

HOW WOULD YOU FEEL after throwing hot coffee at your brother?

HOW WOULD YOU FEEL after calling a stranger Gandalf?

HOW WOULD YOU FEEL if your school friends turned their backs on you?



FIGHTING
the
TOURETTE'S
URGE

Tourette's syndrome is estimated to affect 300,000 people in the UK. *David Conway* reports



Play time for the family pooch

Jade Shorten is 19-years-old. She lives with her mum and dad. She makes animal noises. She struggles with depression and has anxiety issues. She finds it hard to get a job.

Jade was bullied in school. She even considered killing herself.

NOBODY wanted to be friends with me in school because I'd make funny noises. Children at school bullied me. It was difficult because I didn't understand why people had turned their backs on me. I always got told to shut up. I was like I'm not making any noise but I was. I would go home to my family and they would tell me what I had been doing and reminded me it was a habit. They said to me 'stop doing it, you're annoying people.'

Along with my tics I also have problems with anxiety, depression and Obsessive Compulsive Disorder (OCD) which tag along with the condition. It was very difficult growing up. In high school no one understood and all my friends turned their backs on me because I was embarrassing them. They didn't want to be

friends with me because I would make funny noises. Afterwards I would get home feeling like no one liked me.

I couldn't concentrate a lot as my tics tired me out and I would just go in to my own world. Lunch time would vary as my mates would fall out with me one day and not the next. Sometimes I wouldn't eat my lunch because people would take the mick (laugh) about what kind/value of food I eat. Once in year eight I got told to shut up and sit down by the teacher. He didn't get told I have tics. Because he didn't understand it was my tics my vocal tics changed and got very loud. It was different so I couldn't figure out why I was doing it. It was very difficult for me to get myself in to a group sport as people who would tease me about my condition would be

in that group. It was an upsetting time for me and hard growing up feeling isolated from everyone else.

I had hit rock bottom and even attempted suicide. The reason why I did attempt suicide was because I didn't understand what was wrong with me, why am I doing things I can't remember or can't control? Friends at school turned their backs on me and teased and mimicked me because they said I'm embarrassing. Someone threatened to punch me because I said what I was thinking, me not knowing that what I said could upset other people. After I attempted suicide I stopped myself as I couldn't upset mum or dad or anyone else. The thing that kept going through my mind was that no parent or nanny or grandad should see their daughter/granddaughter die

before anyone. I could be there for my future niece and nephews. I just burst out in tears screaming. Mum saw marks on my neck that I had tried to hang myself with a belt, overdosed on medication and cut my legs.

I was six-years-old when my mum, my dad and my Nan first noticed my tics. They noticed something was not right because I coughed a lot and made facial grimaces. My school thought it was just childhood habits. At the beginning we went along with what they said but then as the months passed we thought there must have been more to it.

I didn't know what was going on before I was diagnosed at the age of 8. I didn't really notice it myself because I was so young and you're not meant to notice until you get older. The worst ex-

When I got diagnosed my family became more understanding because they got support through it and knew that I couldn't help it. It took so long to get diagnosed because GP's and schools don't know enough about it, people are more aware nowadays.

When I was young you didn't really know, well my family didn't know anything about tics. It was difficult for them because they ended up having to record me on phones as proof.

To prove there was something wrong with me.

I started to attend counselling with a youth team to help control my anxiety and depression which arise from the tics. I really benefited in terms of controlling my anxiety and depression. They've helped me get back on track and I feel much better. I am not as bad as I used to be, when

there they told me they got in with a small birth certificate and she said I needed a big one. It made no sense, so I felt like I had been discriminated against.

I got a job as a care worker but the clients I looked after didn't understand that I couldn't control or help my tics or cough. They didn't like it.

They would tell me to stop coughing and said do I want cough medicine, I don't like you coughing in our house or they would ring the company up and say I don't want this girl looking after me or helping me out because I don't like how she is, she annoys me or something.

