

# Where You Are

## S6 Episode 4 — Tics and Tic Disorders: Questions, Myths and More

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**Lesley:** My experience was I didn't know. I didn't have the answers. Having a child with Tourette syndrome is not something I've encountered really that often in my own life. And now I can work as an advocate for him in order to help him as well as have a lot of open and honest conversations so that he can self-advocate as well.

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**Char Black:** This is Where You Are, a podcast that helps families and their children promote their mental health and wellness. I'm Char Black.

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**Bryn Askwith:** And I'm Bryn Askwith. At BC Children's Kelty Mental Health Resource Center, we get requests from families for information and resources on a variety of mental health topics. In this episode, we're excited to be exploring a topic we have yet to cover on our show. Today we're diving into tics and tic disorders.

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**Char Black:** In today's episode, we'll discuss what tics and tic disorders are, common questions and misconceptions about tics, treatment options for tics and when to seek help, and challenges and learnings from a parent's own experience supporting her son with Tourette syndrome. Let's get into that conversation.

Our first guest today on the podcast is Dr. Melanie McConnell, a registered psychologist with nearly 20 years of experience providing education and clinical treatment to children, youth and adults living with tics. Welcome to Where You Are.

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**Dr. Melanie McConnell:** Thanks so much. I'm so excited about the opportunity to participate in this podcast. Working with children and teens and parents as well as adults with tics is one of my very favorite professional activities to do.

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**Char Black:** Wonderful. Dr. McConnell, can you start by explaining what tics are and what is the difference between tics and tic disorders?

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**Dr. Melanie McConnell:** So tics are sudden repetitive movements, such as rapid blinking or neck twitching or sudden repetitive sounds, so clearing your throat over and over or making other vocal noises repeatedly that are not done on purpose. There are a number of different tic

disorders. Many people have heard of Tourette syndrome, which is also called Tourette's disorder, which is diagnosed when a person has both motor and vocal tics for more than a year. The tics don't have to have been present continuously over the course of that year. They can come and go. But it's part of a group of neurological or brain-based conditions that are characterized by tics.

So this is this broad sort of umbrella term of tic disorders. And other tic disorders include chronic motor or vocal tic disorder. And sometimes people hear about provisional tic disorder, which might be diagnosed when tics have been around for less than a year. I think it's really useful to keep in mind that these diagnostic categories are really just they're labels based on the type of tics that are present. And for some people tics might be really mild, so mild that they hardly notice them and they don't interfere with daily life at all. And for others, can be a lot more noticeable or disruptive and sometimes quite distressing.

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**Char Black:** Thank you. Dr. McConnell. Can you speak more about what causes tics?

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**Dr. Melanie McConnell:** The exact cause of tics and tic disorders is actually not fully understood at this time. So scientists have certainly found that tics tend to run in families, so there's a genetic connection for sure. And there may be other contributing environmental or developmental factors, but scientists are really still kind of trying to sort that out. On a neurological or kind of brain-based level, tics are linked to differences in the way that the brain processes signals, especially in the areas of the brain that are involved in controlling movement. And most adults and many older children and teens with tics will describe feeling like a really uncomfortable urge or tension build up often in their body before a tic happens and then there's a relief from this really uncomfortable urge when the tics happen. Scientists call this the pre-monitory urge, but in treatment we usually just call it a tic signal.

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**Char Black:** Thank you so much, Dr. McConnell. You did speak a little bit about the different types of tics as well as ones that were more motor-based versus vocal and the certain lengths of time that you described. When should parents or caregivers talk to a health professional?

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**Dr. Melanie McConnell:** When tics are mild, not bothering kids or teens or the individual much at all, we don't need to do anything about them. They're not dangerous. They're just little blips that we really don't need to be too concerned about. It's only when tics are causing significant difficulty with important aspects of daily life that we want to do something about them. So if kids are finding that they're very distracted from doing their schoolwork or reading, if kids are really bothered by tics, if they find them annoying or embarrassing, if tics are causing a lot of muscle tension or pain or a sore throat or these kinds of things, that's a sign that we probably want to be looking into options for next steps. If tics are causing a lot of stress in the family because people aren't sure what to do about them or it's very challenging to even sit down and do

something basic like have a family meal together because tics are so disruptive, then that's a time when we would want a family to be getting some support and some intervention.

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**Bryn Askwith:** I also want to bring into the conversation Lesley. Lesley is a mom of four children, one of whom has Tourette syndrome. She's an inclusion support teacher in the Lower Mainland, where she works passionately to support students with disabilities. Lesley, welcome to Where You Are.

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**Lesley:** Thanks so much for having me.

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**Bryn Askwith:** Lesley, can you tell us about your own experience with your child's Tourette syndrome?

