

Josh in New York City, New York: "Growing Up With Tourette's"

TEENAGE DIARIES

Produced by: Joe Richman

All Things Considered (NPR)

4/15/96

ROBERT SIEGEL, Host: This is All Things Considered. I'm Robert Siegel.

LINDA WERTHEIMER, Host: And I'm Linda Wertheimer. Tourette's syndrome is a neurological disorder that causes involuntary tics, such as sudden movements and verbal outbursts. According to the National Institutes of Health, an estimated 100,000 Americans have the condition. Most begin showing symptoms at around the age of 10 and the tics often increase during the teen years. Josh Cutler is 16 years-old and lives in New York City. He was diagnosed as having Tourette's syndrome when he was 10. As part of our series of Teenage Diaries, Josh was given a tape recorder to document his life with Tourette's syndrome. This is his story.

JOSH CUTLER: I'm getting ready for school right now. Just got out of the shower, got dressed, and now I'm getting ready to heat up my usual TV dinner that I have for breakfast. I think I'll have the spaghetti bolognese. Let me do the introduction now. Hi, my name is Josh, and I'm 16 years old and I live in Manhattan, in New York City. My mom's a theater professor, and my dad's a lawyer. Pop it in the microwave here. [microwave sounds] Um. If you saw me on the street you wouldn't notice anything different about me. I mean, I look just like a normal person but after a while you would notice that I don't act much like a normal person. [clears throat] I have Tourette's syndrome. It's a neurological disorder that causes [clears throat] involuntary tics.

[shriek]

JOSH: It feels like there's a big balloon inside my stomach. And the balloon keeps growing bigger and bigger, like every second extra the tic stays inside it feels like somebody blows up the balloon another notch, until I let it out.

[shrieks, noises that sound like someone mimicking a power saw]

JOSH: Yesterday I saw a show--it was Maury Povitch about people with Tourette's--there was this one big fat kid from Houston named Phil or something like that. And the show was really ridiculous because Maury Povitch was just going on about how beautiful the kids were and everything. Talk show hosts always tell about how beautiful the guests are, especially when they're horrendously ugly or obese.

JOSH'S MOTHER: Josh?

JOSH: [to mother] This is my radio show thank you.

Sorry about that. That was my mom.

[yells to mother] You're not listening at the door are you? O.K.

[telephone dialing]

[ring]

JOSH: Prank calls. I make a lot of prank calls.

MAN #1, on telephone: Bronx School, good afternoon.

JOSH: [in child's voice] Hello? Yeah, I wanna go to school.

MAN #1: You do?

JOSH: Yeah, in September.

MAN #1: Oh, you do?

JOSH: Yeah. Talk to my daddy.

MAN #1: All right, hold on.

JOSH: Hold on.

JOSH: [in man's voice] Hello.

MAN #1: Hello.

JOSH: Hi. Hi there. Hi.

MAN #1: Hi.

JOSH: Yeah. I'm Billy's father.

MAN #1: Uh huh.

JOSH: Yeah. Listen, Billy is kind of an emotionally disturbed child, will you be able to cope with that?

MAN #1: Well, I don't know about that. I could send you the materials.

JOSH: Yes, yes.

MAN #1: Give me your name and address and I'll mail you the information.

JOSH: Right, my name is Wilton

[telephone conversation fades under]

JOSH: I make a lot of prank calls. My mom thinks that it's because since I'm experiencing so much pain that I like to inflict it on others. It's not true at all. I just do it because it's fun.

[telephone conversation comes up again]

JOSH: "Yes, yes. OK bye."

JOSH: Hook, line, and sinker!

[fade in background conversation and sounds at school]

JOSH: I go to St. Ann's School. It's in Brooklyn, NY. And I'm in eleventh grade. I've been going there since I was in first grade.

YOUNG MAN #1, Classmate: what are you doing?

JOSH: I'm doing a project on Tourette's for National Public Radio.

YOUNG MAN #1: Can I, like, sing on this?

JOSH: OK.

YOUNG MAN #1: [sings] I love fishes cause it's so delicious.
I love that.

[school sound fades under]

JOSH: I was really scared to bring the tape recorder into school. I just assumed that they would just look at me as, like, some loser bringing a microphone into school, but as it turned out, they all jumped at the chance to be on the radio. I had to ward people off.

[school sound comes up again]

JOSH: What do you think about Tourette's? If somebody says Tourette's to you, what's the first thing that pops into your head?

YOUNG MAN #2: What do you want me to say?

JOSH: Anything you want.

YOUNG MAN #2: Like what I've learned from you? Well, I see that you have uncontrollable outbursts and well, sometimes they're funny, amusing, but most of the time just a pain in the ass because we gotta put up with you cursing and yelling and running around.

YOUNG MAN #3: Be nice.

JOSH: It's OK, just say what you think.

YOUNG MAN #2: But, you know, you're a nice guy, and so I've learned that from you.

JOSH: Do you think it affects my relationships with other people?

YOUNG MAN #2: Yes.

JOSH: You do? How.

YOUNG MAN #3: What I've heard about it is you say whatever you think.

JOSH: Yeah, that's true.

YOUNG MAN #3: And, everyone thinks things which they normally wouldn't say. For example if I said exactly what I thought about Sophie she'd hit me...

JOSH: I do say exactly what I think about Sophie.

YOUNG MAN #2: Josh loves Sophie.

JOSH: No, no. Just my honey bunch.

[school sound fades under]

JOSH: Girls are a very touchy topic with me, not physically--I wish--I don't know, I guess because I must say--not to gloat--but, I am an attractive person: I'm cute, I'm smart, I have a nice body, but a lot of the Tourettic things I do seem to drive other people, including girls, away.

