S4301 - OCD - Transcript

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Jen: I think it's really hard to parent a child with OCD because you have to go against all your natural born instincts as a parent. When your kid is hurt, you pick them up, you dust them off, you help them. This is what parents do. It's really hard and counterintuitive when a child comes to you for constant OCD driven reassurance about some irrational fear, like the plugs. Your instinct is to reassure, reassure, and then that's this weird cycle where... I love the phrase you're feeding the OCD, but that's essentially what you're doing, and it takes a long time to figure out, okay, well what then do I do?

00:01:03
Bryn Askwith: This is Where You Are, a podcast that helps families and their children promote their mental health and wellness. I'm Bryn Askwith. Back for our fourth season, I'm joined by my co- host, Michelle Horn. Hi, Michelle.

00:01:15
Michelle Horn: Hi, Bryn. It's so great to be back for a fourth season with you. We've got some really great episodes lined up this season along with some wonderful guests, and today's episode is no exception. Today we're going to be talking about obsessive compulsive disorder, commonly known as OCD. Children and youth with OCD experience unwanted thoughts, urges or sensations known as obsessions that drive them to carry out behaviors called compulsions.

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Bryn Askwith: Today on Where You Are, we'll talk about what OCD is, how you as a parent or caregiver can know when to reach out for help, and approaches that you can use to best support your child with OCD at home. Let's get into that conversation. Our first guest today is Dr. Evelyn Stewart, a psychiatrist at BC Children's Hospital and the founding director of the Provincial Pediatric Obsessive Compulsive Disorder Clinic and Research Program. Through her work, Dr. Stewart helps children and youth affected by OCD as well as supports their family along that journey. She's a leading clinical genetic and neuroscience researcher and a professor in the Department of Psychiatry at the University of British Columbia. Wonderful to have you join the show. Thanks so much, Dr. Stewart.

00:02:28
Dr. Evelyn Stewart: Thank you so much for having me.

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Bryn Askwith: Dr. Stewart, let's start by having you share with us what OCD is, what OCD isn't, and how it typically starts.

00:02:38
Dr. Evelyn Stewart: Such a great question, and I'm so happy that you specifically said what OCD isn't. OCD, I think, is one of the more misunderstood mental illnesses or conditions in society these days. OCD is a brain based psychiatric illness that is characterized by really intrusive and distressing thoughts that come back to that individual again and again and again. These are not wanted thoughts. It's a thought that you don't want to have that just keeps coming back. A compulsion is the thing you do to get rid of this absolutely awful feeling that the obsessions bring. Obsessive compulsive disorder is the presence of having those recurrent intrusive thoughts with some behavior or a mental act that tries to get rid of that horrible feeling, but really, a key piece for OCD is that we would not call something a disorder unless it significantly interfered with someone's life or caused a lot of distress, or it impaired them in any different domain.

If you hear someone saying, I'm so OCD, in all likelihood, they don't have that because it's not a pleasant thing to have. It's definitely nothing to brag about. I think you could brag about being able to successfully live your life despite having OCD, but it's not nearly having a few quirks or being a bit perfectionistic. It's this disorder that really significantly impairs individuals. In studies that have been done in the states, they have found that individuals living with OCD have lost three years of their work life related to OCD. This is not something to belittle or make fun of, and it significantly impairs a large chunk of our population.

00:04:32
Bryn Askwith: Dr. Stewart, I really appreciated how well you shared and separated out what OCD is and what OCD isn't. I know in a lot of my parenting circles, they will often say things like, well, kids really thrive on routine and my kids really do things in a particular way or have certain routines that they like to follow. I think it's really hard for parents. Sometimes they'll find themselves asking, is this typical behavior or is this something I should be concerned about? Is this OCD?

00:05:00
Dr. Evelyn Stewart: With toddlers, repetitive behavior and needing to do things a very specific way, or not having the potatoes touch the peas, for example, or a toy being totally ruined because it's directed a certain way, that's very normative. That's a normal development phase, developmental phase, needing things done in a very rigid way or done the same way every time. As any normal developmental phase, you grow through

that. For example, I don't think I've ever diagnosed a preschooler with OCD because what can be normative at one phase in life is definitely not in others. Really, we look at whether those thoughts and the behaviors are interfering with the child or youth best functioning in their life to their potential. If it's getting in the way of those things, that's when we start worrying.

00:05:57
Michelle Horn: Thank you so much, Dr. Stewart. Also joining us today on Where You Are, we have Jen, a mom of a youth who has been diagnosed and is living with OCD. Jen is a writer, teacher and creative director of a podcasting company and really knows the importance and power of sharing stories that matter and the connections that they can create. Jen, thank you so much for joining us on the show.

