

CONFERENCE SPEECH

I've had OCD all my life. I know no 'normal' thinking life, where nagging or frightening thoughts, rituals, anxiety or fear isn't part of my day. I'm now at a stage where the anger and bitterness that I got landed with this illness have subsided and although I still get frustrated most days, I've realised my OCD doesn't own or define me as a person.

The signs of OCD were present in my early childhood, things always had to be just so, but it wasn't until I reached seven or eight that it took a real hold. I began to think that I was about to do something terrible, completely by accident but something so terrible that I would be arrested by the police and taken to prison, and that my innocence would be ignored. I had an escape route planned out of my bedroom window and would spend hours working out how long it would take to get to the window, climb out, jump and run. Everyday I waited in fear for the moment to come. It was the last thought before I fell asleep and the first thought in the morning. I began to develop rituals that magically quietened the horrible thoughts for a while, tidying, cleaning and ordering my room over and over again, if everything was in its place then nothing bad would happen today. I discovered my magic number - the number three. Everything in threes and I will be safe, my family will be safe, and my friends will be safe. As long as I stuck to the rules and always did things three times then it will be OK. Three stayed my number for a couple of years until three suddenly didn't feel good enough so three became three plus one, I couldn't say the number four, always three plus one. Then that didn't feel right and my magic number became four, and

remains my magic OCD number today.

At eleven things escalated, my parents split up and everything was out of control in my head. I focused on rituals to stop my families pain, my pain, I wanted so badly to keep them and their feelings safe. I became fixated on washing. Washing myself four times in the bath, scrubbing my skin until it was red and sore and then rinsing four times. Some days one bath wouldn't be enough, so I would bath two, sometimes three times a day. I started hand washing my clothes, my school uniform, and bedding, believing the washing machine didn't get rid of all the dirt. I became obsessed with make-up and spent hours applying and re-applying until it was perfect several times through the day. All this was kept hidden from my family, my friends, although kids at school picked up on me being different, caught out on a ritual when I thought nobody was watching, and I was endlessly bullied, made to feel a freak, strange and different. I so wanted to fit in and the harder I tried the worse it became.

I left home at sixteen. My fears and rituals although still present became quieter, more manageable. It wasn't until I had my eldest son at 19 that I hit a bad patch. With a new baby my OCD escalated and I centred my fears and rituals around keeping my son safe triggered by him actually stopping breathing at 8 weeks. I was diagnosed with clinical depression after a complete breakdown. I remember sitting against the wall, hitting my head, trying to make sense of my thoughts, really believing I had gone mad. I couldn't speak, eat or sleep. I was given Seroxat and counselling, neither worked, clearly because I didn't have clinical depression but OCD. But it would be many years until

that diagnoses would come.

Life carried on, I got married, worked hard and built a family life. I completed my certificate in person centred counselling at university, and despite wanting to complete my diploma, financial reasons meant I abandoned that and went into paid work, and also doing voluntary work with youth football. I tried to enjoy life, but there was always the underlying anxieties, fears and my washing, cleaning, ordering, checking and counting rituals. Bathing and showering never taking less than an hour, and having the same routine of walking room to room every day putting everything exactly where it should be, lined up, perfectly placed, and cleaning certain surfaces and objects. It was always strange how some things had to be cleaned every day but some things I could allow myself to clean weekly. I would catch myself feeling happy and then BANG in popped a thought that something bad would happen to one of my kids, my family, my friends and no matter how hard I tried to push them away they came back bigger and more frightening. The images of terrible things happening to those I loved were imprinted in my mind and played out like horror films. I would get stuck on things people would say, it might of been said innocently, they may of meant something else, but for me whatever was said was said to hurt me and would be with me forever. I would play, re-play over over again what was said, looking for other meanings, and change the words about. I would re-live the moment over and over again, each time evoking the same panic and a horrible feeling deep in my stomach. I am still stuck on things that were said to me many many years ago. They pop up every

now and again and I begin the whole confusing ritual of playing, checking and sorting

them again. It was hard, and what made it harder was I had no clue there was actually something wrong with me, that I wasn't the only one in the world feeling confused and frightened by my thoughts and rituals my mind told me to do. I'd got this far totally alone convinced I was crazy.

