

CHARGE OCD February 8 2015 Event in Progress: 01:56:43 Captioner is

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Please stand by for real-time captions.

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Well the bells give is a good idea of what time it is. I am showing it  
is the top of the hour.

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This is Robbin Bull with NCCB. I am going to start us with a few  
housekeeping items and I want to welcome everybody with the webinar --  
to the webinar.

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I'm going to hand it over to Lori Swanson in just a moment. She will be  
introducing tonight's speaker.

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I do want to mention that all phone lines have been -- muted so  
we do not have to worry about background noise.

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The question and answer session will occur at the end of the  
presentation. However you can write your questions at the chat box  
anytime during the presentation. It will be monitored throughout the

webinar in preparation for the question and answer session.

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I will mention this webinar will be recorded and archived for future viewing. Please be mindful of your comments in the chat box and refrain from writing personal and sensitive information.

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I'm going to clear that chat pod right now so we start with a fresh Chat pod. I'm going to start the recording. When you hear the recording saying the message -- it has started recording that is your cue to start.

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Hello everyone. Welcome to the charge syndrome foundation webinar. This is part of a webinar series focused on topics that the foundation hopes are the greatest interest and benefit to anyone who are involved with individuals with CHARGE syndrome.

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It appears we have another wonderful turnout for this event. My name is Lori Swanson and I am a board member of the CHARGE syndrome foundation. We are pleased you have joined us. And Nancy Hartshorne as she discusses OCD in individuals who have CHARGE Nancy is a professor of psychology and a school psychologist. She has published and presented widely about development of outcomes for individuals with CHARGE syndrome.

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Her son, Jacob, who is 25 years of age has CHARGE syndrome. As Robbin mentioned this webinar will be recorded and archived for future in -- future viewing. Please be mindful of your comments in the chat box.

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As you know the CHARGE syndrome foundation is a not-for-profit organization that provides support to individuals with CHARGE and their families. Our mission is to gather, develop, maintain and distribute information about CHARGE syndrome and to promote awareness and research regarding its identification, cause and management.

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Providing webinars is another way that the foundation furthers its mission. If you like what you see tonight and you believe in the work of the foundation, please consider becoming a member of the foundation or make a donation to our website.

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Dr. Hartshorn request that the question answer session be saved until the end of her talk. So if you write a question in the chat box please note that the response will occur during the question and answer period.

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We thank you for your continued support and joining us and Nancy Hartshorne this evening.

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Please enjoy the webinar.

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Hello. Hopefully everyone can hear me.

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I want to start out by having you look at the picture on this first slide if you can see it and see if there is anything about it that

bothers you.

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For myself I am really bothered by the pencil just above the pink pencil because the tip of it is a darker color than the rest of the pencils.

Although this is meant to represent someone with OCD lining things up there is still one little mistake in it that just drives me crazy.

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I start off with this slide because I wanted to let you know I personally have a lot of experience with OCD for myself. It is one of the reasons I became a psychologist. I am a fully functioning person in the world somehow, but I have had my bouts especially when I was a teenager. I did have some authenticity when I talk about this subject.

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I am also a psychologist and professor so I teach the subject to my students and finally I have a son with CHARGE. I just wanted to give you a background so you know where I am coming from.

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I want to start by talking about what OCD actually is in terms of -- I can't seem to get it to advance on this slide.

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In terms of what the diagnostic and statistical manual of mental health disorders would say it is. Basically I will start here, the O stands for of session, this -- C stands for compulsion, and the D stands for disorder.

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The person experiences upset that thoughts and these are usually

irrational thoughts and fears. These are thoughts that they can't get out of their mind. For instance a typical obsessive fear or thought somebody will take my stuff. There will be a fire in the house, we will lose something important. Or contamination is another one. I will get a deadly disease, some people will say they feel like they have germs crawling into their skin.

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To a loved one or a fear or obsessive thought that you might hurt someone even though you may not do so you are somehow afraid you might.

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Magical thoughts. I am sure some of you have avoided stepping on cracks before. Step on a crack take a mother's back.

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With someone with OCD this is a big thing. I have one child with OCD whenever we go to CHARGE conferences or go into airports he can only step on one color of tile on the floor. He is leaving all around the airport floor bumping into people, and he is a big kid. I always have to say stop that you have to step on the other color. That bothers him. It is something he does to get rid of the obsessive thoughts.

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A number or a day is good or bad. For me the No. seven was the one I used to target all the time. For my other son the No. seven is the evil number. It is very individualized.

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Hearing or saying bad words. You might send and go to hell if you say

the wrong word.

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Then fear of not having everything just right. We all know people who have to have things perfectly lined up all the time. I was speaking with one of Jacobs caregivers today who was saying when she writes in her planner if she makes a mistake, she has to go get a whole new planner and write it out again. She is on her fourth planner for this year already and this is February.

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She does not want to let go of that control of having everything correct.

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The compulsion or behaviors of people with OCD take part in to alleviate the worry. It is usually only temporary. The one you have all heard of, I am afraid someone will harm my property so I checked the locks, make sure the oven is turned off, I never throw anything away I am a quarter.

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This is difficult, this is the person who will drive all the way to work and then drive all the way home to make sure their locks are locked. They will get back in the car and they are not sure so they go back inside and check the oven several times and they don't feel right unless they check it seven times.

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Contamination is another common one. You are afraid of germs and you're afraid of getting a deadly disease that you wash your hands frequently.

Tipple wash their hands so much that their hands are cracking and

bleeding which of course invite germs. Your's current -- skin is an organ to protect you, you will not get sick from something touching your skin.

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People who are afraid of harm to a loved one they will call and text somebody over and over again to make sure they are okay.

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Logical thoughts, these are the ones I fell victim to. Avoiding cracks in the sidewalk. Everything had to end on a certain number for me, I had to do it is certain number of times. I knew someone who when they hear a swear word that has a religious connotation, they have to under their breath fix it to the milder word. So when they hear the word hell, they have to say heck under their breath to make themselves feel better. It causes them that much anxiety.

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Having everything just right, like I said neatness, orderly, making everything symmetrical. I myself will find that if a carpet is not exactly straight I have to fix it, I have to fix [Indiscernible] so it is straight. Nothing can hang off the edge of the table. Really obsessive pulse of kinds of things that I do.

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I just want to have this overview so you understand is clearly before we go into CHARGE syndrome.

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It is an anxiety disorder. People go through these things because they

have anxiety. Some people when they have anxiety they have a panic attack, some people run away flight or fight response. You panic or go into full flight mode, your heart rate goes up, you breathe shallowly, you may cry, run away screaming.

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Some people find the ways to relieve anxiety by performing compulsive acts. These people when they try to stop their behavior it increases their anxiety.