00:06:20
Jen: You're so welcome, Michelle.

00:06:22
Michelle Horn: Jen, hearing Dr. Stewart talk about what OCD can look like, can you share with us a bit about your child's journey living with OCD and what you first noticed?

00:06:32
Jen: Well, first of all, what Dr. Stewart's describing does sound very familiar with the intrusive thoughts. We've certainly been down that road a lot with my daughter. It took me a long time to understand what I was watching and what I was seeing. I think my daughter knew that there was something different about her thought processes from a young age. She was aware of feeling an inordinate amount of responsibility towards others' wellbeing and having these repetitive thoughts from she says around the age of five or six. I don't think I was aware of any issues until later grade school, kind of coinciding with pre- pubescent time. There's a lot of anxiety around that time, so again, you really don't know what you're looking at. It could just be anxiety. It could be I'm worried I'm going to go to high school next year. What's that going to be like?

What we started to see that finally raised the alarm for me was there had been some fires in our neighborhood, some tragic fires where there was loss of life. After those fires, my daughter started to feel like if she didn't unplug everything in the house, she was going to cause a fire. I thought, okay, I understand that you're worried and those fires were concerning, but it's an unusual response to feel like you have to run around unplugging everything all the time, especially before bed. She couldn't sleep. She'd go to someone else's house for a sleepover and they'd want to know why she was unplugging all the plugs before bed. I think that's when we realized, okay, whatever's

going on inside her mind is not comfortable and it's not something that she seems to be able to control. Then actually, really amazingly, she came to me and said, I think I need help. I don't know what to do. I'm miserable all the time. It was a very emotional conversation. I felt terrible for not having acted on it sooner, but I thought it was pretty amazing that she was able to articulate what was wrong and ask for help.

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Michelle Horn: Thank you so much, Jen. I think also you had a chance to talk to your daughter and have her record some of her speaking about her experience in her own words.

00:08:57
Jen: I did, yeah.

00:08:58
Michelle Horn: I'm wondering if we were able to play a clip now. I think we have one of your daughter speaking about her experience.

00:09:04
Jen: Oh, great.

00:09:07
Nora: It's very hard to describe. For me, most recently at least, it has been mental compulsion, so that can be going over something a lot in your head, like a memory or just reassuring yourself, but it's also just very annoying and it's very time consuming. I think that being alone with my thoughts was really hard. Actually, I think a lot of mental illnesses cause people to isolate, but I actually did the opposite. I was always out and I was always with people because I didn't want to think about things. It's kind of just a temporary solution to just be with people all the time. I would feel really guilty about things when I was younger, and I wouldn't really know why. I would be like, that's not actually a big deal, but I would feel the need to confess it all the time to my parents. I just always felt a really strong sense of responsibility for everything I was putting out into the world and everything I was doing, and an urge to get reassurance from the older people in my life that it was okay.

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Michelle Horn: Jen, just hearing your daughter speak, what's your reaction to that?

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Jen: I just feel so badly for her that she has... she's a great kid. Despite all of this, she does well in school. She coaches, she's artistic, she's a poet, she's athletic, she's kind, but at the same time, she's got this running track in her head telling her she's going to be responsible for the death of people that she loves. I can't imagine how difficult that is. It's very unfair that anyone should have to deal with that. Eventually the realization that I came to is that she's exhausted. She's a shell of her former self. She's not having a good time on planet Earth, and she's a teenager. Some of that journey is supposed to be miserable, but some of it is supposed to be great. I just wasn't seeing the great, and I think it's not fair. She's done everything that they tell you to do for your mental health and more and she's still really suffering. It's more than just adolescent moodiness. It's something else. That's when we finally started to investigate the possibility of medication.

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Bryn Askwith: You're listening to Where You Are. You can find all the resources in today's episode on our podcast page, keltymentalhealth.ca/podcast. Looking to learn more about OCD? Find information and resources at keltymentalhealth.ca/OCD.

00:12:26
Michelle Horn: That leads us to our next question in the podcast, where we're going to shift actually what helps manage the symptoms of OCD and what can be helpful for these children and youth. Dr. Stewart, we know that there are treatments that are proven to be helpful for children and youth with OCD, and we wanted to explore that a little bit with you today and talk to you about that. Before we do that, Jen's daughter also had some experiences to share about what has been helpful for her in managing her OCD symptoms, so we're going to listen to that clip quickly and then come back to you and speak to you more about what is helpful.