Everybody has defining moments through life. Three of mine came within months of each other.

The first one happened after I had come across a mental health survey on the internet, and just out of curiosity filled it out thinking I would score highly on the depression side of things. I was shocked when the result showed I scored highly for a condition called Obsessive compulsive disorder. I remember looking down the list of symptoms hardly being able to breath, and dared to think that maybe, just maybe, its not me, maybe I'm not crazy. The recommended reading for OCD at the time listed the book 'Brain Lock', and I ordered it that night. I was in limbo until the book arrived. Part of me felt like this was another trick of my mind, and actually I was simply mad and how

could I dare to believe there could be a reason I do the things I do. The book arrived a week later, I started by just reading through the case studies, each one I could relate to,

each one felt like that's me! It was a mix of excitement and relief. I made an

appointment with a gp at my surgery that day. I remember saying to her 'I think I have

OCD', and pouring out with the things I do. I was one of the lucky ones, the GP I saw that day listened and said 'I think you are right I'm referring you to see someone'. No questions, no battle to get help, she got it completely and I now refer sufferers to her

knowing they will be met with complete understanding. Things happened quickly for Me. I didn't make a conscious decision not to tell anyone about me having OCD except my husband, not for any other reason than it would mean opening up about my secret thoughts and rituals and I wasn't ready for that.

During the time I was waiting for my appointment with a link worker I collapsed at home after feeling faint and sick, totally blacked out. I played it down afterwards, thinking I must have a virus or something, but the next day I couldn't breath, had chest pains and couldn't speak more than a couple of words due to my breathing. I was told by the NHS helpline to go to Cromer hospital. My step mum took me whilst dad stayed with the kids. An ECG showed my heart rate going far too fast and not beating right and I was told to get to Norwich hospital. I remember my brother driving me, he must have been worried but remember him trying to make me laugh all the way. A day of tests showed my body was starting to show the signs of flagging after long term anxiety. My heart was going at 108 continually and I was physically and mentally worn out. My appointment to see the link worker was fast tracked, the Drs hoping that targeting the OCD and anxiety directly would be more beneficial than being put on medication to bring my heart rate down. Three days later I sat in front of Ron, my link worker and through nerves told him everything I had kept hidden from the world. Again I got lucky, he understood. I decided against medication. Previously taking seroxat had been a bad experience and I wanted to brave the journey of supported self help and CBT raw and unaided with tablets. A personal decision that isn't right for every sufferer, but for me I knew I had to feel and experience

challenging my OCD without leaning on temporary relief. I spent nine months, talking, reading through OCD books, challenging my thoughts, writing a diary of my OCD, challenging the need to do rituals. Some days were good, some days were still bad. I can't say the process made me better, but what it did do was enable me look inside and separate the OCD from what I had always believed to of been 'just me', And it gave me massive insight.

I also saw a stress and anxiety specialist, Jo, who would come out and push me to work through learning tools to help cope with my anxiety. Jo and I clicked, and I won't ever forget her encouragement and faith that I could get through anything. She helped me find my own confidence.