It makes me very angry. I hold my tics in very hard and it does make me worse and I let him out when I get home and so my family see the full face of it. My poor brother he deals with it so well, he gets like cups of coffee thrown in his face freshly made, knives and forks thrown at him, food at him, and I break plates on the table because I can't let him out in public. I'm so scared of people's looks that they give me. I called someone Gandalf because they had a big long beard the other day. I was so embarrassed. I just have to deal with it. I talk to a support worker if I feel stressed about anything. Sometimes I just feel so ashamed about myself. I haven't got use to myself yet.

There are loads of myths about tics. People don't know what causes it but it is how the public view it. You see someone with tics and they swear a lot like Pete from Big Brother. Everyone thinks it revolves around swearing, if you don't swear you don't have tics but you can get different kinds of tics. It's hard because people don't believe you and think you're faking it. It's hard to cope with. The people who go on TV are brave. They have the confidence that I would want. They don't care about what people think of them which is so brave. They are amazing.

I'm unsure about what the future holds. I've lost any sort of confidence I had built up. It has taken a dive each time I have had a bad experience. It has reached the point now where when I have a job interview I back out because I am scared about suffering another rejection.

There are a lot of ignorant people in the world so it can be difficult. I don't think people, think about what they say. When they see me do something they stare at me or comment. Sometimes something good, sometimes they ask questions. It is mostly more kids who aren't very nice. People are quick to judge before getting to know the person or talk to the person. I'm just a typical teenage girl at the end of the day. I'm happy I have a supportive family and a nice boyfriend. I just need a job now.

"I had hit rock bottom and even attempted suicide. I didn't understand what was wrong with me. Why am I doing things I can't remember or can't control."
Says Jade

perience early on was the uncertainty about what was going on, the endless GP appointments and my nan and grandad holding my head to keep it still because they thought it was a habit.

I'm going out to town I don't have to have some one by my side. I can walk down the street by myself and not feel anxious.

I still struggle to get a job though which is frustrating. I've applied for Tesco. They said I couldn't have the job because I only had a small birth certificate but when I mentioned I had tics her facial expression changed. When I called up to see if I had the job, they were like 'no no it's nothing to do with your condition, she kept going on about the condition which obviously played on my mind that yes it was about the condition. But because my friends have worked