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For instance let's look over here at the chart. You have an obsessive thoughts, I am worried I'm going to go to hell. Cause of anxiety, fear. You pray as hard as you can seven times, one thing I used to do, then you get temporary relief I am okay. But then the thought comes back and you have to do it again. Every time you get that temporary relief you are getting reinforced for the compulsive behavior . Every time I say the prayer it makes me feel better that is a reward. That means I will say the prayer again and again. It just snowballs on itself. It gets worse and worse and worse.

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It is a -- considered a disorder if it gets in the way of the life.

Someone who is so afraid of germs it cannot leave the house. That is a disorder.

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Here is an example of what I went through.

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Robbin , do know how I can make my PowerPoint show up with my animations. It is not coming through this way. It was working the other day.

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When I was running it through it was showing the animations coming through when you press the arrow. The animations are not coming through?

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No. Nothing is coming up.

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There it is. Maybe it is taking a while.

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I pressed that so I don't know. Maybe I should put you up to host just in case. I will move you up.

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Thank you.

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Try pressing the arrow yourself. I am not getting anything when I click.

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If you want to say forward I can press from here.

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You can go ahead and forward through this whole slide.

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I have this obsession, I was going through puberty it was really upsetting there was a lot of hormonal stuff going on, I brain was changing, this was a time when a lot of people develop pretty serious OCD.

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I had this obsession over send, fear of hell. I could be excessive and repetitive praying before I would go to sleep at night. Some nights I would pray for 30 minutes. I would say things over and over, saying them seven times, things like that.

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Fear of not waking up. I would just a awake and not go to sleep.

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Rigidly applying rules. I had to have everything and on seven and if I went over 715, 17, 25, 37 saying and touching things seven times.

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If I turned around in a circle I had to unwind my cell.

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I would get really afraid at nighttime because I knew I would be afraid of going to sleep so I would sit outside the smack my sister thought I was nuts -- I would sit outside and watch the sunset until went down and then have a panic attack.

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And then saying religious swearwords and saying there are alternatives under my breath.

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What I suggest to you unless you recognize these things -- you can push this through Robbin .

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Individuals with CHARGE to not have true OCD. Some may, I am not saying

they don't. That someone with true OCD has the irrational thoughts that leave them to irrational anxiety. In order to treat it what you do is expose a person to the irrational thought and you don't let them do the compulsive lots.

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The therapist would have the person listen to swearwords but not allow them to fix it under their breath. Of course the anxiety will grow and grow , but you are trying to help the person stay,. This is called exposure therapy and it is how we treat phobias and anxiety behaviors. Eventually they learn that this will not hurt them, in a cognitive way. Even though I knew they wouldn't I knew rationally they wouldn't but the irrational fear does that to you.

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I think people with CHARGE syndrome have real anxiety. I think it is understandable anxiety. My personal experience is it is not coming from irrational thoughts, it is coming to real -- coming from real anxiety.

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These are the kinds of OCD like behaviors I have seen in CHARGE .

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My son Jacob uses everything must just be exactly right. He will order things, line them up for instance, sit at the dinner table and put his plate right in the center and his Has to be in the certain place and his food over here and a magazine he is looking at. If you move anything just out of place he puts it right back.

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If anything is out of place where he needs it he puts it back where it is. He has to have the light switches on every time he goes in a room and off when he goes out.

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He closes certain doors, if the front door is open in his house just to let in the breeze he will slam it shut because that is not how things should be.

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Whenever he sees his sippy cup picks it up and handed to a caregiver it does not matter where is it is not supposed be there so he hands it to the caregiver.

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I have seen a lot of individuals with CHARGE do these kinds of things.

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Other things I have seen is repetitive question asking. I have seen several children with CHARGE have come up to me and ask me what color is my car, what colors my house, where do I live, what is your age, how many kids do you have. They are going around and asking the same people the same questions over and over again.

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I know a couple of kids who like to stuff things into slots, especially things that are hard to get things out of. They will take their favorite blankie and stuffed it into the vent, the air conditioner vent. Than one parent has to unscrew the event and get it out because the kid has a meltdown because they don't have their blankie. And am not sure what is

going on there.

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Erratic Savior, rocking, takes, my son does this a lot. My son does this kind of thing with his hand over and over again.

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Rigid inability to switch activity. That is a hard one to. You are in the middle of something and it is time to do something else and you have to finish what you are doing first or you just need more time to transition.

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My husband Tim will tell you I have trouble with that. We are often late to places because I say I have to finish this first. He laughs about it, sometimes he laughs sometimes he doesn't.

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All-consuming focus on one idea, activity or item where it is not just an intense hobby or interest but you can stop doing it.

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I have this thing that I show sometimes that says we have hobbies [Indiscernible]. We look at people with special needs and their hobbies are not okay, but ours are. I hope you get what I am saying.

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I know one young man with CHARGE who is very quote unquote obsessed with the game Zelda, plays it all the time, loves to look at magazines of it, we did some intervention with him, we used pictures with Link and Zelda and the pony. And we use that as an award for getting his work done.

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It is all over his room and his parents were worried about this  
obsession with Zelda.

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I do this consultation and I come home to my 16-year-old boy and I go in  
his room and there are posters of Zelda all over his room, he is playing  
Zelda on his Game Boy, he has Zelda on his desktop. He loved it. He was  
a teenage boy and he loved the videogame. He is typical in every way.

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Why is that not okay for this gentleman?

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Keeping in mind we all have intense hobbies and we really get into  
things intensely and what we do to help wind our mind down, sometimes  
you can get one idea, one focus that seems autistic like where you  
cannot get the person to do other things because they are so focused on  
that.

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I would like to hear in the chat area if you like to hear other kinds of  
things that you are facing with your individuals that you are charged to  
learn about.

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We can talk about those later.

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Let's look at the prevalence really quickly.

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Tim Blake and I did our study at the last conference where we interviewed a lot of people. There were 53 participants over half were male we found about half of them exhibited OCD like behaviors, compulsive behaviors. And 45% of them reported themselves or the parents reported they had significant anxiety.

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This is a big thing in CHARGE syndrome. We see it a lot.

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I had a little talk with David Brown about this because I wanted to make sure he thought I was on the right track, I also consulted with Tim Hart and also Casey Stratton and Kim Blake, you can do [Indiscernible] without consulting all the experts that know about the behavior.

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What they would Brown said to me is quote" a lot of what looks like OCD in CHARGE is really just a reaction to having three impairment -- multisensory impairment.

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We may see more anxiety with kids with CHARGE that we do in the general population but kids with CHARGE are not just deaf blind, many do not have a sense of smell, many do not have a sense of balance, many have problems with sensory and touching things. All senses are affected.

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We purport to these are actually really creative responses to their abnormal anxiety provoking circumstances.

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What can possibly be making our kids [Indiscernible].

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As a caveat I want to say you could have someone with CHARGE syndrome who has typical OCD. Someone with CHARGE syndrome could have schizophrenia, someone with CHARGE syndrome could have your autism, they could have diabetes, not just because they have CHARGE I will not say no one has OCD . I think there might be some people out there who do.