It was during this process that I had defining moment number two. I had been painting the newly built kitchen extension with my brother, we had been laughing and joking around and suddenly out of the blue I remember saying 'I've just been diagnosed with something called OCD', and trying to explain what that meant and some of the strange

things I do. He was the first person apart from my husband I had ever told and what happened next will remain one of the most painful things that has ever happened. He just looked at me and said 'So do I, I have OCD too'. I will never forget those words. All those years of rituals to keep all three of my brothers safe and not only was he **not** safe he had been going through the same suffering, and I didn't know. I listened as he described his some of his rituals, like playing all conversations backwards in his head, and counting, counting to four, in multiples of four, just like me. I only got the full extent of his OCD when I read his story on the OCD action forum a couple of weeks later. It was hard to read, hard to comprehend that as a young child he was stepping

up

and down his cabin bed ladder in fours, night after night, not understanding what was happening to him. I felt guilt, real guilt. What came out of this though, was I had finally met another sufferer, and so had he. We could talk, lean on each other and would recognise when things were bad for each other. And even after he moved to West Sussex, we both knew if things got bad then we were both only a phone call away.

I'm so proud of his progress to a life with quieter OCD, medication worked well for him and he now lives a life which he describes as being able to wake each morning with stability in his mood, in his OCD, not dreading what the day will bring, he has some element of peace and that's amazing.

The third defining moment happened one evening when I was watching a documentary called 'My street'. It was about a journalist who decided she actually didn't know any of her neighbours in her street and went about interviewing the 116 residents and discovering their stories to produce a film. She met a young man called Adam. Adam had tourettes and OCD, and living by himself was clearly struggling to cope with his illnesses. He had been in and out of the mental health system but I guess the options had run out, and this intelligent, likeable person sat trying to explain through continual tics how hard life had got for him. What was apparent was that he was coping with this alone, totally alone. The system, friends and support had abandoned him. The film went on to other peoples stories for a while and I remember thinking why is nobody helping him, I want to help him. Then the next scene went back to Sue, the reporter to do her second interview with Adam, as she walked up the

road the cameras caught the sight of Adams body being carried out of his flat. He had taken his own life. A young man with so much ahead of him had given up in the battle of Tourettes and OCD because he was alone. I remember having an appointment with Ron the next day and all I could think about was Adam. I asked Ron 'did you see the my street documentary last night'? He said no so I explained. He seemed un-phased by what I was saying, and said 'it happens on streets all over the country - people give up. The system can't help everyone nor can we reach everyone'.

I couldn't understand, I had been given the help when I asked, I was lucky to have a supportive family, close friends who I had slowly began to tell about my OCD and had

never been judged or abandoned. How could this of happened to someone?

This question took me on to ask Ron and Jo about local supports groups for sufferers of OCD. The nearest one I found out was 26 miles away, and funding had just been cut for a local therapy group. So in that moment I decided that I would set up a support group. I had no idea or clue where to start but Adams story had put fire in my belly and I knew it was something I had to do. In times where my OCD is bad and I doubt what I am capable of I always remember Adam, a complete stranger whose story keeps me focused that I can't let my OCD win.

Things happened quickly with setting a support group up in Cromer. By chance I had heard an interview on a local radio station with two members of OCD Norfolk who were already running a support group in Kings Lynn. I contacted the radio station and asked them to pass my number on, hoping that I might get some needed advice from them, meanwhile researching what I would need to do. When they got in touch, I was

offered the opportunity to visit the Kings Lynn group and that maybe I could go on board with them and open a Cromer group under the umbrella of OCD Norfolk.

Which is exactly what happened. My first visit to the Kings Lynn group was a real eye

opener and apart from my brother I hadn't met any other sufferers. I was scared stiff, but made to feel really welcome and accepted and it re-enforced my goal to open a

group in Cromer. I found a venue, got a grant approved and began advertising. I

contacted the local newspaper to see if they would run a piece before the start date,

and was contacted back by a reporter who wrote a regular piece called face to face,

which was a weekly article about someone in the local community.

She wanted to write about my life with OCD. I spent a lot of time wondering if I

could go through with it. Although I had told my family and close friends about my

OCD, I didn't disclose it to anyone else and I knew that once the article was written

there would be no hiding it. I also felt strange about telling a stranger my inner most

thoughts, your mental health is such a personal thing and here I was about to tell

Norfolk! Karen, the reporter was so nice, we did the interview, then we chatted for

another hour as she had really no idea what OCD was really about and was genuinely

interested. The response to the article was fantastic, not one single negative comment

and so many people said that they had no idea that OCD didn't mean constant hand

washing or checking the front door all day! The article also had its desired affect in

triggering a response in sufferers interested in coming to the group, and on the

opening night we had 9 attending.