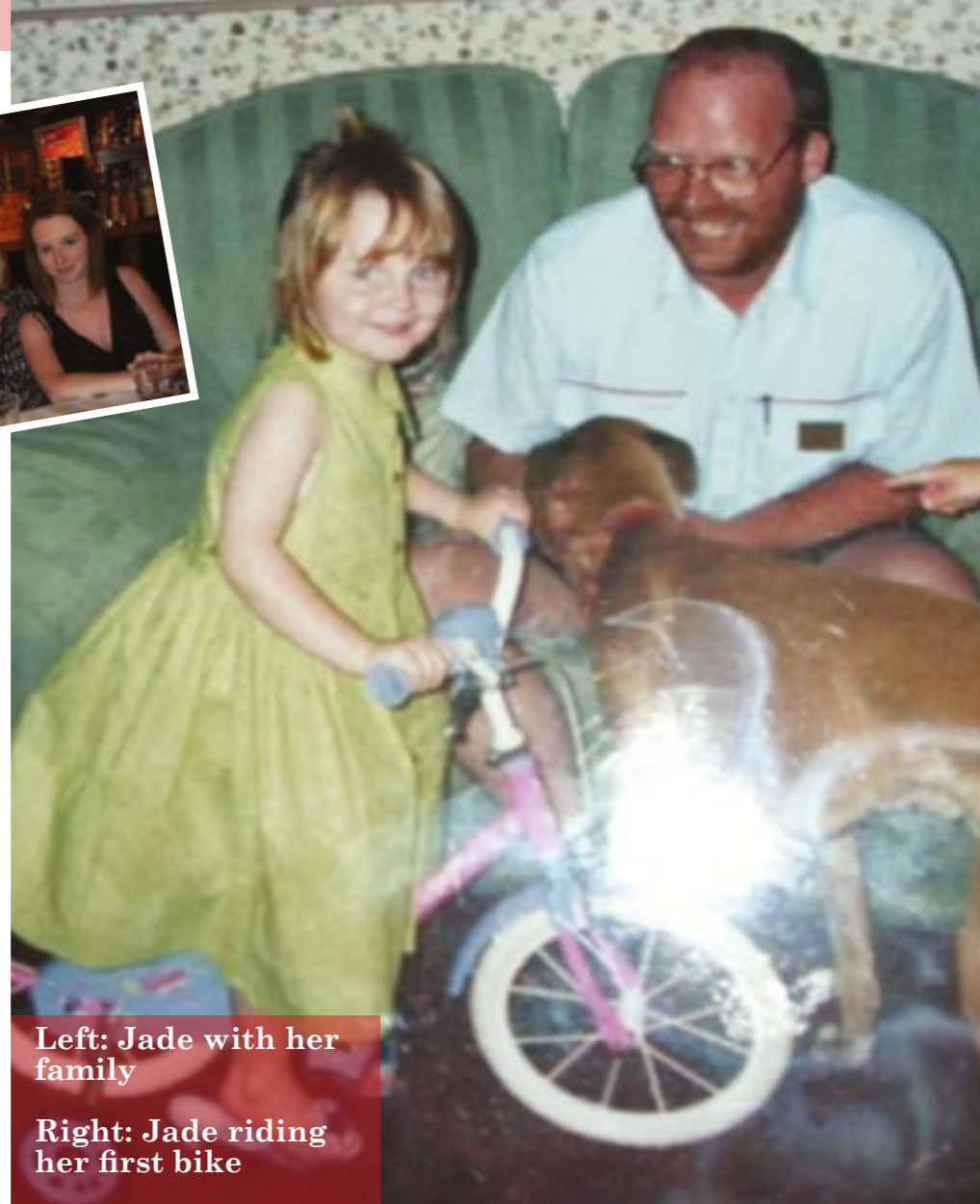
Raising Jade

Jade lives at home with her parents in Norfolk, East England in a three bedroom council house which she describes as a 'quiet but great' place to live. She enjoys living in Norfolk and the close relationships she shares with her family and the pet dogs and cats they have.

The beautiful beaches help provide a place for Jade to gather her thoughts and the strains of everyday life abandon her. It is a popular place for Brits to visit for a break. Jade has lived in Norfolk for her entire life and she is settled. Her family is close and the traditional home full of photo frames of the family members reinforces the bond they share with each other. They bowl together and regularly go out for meals, Marie smirks and says "but not so much now since she got a boyfriend."

Jade shares a strong bond with her mother Marie. They are great friends and can talk to each other about anything. But as a family it has been difficult for them to deal with Jade's condition. They have had many rough times, especially when Jade tried to kill herself. "We took it as though it was our fault because she's our daughter. That it was our fault that she was like that and our fault she was getting bullied. We couldn't do anything about it because the school didn't understand what tourette's was," Marie admits.

Marie shares a sense of blame for Jade's condition. She has dyslexia and is unsure whether this and the fact Jade's father has a mild form of OCD have led to Jade inheriting tourette's. Whether this is the case remains unclear and is a frustration to the whole family. The family initially received little support early on and they had to band together to support Jade. "There was not a lot of support given to us early on. We were more or less left to deal with it. When things did go bad she went to child support and had to talk to different people which we didn't find was a lot of help," she tells me. Jade is quickly growing up into a young woman and despite her condition her family love her all the same. "She's no different than anyone else in our eyes. She's just Jade," she said.



Left: Jade with her family

Right: Jade riding her first bike

"She's no different to anyone else in our eyes. *She's just Jade,*" Says Marie Jade's mum



Meal time for Jade and her friends



The mystery surrounding Tourette's Syndrome

Research suggests tourette's syndrome (TS) is more common than people realise affecting one in ever hundred people.

It remains a constant problem for researchers as they still do not know what causes the condition or how to cure it.

