challenges. We had to get a special cup and mark a line on it so she would get the same amount of water each time. If it was too much water she couldn't drink it all, if it was too little water she would be able to taste too much of the medication. Once we got the water level right and it became a morning routine, it became much easier for her to take. Plus, she started becoming much more relaxed just a few weeks after starting the medication. She was much more compliant with requests and wasn't pushing back as much as before. It made us all relax a little more!

We were on the 5 mg dose for about a month and our daughter was showing some improvement in therapy. She was able to start making eye contact and communicate by holding up her fingers to questions like "which type of ice cream do you like better, hold up one finger for vanilla or two fingers for chocolate." But, she still wasn't able to verbalize or talk to me at a normal volume in front of her therapist. So, we decided to increase her dose to 10 mg or 0.5 mL. With a new school year just around the corner, we wanted to give her the best chance to start the school year with less anxiety than the previous year. Each time the dose is increased, it can take 3-4 weeks to see its effects, so we wanted to make sure the new dose was at full effect by the time she started school.

She was on 10 mg for about 6 months. She was no longer in therapy, but we were doing exposure therapy on our own and she started on an IEP at a new preschool which helped give her support. But, she still wasn't talking to a majority of people in her classes. We decided to do another med increase, this time to 15 mg or 0.75 mL. Our daughter did complain of headaches with this increase, but they went away rather quickly. The best side effect we noticed was her talking more! Two months after starting her on the increased dose, she was talking to all of her teachers and almost all the kids in her class. We were happy with her progress, but we were worried about how she would be starting Kindergarten. She was at the same preschool for 3 years, going to Kindergarten was going to be a much bigger challenge. We decided to start her on 20 mg or 1 mL about a month before Kindergarten started. Over the summer we would visit

the school once a week to start getting her acclimated to the school. I would do different exposures with her throughout the school to help decrease her anxiety for when school started.

In October of her Kindergarten year, we attended the Selective Mutism Association's annual conference. My husband went to a talk about medication and he learned that it can be common for kids to be underdosed on medication when they are trying to overcome their SM. We started looking at our daughter's dose and how far away she was in overcoming her SM. Based on what my husband learned at the conference and the struggles our daughter was still having, we had a goal of doing small medication increments up to 75 mg. Every 8 weeks we would increase her dose by 10 mg until she was verbal in almost all situations. By February of her Kindergarten year, which was a year and a half after starting medication, we were up to 50 mg sertraline and she was doing wonderful. We had started tablets instead of liquid, which presented new challenges as she wasn't able to swallow a pill. We would crush up the tablet and mix it in yogurt. Eventually we got to the point of placing the tablet on a dollop of yogurt on her spoon and she would swallow it down. Now, I should also mention that at this point she had started OT and was starting to get the right support at school. But, she was talking to almost all immediate family members, peers, and some teachers.

The summer after Kindergarten we went on a family vacation and this was going to be our test to see if we needed to continue increasing her dose or if we were at a therapeutic dose. We spent a week with relatives that she didn't see very often and she was able to talk to every single one of them! We were so happy and proud of how far she has come. We kept her on the same dose of 50 mg when starting first grade and by the 3rd week of school she was talking to over a third of the school staff. It was at that point we decided to start weaning her off medication. When we started medication at the very beginning, we were told to go through a year of firsts – first start of the school year, first family get togethers, first holidays, first birthday- all while on medication. If there were no setbacks during those big events, it was an indication that we could start weaning her off the meds. So, we felt very confident about decreasing her medication. She did great with the decrease during the first month of school and the real test was going to be how she was going to do with us moving. We ended up moving across country 6 weeks into the school year. We didn't know anyone where we were moving to and we wouldn't have an opportunity to do meet and greets with her new teacher or tour the school since Covid was at its peak. It really was going to be her toughest test yet!

We were completely amazed at how well she did with the transition! She was able to talk to her teacher by the 2nd day and was talking to peers immediately. After about a month, since she appeared to be doing well, we decided to decrease her medication to 12.5 mg. After about a week or two on that dose, to be blunt, shit hit the fan. She was constantly complaining of stomachaches, was having a hard time sleeping due to worry, and was trying to run away from school staff at drop off. Yikes! To say I felt like a horrible mom was an understatement. I felt so guilty for creating so much anxiety in our daughter because I thought she was ready for her meds to be decreased. Needless to say we had to increase her dose back to 25 mg and it took months to get her back to a point of not having stomachaches due to anxiety. Granted, the school she was at ended up being very anxiety provoking due to their way of handling unwanted behavior. It was a recipe for disaster that ended up in us doing distance learning.

She has been seeing a psychologist for anxiety for the past 3-4 months and we all agree to keep her on the 25 mg dose until at least this winter. We will be switching schools again and want to make sure she will be able to be successful and continue to overcome her anxiety. She is at the point now where a new person would have no idea she has selective mutism because she is able to talk anyone.

I've learned a lot through this medication journey. I think medication can be very beneficial if it is combined with therapy. We weren't in CBT for very long in the beginning, but we continued to do exposure therapy with our daughter and started her in Occupational Therapy. We also found the right support at school to give her the confidence she needed. More importantly, we learned what anxiety looks like for her when she is not at a therapeutic dose.

My advice to you as a parent is to assess your child. If they are completely frozen like our daughter was or if they have other comorbidities such as social anxiety, separation anxiety, and/or OCD, starting with a low dose of medication may give your child's brain the break it needs so they can have an opportunity to do something brave. Their brain wants to protect them from danger, but we want to teach them that communicating to others isn't dangerous. Medication could be enough for them to start the process of overcoming their SM.

Now, at the beginning of the podcast I mentioned that I would talk about an alternative to medication. During this journey I was introduced to rhythmic movement therapy which has completely changed my thoughts on medication. So, in my next episode, I'll be talking about rhythmic movement therapy and how this could be a way for those that are in an area where medication isn't a possibility could still see changes in their child similar to how an SSRI can help an anxious child. Make sure to listen to the next episode available Thursday, August 5th! In the meantime, if you have any questions, feel free to email me at smhelp2020@gmail.com or visit the website www.smhelp.org

Here are the links for the studies mentioned in this podcast.

[https://www.jaacap.org/article/S0890-8567\(09\)63935-6/pdf](https://www.jaacap.org/article/S0890-8567(09)63935-6/pdf)

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