The whole process of setting up the group had tested me and I had one of my worse

OCD episodes in the months before. My OCD was full on, with intrusive thoughts

streaming through my head 24/7 and my rituals taking longer and longer to do. At

times I really felt on my knees and there was little light at the end of the tunnel.

People

used to say to me if you realise what you are doing why can't you just stop? I always refer back to the mathematician John Nash who had schizophrenia and went on to win a nobel prize who when asked 'how could you, a mathematician, a man devoted to reason and logical proof,... how could you believe that you are being recruited by aliens from outer space to save the world? How could you?' Nash answered slowly 'Because the ideas I had about supernatural beings came to me the same way my mathematical ideas did. So I took them seriously'. It's the same with OCD.

Shortly after the Cromer group opened, I separated from my ex husband. It was a huge

lifestyle change, suddenly being on my own with the two boys and adapting to a new house. It threw my OCD in chaos and I think for a few months I was just surviving, but I asked for help and even decided to take anti-anxiety tablets for a couple of months to see me through the worst.

That was two and a half years ago and I haven't looked back. OCD Norfolk after a total rebrand became Norfolk OCD Support and I was proud and happy to take over as

chairperson a year and a half ago. Our organisation has gone from strength to strength,

we now have three groups running across Norfolk and are looking to open a forth in the New year. We have a good website and provide phone or email support for those unable to attend a group. I speak with pride when I talk about the Norfolk OCD Support team, they all have their own OCD struggle yet turn this into a positive by reaching out to other sufferers. The importance of support groups across the country

is

vastly under-estimated. Treatment and medication are hugely important to helping sufferers gain control of their lives again but support groups offer the sufferer long term help, support and information. But what its also really about is not being alone, having people to lean on and allowing people to lean on you. And there are many many people through the UK who have made the decision to run groups and provide somewhere for sufferers to go, although very few of these leaders recognize the amount of good they do. We need more sufferers to step forward and help make a difference in their areas by opening groups where at the moment there are none. To help reach those suffering alone, silently or help support families of sufferers.

I'm in a much better place with my OCD these days. Yes, I have bad days, bad weeks where I shut down from the world for a bit, but now I know that the bad times pass eventually.

I still get stuck on things people say, but working through it takes less time, I still order and clean but it is halved from a few years ago, my counting is virtually non existent and yes it takes me still an hour to bath and shower but hey cut me some slack

I'm doing good!

During the newspaper article I cited my one of my heros as Stephen Fry, for his honesty about his bi-polar and work in mental health campaigning. Last year, I was privileged to finally meet him and he signed the article for me and asked about what we do. I also cited my other hero as my brother, Elliott for his bravery with his OCD and for being my support. I am so lucky to have a supportive family around me,

my other brothers Serle in Nuneaton and Finn in Australia, thank god for Skype! And my dad and my step-mum Tracey, and my partner Stu who I met a year and a half when he taught me how to jump out of planes because I decided I wanted to experience positive fear, if you can call skydiving a good fear! And of course raising money on my level one accelerated freefall jump for Norfolk OCD Support. Level two not going so well, landing in a field a mile from the drop zone! But the point is even though we have OCD, we CAN have goals and dreams - having OCD just means the journey to them is a little longer, harder and sometimes there are a few more hurdles, but we CAN get there in the end.

I would like to finish with a personal tale that sums up how far I've come. My five year old Jay was going round saying what people were good at. He came to my partner and said 'Stu is good at jumping out of planes', he went to my eldest Kye and said 'Kye is good at guitar', when he came to me he said 'My mummy is good at group'. And so now on bad days I remember always that.