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I believe the compulsive behaviors you see in CHARGE are not true OCD as I described before, they are more a reaction to circumstances that are living with them -- that they are living with that causes to anxiety.

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I love this picture of my son Jacob. What could our kids possibly have to be anxious about?

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I want to break this down into a few different sections . I want to talk about the real and understandable anxiety that individuals with CHARGE may have . Triggers that cause fear, anxiety and then produce compulsive behavior.

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I have seen and worked with a lot of kids with CHARGE syndrome, but the majority of my experience with my own son. If any of you know him he is on the lower end of the spectrum for CHARGE in terms of education . He is not literate, his language is pretty literate -- limited to sign and text pictures. I know a lot of you have kids and young adults who are



doing much more than Jacob and I want to build to address your symptoms as someone who's son just finished college and independent. I just wanted you to know where I'm coming from.

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Pain. I found this picture and it was just perfect. It really illustrates how sometimes pain does not come with a big sign . When I am in pain myself sometimes I do not realize it right away. You get an underlying headache kind of thing, you get irritable and you're not sure why and you realize you have a headache coming on.

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I have another son who does not have CHARGE , he will get in a really rotten for a day or two, and we all look at home and we say he is getting sick. A couple days later he has a bad cold. He gets in a really bad mood and we know that is what is going on.

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My son Jacob will get ear infections every three weeks to a month all his life and it probably will never go away and he has certain pain behaviors but it took us a long time to figure out when it is an ear infection when is something else.

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Sometimes you have pain and it can cause you a lot of anxiety especially if you can't get the message across. Some of our kids don't know how to express their pain. Some of the kids in the Bay have really good language skills still have trouble expressing pain.

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Sensory overload or underload issues. Look at these kids here. I love this picture one building the castle had to touch sand. You have the little girl at the bottom with the chew we things, many of you have seen those are have them for your kids.

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Summary has too much noise coming in and they can't stand it and sometimes you get overwhelmed and you want to crawl in a corner. I feel like that sometimes. I am really introverted and I cannot stand too much sensory stimulation. I am a person who would never go to Black Friday, ever . It is too much for me. I can't stand being in noisy places, big parties, I would rather have a few friends around. My favorite thing to do after work is to go in my bedroom, turn off the lights and read my Kindle. That is where drama energy from is being by myself.

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Some people like to have more stimulation. Some people love going black Friday shopping, love going to noisy bars in concerts, that is not mean. You can see some of these kids are getting too much stimulation. The one who had to touch sand, the one with too much sand coming in the ears, and the L [Indiscernible] and the girl in the middle is not getting enough stimulation so she has stimulation for her teeth and jaws.

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These kinds of things can cause OCD like behavior.

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How about just plain boredom? This is an under stimulation issue. What do you do when you are bored? Do you tap a pencil, do you wag your legs,

do you play with your hair, bite your nails. You know what? I used to take my son to doctors appointments at the teaching hospitals and have to wait a couple of hours and it would be so boring. Now I have my smart phone there are lots to do. You can sit there forever. Jacob can't do so much like that.

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We need to keep our brains occupied. We have to keep ourselves aroused and alert.

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What do you do to keep from getting bored? I know lots of women because women's brains make it easy to multitask they have a hard time just watching television. My husband and I could be sitting on the couch and he is just watching television, but I am watching television and knitting, or working a puzzle, or I am watching television or playing Candy crush on my phone. All the same time and I can take it all in.

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Sometimes I cannot just sit there and watch TV I have to have something else to do something with my hands in particular. How do keep yourself aroused and alert. If you're at a conference had to keep yourself from falling asleep? How you keep yourself focused for instance on this webinar right now? If you're getting tired it is Sunday night, I don't know about you but we're getting a big dumping of snow in Michigan, that makes me tired looking at it and what we have to do to clear it out tomorrow.

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Some people choose gone that helps. That is [Indiscernible]. Some people chew on pencils and bite their nails. If you are bored do you just do these things?

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Checking behavior. Very common in OCD --

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Robbin can you advance the slide, please ?

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Checking to see the oven has been turned off seven times is a OCD kind of behavior. David Brown gave me this idea. He said to me, if you don't have all of the sensory information you need to be reassured you don't get complete information about your surrounding, and if everything is kind of chaotic doesn't it make sense you will run your hands along the edge of the table, Things, put things in certain arrangements to confirm where they are, check to see if things have changed.

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My son Jacob, like I said [Indiscernible] he will also move the chair where blogs and put a blanket where it longs. Sometimes he's really a need [Indiscernible] with the way he puts things away. He has significant vision impairment, he is legally blind in his left eye and does not see anything out of his right and completely daft.

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He needs to know like any blind person things need to stay where they are because you do not want to trip over them and you need to have those assurances.

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We had a fun thing happened today we took all of the cups staff for a death -- deaf blind stimulation. It was 11 staff members, they are all special Ed majors at the University. And we put simulators on them so they could hear nothing and they could see nothing. Then we put them in cars which is difficult because it is very slippery out today. We took them to another place and had a silent supper. We served them food.

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It was interesting to watch them. We show them the video and they think it is interesting to. Many of them kept reaching out to see whether can of pop was, they kept moving their plate right where they thought it should be, when they were waiting for food or when they got served something new, they kept reaching out making sure everything was where it should be.

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When they took off the simulators and we talked about it they said we really understand why Jacob does that.

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We all thought it was funny because he moves his couple little bit and he puts it right that. But now we really understand. He just needs to know his things are reliably where they are or he gets anxiety about them. You get worried when you can't find things.

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How about sleep? Sleep is a big issue for people with CHARGE syndrome. Kim Blake and I found that 60% of people and our sample of adolescent

adults have sleep problems. Waking up not being able to fall asleep  
waking up too early not being able to go back to sleep. When you look at  
sleep and anxiety in the general population they are highly correlated.

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When people have a lot of anxiety it interrupts their sleep. Face and  
point when I was 16 OCD lots of fears I cannot sleep.

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When people do not get enough sleep it can increase their anxiety. A lot  
of good things happen when you are asleep especially rapid eye movement.  
All of the proteins you have taken in in the day begin to metabolize  
into your body, your brain repairs itself, all of these things happen.  
If you do not get good rapid eye movement sleep you do not get good  
quality sleep at all and you will wake up and feel lousy and you have  
more anxiety.

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It is a Catch-22 . You have got to get good sleep to decrease anxiety,  
but you also need to decrease anxiety to get good sleep. This is a big  
issue for some of our kids.

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Also, you can help with sensory issues, that helps with sleep. You can't  
alleviate pain, that helps you sleep, and you can make life more  
predictable and that will help with sleep.

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Look at this picture here. This picture makes me crazy that is why I  
chose it. With my little OCD I look at that and I try to line it up and

I tried to see the bodies and faces and I can't put it together and I really don't like looking at it it makes me a comfortable.

