



# Charlotte's Tourette's Story

I'm Charlotte, I'm 23 years old and I'm from just outside of Liverpool. I'm currently studying music composition at the Royal Welsh College of Music and Drama in Cardiff.

I've had tics since the age of 4. My tics were very mild for most of my childhood, but unfortunately, they did draw a lot of unwanted attention when at school. I didn't have a name for the twitches and noises I made until I turned 16. My tics had significantly increased in my teenage years which led to seeking medical advice. Doctors and neurologists asked my mum why she had never brought me to see a doctor before now, but my tics had never caused much of an issue and a lot of children experience tics and other behaviours that they often grow out of. Other members of my family also had small tics, including my grandad who was a GP!

My mum frequently told me as a young child to "try not to make that noise" or "try not to pull that face", but I often had no awareness I was even doing anything until someone told me to stop doing it! The feeling of suppressing my tics made me feel so uncomfortable - I just couldn't sit still no matter how hard I tried. The older I got, the more I began to struggle with other things besides tics such as intrusive thoughts and debilitating migraines.

I began experiencing complex tics shortly after my 16th birthday which became completely disabling, both physically and socially. I developed severe social anxiety due to my tics, and spent the next couple of years on medication to try and control my uncontrollable movements and sounds. I was officially diagnosed with Tourette's Syndrome in February 2015, 5 months after initially seeing a neurologist about my tics in 2014. I felt relieved to finally have a name for what I'd been experiencing since such a young age, but I had no idea how much stigma surrounded the condition. My tics were embarrassing and exhausting. My mental health declined significantly and I spent the majority of Year 11 out of lessons with 1:1 support. I became very isolated and spent a lot of time on my own. I had a couple of really good friends who didn't treat me any differently to before my diagnosis, and we are still friends now!



**(Image of Charlotte and Lexi standing outside the gates of LIPA after receiving her results)**

## **"Music was the only thing that stopped my tics"**

The school's music department was my safe haven. I spent every break time there, and even ate lunch there instead of in the canteen! Music was the only thing that stopped my tics, so I would spend hours playing the piano and French horn to get a break from my tics. Unfortunately, this meant that everybody had to listen to I Giorni and River Flows in You for hours on end, because that's what I enjoyed playing at the time - sorry!

Not long after first seeing doctors about my tics, I discovered people in America who had service dogs that had been specially trained to help them to manage their Tourette's. I researched assistance dogs for many months before I decided an assistance dog would be beneficial for me. I got Lexi, a golden retriever, when she was 11 weeks old. Her first year of her life was spent the same way as any other assistance dog and guide dog puppy is raised - learning basic obedience and being socialised in lots of different environments, meeting new people, animals, and objects along the way. For two years, we attended weekly puppy training classes where we learned all of the commands and tasks Lexi would need to know throughout her life as a working dog. We would practise during the week, both at home and in public spaces such as college, shops, and the town centre. As she matured, our bond grew stronger and after almost three years of hard work and persistence, Lexi passed her training and became my assistance dog!

Lexi performs a number of tasks that makes my life easier, such as picking things up for me and helping me to get undressed, as well as helping me to travel independently, safely cross roads and navigate busy environments. She also alerts me before I have a 'tic attack' and can bark to alert other people's attention if I get into difficulty, although fortunately I don't experience tic attacks as frequently as I used to. 5 years ago, I was preparing to go to university for the first time. My tics were still quite severe and not well controlled. Lexi was making a massive difference to my life, but she was still quite a young dog with not a lot of experience, and I was anxious about the future. I had to learn how to live independently before going away to university - how to cook meals, how to organise my time, balance my studies and free time, as well as going away from home, as well as meeting and living with new people. I look back now and wonder why I was so anxious about it all.

## "I live completely on my own with Lexi and I'm managing very well!"



(Image of Lexi at 11 weeks old)

5 years later, I live completely on my own with Lexi and I'm managing very well! I had a lot of therapy after being diagnosed with OCD at the age of 18 and I have this almost completely under control now, although I still see a mental health mentor at college every week during term time. I've found that my tics have plateaued now that I am in my early 20s, and I don't experience the complex tics like I used to - although I still don't risk using sharp knives! I still tic constantly and I don't think my tics will ever completely go away, but I found a medication that helps me during flare ups which reduce my tics enough to allow me to carry on with my normal day to day life. Lexi is now 7 years old - she is very calm and confident when working, but she's still a puppy at heart and loves nothing more than rolling around in a muddy field with my mum's dog!

She is incredibly reliable when out working, and I really couldn't have asked for a better dog. We are beginning to make plans for her retirement, as assistance dogs typically retire between the ages of 8-10. Hopefully she will continue to work until I graduate in 2024, and she will go into semi-retirement whilst I train my next dog. I don't want to think about it too much yet!

I love all kinds of music, from classical to modern rock and pop. I am a brass player and spent many years learning to play the French horn and euphonium with plans to become a classical performer, until I began learning the piano and spent a year studying popular music at LIPA Sixth Form College in Liverpool. I discovered my love for composing at LIPA, and with the support of my brass teacher (who is also a composer) I applied to study at Salford University. Things didn't quite work out for me at Salford and I wasn't doing as much composing as I would have liked, so I decided to transfer to the Royal Welsh College of Music and Drama to study composition. I moved to Cardiff in September 2020, a brave move in the midst of a pandemic, but I love College and the city! I will be starting my 3rd year of my BMus in September which I am really looking forward to.

Unfortunately, living with constant repetitive motor tics has resulted in secondary disability and my mobility has declined significantly over the past 18 months. I have nerve damage in my right leg due to compression on the nerves in my spine which means I can no longer lift my foot and I have difficulties lifting my leg up to climb stairs. I was found to have a leg length discrepancy and hypermobility in my hips and ankles which has been made worse by my tics. I have special orthotics in my shoes to help me to walk better, and I use walking poles too. I have had a lot of physiotherapy over the past year to help me to stay as mobile and active as possible. I really enjoy swimming and have found that this helps massively with my tics and joint and muscle pain.

I also received funding for an electric hand bike last year which means I can go out cycling and also use it to travel to college without having to get the bus. I love walking, although I do find it more challenging now and I can't walk as far as I used to anymore and sometimes have to use a wheelchair, but I find walking and being outdoors great for my mental health. Despite the challenges my Tourette's has caused over the years and the physical disabilities I now have to deal with, I am incredibly hopeful for the future. I plan to complete my PGCE back in Liverpool after graduating from RWCMD and become a music teacher. I will continue to compose music which I hope will inspire other people to write music too. I am currently learning to drive an adapted car with hand controls so that I don't need to use my feet, and I don't tic at all while I'm driving.



**(Image of Charlotte and Lexi)**

This will further increase my independence so I won't have to rely so much on public transport or lifts from other people, and means I will be able to take Lexi on plenty more adventures around the UK!

I was also recently appointed as Vice President of Equality & Diversity in the RWCMD Student's Union and will be the voice for students at college with protected characteristics to help improve their time while studying at the college.

I never imagined that I would have to deal with so much at such a young age, but I also never would have imagined I'd have achieved so much despite everything I've had to deal with. I still struggle to accept my Tourette's diagnosis at times, but I am grateful for all of the opportunities it has opened up for me and all of the wonderful people I have met because of it.

**I hope my story helps other people who may have recently been diagnosed with Tourette's Syndrome or another tic disorder, and that you can still achieve great things and live a full and exciting life - just a little ticcier!**



**(Image of Charlotte and Lexi outside RWCMD)**

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