[school sound comes up again]

JOSH: Sophie, do you want to say something else? OK she wants to sing.

SOPHIE: [Sophie and friend sing] I love fishes 'cause it's so delicious. I love fishes.

YOUNG MAN #2: Sophie.

JOSH: Wasn't that wonderful? Thanks. Let's see how this came out.

[tape recorder clicks off]

[back at home]

JOSH: When I'm holding in a tic. When I'm holding it in all day in school, I just can't wait to get home 'til I can explode...

[screams]

JOSH: I have lots of different kinds of tics. There's coprolalia where you just start screaming profanity for no reason. And echolalia where you hear something or see something and you just have to repeat it. Like if you see something on TV.

[tics in the background, spitting noise]

JOSH: Sometimes I grab people and shake them around, usually just my parents, fortunately for that. Even in New York I'd look pretty weird on the street, just going up to people, shaking them around, and screaming at them for no reason. (pause) It really just pisses me off sometimes, if you can say that on the radio. I didn't do anything to deserve it.

[Shouting "fight" over and over again in the background, continues shouting at the TV, then fades]

[telephone dialing, telephone rings]

MAN #2, Health Club Receptionist: Hello?

JOSH: Hello.

MAN #2: Hi, how are you?

JOSH: I'm fine. Listen, I'm interested in getting fit.

MAN #2: OK. This is a new club. Are you familiar--are you a member?

JOSH: No. You see, I weigh 800 pounds.

MAN #2: You weigh 800? What was that?

JOSH: I weigh 800 pounds.

MAN #2: You're 800 pounds.

JOSH: Yes.

MAN #2: OK.

JOSH: Yes. I'm blobs of fat all over the place.

MAN #2: Yeah, that's no problem, we can get rid of that. What's your name?

JOSH: Blorb.

MAN #2: Excuse me?

JOSH: Blorb.

MAN #2: [laughs] That's not Jeff is it?

JOSH: No.

MAN #2: OK. Hold on one second OK.

[muzak on telephone, then fades]

[sound of piano being played in nearby room]

JOSH: You can hear that over there. That's my mom playing the piano. My relationship with my mom. We get along sometimes, but she always tries to butt into everything. A lot of times kids' problems with their parents are that their parents don't pay enough attention to them. I think my parents pay too much attention to me. They just won't butt out of my business. Back off.

[piano music fades out]

MOTHER: Josh. What's the one thing you would want people to know about living with Tourette's that would help them understand you?

JOSH: I told you this already, I don't care to help people. People have to deal with their own problems.

MOTHER: So what do you think about the way dad and I have had to deal with you? Do you think we've done a good or a bad job?

JOSH: You can't say just either one.

MOM: What do you think? What do you feel when you think about us?

JOSH: [screams] You suck!

Sorry. I know you try to do a good job. I don't know. I think you try too hard.

MOTHER: What do you mean try too hard?

JOSH: Like you get in my way too much. Like when you don't let me watch TV. Just let me watch TV and leave me alone. [scratching sound] I'll scratch my ass.

MOTHER: You think it's been easy living with you?

JOSH: I doubt it, most of the time. [Whispers] Itch.

MOTHER: Do you want to hear my deepest wish?

JOSH: What's your deepest wish? That you want me to be happy and to leave you alone?

MOTHER: No.

JOSH: No?

MOTHER: Surprise.

JOSH: What?

MOTHER: I wish that I could just have a conversation with you like other mothers have with their teenage children.

JOSH: You could.

MOTHER: I can't.

JOSH: Yeah, you can.

MOTHER: You fill your conversation with so much defensive stuff.

JOSH: That's because you always bring it up. How would you like it if I started talking about the things that trouble you? You'd do the same thing.

MOTHER: No I wouldn't.

JOSH: [yells] Yes you would.

MOTHER: No I wouldn't.

JOSH: Yes, you would. [sighs] What do you want me to say?

MOTHER: Say what you're feeling right now. [pause]

What do you think people think about you?

JOSH: That I'm a wacko. That I'm a loony bird. That's just who I am. But that's combined with a disease that makes me more of a loony bird so that makes me a double loony bird and I go over the edge.

MOTHER: Do you think you'd be a loony bird at all if you didn't have this disease?

JOSH: Yeah. You and dad are both loony birds so...

MOTHER: How do you think we're loony birds?

JOSH: You remember all of those little stories you used to make up for me? Those

things don't leave my head you know.

MOTHER: You want to hear something?

JOSH: What?

MOTHER: When you first got Tourette's, I wondered if all the funny songs I made up gave it to you.

JOSH: [laughs] You thought that? You're stupid.

MOTHER: [laughing] I thought to myself: "Oh my God, if I hadn't made up all of those silly songs maybe he wouldn't have gotten Tourette."

JOSH: I don't think so.

[piano music begins playing again]

JOSH: People are always taught to think before they speak. Everybody has deep dark things that they don't want people to know they're thinking about.

[shriek/tic]

JOSH: The bottom line is sometimes I actually have to teach myself not to care. I can't care because most of the time I can't control what comes out of my mouth. I control what comes out of my ass better than I control what comes out of my mouth. But, the last thing I want people to think is: "Oh, poor Josh." It's not like I'm in a wheel chair or I have snot dribbling down my chin. I really just don't want anyone to be feeling sorry for me. This is not a Sally Struthers commercial.

[yawns]

JOSH: I'm getting tired. The low battery sign's on the tape recorder. Gonna have to replace it soon. I guess that's just about it. So, signing off for now.

[tape recorder clicks off]

[piano music continues, then ends]

LINDA WERTHEIMER, Host: This story was written and recorded by 16 year-old Josh Cutler, and produced by Joe Richman as part of the series "Teenage Diaries." It's All Things Considered.

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