

# Classroom Adjustments: Tourette Syndrome

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Robyn Latimer:	I think the biggest misconception is that Tourette's is bad behaviour. Or the second one is that it always involves swearing or the tic called Coprolalia, when in fact that tic only presents in less than 10% of people that have Tourettes.
Serpil Senelmiss:	I've got to be honest, that's what I thought it was for a very long time and I suspect most people would too.
Robyn Latimer:	It's what is mostly shown in the media, but it is obviously a very difficult anti-social stigma to have for those that do experience it and particularly in the education setting amongst young children it can cause a lot of isolation, not just for the child, but stigma around the whole family.
Serpil Senelmiss:	There's nothing quite like getting the misconceptions out of the way early. Hi, I'm Serpil Senelmiss and this podcast is part of an NCCD portal series. In this episode we'll get an accurate explanation of what Tourettes syndrome is and we'll discuss some adjustments that could be made in the classroom to enable students with Tourettes to participate on the same basis as their peers. You'll hear from the president of the Tourettes Syndrome Association of Australia and a teacher who has worked with a number of students who have Tourettes. And I'll introduce you to Scott and his 11 year old son Mark, who explain that the tics can be a challenge, but it's the anxiety that creates the greatest learning challenge.
Robyn Latimer:	Hi, my name's Robyn Latimer, the President of the Tourettes Syndrome Association of Australia. Tourette Syndrome is a neuro biological disorder, so it's genetic. Its symptoms involve both motor and vocal tics, and importantly they have a natural waxing and waning variation in how it presents. And the tics are described as rapid, repetitive, involuntary muscle movements and vocalizations. It can often involve behavioural difficulties and often also has a lot of co-morbid and associated conditions that come alongside those tics of Tourettes.  Dysgraphia is very commonly one of the associated conditions with Tourettes syndrome. So problems with handwriting, and note taking and sequencing is very common. Attentional difficulties with ADHD that often comes along with Tourettes also adds to that and compounds the issue. Skill gaps for most students with Tourettes involve organization, so things like sequencing information, being able to organize their thoughts and stay on task.
Serpil Senelmiss:	Robyn's going to give us some great insights into Tourettes syndrome and some valuable ideas for classroom adjustments. But first, I want you to meet Malia Story, who's a primary school teacher working with students who have Tourettes. Like Robyn, she recommends distributing notes for students wherever possible.
Malia Story:	So printing out those notes at the end of the day, you've already got it on your screen, is a very easy process to do and handing it to the student, or emailing it to the parents for younger students and saying, "This is what we talked about today at school. These are the notes we had. You might like to recap because

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	your child was out of the classroom having some time out,” and that is also increasing that communication with the parent at home, which I think is really important.
Serpil Senelmis:	The reason they may have been out of the classroom is to help them manage a tic. And while it's not always about involuntary swearing as is often depicted in the media, one of the challenges of Tourettes is that tics can take many forms and often appear without warning.
Robyn Latimer:	Tics are triggered by many, many different things. One of them we know is environment. So there's tics that are called Echolalia and Echopraxia tics. So a student might meet someone on the weekend that somehow triggers some kind of tic that echoes something they've seen or heard. So that could just then be retained for a period of time. It might be retained for one or two weeks, it could be retained for six months, there's no telling.
Serpil Senelmis:	So how can a teacher plan adjustments around a condition that can be so unpredictable?
Robyn Latimer:	Because the symptoms can vary enormously, the list of tics is huge. It is difficult for teachers to prepare in advance a lot of the time when tics change. However, there's some very general adjustments that can be made that would affect all types of tics, just general things to reduce stress, reduce anxiety and lower those levels of concern for the student. We know that stress is a trigger for tics, whatever their tics are, so anything to do to make the child feel more welcome or accepted and also importantly able to tic in a safe environment because they must release their tics, they can't just hold them off, they will eventually appear. That could be having tic breaks, some kind of signal between the teacher and the child pre-established, and building that rapport of trust and true acceptance from the teacher is really important, because that cues the acceptance from the students in the class setting as well. They will follow suit.
Serpil Senelmis:	For some students it can be beneficial to establish a safe place, but it really depends on the individual. Robyn suggests discussing possibilities with the student to collaboratively agree on what would help them feel most comfortable.
Robyn Latimer:	It may be a safe place to go in the corner of the room at the back so they're not seen and visible by the other students. It may be preferential seating being near the door so it's easy for them to leave quickly, so that if they have very complex motor tics or loud vocal tics, they're able to step outside to release those tics if they feel the urge coming on. Young children and some older children don't get an urge as well, it can just appear and they have no warning.
Mark:	Hi, my name is Mark. I'm 11 years old, turning 12 and I'm in year six.
Serpil Senelmis:	Tell me a little bit more about Tourette Syndrome. What does it feel like? How does it affect you?
Mark:	I don't know how to describe it feeling like, but it affects me randomly.
Serpil Senelmis:	If you were to explain it to your friends, what would you tell them?
Mark:	It's stuff that I can't help doing because my brain is so fast that I just can't help it.
Serpil Senelmis:	I love the way Mark describes his tics as random. While it might sound like a throwaway line, Mark's dad, Scott agrees with the randomness of Mark's tics. When the tics first emerged, they created a lot of confusion for Mark's parents and the diagnosis of Tourette syndrome didn't come easily.
Scott:	We initially thought maybe some sort of epilepsy and that was ruled out, had numerous tests and poor old Mark went through a battery of all sorts of

