

Episode 20 – A Message to Parents

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 honor of Mother's Day recently and Father's Day coming up, I wanted to send a special message to you hard working parents to show my support and understanding when raising a child with Selective Mutism. Let's get started.

Welcome to episode 20 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. And being that I am a parent, I have a pretty good idea of what you are going through while you are trying to figure out how to support your child in overcoming their Selective Mutism. I'll never forget the moment I learned about Selective Mutism and the rush of emotions that swept over me. It was a mixture of relief, uncertainty, guilt, excitement, overwhelm, and frustration. I was relieved because I finally had an answer. I felt uncertain since I knew nothing about SM and didn't know what her future would hold. I felt guilty because of the way I parented our daughter in certain situations when I thought she was being rude or defiant. I felt excited because I could start researching and understanding what was going on. I was feeling overwhelmed because I knew I had a lot of researching and understanding ahead of me while raising three young kids. And I was frustrated because I wish someone could have told me about it sooner. Why didn't teachers know about SM? Why were pediatricians not telling me about the possibility of SM? All of these feelings were from the very first moment our journey started.

It has now been 4 years since our daughter was diagnosed and I'm pretty sure I have felt every feeling and emotion a human can experience. Through all of this, not only have I seen tremendous growth in our daughter, but I have seen tremendous growth in myself and in my husband. Parenting is hard. You think it'll be easy, but soon realize it is hard! Then you throw in selective mutism and other diagnoses and it just got that much harder. But, when life is difficult, you start looking at situations differently and start to find the ease within them. You are able to open your mind up to different ways of understanding new situations. I have grown into a more understanding person. I stopped looking at my daughter's behavior as her being defiant or rude and started seeing it for what it really was which was anxiety. I started seeing that she had no control of not being able to speak or not being able to look at people. Her brain was being hijacked and steering her away from a situation it deemed dangerous.

I grew to be more self-forgiving. As a parent, especially a mom, we feel that how our kids behave is a direct representation on how we have raised our children. When my daughter would completely ignore her grandma or not say Thank You when someone gave her something, I took it personally. I felt like it was my fault that she was acting this way and I didn't do enough to teach her proper manners. Then when everything I was reading was pointing towards a genetic component and SM gets worse because of parents rescuing them, I felt even worse. But I learned to forgive myself. I had no control over my family's genetics or my husband's family's genetics and how they got passed on to our daughter. I wasn't rescuing her

to be malicious in growing her SM, I was being a good mom and protecting my daughter when she showed distress when someone asked her a question in a store. I didn't know about SM. I couldn't expect myself to do all the right things when I didn't even know this existed.

I grew to be a better listener. Instead of just assuming how easy or hard certain challenges were going to be for our daughter and deciding what we would work on, I began asking her and really listening to what she had to say. I learned to not be judgmental when she told me that something was going to be really hard. Just because something seemed easy to me, didn't mean that it was going to be easy for her. When she said it would be hard to hold up a sign that read "Hi" to her friends and I didn't believe her because to me that seemed really easy, I wasn't listening to her. So when I told her she had to do it in order to earn a brave ticket and she completely shut down and buried her head in my lap when the opportunity came, I realized that I wasn't listening to what she said. Once I understood that, even at the age of 4.5, she knew exactly how easy or hard something would be, I started listening. When I started listening and we worked on challenges that she said wanted to work on, we started making progress. She grew to trust that I wasn't going to make her do the things that were too hard, and I grew to trust her insight.

I grew to understand how important the right support is. Just because someone is trained in a certain area, doesn't mean they are going to be the right fit. Once I began to understand the type of person that our daughter was drawn to, I began to look for the right personalities to support her, not necessarily the right credentialing. Even though working with an SM specialist seemed to be the right way to go, it wasn't the right fit for us. Occupational therapy isn't the most traditional way to help support someone with SM, but our daughter's therapist was the perfect person for her, and we started seeing tremendous growth because of it. Even though she was assigned to a particular special education teacher due to her IEP qualifications, that didn't mean he was the right person for her. We ended up switching case managers half way through her kindergarten year because we didn't have the right person in place. Once we got the right person, our daughter made huge strides. Trust your gut. Trust your child. Trust that you have the power to follow whatever path feels right for your situation.