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For my son Jacob this is what life is like all the time it is chaotic, he can't hear, he can't see, he can't balance, he never knows what will happen next. For a lot of kids who are deaf and blind and have CHARGE they are taken from one place to another they don't know where they are going, they don't know what will happen the next day life is very chaotic. That causes a lot of anxiety.

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Stress in and of itself can be hard.

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Here is where we get to the nitty-gritty. People want to know how to help. What to do . My philosophy is I can't you the exact steps to take with your child. I can give you a lot of ideas and I can give you the theories of why we think this is happening and hopefully that will help you find the right way.

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One question I have is to do or not to do? Do we intervene or do we not intervene?

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We have several steps. Step one, figure out the purpose of the behavior. What is the goal of the behavior? Almost all behavior serves a function. Like I said if you are tapping your pencil it is keeping you awake. If you are crying, it may be because you are sad. Any behavior you can

think of that you do at any one time has a function for you. Somehow it helps you get along in the world.

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If you can figure that out then it is easier to figure out what -- when you should intervene or whether or not you should intervene.

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I say that because the goal of the behavior may look inappropriate to you but it may be masking something else.

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For instance the person with CHARGE who asks what colors your car, what color is your house repeatedly, there are three general reasons why this would happen . There may be more but this is what I could come up with.

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Do they have a need for social interaction but they don't know what they are supposed to do. I have seen kids at CHARGE conferences and all the parents are talking to each other and they keep going around and asking people the same question. They know they are supposed to be interacting but they are not quite sure how to do it. So they fall back on their one thing that they know they can get an answer for.

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This is what they know how to do.

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Second, do they need to do something to organize the chaotic situation. There are lots and a lot of people around, sometimes when I go to CHARGE conferences I get really overwhelmed at the carnival. I love the



Carnival, it is so loud that I have to leave the room. I have to take my son out sometimes for the same reason. It is fun for extroverted people's but some people get overwhelmed.

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If it is a chaotic situation and people are running around, there is a lot of noise, I am overwhelmed and what do I do to make the situation understandable. I will impose my own structure on it. So I will go around and ask people the same question over and over to make me feel comfortable to lessen my anxiety.

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Finally, you need to know more about people to feel safe around them. If you are around a bunch of strangers even know they are parents of children with CHARGE. We all know we love each other and we would never hurt a hair on anybody's finger these kids don't know that. All they know is there are a bunch of strangers around them, they feel safe but they need to ask these people these questions to find out if they are nice and if they answer the questions.

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There old may not really be to know the color of the car or the color of the house. But they may have other goals behind that behavior.

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An example of this, I was working with a young woman once and we were doing a personal center plan for her where you help someone find out what they want their life to be like as an adult. It was a person with cognitive impairment. She kept saying she wanted to be a professor. She

wanted to be a professor. Should be back --

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She was limited cognitively she was not going to be able to take a college class let alone get a doctoral degree.

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We just kept working with her and asking her and asking her. Finally what we found out is what she really wanted was recognition and a title. To feel important. It was not just to be a professor. We talk to her about how about if we get you a name tag that says you are the supervisor of something. She was so excited. She just wanted to feel important. We all want to feel important. Her saying I want to be a professor was masking a different goal for her. Trying to get at what that different goal is for people is sometimes elusive but we try to do it.

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Step two. I have another David Brown thing here. We all know he is brilliant. He is talking about the urgency of intervention questions. I think this is a really and list. Think about the behavior is there something that just bugs you personally and can you learn to accept it and it or it -- ignore it.

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As you saw my son Jacob in the picture he rubs his for head like this constantly. It could be to hold his head up, maybe to change his vision to make it more interesting, maybe rubbing his temples helps his headache, there are a lot of reasons. It used to really bother me and we would tell him to tell -- put his hands than when he was little boy.

Than we realized big deal. He rubs his head, if people don't like it then they don't have to look. It doesn't matter to me.

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Second step, is this a behavior that seems to help the child function in a positive way so it can be excepted and it or -- ignored? Some of these kids need to hold her head straight and my son does not have these canals and without holding his head straight he really doesn't Seawell. He cannot get his vision to work well he has to hold his head still.

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What about rocking. How many of you kids rock. Mine rocks especially in church we sit in this to the squeaks that rocks. Maybe he is understimulated and the rocking keeps them awake. Maybe it gives them visual stimulation, maybe it is soothing to him like a baby, rocking the baby to sleep. Maybe he is using his senses vestibular kinesthetic sense to know his space. Maybe he is rocking to the music there could be lots of reasons.

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Is it important for us to stop his rocking if it is helping him ? It is not important to me. Everybody in my church knows Jacob and they don't care. Sometimes Jacob blows raspberries in the middle the sermon everybody loves that they laugh so hard.

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No. three, is this a behavior that seems to help the child function in a positive way but can be reduced or replaced by something more appropriate?

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Biting nails, biting your fingers for stimulation, pinching yourself, picking at your nails until they bleed. I have a son who choose unclean next. He choose unclean next because he wants to get that soft input. A lot of times we find input to the job helps people and I coronation. They say that some kids if you give them gum in English class they do better handwriting. It is a weird neurological connection. My son is chewing unclean next, not really appropriate and who knows what is in the Kleenex. What can we replace? I give him a piece of sugar-free gum. That works great for him he no longer choose unclean next.

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You have kids biting their nails like crazy. Give them a piece of gum same thing. Or maybe they want the input with their fingers. We had a student with CHARGE who was really picking at the fingers and was making them bleed, we got them under Armour gloves and cut off the tips so they could still use their fingers and it gave them that tight pressure they needed. They got that real kinesthetic pressure that help them organize their sensory system and the stopped doing it. It was wonderful.

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My son Jacob walks around with one hand over his right eye. That used to really bug us and we would take his hand down. How can you see with one eye you've got to take your hand down. Then we figured out this I is really light sensitive and it doesn't Seawell. So maybe it is affecting the vision he has a making it harder to see. Now he does it all the time. It doesn't bother me. PCs better and he no -- he knows what works for him.

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Is a behavioral undesirable and needs to be reduced or replaced over time? Like pulling or twisting your hair here -- hair so it comes out and you're getting bald from it. I have think it's like that.

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Picking your nose. They are not immediately dangerous, but you don't want to see it happen all the time. Can we replace his overtime, can we give the kid another way to get the same sensory stimulation so they do not need to do that anymore.

---

Is this a behavior that needs to be prevented immediately?  
[Indiscernible] or headbanging. Those are the things you need to intervene immediately. Or my son Jacob sometimes will just hope the floor trying to get sexual stimulation like that. We say go in your room. Those are the kinds of things you do not want to see him doing in public like at my other kids soccer game.

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Not just because it looks strange but because it takes away his dignity and other people look at him as if he is strange .