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	appointments to find out what was going on, we just didn't know. Started with his eye rolling and then he would spin, sometimes for up to 40 minutes without getting dizzy, but he actually fell over in a shopping centre and broke his front teeth and then his arms started to flail about and we became more and more concerned. Tourettes is so interesting in its variability. It's very difficult to determine whether something is behavioural, or some sort of tic, or anxiety, or OCD or whatever.
Serpil Senelmis:	Mark, can you tell me specifically how it can affect you at school?
Mark:	It makes me not do my work. It makes me anxious and want to go home.
Scott:	So Mark can be incredibly anxious. He can get so anxious, he doesn't even know who we are and becomes very distressed. That's really difficult.
Serpil Senelmis:	So one of the key adjustments for Tourettes is to reduce that anxiety. Tourette Syndrome Association President Robyn Latimer suggests using a little bit of creativity to help students manage their tics discreetly.
Robyn Latimer:	If they've got tics that involve wrist and hand movements, things like stress balls, put an elastic band on their wrist and they can flick the elastic band to help relieve some of that movement. There's a lot of those fiddly toys, you can get spinners and things like that. Keeps that restlessness busy so that then they can focus on what the teacher's saying because that's done as an auto movement, they're not focusing on that at all. Or it might be having something sensory in their pocket that's soft and furry. So if you can do things where they can stay busy but it doesn't disrupt the rest of the class, that can help the child and the whole class.
Serpil Senelmis:	As a teacher, Malia Story emphasizes the importance of acknowledging Tourettes as a neurological disorder with tics that are involuntary.
Malia Story:	I think the first learning challenge for a child with Tourettes is that people don't identify with the condition. It tends to attract negative attention from others. The child then can react to that in a number of different ways. They can be isolated, they can lash out and become disruptive, they can become withdrawn and I think it's about the educator and the community starting to understand that every child has a different set of consequences because of it. Through verbal, to physical, to withdrawn and I think that is their biggest challenge is us really understanding the individual with Tourettes, and not trying to put a band-aid on it and saying, "Well Tourettes is tic and it's the child calling out and saying inappropriate words." It's actually a lot more than that.
Serpil Senelmis:	So once we recognize that the tics are involuntary, we can move on to helping students to manage those tics.
Robyn Latimer:	Regular tic breaks are really helpful. Allowing a lot of movement for children to walk around, using children for delivery of notes and errands because they get to have that movement aspect and at the same time they feel important that they've been given a job and they feel worthy, so it helps their self-esteem. You tend to find that they need to have more breaks because a little bit of physical movement often allows them an opportunity to come back into the learning environment with a refreshed approach.
Serpil Senelmis:	Robyn from the Tourette Syndrome Association explains that the wax and wane means that new tics may develop an old tics that you've made adjustments for may disappear.
Robyn Latimer:	Tourettes has a very particular part within it called waxing and waning cycles, which is very unique to Tourettes, which means something that you've set up in