As I mentioned early, I wasn't the only one showing growth, my husband was as well. He will admit that it didn't happen as quickly as my growth, but it did eventually happen. At the beginning there was a huge disconnect between how my husband was understanding our daughter's diagnosis and how I was understanding our daughter's diagnosis. He has since told me that it was hard for him because he is very linear in his thinking. He was just trying to get from point A to point B and trying to figure out that path was too overwhelming. I remember when our daughter was invited to a birthday party and my husband was going to be the one bringing her. It was going to be at an amusement park. I told him to get there early and to ask her the three questions we had been working on – what is your name, what is your favorite color, and what is your favorite animal. I told him to take her to the area of the amusement park that had bins of legos and to comment on what she was doing and build the same things she was building. What I failed to do was explain why he needed to do these things. In his mind he knew how to talk to our daughter and how to interact with her so why did he need to do all of the things I mentioned. After his frustration subsided and I realized that I didn't communicate as effectively as I thought I had, we were able to have a better conversation

about the importance of the strategies I mentioned. Once he understood it, practiced it with our daughter, and saw the positive impact it had on her, he was onboard with using the strategies. He started doing more exposures with her and even made laminated cards that we used when our daughter was practicing answering questions from people she didn't know. She enjoyed proving to dad that she could talk to people in public and it took a lot more pressure off of me. Plus, it ended up being easier for her to talk to others around dad because he didn't have the history of saving her like I did. She actually did better with him than with me.

It is so important to have both parents on the same page when supporting an SM child. Believe me when I tell you just how mentally and emotionally exhausting it is to be the only parent researching, implementing, and strategizing all that goes into supporting an SM child. If you are the parent that may not believe that SM is real and that your child will outgrow it or that they are being manipulative and choosing not to speak. Please, take just a few moments to Google Selective Mutism. It can be hard to come to terms with your child being labeled as having a disorder. You may not want the stigma that comes along with having a child diagnosed with something. You may think that your family and friends are going to think less of you. But, none of that matters. What matters is giving your child the best chance at living their best life. You may even reflect back on your own childhood and remember that you had difficulty talking in certain situations. You may remember your own parents telling you how rude you were being for not saying thank you to someone or saying hi to someone or for not being able to give a presentation to your class. You may remember how frustrating that was or how lonely it made you feel. Wouldn't you want your child to avoid those feelings and help them understand that they aren't alone? I hope the answer to those questions is yes, you want them to avoid feeling that way and you want them to not feel alone.

I'm not going to lie and tell you this journey has been easy. There were many tears in the beginning due to feeling alone, worried, and scared for our daughter's future. But once I began understanding SM and started finding the ways to help our daughter make small steps, I started having tears of joy. Hearing her talk to her friend for the first time is a moment that will stick with me forever. To most that situation seems uneventful, but to a parent of an SM child, those moments are everything. Those are the moments that push away the worry and bring hope back. I'm also not going to tell you that this journey will be over before you know it. This will take time. This will test your patience. You will experience a lot of highs and a lot of lows. But, you are going to grow into the best version of yourself you never knew existed. You will be able to handle anything that comes your way. You will be able to be a role model for everyone around you.

Although this has been the most difficult experience I will probably ever go through, I wouldn't change it for anything. This journey has given me an opportunity to help people from around the world support their own child with SM. It has given me an opportunity to work one on one with parents to help them shed the worry and the guilt and to give them the tools they need to support their own child. Once you have reached the finish line of your child overcoming their SM, I challenge you to find a way to spread awareness about SM. Find a way to help someone starting out on their own journey. Together, we can give these amazing kids their voices back. My final message to those parents that are listening is that you were meant to be a parent of a child with SM. Never doubt yourself. You have what it takes to support your child as they

overcome their SM. If you ever feel hopeless or alone or stuck, please know that I am here for you! I've got your back! I'm just an email away, so please don't hesitate to reach out by emailing smhelp2020@gmail.com. Take care.