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**Lesley:** Yeah, absolutely. So our journey with Tourette Syndrome started when my son was about eight years old. He started with a throat clearing tic that came on pretty suddenly and was fairly intense for a long period of time. We weren't sure what it was and kind of went down the avenue of exploring, "Is this allergies? Is this something to do with stress?" We were referred to an ear, nose and throat doctor and we ruled out that it wasn't anything medically affecting his ear, nose and throat. And starting around Grade 3, his tics started, and he is now almost 19 and they are still around.

The throat clearing tic has stuck. It's the one that we can tell his level of stress. If there's the highest level of stress for him, the throat clearing tic comes back. And stress being stressed and excited, excited about an upcoming holiday or it's something that he's super looking forward to, the throat clearing tic will increase. But also stress from peer relationships and stress from everyday life and those sorts of things definitely impact that. The impact for him mostly is that his throat clearing tic and the tics with more facial involvement have actually impacted his ability to communicate clearly with adults and peers because when he starts to speak, his throat clearing tics often will take over, so it just takes a little bit of extra processing time for him to get his words out.

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**Bryn Askwith:** Lesley, can you share what your experience was like connecting with professionals for your son and also what supporting him throughout this process was like for you as a parent?

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**Lesley:** My son had been followed by pediatrician from about the age of three just for some other stuff that was going on. When this tic started in Grade 3, we absolutely kind of jumped on investigating, "What does this mean? What's going on?" The very first person that we went to

after we'd seen the ear, nose and throat doctor, was a psychiatrist. We went and it was like, "Well, why are you here?" Because we arrived to an appointment, he was calm, there was no tics, and we were kind of like, "In the future, come back if this as a concern." We started noticing them at the beginning of Grade 3 and he was not officially diagnosed with threats until Grade 7. My experience was I didn't know. I didn't have the answers and this was something that was new.

To be perfectly honest, having a child with Tourette syndrome is not something I've encountered really that often in my own life, professionally or personally. And I think that that has an impact too because it felt lonely. It felt like no one got it. Teachers hadn't experienced this as well. Kids have lots of questions, adults have questions, and I didn't have all the answers. I've done a deep dive into research and trying to figure out the best way possible to support him and understand. And checked all of the boxes to being able to say, "I've got the information and now I can work as an advocate for him in order to help him work through the challenges that Tourette bring for him."

As well as we've had a lot of open and honest conversations, like our family and him, so that he learned how to self-advocate as well. And so we've had to do a lot of explaining, just kind of giving the schools and other people and parents of who he's been involved with the most information we possibly can has really helped him. All of that, of course, is done with his permission. I don't share his story without asking. But he is generally really willing to have that shared so that people can have a broader understanding of what he's dealing with.

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**Bryn Askwith:** Lesley, I love that he's at a point where he can have language to be able to answer questions that might be coming his way. I think that's really something so powerful for youth and where they're at. And I know that's something that will resonate with a lot of the families listening to this podcast.

Dr. McConnell, how is a tic disorder diagnosed and what can families typically anticipate in that process?

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**Dr. Melanie McConnell:** So I think if parents are noticing some repetitive movements or sounds and they're not sure what's going on or they suspect maybe these are tics, the first step really is to consult with your child's primary care provider. You'll go in, you'll describe the symptoms that you're seeing. It can be really helpful if you can have a little video of what you're seeing or hearing so that you can show your practitioner because frustratingly, as Lesley described, sometimes when we get in front of the person who's supposed to be providing us with help, the tics just completely settle down. And so then you've got a little bit more detailed information that you can share with your primary care provider.

They'll look at the family history to see if there's an increased likelihood of tics. They'll probably do like a neurological screening exam to rule out any other possible causes for tics. As Lesley

described, they may suggest seeing some other specialists. Your primary care person is usually the first place you'll go. Sometimes a primary care provider will refer a family on to a pediatrician for a more thorough assessment. That's not something to be concerned about. But in those early days, there's not always a need for additional assessment. Not every kid with tics needs a thorough neurological assessment at the hospital. Sometimes all we need is just to have a look and watch over time.

One of the things that can be puzzling and a little bit tricky in the early days as you're trying to understand what's going on is that tics naturally go up and down. They call it waxing and waning and they change over time. And so we need to wait and see how things are going to progress before we really know whether tics are going to be troublesome for a young person. It's also very common for tics to come on the scene in the early elementary years for a short period of time and then go away altogether. People call those transient tics. So that's one of the reasons that families often get that just wait and watch kind of approach, because we can't predict which tics are just going to go away on their own over time and for whom they're going to carry on.

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**Char Black:** Thanks, Dr. McConnell. Lesley, I want to go back to you. You did describe earlier a few things around how tics impact your son's daily life. Is there anything else that you want to share in terms of describing some of these challenges at home or at school that you haven't already shared?