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Nora: I think medication is really helpful. Personally, I think that it just took the edge off. I definitely had to do a lot of work once I was on medication. It didn't just ultimately make everything better. I still had to do a lot of work on my own and with people and stuff, but I think that it definitely helped me a lot and it made it easier to do that work. Since it's such a relentless thing, it can get very tiring and it can be hard to do other things when you're thinking about something all the time. Something a therapist suggested to me was just putting a timer on for 10 minutes out of your day. Not much more than 10 minutes, but around that, and just using that time to acknowledge that you're worried and what you're worried about and how it makes you feel so that you're not fully pushing it down, because that doesn't help either because it's just going to come out in a more extreme way later on.

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Michelle Horn: Dr. Stewart, hearing Nora talk so eloquently about her experiences is amazing that she's so articulate about what she's experienced and what's been helpful for her. She mentioned a few things that helped her, including therapy and medication. Can you talk a little bit more about the role of both of these in the treatment of OCD?

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Dr. Evelyn Stewart: First, I'd just like to say to Jen, what you're sharing with us is, sadly, so common. Parents often feel so horribly that they somehow missed OCD. Something to know is that OCD is a disorder that kids and adolescents and adults keep secret, because very often folks who have OCD are just lovely, empathic individuals. They don't want to burden others. It's definitely not an indication of the relationship she has with you. It's really a characteristic of OCD itself. It's just so hard to live in a home where OCD is the boss, but that doesn't mean there's not hope.

In terms of the proven treatments, the first one is cognitive behavior therapy, specifically something called exposure and response prevention. That really, in essence, means challenging the OCD, not trying to distract yourself, like Nora described a bit, going out with friends, not trying to run away from it or please the OCD by confessing enough times, but by pushing back; doing what the OCD does not want you to do. Not running away from the thoughts and daring to maybe not apologize or to not say that prayer or to not do that thing again and again in one's head. It's not just sort of a magical thing.

I think of it like building a muscle. If you go to the gym and workout and lift weights again and again, you're going to see changes. Similarly, with OCD, if that youth or child is working on practicing again and again and again at pushing back on the OCD, not doing that ritual. We don't so much focus on trying to make those thoughts go away. We more focus on decatastrophizing their thoughts, but very often kids or youth may just feel overwhelmed. Then they think, that's looking up at a huge mountain that they have to hike and feel like it's absolutely impossible. I'm not even going to try. Forget it. It's just too much.

This is where medications can come in. There are medications called serotonin reuptake inhibitors that have been shown to be helpful. When I'm talking to families, I want to make sure that they know this is not going to change your personality. This is not to drug use, you're just too sleepy to do rituals. That's not at all what it is. It's not to make you something you aren't. It's to help you take back more what you are; that the OCD is taking less of that brain space. Rather than making that OCD mountain disappear, it makes it smaller. It makes it more like, ugh, maybe it's a hill. The notion of

taking it on through ERP, which again is that key piece, seems much more reasonable and less overwhelming.

00:17:28
Jen: I'm curious to hear you say that. I'm wondering, in your experience, are they normally on medication for the rest of their lives because it's a brain chemistry thing, or is it something that gets them over the hump?

00:17:47
Dr. Evelyn Stewart: Definitely not. I've worked with, gosh, hundreds of families impacted by OCD over the years. Really, as I'd mentioned before, a part of pushing back on OCD is believing you could do it and practice, and those brain changes that happen when you've had experiences again and again of pushing back of not doing that ritual. The medication can enable that experience to happen, but typically what I will say is if someone has OCD and then medication is helpful for them and it gets it under better control and if they haven't really had any impairing symptoms for, I'd say, between eight months and a year, then you can look at, okay, maybe we can see. For some youth or families, they'll say, no way. I'm never going off this. It's not causing side effects. Life is so different now. We're happy to stay on it. For others, would just rather not. They just don't like the feeling of being on medications, for example.

What I recommend is to do it in a planned way, rather than just letting a prescription run out and just stopping cold turkey. With OCD for sure, I think the chances for best outcome are just to decrease the dose a little bit once every month or two, see how things are going, and then to continue forward. I think doing it in a planned way and at a time when you're not already stressed. Very often for youth that could be during a summer would be a time to start decreasing the med dose. If some symptoms do come back, not a cause for panic. Then I think that's the time to try ERP. Try and squash them back down with the skills that you've learned before, but if even the ERP isn't working and it's just feeling overwhelming again, then that might be a signal that it's probably worth it to go back up on the medications.

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Bryn Askwith: Jen, like with many other mental health challenges, parents can play an important role in OCD treatment. What were some of the challenging moments for you when you were supporting your child at home during treatment and what helped you during those moments?