David Conway examines the facts behind the mind baffling condition.

Tourette's syndrome is a neurological condition which affects both the brain and nervous system. It can be identified through a combination of involuntary sounds and movements which are commonly referred to as tics. It tends to be identified during early childhood and continues through into adulthood.

The condition is named after French doctor, Georges Gilles de la Tourette, who first described the syndrome and its symptoms in the 19th century.

Tics can be:

- vocal (sounds) - such as grunting, coughing or shouting out words
- physical (movements) - such as jerking of the head or jumping up and down

They can also be:

- simple - making a small movement or uttering a single sound
- complex - making a series of physical movements or speaking a long phrase

Most people diagnosed with tourette's syndrome have a combination of physical and vocal

tics, which can be both simple and complex.

The tics don't usually pose a serious threat to a person's overall health, although physical tics, such as jerking of the head, can often be painful. However, children and adults with tourette's syndrome may experience associated problems, such as social isolation, embarrassment and low self-esteem.

The cause of tourette's syndrome is unknown. However, it's thought to be linked to problems with a part of the brain known as the basal ganglia, which helps regulate body movements.

In people with tourette's syndrome, the basal ganglia 'misfire', resulting in the characteristic tics.

In around two-thirds of cases of tourette's syndrome, symptoms improve significantly (usually around 10 years after they started).

In many of these cases, medication or therapy will no longer

be needed to control the person's tics. Some people's symptoms become less frequent and troublesome, or they disappear completely.

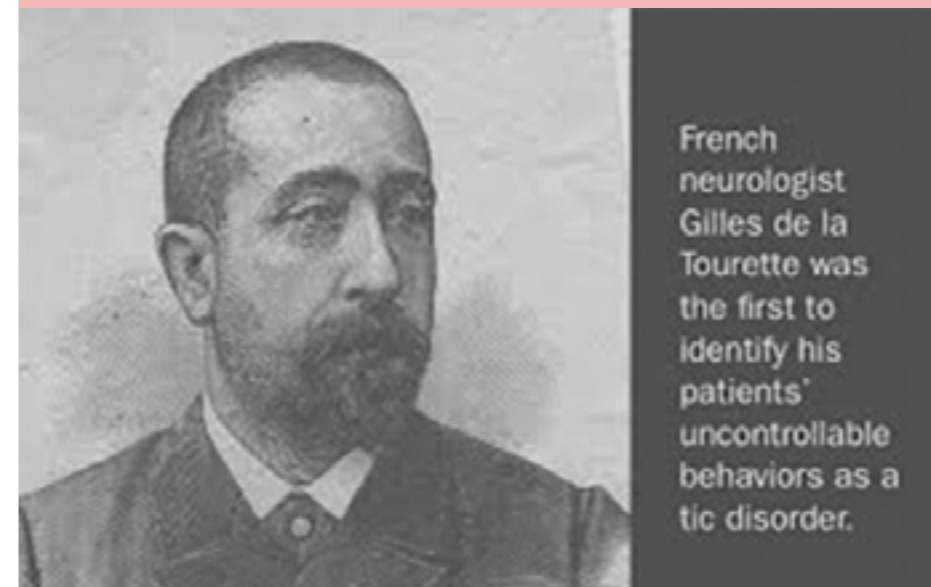
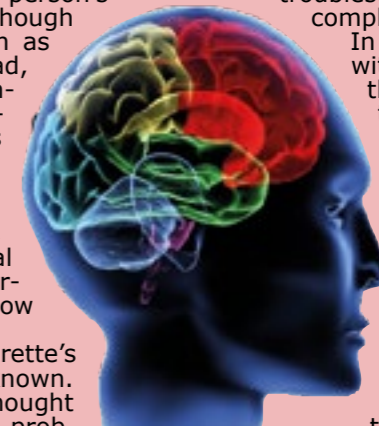
In one third of people with tourette's syndrome, the symptoms continue throughout their life. However, they usually become milder as the person gets older. This means the need for medication and therapy may pass over time.