---

Finally, this is the most important point I think there is here. How can we change our behavior and the environment to fit the person. What is it about the environment that is causing them to feel like they need this behavior? The rocking behavior in church. If my son is completely bored in Church, he doesn't get anything out of it maybe we do not keep them

in their salon. The reason we keep taking him is there is a community there that loves him and they want to see him. Maybe he does not need to sit through the whole service if you cannot see or hear it's what does he get out of it.

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Can we change the apartment for him? Can we give them a more comfortable place to sit than a wooden pew, it is uncountable for me and it may be really bad for his balance problem.

---

I have heard David Brown Heusen example of letting the child get up and move around and have a sensory break. They cannot sit there that long.

---

Letting the child hold onto something while they are standing so they can stabilize their head, things like that. There are all kinds of environmental things we can change so that they are comfortable, they are not under or overstimulated, all of these kinds of things.

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Step three, once we figure out if we need to intervene, how do we do that? How do we intervene?

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Let's go back to pain. Communication of pain can really devolve. If I come home and I say I have a headache and nobody really listens to me, I might side and wine in say I had really hurts. If nobody listens to me I might start banging my head on the table and say I need some sympathy I have got a headache. I will keep communicating in different ways until

the person hears me.

---

I know this happens with my own kid. When he is in pain and he is at school, he made clear his table he does not want to do the work you may put his head down. He may drop to the floor and lie down. He knows that is a no-no. If nobody listens to him and try to get him to keep working and he is a horrific headache, then he may start crying and whining and acting out, trying to walk away from them, pushing things away. Finally, if nobody is listening to them he may start pulling his hair, he has taken right out of people before. He does not necessarily get really violent, but basically it was our fault for not understanding what he was telling us. He was trying to communicate his pain all along and we didn't listen to him. So to get heard he had to escalate his behavior.

---

We have now figured out his pain behavior. We have tried for years and years to find a more appropriate way for him to communicate pain, very difficult. For instance in infections are usually what he gets. So when he hasn't your infection -- has an ear infection, you do not feel it in your ears until there is a lot of pressure it's around to glands in your head and you get a headache. It is not like you can point to the ear and say that is what hurts. We figured out when he starts digging things into his neck will -- like something really hard like a clean next box and he will jam it into his neck. When he does that we know it is his ears just from lots and lots of trial and error.

---

He will start doing that after he has been listless, is the want to do things just want to lie down. We figure it is years it is time to go to the doctor.

---

When he blows raspberries over and over and over and doesn't stop we know he has gas pain and cramping. That Israel intermittent because it'll happen for five minutes and then it will stop. Than an hour later it will start and stop. We have learned that is gas pain and cramping.

---

He does not have a way to tell us these things, we have learned over time to understand these behaviors.

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Right here is [Indiscernible] Stratton charge non-vocal pain assessment.

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This is off set since the PowerPoint was uploaded.

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She had a non-vocal pain assessment that was a general pain assessment for people who were vocal and she had a lot of people -- parents with children with CHARGE and these are the things that came up the most as pain behavior that these children showed. They are less active or they are agitated, or they are hurting themselves, they get aggressive, they act out, disturbed sleep is a big one. We know Jacob is sick when he wakes up in the middle of the night and can go back to sleep. Don't eat as much, don't want to be moved an increase in anxiety or compulsive behaviors. Anxious that you are in pain, nobody understands, nobody is



helping you you will have more compulsive behaviors.

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Sensory issues. What can we do about this? You are overstimulated, you are understimulated.

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Think about if you ever had a massage, have you ever had a massage or somebody rub your shoulders really hard, deep pressure helps you relax, it helps bring your arousal level down. There is something about deep pressure that re-organizes your sensory system so you can relax.

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For instance, have you ever done brushing, [Indiscernible] compression any sensory techniques on your kids. For many kids it helps to calm them. Jacob has a weighted like it, when he gets really overwhelmed with sensory stuff the puts that on. It just calms him.

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I can go to sleep unless I have a heavy blanket on me. If I have a nice warm comforter I am fine but if it is not heavy enough I can't fall asleep. There something about the weight that makes me feel comfortable.

---

Sensory breaks to bring the arousal level up. So if you're really bored and falling asleep you need to do something to wake yourself up. Sometimes kids need to get up and do something different and bring their arousal level up or all kinds of light up, toys, fans and that is the arousal love -- level up. He breaks pretty for me. He finishes the job he is a century break. He finishes a new job he has a century break.

When he is overwhelmed we let him withdraw. When he is at his house, something happened today we had a big deaf blind simulation at his house, little tiny house with a small living room there are 15, 16, 17 people in that room he was fed up after the whole thing was over. He knows that is his house and his beasts -- space he grabbed a character giver -- caregiver he took her outside with for a walk he withdrew because he was overwhelmed.

-----

You can set up a better sensory situation for the environment. Like I said if somebody is overwhelmed with a lot of noise and activity have them work in a place that is quieter . Whatever works better for them. I'm not saying segregate, I'm not a big fan of segregation, if it works for somebody to be an acquired or place allow them to do it.

-----

Jacob often gets bored because we have to wait in Dr. waiting rooms, meetings and restaurants were he does not eat well. He can get all kinds of strange looking behavior, sitting, walking all the things I've talked about before. He can't see the TV in the waiting room like everybody else, he doesn't have a smart phone, like I said what did we do before we had those? He needs something to stimulate his brain. This is a picture taking -- taken last week at Jacobs team meeting at school. We're all in this room talking about goals and objectives and his intervenor brought this big basket full of his sensory things. He sat there and to control the first thing he did was get out the big heavy blanket that he likes on his lap. He loves the woolly texture and the

weight. Then he started arranging all of his things around the way he likes them. You can see him moving them.

---

He made them certain spaces across some each other so he can find them all. That helped him get through the meeting. We did not see any odd behavior, we would not have minded anyway because we are used to Jacob and his sounds and noises. We all accept that. He was not distressed in any way. He had plenty to do he was not board.

---

What about checking behavior. Again, the checking behavior of true OC these is checking your oven seven times.

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The checking behavior that our kids do alleviate the anxiety. Like Jacob shuts the front door and alleviate the anxiety of people coming to his house. He will shut his bedroom door when he is in there because it alleviates his anxiety about whether people will come in and make demands of him like time to go to work or go eat. When his door is shut he knows nothing will happen. What can you do?

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First of all allow this. It is [Indiscernible] for them. He needs to have his cup and bowl all in the same place. He needs to have all of his things organized in a way where he can find them because he does not have enough sensory information to see them from across the room.

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There all the old Helen Keller jokes that we heard when we were kids

they are horribly cruel, we were little kids, but how did Helen Keller's parents punisher they rearranged the furniture. Horrible joke. Literally our kids need to be stable and in one place. They need to have that predictability and know when they go out it is safe. They do not have enough sensory information to be able to get things back the way they want them if they are out of place.