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**Lesley:** I would say at home there's not a ton of support that he's needed. He's accepted for who he is here and my other kids just know that that's part of who he is. We have lots of open conversations with our family and our kids and our kids' friends and their parents just to sort of say, "It is what it is," and to, "Ask the questions." In terms of where it's hard was school. Elementary school was okay. We were able to advocate for really good support systems, create environments that was really lower stress. High school was hard. Kids didn't understand and he got made fun of a lot and picked on by people who didn't really understand and weren't given the opportunity to understand.

My voice was smaller in high school. I was able to have a lot of advocacy pieces in elementary school, whereas not so much in high school. It's a bigger environment, I suppose, and just a lot more kids to encounter and you don't know the parents of everybody as well. Peer mediated interventions and supports would've been really helpful for him, just so that people understand like, "Hey, this isn't something he can help." And so I am a very strong advocate for ensuring he reaches success in the best way possible that makes the most sense for him because. My idea of success for him may be different than his idea of success for himself. And so he is super okay with his peers knowing and is willing to have those conversations. But just making sure that the information provided back to peers is also safe and things that he's kind of said, "Hey, yeah, that's accurate about me. I'm willing for that to be shared back out."

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**Char Black:** You are listening to Where You Are. I'm Char Black. To learn more about tics and tic disorders, including resources that can be helpful to parents and caregivers, visit our website at [keltymentalhealth.ca/tics-tic-disorders](http://keltymentalhealth.ca/tics-tic-disorders).

Are you busy and perhaps overwhelmed supporting your child's mental health and wellness and can use someone to talk to who can relate? Contact a trained Kelty family peer support worker who can offer a non-judgmental listening ear and connect you to mental health resources in your community. Connect by phone, email, or via Zoom. Find out more at [keltymentalhealth.ca/contact-us](http://keltymentalhealth.ca/contact-us).

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**Bryn Askwith:** Dr. McConnell, I want to do a bit of myth busting. So can we talk about common myths about tics that you hear from families and maybe you can debunk maybe two or three of those from our listeners and offer some strategies that might help?

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**Dr. Melanie McConnell:** For sure. One of the myths that we often encounter is that tics are very unusual and very uncommon, and people are often quite surprised to find out that they're a lot more common than many people think. Transient tics is tics that might come briefly during childhood and then go away after a few days, weeks, or months. They're especially common in childhood. So research suggests that up to about 20% of all school-aged children will experience tics at some point during their childhood. And current estimates, at least in North America, suggest that about one in every 50 kids meets diagnostic criteria for a tic disorder, and about one in 100 kids have Tourette's. So it's actually much more common than we might think.

Another quite common myth that we encounter is this idea that if a child is experiencing tics, they must be highly, highly stressed or they must have encountered some really traumatic life experience that's causing that stress or anxiety to be displayed in the form of tics. It's a little bit confusing sometimes the link between stress or anxiety and tics. While it is true that anxiety can make tics worse, there's actually no evidence that anxiety or stress or trauma causes tics to start in the first place.

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**Bryn Askwith:** Lesley, any myths that you would like to debunk?

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**Lesley:** I think for me, one of the myths that we've had to dispel as parents is tics is not what you see in the media. It's not accurately portrayed in the media. Often it's like a more severe case. Whereas some of them can be quite not obvious to someone who didn't know. And there's oftentimes where my son has tics that I see that no one else would. His tics aren't always present. That's another piece that people don't understand. And we get questioned a lot about like, "Well, why can't you just turn them off?" Or people are like, "Can't you just stop that?" We know that we can't ask him to stop because we actually know that that just increases his stress and then it just makes them more prevalent in those moments.

But my son's a performer and it is astounding to watch him on stage. He plays musical instruments, he sings, he performs in theater. And when he's on the stage, he would absolutely have no idea that he has Tourette syndrome. But then he comes off stage and has a whole moment of getting all of his tics out, and then he goes back on stage. And if you didn't know, you wouldn't know. So those are high stress things, but they feed his soul. So in those moments, he is able to kind of manage them a little bit better. But he can't just turn them off when people ask him to turn them off. And I think that's one of the things that has impacted him a lot too, is people just asking those questions of, "Why don't you just stop?" But you can't, right?

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**Bryn Askwith:** That's a good myth to dispel for sure.

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**Char Black:** And I want to go back to Dr. McConnell. What types of treatment options are there for tics?

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**Dr. Melanie McConnell:** If you look at the standard treatment guidelines and best practice guidelines, they all really converge on sort of three different pieces. So first, when tics are in the picture, we want to make sure that parents are accessing accurate science-based information. There's a lot of sensational stories on the internet that can be really alarming and confusing. So I think really the first step is we encourage parents to seek out reputable information that's backed by scientific research and endorsed by medical experts. And for folks who are not experiencing much day-to-day impact, that's all that's needed. If individuals are struggling with tics impacting their day-to-day lives, then the next step that we want to do is add onto that education and information evidence-based psychological or behavioral treatment.