Seonaid Anderson research manager at Tourette Action said: "Sometimes it's frustrating when I explain to people that I work

with people who have tourette's Syndrome - people often don't take it seriously and generally think it's about people swearing. We need to break the stigma and assumptions around Tourettes Syndrome - one of the main aims of Tourette Action.

"Research has shown that different environmental factors may, in some cases, contribute to the onset or affect the severity of TS. These include pregnancy and birth related problems such as complications during pregnancy, smoking during pregnancy, severe nausea and/or vomiting during the first trimester and premature low birth weight children.

"People are generally very keen and interested in hearing about the latest research - sometimes it's frustrating that there isn't more to report or more funding available," she said.



French neurologist Gilles de la Tourette was the first to identify his patients' uncontrollable behaviors as a tic disorder.

Source: National Health Service and Tourette Action Research Manager Seonaid Anderson

Standing out from the crowd

Standing up for herself

Standing up against the myths

STANDING UP FOR PEOPLE WITH

Tourette's Syndrome



Ellen striking a pose during a hike

Ellen Clifton, 18, loves to play the trombone. She has been playing since she was eight-years old and enjoys playing in a band with her friends. She likes the sights and sounds she hears. Music is a big part of her life because it allows her for a short space of time to escape the world and forget her worries. She has a lot of confidence for a young person and is prepared to try new things.

You would struggle to notice Ellen has tourette's syndrome. She wants to banish the myths created by the press and public towards the condition. And in sixth form she decided to make a stand.

"I decided to do a presentation about the condition and the stigma attached to it, to raise awareness of what it actually is. It was quite a weird experience because nobody knew I had the condition apart from some of my close friend and some of the teachers. At the end people came up to me and were like literally we had no idea that you had it. They also admitted they didn't realise that you can raise a level of suppression and not everybody swears," she tells me. I ask her did anything change. How did people treat you after the presentation?

"People were careful of what they said initially. Before I told anybody you do sought of hear comments in the corridors about tourette's because it is quite an interesting condition and it raises a lot of talking points. Obviously not what everyone said was good. I did learn to cope with that and thought they didn't know what they were talking about. They don't know about it enough, so there ignorance is getting in the way of them respecting it. I was aware that people were talking about me, behind my back. I wasn't really bothered about that because I knew it was going to happen. So if I didn't want it to happen I wouldn't have done the presentation in the first place. A few months after the presentation, people eventually forgot about my condition."

She gives the impression that other people's opinions fail to make her feel down or depressed. For someone so young she comes across as very brave and content with her condition.

"It was a relief. It was more acceptable or appropriate for me to have a tic and let it out. It was a weight off my shoulders because I felt like

I didn't have to hide myself," she laughs. "Is that a bit cliché? I don't know," she says.

"My family were supportive. They know I'm not the person to do it for attention because I know a condition can sometimes be used in the wrong way so that you gain attention or fame."

Its clear fame isn't the goal for Ellen. She just wants to give support to others with the condition. It can be such an overwhelming thing for anyone let alone a child who has to balance so many things including tourette's.

"Tourette's has a reputation for being uncontrollable. It is bizarre condition as you subconsciously do things. In school it was difficult to balance. When I did my mock exams in year

mother Julia is a GP. Despite the fact she is Ellen's mother she has provided medical advice and was the first person to notice Ellen's condition.

"It has definitely helped having her. She knew more about it than I did. She has seen it before as well so it made it easier to talk to her just like with any other medical issue," she admits.

Ellen was officially diagnosed with tourette's syndrome at age 14. I ask about the delay. Why did it take so long to confirm you had tourette's?

"It was a long process. There are not a lot of places in the UK that you can go to, especially as a child. It's quite annoying. It's not such a common thing that people know how to diagnosis it. Once you become an adult you get sent into a different

been some good programmes but they always pick people who have incredibly obvious tics and I think that's why people aren't aware of this other type of tourette's."

We begin to talk about some of the embarrassing moments in Ellen's life. She smiles and recalls one moment in particular.