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	three months' time mightn't be required anymore because the symptoms have changed and the waxing or waning periods have changed.
Serpil Senelmis:	Can you tell me about the way that Tourettes effects you on an average week?
Mark:	That's hard because sometimes it's just not there, sometimes it's everywhere, there is no average.
Malia Story:	We know that Tourettes can wax and wane in the severity of their tics and their condition. So we might have allocated 11 o'clock on a Monday to do a maths test, but that may in fact be the worst time for that child to do it, and use resources within the school to gain some support to be able to do that at one o'clock or later on in the week when that student really needs to.
Serpil Senelmis:	Tourettes has a habit of bad timing. It can make it difficult for students to shut down and get to sleep at night, impacting on their circadian rhythms. For Mark, this also makes it difficult for him to stay asleep.
Mark:	I just wake up really early sometimes and I go on the trampoline because it feels good.
Serpil Senelmis:	What's really early?
Mark:	Like 4:00 AM.
Serpil Senelmis:	So you're on a trampoline at 4:00 AM?
Mark:	Yeah.
Scott:	The Tourette seems to take over and remove any normal expectations around what most people would experience. So he's been at times up all night and then continued all day as if nothing had happened, full of energy bouncing around in those periods where the Tourette's has been particularly vicious. And then at other times he is fine, you can't even tell he's got Tourettes at all.
Serpil Senelmis:	So for teachers, one of the first adjustments for students with Tourettes is patience. With disruptive sleep and disruptive tics, they may not be able to comprehend information the first time they hear it.
Robyn Latimer:	For an average child, it might take three times to say something for the information to go from short term to long term memory. For a child with Tourettes and attentional difficulties associated with it, it might take 30 to 50 times for that same information to go from short term to long term memory, and just knowing that really helps family members and educators with tolerance levels and the ability to repeat and repeat.
Serpil Senelmis:	What are some examples of adjustments the teacher could make to reduce overall stress in the classroom?
Robyn Latimer:	To ensure everybody knows what's happening throughout the day, so there's no anxiety about what's coming up. Children with Tourette syndrome often don't like change and transitions, so if they're prepared well in advance, that reduces their stress and anxiety.
Malia Story:	Yeah, I think it's very important to have a routine in the classroom that a student with Tourettes fully understands that on a Monday, Tuesday, Wednesday and Thursday, this is what we're basically going to do. It's fairly similar across the days.
Serpil Senelmis:	And in addition to a routine, it's a good idea to provide plenty of information and guidance about what's coming up next.
Robyn Latimer:	Transition morning is another really big one, so if you're going to be stopping an activity in 15 minutes to prepare to leave to go to assembly or some other activity, give those time warnings. And also chunking information is a really big help for children with Tourettes. Expecting them to follow three or four instructions in one go may be too much for them.

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	<p>Yeah. Can you get your book out now? A direct question because a Tourettes student can often find that organization quite challenging. So you need a lead pencil, you need your writing book, not just we're doing writing and everybody gets it out. Sometimes they need that very direct question. The next would be allowing time to get organized and to get through tasks. I think that that's really important. It's not a course on limited time, but sometimes that thinking process takes a little bit longer.</p>
Serpil Senelmiss:	<p>Teacher Malia Story has found that adjustments to the classroom layout and seating arrangements can be effective in reducing stress for students with Tourette syndrome.</p>
Malia Story:	<p>Classrooms are very busy. I can have 30 plus children in them that all make noise and move about, but it's about the way you set up your desks. The rows aren't going to really do a Tourettes child because people will be bumping into each other. Small groups of tables are much nicer that they had some space around them. Setting up quiet areas in the classroom that they can have space to time out is very important. Preferential seating, it could be down the front to avoid distraction for one child. However, for another child with Tourettes, if they have a very sensitive ego and low self-esteem, they might prefer to sit at the back because they might feel highly exposed at the front, so it's about finding what's right for that student.</p> <p>A lot of students find having a safe space and a bean bag, for instance, in the corner of a classroom where they might have some headsets to put on to remove a lot of the sensory stimulation of the classroom setting helpful. It might be listening to music and that that music can be on in the background while they're actually reading or doing some work that they need to do to remove the other stimuli from their setting.</p>
Serpil Senelmiss:	<p>To make safe spaces work effectively, Malia recommends taking a whole of school approach to the support and supervision of students with Tourettes.</p>
Malia Story:	<p>Set up a space in the school because you've already communicated with the school community, they're all on board. It might be sick bay near the office, that if they're feeling like they can't control that tic, that they've got a space that they can go to that may be out of the classroom, where they can go and have some space where they don't feel they're being watched or listened to and they know that they can go there, and whoever's receiving them at the other side knows exactly what is happening at that time.</p>
Serpil Senelmiss:	<p>It's this sort of trust and full school supervision that Mark enjoys with his teachers and support staff.</p>
Scott:	<p>He tends to be triggered by school hall for some reason, so if he's in the hall, he has teachers nearby who'll assist him if starts to feel anxious and tic pretty badly and they'll take him out and just walk around a little bit until he feels better.</p>
Serpil Senelmiss:	<p>For Mark's teachers, it's less about controlling his behaviour and more about supervising him safely.</p>
Scott:	<p>I think the most successful adjustment is responding to how he is at a particular moment, so that could be just letting him spin, or somersault, or whatever's required, or it could be allowing him to move around the classroom or even outside the classroom so that he doesn't feel constrained, which in turn increases the tension and increases the tics.</p>