So comprehensive behavioral intervention for tics is a form of cognitive behavioral therapy that's in repeated studies been found to be effective for the majority of people who participate in it, and it's considered the first line treatment. So comprehensive behavioral intervention for tics, or CBIT, involves two main parts. So one is figuring out what seems to trigger tics or make them worse and trying to minimize those triggers or problem solve around how to reduce the impact of those triggers. And identifying what we sometimes call tic tamers or those things that tend to calm tics down. And then the second part is called habit reversal therapy or habit reversal training. And this is where we teach people to become more aware of tic urges and when tics are happening and teaching people how to identify and do a certain type of competing behavior that can help to block tics.

And while CBIT is not a cure for tics or a tic disorder, it does teach management strategies, tools to use to minimize tics and their impact when they're bothersome. If behavioral intervention, if CBIT is not effective and folks are experiencing quite severe impacts from tics, then another treatment add-on can be medication. And there are some medications that can

help with managing tics. They aren't cures, but they can certainly be helpful. Ideally if a medication is on board, it's happening along with behavioral interventions.

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**Bryn Askwith:** Lesley, in terms of treatments of Tourette syndrome, was there maybe one thing that was helpful that you noticed as a parent or caregiver that helped you or helped your son?

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**Lesley:** So we have done all of the above that Melanie has suggested. He did CBIT twice. Once was when he was quite young and he wasn't ready. He did it again later as a teenager, but it was in a really high stress situation. So we turned more to supporting him with counseling and psychology just to work through the harder pieces, how he was being treated by peers. The support team that he had, just with the mental health professionals that we've seen, has definitely been instrumental in his success and just his understanding of who he is as an individual and just allowing him to have the supports that he needs and the people that he can reach out to as well as the people that we can access to make sure that we're all on the same page about the best ways to support him where he's at right now.

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**Bryn Askwith:** Oh, Lesley, thank you so much for sharing that piece of your journey and your story. And I can very much see the sense of pride that's coming through in your tone as you're sharing it with us. So thank you for that.

One thing we always like to ask on our show is helpful resources that we can be sharing with parents and caregivers. So Dr. McConnell, are there one or two resources that you would recommend for parents or caregivers supporting their child with tics?

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**Dr. Melanie McConnell:** Yeah, the most helpful resource is the Tourette America website, which is all science-based and reviewed by medical experts, and there's sections for individuals experiencing tics, family members, and also clinicians and medical professionals. So that's my number one go-to place. And they've recently added a lot of really helpful video resources. If you're not able to access a parent workshop or a group for youth in your area, you can still sort of have some aspects of your experience reflected back in some of the videos and testimonials on that website. So Tourette America is sort of our main go-to resource.

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**Char Black:** Wonderful. Thanks for sharing that, Dr. McConnell. And for Lesley and Dr. McConnell, this has been such a wonderful conversation, we always like to end with some final words of wisdom that you'd want to share for our listeners. So maybe Lesley, what would you want to share and what would be helpful for other parents and caregivers navigating a similar journey as yours and your son's?

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**Lesley:** I think primarily would be surrounding yourself with who get it, listening to your gut as a parent and knowing that seeking answers and support is always okay. And not being afraid to advocate because there's always people who aren't going to get it, and it's our job to make sure that we are the voice for our kids while they're still learning about their journey and their story. And just making sure to find the safe people to have those conversations with, whether it be professionals or friends, but to be making sure that your support system is there and strong.

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**Char Black:** I love that, Lesley. Dr. McConnell, do you want to share any final words of wisdom for our listeners?

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**Dr. Melanie McConnell:** I think the most powerful thing we can do as parents is create a supportive, understanding environment where our children feel genuinely accepted and truly loved exactly as they are. I want to leave folks with a message of hope and encouragement. Remember that tics are just one part of who your child is. They don't define their potential, their character, or the incredible things that they're capable of achieving. So focus on your child's strengths and what's going well for them, what they're passionate about and their potential. And know that support and treatment, while they may be challenging to find, they are available.

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**Char Black:** Wonderful. I think we want to end there because how could you end any better than that, right? So true.

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**Bryn Askwith:** Thank you so much, Lesley and Dr. McConnell for your time today. I really appreciate you both sharing information, and you, Lesley, around sharing your story. I think it'll be really impactful for our listeners.

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**Lesley:** Thank you so much, Bryn and Char and Dr. McConnell for including me in this conversation. Thanks so much for the opportunity.

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**Bryn Askwith:** Thanks to our Where You Are listeners for tuning in today. We're grateful to have you join us each episode.

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