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Jen: Yeah. I think it's really hard to parent a child with OCD because you have to go against all your natural born instincts as a parent. When your kid is hurt, you pick them up, you dust them off, you help them. When they come to you with a question, you answer it. This is what parents do. They try to be helpful, they try to be encouraging, they try to be supportive. It's really hard and counterintuitive when a child comes to you for constant OCD driven reassurance about some irrational fear, like the plugs. Your instinct is to reassure, reassure, reassure, reassure, and then that's this weird cycle where... I love the phrase you're feeding the OCD, but that's essentially what you're doing. It takes a long time to figure out, okay, well what then do I do? I know I shouldn't feed the OCD, but do I just say, yeah, you'll probably burn the house down. No. What is the alternative? If you're not being encouraging, what are you doing? I think that what started to work for us was for me to say things like, that sounds like your OCD. You maybe just need to sit with this for a minute on your own, because you want them to go and find a way on their own. Maybe with the support of some of the therapeutic techniques that have been mentioned, but if you're just always propping them up like a crutch, you're not really helping them get over it or get through it in a meaningful way. You have to go against all of your instincts, so it's really hard.

00:21:43
Michelle Horn: Dr. Stewart, just listening to Jen speak and through all of your work with families and the research that you've done, what would you add to what Jen was saying about how parents can support their child at home and get through what I imagine would be very, very challenging moments?

00:21:57
Dr. Evelyn Stewart: Yeah. I think Jen described that so beautifully. I think it's some of the hardest things parents do, that we ask them to do. To get OCD, I think, is to understand that it's what used to be called the doubting disorder or the doubting disease. OCD hates uncertainty. It hates it. When children or youth come to parents, and that's a very common ritual, asking for reassurance, in the normal world, in the non OCD world, of course. It's a lovely empathic thing to reassure them, but if you're in the land of OCD, all that does is feed the beast. I think there's nothing wrong with assurance. If there's a whole new question, different theme and your child asks you something, great. Answer it, but if they come back a few minutes later or ask in the exact same way, that's a sign that may be a ritual. It's OCD trying to get that assurance again and again.

I think the way to manage this, as Jen said so hard, is talking about it outside of an OCD moment, getting a common understanding of what OCD is. When it's a calm moment, they'll say, okay, what should we do the next time OCD is wanting to take charge?

Maybe is it okay if we work together and I say, how about you come back in five minutes, for example? Or how about I give it the answer it doesn't want to have; the exact opposite thing it wants to hear? Then sometimes a child will give you permission to do that in the moment.

One of the most frustrating things that OCD does not want to hear is, maybe, maybe not, because that doesn't give any certainty. Often kids, even if the parent is trying not to be reassuring, the child can read their body language and be like, I know they love me. If they were really worried, I could see on their face right now. Even though they're not giving me what I want with the words, they're giving it to me through not panicking. I think for parents to talk with their child ahead of time, explain what they're doing, and then afterwards to say, that was really hard. It was hard for me to not give you the answer and I could see it was hard for you, but look, we did it. This is awesome. We're starting to take back our lives from OCD.

00:24:21
Jen: Yeah. I think that gets easier as your kids get older. It's easier to have those calm moment conversations that are constructive outside the OCD. We call them the OCD freakout times. Sometimes it's... I'm sure I'm very lucky that I have a window into my daughter's OCD, but a lot of parents, I think it must be stabbing in the dark.

00:24:43
Dr. Evelyn Stewart: Yeah. I think there's a couple of things parents can do just to just make it hard for them, hard for themselves. One is when there's an OCD blow up happening, trying to get the child to see what they consider common sense, trying to get them to understand it and work through it and all of that. When you're in an OCD moment, OCD has taken over. Trying to work through anything, that is definitely not a time. In the world of OCD, it can be different, but it's not necessarily the case that the parents need to know all of the details of the obsessions and so on and so forth, because it's not a disorder, this notion that, there's some deep dark secret, and if you could just pop the abscess and it's all better, it's not that at all.

You know what? Sometimes a thought is just a thought. How OCD works is it gets someone's attention by clunking a thought in someone's head that is not the thought they want to have. For intrusive thoughts, everyone's got random thoughts. Often I'm up at a height, I will often look over and like, what if I fell or what if I jumped? Does that mean I'm suicidal? No. The thought will just jump into my head. If I had OCD, having that thought could be highly distressing, but people have all kinds of weird thoughts. For most of us, fortunately, we can just ignore it and move on, but if you're someone who is

prone to be overly responsible, who has OCD, where those sticky thoughts don't go away, then it can be quite tormenting.