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Serpil Senelmis:	In the classroom, it's helpful to focus on the purpose of learning activities. With some simple adjustments, students with Tourettes can demonstrate their understanding while avoiding difficulties with hand-writing.
Robyn Latimer:	We often suggest to teachers to focus on quality over quantity. If there's 10 questions they need to do for homework, maybe focus on a really important core four or five and achieve those really well and succeed rather than have a sense of failure trying to do all 10 and build up their confidence because we know that success breeds success.
Scott:	Mark's handwriting's atrocious and he holds his pens and pencils really tightly and in a bit of a not grip. His handwriting's quite big, but he actually does write a lot and loves exploring writing creativity and just doesn't let that get in his way.
Malia Story:	Longer, more challenging writing tasks can be recorded. The verbal recording of the voice going to texts now is very good, and then allowing the child time to edit that because I think that's an important step. If you're doing it verbally, it changes the task but then breaking it down for them to be able to take the time to read it and change the tics as they see appropriate. I think the ability to use photographs, especially with iPads, taking a snapshot of a screen instead of writing it all down and then adding your notes on top of it, there are a number of apps that set allow you to do that now.
Serpil Senelmis:	Teacher Malia Story says another good adjustment is to get everyday underway with some physical activity.
Malia Story:	<p>We do sport in that first morning block because that enables all students to release a bit of energy. When you get into the sporting arena or the musical arena, children with Tourettes syndrome are exceptional because it's a very physical thing and they're actually moving, and it's got rhythm or it's got activity, giving them opportunities to shine in those ways so that when they come back into the classroom and they find it challenging, you can actually get them to draw on those strengths so they can succeed.</p> <p>For one student it might be sport, for another it might be singing or playing an instrument, for another student it could be maths or playing chess, so it's looking for that activity for that student and then you can build from that success and start showing them that when they can get their focus to happen, they can really succeed. It's like a ripple effect, it starts to expand into other tasks and other activities in learning environments within the school as well.</p>
Serpil Senelmis:	Tourette Syndrome Association President Robyn says, that when they do something they really enjoy, students with Tourettes can have the opportunity to experience a freedom from tics.
Robyn Latimer:	If they find something they enjoy, they can focus really, really well on that and when students are focusing on something in a task that's very absorbing to them, their tics subside. So they get to experience being tic free, but they also importantly get to experience success in what they're doing.
Serpil Senelmis:	How important is it for a teacher to get to know the student really well? To understand not only the academic capability but also the coping skills in the social context of the classroom?
Robyn Latimer:	Communication with the child and the family or the carers involved is really important because Tourettes is changeable. Quite often they don't realize something they're doing is actually a tic, it depends on the individual child's insight into what's happening and their own awareness, which in very young

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	children can be zero at times, they're totally unaware of what they're doing. If I had a student that I knew was coming into the classroom, had been identified that had Tourettes, communication with the family is my number one point. A meeting before school starts, face to face is always valuable, already have building up some relationship with that student before they actually come into school in hope that that anxiety will be reduced for that student coming in. The parents and the family are an invaluable source of support and information.
Scott:	I know the teachers really well. They engage us constantly if there's a change to the plan, or if Mark's tics change or are interfering with his schoolwork, or anything at school. So we're in regular contact and supportive of them just as much as they're supportive of us.
Serpil Senelmis:	And what about Mark? How much of a say does he get in the adjustments that are designed to help him?
Scott:	He's fully involved in all of those arrangements, which I think helps him not only feel more in control, but also understand what those arrangements are so that he can leverage them.
Robyn Latimer:	<p>Having that element of trust, talking to the child, helping them generate that awareness, so that then everybody can work together to work and focus on the tics that are causing the most problems. So for some children, a tic could be quite an antisocial tic, coprolalia with swearing or Copropraxia, which is rude gestures, or tics that involve other students like touching other students for instance. Those sorts of things are what should be focused on first and then if there are other incidental tics happening like throat clearing, humming little noises, vocal tics and things that don't really impact on others so much and affect socially, then let those ones go.</p> <p>Trying to deal with everything all at once is just way too much for the child. It is a very difficult, complex condition, so it's just about being creative. Sometimes it's as simple as the child has a tapping tic, their fingers or a pencil on a table, how about I put a piece of foam there so the rest of the class can't hear it. You can't say stop doing that because the child can't stop doing that. So we look at ways to prevent it from impacting the world around them.</p> <p>I think it's really important to involve the carer or the parent of the child, particularly young children, to maintain consistency of strategies at home as well as at school.</p>
Serpil Senelmis:	So if you have a student with Tourettes syndrome in your class, it's important to be patient, reduce anxiety and get to know that student and their family or carers. Scott says it's a learning experience for all involved.
Scott:	He understands more about it. He's met a lot of people with Tourettes now and that's incredibly invaluable because he understands the complexity and how other people are coping. Earlier on, I think it was somewhat confusing for him.
Serpil Senelmis:	And Mark's advice is to respond positively to whatever is happening.
Scott:	He becomes a little bit fixated on things, if anything he wants to do, it's quite amazing. So he can do it at school and brings ...
Serpil Senelmis:	This podcast is part of a series that highlights adjustments that could be made in the classroom to enable students with disability to access and participate in education on the same basis as their peers. You can find all episodes on the NCCD portal. I'm Serpil Senelmis, thanks for listening.

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