---

What can you do for sleep? There are a couple of things. Reducing anxiety is one because we talked about how anxiety and sleep are related, but to improve the quality of sleep there are some things that can be done. Pay attention to the sensory overload is the one I have seconds and I'll talk about that first.

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Inc. about little kids. If you have little kids and you try to get them to bed at night it is really nice to do calming activities, bathing, reading a book, saying a prayer, singing a song to help them get to sleep. You don't have them go outside and run around for five minutes before they go to bed. That gets their sensory system going and get them want to work like we talked about before.

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Pay attention to sensory overload try not to get people to overloaded before they go to sleep.

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Sleep hygiene is an interesting topic that has been well researched. If you have a very specific routine before you go to that, you will start

associating those things with getting sleepy. It is proven.

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I have sleep hygiene. I have to do my stretches for physical therapy, then I brush my teeth, then I floss my teeth, then I get in bed, then I read my book or 10 minutes. Then I floss my fellow and I lay on my right side and I fall asleep.

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If I don't go through that routine it is really different. Think about going in the hotel is sleeping there for the first time it is hard to sleep that first night. I go through that same routine every time I get sleepy because I start to learn that brushing my teeth I should start feeling sleepy now because I will follow sleep. It is the same routine especially with little children that works really well, with typical children, read a book, take a bath, kiss good night, go to sleep. Same time same way every night the kids will learn the bedtime routine.

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Kids with CHARGE syndrome it is a little different. Some of them do not have vision to get the nighttime cues of the darkness that releases melatonin in the brain to make you sleepy. Having that nighttime routine can have really -- really help. For Jacob it is take a bath, put on your pajamas, pressure teeth, get in bed and he covers themselves completely up with this comforter and you close the door and leave. He is usually asleep and 10 minutes. It has taken a long time to get their.

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Finally I am not a physician so I am not wrecking -- recommending

anything but melatonin is released from your brain to help you go to sleep at night. It is triggered by the darkness. Some people have found it to be helpful to help their children with CHARGE falling asleep. If Jacob is having a hard time I will give him a melatonin pill -- pill [Indiscernible].

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Reduce the anxiety. If you can get people calm and comfortable have things be predictable for them than anxiety will go down and they should be able to sleep better.

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My final topic I want to talk about is the key to relieving stress and anxiety to make things as predictable as possible. This is coming from my husband Tim, we will present all of this together at the CHARGE conference this summer as well. The more chaos there's is the more order we want to put on a. The more predictable you can make your life the easier it is to handle.

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Look at this. How many of you carry around a calendar or a phone with a calendar on it or a planner or keep a calendar in your house. You know what is going to happen. You know what you're supposed to do now, you know what you're going to do next, you know what you just did. If I pull up my calendar on my phone, I get this, you probably can't see it. It shows my week, maybe you can see the blue dots those are all the things that have to do this week. Much of it is teaching classes.

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I look ahead at my week at the beginning of the week because I need to know what I need to do each day so I can get my energy toward it. For instance today I knew I had to do the deaf blind simulation and do the webinar in the evening and I had to keep my energy up for this.

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Having that predictability helps me know what is coming next.

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Why use a calendar system? Like I said I am talking about deaf blind method calendar systems here. It gives our kids the security of knowing what is going to happen next just like we have. You can anticipate and look forward to things, good things and bad things. You can be alert to unexpected changes in the routine if you have a way to show that. You can participate in the decisions about events. If you have a calendar and you can give people choices about what they could do next that is really helpful because that is self determination to make a choice.

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You can talk about what has happened. Like I just talked about we had the deaf blind simulation today, it went great, all the kids loved it. If you didn't know what was going on it would be hard to look back and talk about what happened.

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You can have our locks about it. A clearly represents the passage of time you could see how time is going by. And it reduces anxiety because you know what is going to happen.

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Passage of time. When I get up in the morning, Tim is up in the morning we both talk about what we are going to do that day. Sometimes it is a competition about who has more to do that day. I wonder if any of you have that experience. Don't forget I will be gone tonight I have this meeting, don't forget I will be late coming home because of this or that. I had to speak with students about this, I have several meeting about my promotion, I have to do webinar tonight. Those kinds of things.

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When we get home we talk about how was your day? What did you do? What happened? How hard was that? What did your student do that was ridiculous or wonderful? What are we doing tomorrow? Let's dream about what we do the summer when we model are the gym -- the dream -- bedroom. Psychologist talk all the time about how many of us don't live in the moment because we always think about the past or future.

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Our kids live in the moment because they don't have a way to talk about the past or future often.

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Imagine waking up and have no idea what time it is, you don't know what will happen today, how soon something might happen, what the expectations for what will happen, you can't detect whether time is going by are not or how late it is or how many hours have gone by and will I like what is going to happen.

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Often I say we put Jacob in the car and he doesn't know if we are



driving for two days to Kansas to see my parents or if we are taking them to Ann Arbor for surgery, or if we are just going down the road to see the doctor or taking them swimming or something fun.

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How can he gets in the car without having anxiety. He has no idea what is going to happen.

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To start you want to make sure you have some kind of communication system. I know many of you do. Many of you have kids that are much more meditatively -- able to communicate and take a. Is it more sophisticated like on the phone or is it like what I'm showing you here. Do you communicate with objects, pictures, signs or words ?

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My son uses a few signs but for the most part he uses pictures. What you see here is a picture exchange communication system. This is a picture I got off the web but this is what we use for Jacob so he can ask for things.

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Then we want to have activity routines. Things that are routine that happen all the time. I remember when my kids were little I would say to them Monday, Tuesday, Wednesday, Thursday, Friday our daycare days, Saturday is stay home day and Sunday's church they.

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That is how they learned the routine of the week and what to expect. Having the predictability helps everybody feel less anxious.

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Here is an example of an anticipation calendar. This is for someone who is just learning calendar system. This is how we had to start with Jacob. Here are two very distinctive baskets. One is what you're going to do right now , and the yellow one is the finished basket. When you're finished with the activity it goes in the finished basket. You have a very clear idea of what is happening now and a very clear idea of when it is over.

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This object which is a toy may represent free play time. The child sees that in the basket, they know it is free play time they go to the free play area and they have their free play. Then when their intervener or somebody working with them brings them back they say free play is finished and then the child physically takes the free play object out and puts it in the finished basket.

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This is a way to begin and by doing they will learn.

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This is a bit more sophisticated. This is a simple daily calendar for this person it is a two hour shift of the day. Maybe they start out with the first object, this is someone who obviously needs to use objects instead of pictures , the vision may not allow for it or they are completely blind. Their first one might be a toy for a while.

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The second one when they finish free time there is a piece of cardboard, that may represent it is time to do recycling. When that is finished

they come over and it is time for lunch or PDA sure or tube feeding something like that.

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It shows a sequence of events it -- they learn what before and after means, now, yesterday, tomorrow all those concepts that are difficult to teach them when they do not have her sophisticated language.