"One time I was in school after I'd done the presentation. Bare in mind, Ellen has tourette's is not the first thing on everyone's mind. I was in a lesson and I knew it was going to happen and I made this quite weird noise and everyone was like 'that's so funny, what was that?' And I blamed it on the fact I had a cold because I didn't want them to feel worse by saying actually that was a tic. That was tourette's because that would make me feel bad for making them feel bad so I let it pass. In a way they're not the sort of people who would of wanted to offend me or would of said anything to upset me. It made me embarrassed about the fact that I had made that noise," she tells me.

Now studying English literature and language at Newcastle University, Ellen has left her little town of Hornsea and branched out. She does not get homesick and is happy to be not too far or too close to home. She enjoys her independence. She has changed a lot since her younger years and is ready to make a career for herself ideally in TV production with the BBC an ultimate goal of hers. Ultimately her tourette's have made her the person she is today and now with all that she's experienced she wouldn't change that for the world.

"When I was younger if someone had said here's a magic wand it can take away your tourette's I would have at the drop of a hat. But as I got older I started to appreciate the fact it has made me who I am. So I am more aware and appreciative of other conditions. I make an effort to not judge people on first appearance and it has made me mentally stronger because you have to deal with two things at once all the time. I think now if someone said do you want to take your tourette's I'd say no. I'd maybe take the pain away, well dampen the pain but it is part of me. So taking it away would take away a part of me."

I ask what advice she would give to youngsters with tourette's? She quickly responds. "To not let what other people think of you determine who you are or how you act regardless of whether you've got tourette's or whatever. At the end of the day you're your own person. No one else's opinion should matter and if it does maybe they're not the sought of person you should be hanging around with in the first place," she says.

Through chatting with Ellen, you would probably assume she has no condition but you would be naive to think so. Ellen has developed her confidence since she was first diagnosed with tourette's syndrome at the age of 14. She is a true role model for young people with tourette's. An inspiration that doesn't let her condition stand in the way of what she wants in life.

"They don't know about it enough, so there ignorance is getting in the way of them respecting it."

11 it was awful because you have to put too much effort into controlling them. You lose your train of thought a lot as to what you're actually concentrating on in the exam at the time. I wasn't allowed to have extra time as apparently it doesn't qualify but I was given a room on my own so it was just me and one examiner. It was easier to let my guard down and it really helped. I didn't have to think about two things at the same time." She says in a more assertive tone.

"When I'm really stressed and tired they get worse around the exams. It's kind of ironic because the more stressed I get, the more I feel the urge to tic and the more I tic, the more stressed I get about not being able to hold it in. It's like a cycle. When I get really tired they become hard to control, when I used to come home from school after a long period of time of suppressing the urge to tic it would be non-stop." I stop her mid sentence to ask whether she feels any pain from her tics.

"It's painful to hold them in but it's also painful when you tic. You can't escape the pain. Suppressing them is more of a mental pain. When you're thinking about keeping your head still, you have to tense your neck and when I tic they're quite facial and I may violently move my head. Then they're more physically painful particularly if I'm sat next to a wall. I may hit my arm or head. It's a bit shit really." We both laugh despite the sad reality of her situation.

From the seaside town of Hornsea, Ellen opens her window to bright blue seas and sunshine on most days. She has a close bond with her family. Her

range of facilities. It was quite difficult to find something close by when



Ellen in New York

I was young," she says.

Does the mystery surrounding the condition frustrate you? I ask her.

"It makes me curious as to why not a lot is known about tourette's. People still haven't discovered the cause of it but then I guess people still haven't discovered a cure for cancer and that's probably more likely to happen first. I would rather see funding go into helping people who have tourettes to live with it and to raise awareness of it as opposed to people making TV programmes about it. I'd like to see a bit more appropriate awareness to see a person like me. People are drawn to the extreme of things, so having someone like me on telly with my kind of tourette's would be a boring programme. There have

Battling Tourette's Syndrome

The Tim Howard Story

Tourette's syndrome does not define who a person is. You can go on to achieve great things. It is all part of your own journey, you have to face adversity and persevere on the way.