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Bryn Askwith: Jen, what have you found helpful for yourself in dealing with Nora's OCD? Have you ever attended a parenting group, for example?

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Jen: Honestly, what's helped me the most is my daughter because she has done so much research into her own condition that she has educated me. I actually haven't done a parenting group because I've had a daughter who basically told me, this is how you should parent someone with OCD. I'm really, really lucky, but I have other friends whose kids are struggling with it. It's more common than you think. They have told me that parenting groups, to learn a few tactics for exactly what we were just talking about, like how to help your child without feeding the beast of OCD, just learning to walk that line has been helpful for them, and that's been helpful for me as well. Understanding that there's not a root cause per se necessarily. It's not necessarily a big, deep, dark secret that if we could just... that's the perfect analogy. Pop the abscess. It would all be psychologically better. It's not that. It's learning to manage a condition.

I think time and watching her grow up has been helpful. If anyone's just going into the funnel of OCD with a younger teen or something like that, there's definitely progression as they mature. I think that's helpful if you get them the help and support them. Then for me, conversations like this, just talking about it with people who know a thing or two about it was super helpful and just de- stigmatizing it and understanding... it's great to hear that it's not necessarily going to plague her for the rest of her life, because I know there are adults that suffer terribly with it. It's a possibility that it can last a long time. It's great to hear that it's not necessarily a foregone conclusion. I think that's important. That's very helpful.

00:28:23
Dr. Evelyn Stewart: Yeah. Something I'd really like people to take home after listening to this is that there is so much room for hope. 50 years ago, I think having OCD, kind of a different scenario, so I'm fortunate to be in a lifetime where I've been able to help contribute to this somewhat. We know there's approaches that really work. The other thing, Jen, is that one of the best predictors for good long- term outcome is early intervention. I think a lot of those adults who are suffering with OCD may have not been diagnosed when they were a kid, and they may have had years and years and years of reinforcing and building up the OCD. If you have a child or youth with OCD, I'd really encourage you to consider trying to seek help. If you're not able to access it, there's

resources out there, such as the Kelty Mental Health Resource Centre, where there's big lists, and you can start to plug away at it. Just hearing what you've shared, I think Nora has a fantastic prognosis.

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Jen: Thank you. I do too. I do too.

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Michelle Horn: Well, thank you so much Dr. Stewart and Jen for joining us today. We usually end each episode with just asking our guests to share their final thoughts or words of wisdom to our listeners. Dr. Stewart, you brought us very nicely into that question by providing some of what you wanted listeners to take away from this, but Jen, is there anything you wanted to add as your final thoughts or words of wisdom? Then Dr. Stewart, I'll give you a final chance if there's anything you wanted to add.

00:29:59
Jen: Well, I'm trying to work on being careful around the casual pop culture version of OCD, because it's really hurtful to my daughter when people come in, they're cleaning the living room, they go, Oh my God, I'm so OCD or whatever and they're just tossing the term around and it belittles the really serious struggle that she's been having. I'm trying to be cautious around differentiating and not using the term lightly. I've come to understand it as a really formidable foe that needs full cooperation and help, and if you fight fire with fire, you'll be okay, but if you just minimize it, it can get worse. That's what I would say is just to not minimize it. Get them the help and then you probably will see good results. We've definitely seen really big improvements.

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Michelle Horn: Thanks so much, Jen, and Dr. Stewart, anything you wanted to add?

00:31:02
Dr. Evelyn Stewart: I guess just to reiterate, there's so much room for hope. OCD makes it seem that it's going to win. A family can always win when it comes to the battle with OCD, and pushing back is possible, so just keep on trying. It really is phenomenal what could happen, actually not buying into what OCD is saying and as a family working together.

00:31:30
Michelle Horn: Well, thank you so much to both of you for joining us today. I learned a lot in this episode and it was just great to have both of you join us.

00:31:37
Jen: Thank you.

00:31:37
Dr. Evelyn Stewart: Thank you.

00:31:47
Michelle Horn: Bryn, it's been great co- hosting this episode with you. Thank you to all of our listeners. This episode of Where You Are is brought to you by the BC Children's Kelty Mental Health Resource Centre.

00:31:56
Bryn Askwith: Our show is produced and edited by Emily Morantz, with audio engineering by Patrick Emile and Sam Seguin. Audio Production by JAR Audio.

00:32:05
Michelle Horn: If you enjoyed this episode, please leave us a rating wherever you might be listening now.

00:32:09
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