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Here is a calendar we use for Jacob. He has four shifts a day, these are weekend shifts when he is not in school.

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During each shift the person will pull that colored strip off of the calendar and sit with Jacob and they will plan the shift together. There are certain things that have to be on their like eating and going to the bathroom and taking a bath and going to bed. Sometimes Jacob can choose the other things like where the break will go, when he gets to play with his iPad, when he gets to play on the trampoline, when he gets to go in the hot to. He has control over it.

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Once they talk about it it is set and then they follow it.

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You know Jacob understands it because if there is a place there is work to do he will take the work office which it with the break. He knows how this thing works and he can manipulated himself. That is okay he is at his own house on the weekend he should build have choices about those things.

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Here is Jacob working on one of the calendar's. He has just finished, the yellow means free time he just finished break time he is going onto the next thing on the calendar. Here is Lauren she is his intervener and she is taking the break off of the strip and putting it into the box. He will look down on what the next thing is. He knows exactly what to expect all day. There is no confusion, no anxiety. Maybe there is something that says you are going to the doctor to get a shot but I would rather he know he's going to the doctor to get a shot than not knowing what is going on at all. We all deserve to be able to predict that.

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Here is the way we predict Jacob's week. These are the days of the week. The yellow ones are the weekends Saturday and Sunday so there is a picture of home want each one.

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These five days are the schooldays. We generally just use the top Velcro you can see the bus represents school. I wanted to show this picture because on this day school was cancer -- cancel because of the snowstorm. The big X means school was canceled and you put the picture underneath the asked to show he will stay home.

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Every night he goes by and takes these things off and puts them in the finished basket so he knows that day is over.

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Here is a calendar word days are highlighted by activities. On Monday

this person is going to work at the pet food store. You can see the orange marker on Monday so they know which day it is. Tuesday they go to the eye doctor, Wednesday they go swimming you can see each day has a distinct activity to help them understand what will happen that day.

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Here is what we use for Jacob for eating . He pretty much does not need the pictures anymore, he has got this pretty much memorized. This is his dinner routine. He has to get the ball and put it in the tray and the spoon put it in a tray and get his food out of the fridge and he puts it in the microwave and puts it in the tray. Takes it all to the table and he gets his cup and his meds and takes it to the cable and gets his nose spray and his melt. But every time he gets something he takes a picture off of puts it in the finished basket.

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We have talked a lot about this calendar to tell you what you are doing now, what you're doing later, what we just did. Week it the finished box at the end of each one and we say look what you did today you went to ride your horse, wasn't that fun and then we went to swim, and we went to the hot tub. Once the individual understands the concept of the calendar you can do all stuff -- kind of stuff with its. Once they get it, there is really nice technology not Jacob has on his iPad the if then schedule. I think that is correct. We use it for a calendar system now we no longer use the pictures and he swipes things when they are finished or puts them in the envelope to show they are finished. It is really nice.

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I know we have been talking about the calendar systems which have been developed for kids who have less literacy than a lot of your hits, the eye via is -- the idea is a predictability to get rid of the anxiety that is causing compulsive behaviors. The more predictable you can make the environment in any way shape or form the better.

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It looks like we have about 20 minutes for questions. Where do we go from here?

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Thank you Nancy. What an incredible webinar. This is Lori Swanson. I will like to direct your attention up to the portion of the chat box where people gave examples about their children's behaviors. Some of these examples were very interesting.

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Sue asked the question what if your child quote hobby unquote is considered inappropriate for dark.

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Okay. Obsession with death.

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The one prior to that, they are all interesting, but the one above it is inappropriate, dark and then it says obsession with death, holding breath, Muslims primary but all religion torture the villain.

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If you like to take a few moments to address those concerns I think that

would be informative for all of us.

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Nancy, that is the kind of thing that my husband and I were talking about it whether it is true OCD or not. It is possible that those hits are getting into some of those really disturbing thoughts that are reoccurring.

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Can I get more information about that?

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If these individuals would like to type that would be fine, or if they press \*6 that would unmute their phone.

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If you can start talking with the information you have perhaps they will add more information.

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I guess I need to know what exactly you mean. Holding breath , when I hear this as a psychologist I'm always looking at what is the goal for the behavior. Holding your breath with a child more typical is often a way to try to get attention, but without knowing more it is hard to know. Or is holding the breath some kind of sensory feedback which they really like, maybe they like seeing stars in her head. But without having more of the story it is a lot harder to address.

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Nancy, this is Sue. I was the one that brought up the dark issues. Can you hear me?

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Yes.  
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My child for instance she is obsessed with the Muslim faith. You may say where did she find not works I don't know probably on the computer. At school, this is not a bad of session, she is not having bad thoughts about the Muslim faith but she is obsessed with it. At school they do not want her to talk about it or bring it up. It is something she has to keep at home, and she also goes into an interest in torture, shoes and torture anybody or do anything adverse at home but it is interesting . It is much more appropriate if she is interested in snow white or Tinkerbelle, she could care less. But it is hard for her to know -- we let her pretty much have her hobbies at home, but when she gets to school she gets in trouble for her hobbies. It is hard to balance this. I don't know exactly how to help her.

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She is not able to understand where it is appropriate and where it is not appropriate?  
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She does. She is academic. She's probably a variant CHARGE a lot of things she does is not typical CHARGE that she is CHARGE She can curb herself from talking about it at school works

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Pardon?  
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Is she able to keep it to herself at school without being stressed?

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She is. It probably works okay. My question is do we try to redirect her at home or just let her be her and as well -- long as she manages it at school not worry about it. Although it does create issues with the people in charge.

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The person who has a behavior problem might be the people at school. If it gets inappropriate or is threatening to someone, but if it is just expressing interest.

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All of our kids do these things. My son was upset with guerrillas from one-time. Every time he was asked to write a paper he wrote about guerrillas. So why couldn't Muslims or torture tactics be the same thing? Torture is a very vastly studied thing in psychology. Social psychologists study why torture works, why it works and what kinds of torture is used. Maybe you have a budding psychologist on your hand.

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My own feeling with those kinds of obsessions they do not go away until they get fully realized and played out. The more you try to stop it the more she may want to do it.

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Trying to stop it does not change anything.

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They have books about it. Do it with her so she understands. There are

all kinds of people who are interested in more dark topics but as long as she's not going down a dangerous path with it I don't see anything wrong with it.

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Thank you.

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Kevin Moore has an interesting question. He says the problem is not falling asleep it is staying asleep. To have any suggestions?

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This is really tough. Kim Blake and I talk about how we need to do more research on sleep. I know my husband's [Indiscernible] is working on this, I think it will be more of a matter of finding out what works for people. We have not found a solution for our son except for him sometimes it has to do with what it is that is waking him up. For him it is often he needs to go to the bathroom. We found if he doesn't have anything to drink after 8 o'clock he sleeps through the night. If he drinks after 8 o'clock he will wake up at one or two in the morning and wet for his sheets and then he can't fall back asleep. He was never a baby who took naps he never slept in the car he only slept seven or eight hours a night his whole life. For him it was often the need to urinate woke them up and then he cannot get back to sleep.