Tim Howard is an example of making the most of his life despite his condition. Some of you may not know that Tim is a successful goalkeeper who plays in the English Premier League for Everton where he has played at for a number of years.

Tim also has tourette's syndrome and like so many other people who grow up with tourette's syndrome he has been faced with problems along the way.

At the age of 10, Tim's symptoms started to appear. His first sign of having tourette's was touching random items. When he walked through his home he would touch objects in a particular order. A railing. A door frame. A light switch. A picture. A wall. He was always touching random objects with the order varying each time.

"If I tried to resist - I had to start all over again, until I got it right. It didn't matter if I was starving and dinner was on the table. It didn't matter how badly I needed to go to the bathroom. I had to obey the pattern inside

my head. I had to touch these things, and in exactly this order. It was urgent," Tim says in his autobiography.

Why couldn't I stop and what was wrong with me were questions which continued to circle through young Tim's mind. He began experiencing similar things in school collecting rocks on his way in.

"Pick up that rock, my mind commanded. You'd better pick up that rock. I tried my damndest not to. I gritted my teeth and stared ahead, trying to convince myself that everything was OK, that I could leave the rock. I might manage to walk a few steps before my heart started pounding. Go back, my body urged me. Pick up that rock," Tim says.

This awkward routine became physically painful and a demanding process for Tim. When people with TS try to hold the urge in they lose a lot of energy. It drains their strength and will power. For Tim he sometimes needed and wanted to physically vomit. It would always result in Tim picking up the rock.

Tim would carry his bag into school full of rocks as if it was perfectly normal, putting on a brave face for the rest of the world. But the truth was he didn't have any explanation as to what to say.

By the time he reached 11 his tics started. The unstoppable urges made Tim blink uncontrollably and his body would shake.

"With each of them it was the same pattern: that awful sensation welling up, the one that could only be relieved, inexplicably, by some action. As soon as I did it, I felt normal again. Seconds later, the cycle would repeat. Terrible sensation. Build-up of stress. Action. Relief. In school, teachers snapped at me - sit still. Stop clearing your throat. Other kids laughed. What's going on with your face? At home, mom stayed quiet, but I could feel her watching. I saw how her eyes zeroed-in on whatever part of my body I'd moved, the flicker of concern that passed over her face. I hated that I couldn't knock it off, be a little easier on a woman who deserved some peace of mind. But, of course, that was impossible," he said.

When Tim took up football or soccer as the Yanks persist to call it, he had a way of controlling or distracting his condition. His symptom's eased and would vanish while he was on the field. His focus would turn to football and his mind cleared.

"Only one thing remained in sharp focus, its every detail vivid: the ball, moving toward me. I would kick it or catch it or parry it. Or it would elude me and I'd have to pick it out of the net while the other team celebrated. Either way, whether I had succeeded or failed, that's when everything became crystal clear again - players, colours, spectators, scoreboard. And then, too, the intrusive thoughts. Touch the ground. Touch the post. Twitch, jerk, cough," Tim said.

The power of football has helped Tim keep some control over his tourette's and is proof that the condition doesn't rule your life. You can still go on to follow your dreams and achieve great things.

Source: Tim Howard 'The Keeper'



Tim as a child



Quick reflexes as Tim saves a shot

Keepers Corner

1. He's an Animal Rights Advocate & a PETA Spokesman
2. Despite being a goalkeeper he has scored a goal after a freak bounce saw his long kick up the pitch reach the back of the net in a match against Bolton
3. He has played in 388 matches for Premier League team Everton FC
4. He has collected three trophies in his time playing football in England. The FA Cup, League Cup and Community Shield all for Manchester United
5. The U.S. Tourette Syndrome Association described him as the "most notable individual with Tourette Syndrome around the world"
6. He holds dual American and Hungarian citizenship
7. Howard is a Christian, and has claimed the most important thing in his life is Christ
8. In 372 Premier League appearances Tim has kept 125 clean sheets