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Often we will give him a melatonin to help them get back to sleep.

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One question I would have also is the sleep hygiene. This is not to do

with CHARGE, but often young children will not be able to get back to sleep unless their parents come back and read the story again and a need to learn to get them self to sleep and self sooth. Parent to stay with their kids until they fall asleep often find their kids wake up in the middle of the night and have to stay with them again. If you can teach your child to fall asleep on their own they can often fall asleep again in the middle the night. If that makes sense. I don't know if that applies to your child at all. It may be completely unrelated, but it is something to think about.

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That is a really tough one.

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It is. Thank you for that answer.

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The next question is our daughters of session are thought versus action. They give the example of one example she constantly talks about what happens on March 1 because she's anxious on going on holidays again. She will ask over and over if she can come with us. She does not want to come but she needs to hear our answer over and over again.

---

That is interesting. She's really anxious about that it sounds like.

Without more information, I don't know where you are going or what will happen to her while you are gone. Issue worried about that? It may be one thing were the role of her question is different that what you Inc. it is. -- Think it is. She may need reassurance of what will happen.

Maybe she can have plans written out or pictures made for herself so when she has the question you can direct her, yes we are going out of town, no you can't come with us and here is what will happen. Look at your book. And it redirects her so she has a predictable place to look at what will happen to her.

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Without having more information, I've just tried to give you some things off the top of my head that could help.

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I didn't read all of it, is as they do use visuals and calendars and assurance that others will be there, a calm voice on and on, that is another tough issue.

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The next question is are those visual Cannell -- calendar something you can purchase? Do recommend any from Amazon or anywhere else?

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If you are talking about the ones we had on Jacob's wall, we made those. You can go online and look up calendar systems, you can make them out of cardboard as long as visually the person can see them. It can be a piece of cardboard and magic marker. It does not matter what it looks like as long as they are able to access it visually.

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We have tried all kinds of things. We used to use little boxes that you get in hardware stores that hold screws and line them up. They would all be clear except for the last one that was yellow and that was

finished. Whatever you set up make sure the person sticks with it.

---

Again, if you have an iPad there are great software out there we use one called [Indiscernible] to go it is developed for kids with autism it works great for pictures. You can take the picture with the iPad you can upload it and put it together anyway you want. The second one I talked about again is called first then. It is not if then that's what I said before it is called first then and it shows what you will do right after the other thing.

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You can create these things from nothing.

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The next one is about saying no. This mom said we notice that saying no causes their child lots of anxiety. It is much better to tell her what she can do otherwise she obsesses what she -- you said no to. She very much wants to do what you want her to do, but her obsessiveness compels her to first do what you said no to so that the obsession can be alleviated. It took us about three months to eliminate the word no and don't from our vocabulary.

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That is really interesting. It sounds like you are setting up the environment to work for her. That is really fascinating. Saying no and don't would make her so upset that she would have to do it anyway.

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Right.

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Is really hard to do this off the top of my head. It is possible that she has anxiety about being naughty. So she compulsively has to do it once you say it. That can be one of those things that is more like true OCD. More like I have these thoughts in my head that I am not supposed to be noddy, I'm not supposed be noddy. I have to be noddy so I can get it out of my head and move on.

-----  
I want to quickly go back to the person who said they tried to say calming things. I'm thinking about how little children often will keep asking any have to keep telling them yes mommy is going out of town in two days, mom is going out of town one day remember you will stay with grandma. We often have to reassure our kids and like I said as annoying as it can be it may be all you can do to relieve their anxiety.

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Kevin Moore the individual who was talking about holding the breath added to his comment and he says when driving in a car or in a restaurant he holds his breath repeatedly.

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To have any more to add to that?

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His child holds with more when driving in a car and sitting in a restaurant.

-----  
I wonder about smell, maybe there is some odor, I don't have all the

information but that is one thing that comes to mind. Maybe the food doesn't smell good. A lot of our kids don't have a sense of smell. Does it help them stabilize their body in the car, are they getting attention for it? Are you asking them to stop holding their breath repeatedly? There are so many things that could be. Could it have to do with not wanting to speak, being afraid to blurt things out that they shouldn't. It is hard to know without having more background.

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Very interesting thoughts.

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April says Heather has an up session with children adults with other disabilities.

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That is interesting. That may be just an interest -- way to connect. Tried to think of the purpose of that behavior. Issue trying to make herself feel okay by talking about others who are different as well. We often seek out people who are like as if we fill different. Think about support groups. That may be a rudimentary way of her trying to do that.

---

That could be.

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Candace says my.has a fascination with sexuality. Schuster teen. She seems to be particular fascinated with women and girls, with me as well. She asked very mushy and wants to improperly touch and talk about socially unacceptable conversation topics. She is quite high functioning

but also has very poor attachment. In the -- judgment. Any advice?

-----

My biggest piece of advice you right now is to try to come to the conference. I know there is at least one session submitted, I'm not sure if it will be accepted, or talk to Casey Stratton you can find her information I think on the website, I'm not sure, about sexuality and how to teach kids about sexuality when they have CHARGE syndrome. She would be the expert to go to on that.

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Again sometimes with up session the more taboo it is the more you feel like you compulsively have to do it.

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Good advice.

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Any good iPad at -- abscesses with calendar schedules.

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Absolutely. I have heard so many people talk but the first then visual schedule. That is the best one out there and the most popular. First-then.

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You put in your own picture you take the pictures with your iPad and it is very easy to use. It has several different modes to use.

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Sue asks has there been any research with percentage of CHARGE and anxiety and anxiety with the typical [Indiscernible] developing child?

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That is interesting. As I said with CHARGE syndrome it seems at least an hour study -- hour study there are only adolescents and adults, I think my husband Tim has a lot more research that will show per 10 inches -- percentages but it looks like have had anxiety issues.

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Typical children, I don't know the percent that is a real good question I know it is much less. I think in this day and age I really believe because our world is moving so fast we have so much knowledge he that more and more children are becoming anxious.

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We are in our final minutes. I just want to say thank you very much for spending your Sunday evening with us and for sharing all of this valuable information. If people want to contact you, is there a way they could connect with you?

---

Absolutely. They can send me an email, send me a phone number I am happy to talk. Tim is happy to talk with people as well.

---

Do want to put my email in there or shall I give it to you?

---

Why don't you do it orally and we will add it in.

---

nancy.hartshorne@cmich.edu

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Again thank you Nancy so much. Very wonderful information.

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Have a good evening.

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Thank you you to.

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Goodbye.

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Thank you, Nancy.

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Absolutely.

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[Event Concluded]

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