

2011 OCD Action Conference Speech (edited for use on the OCD Action website)

by Steve Kelly

Hi, my name's Steve, and if you attended the OCD Action Conference in November 2011, then you'll have seen me get up on stage and talk about my experiences as an OCD sufferer.

I was honoured and privileged to be asked by Joel and the team at OCD Action to get up and talk about my life. To be honest, my initial reaction when I was asked to do it was to say, "Thanks, but no thanks." I've spent my life shying away from opportunities like this, and it's a difficult habit to break. But after I'd had a moment to think about it, I realized that this was a golden opportunity to do a behavioural experiment. I could think of it like an exposure task.

Cognitive Behavioural Therapy (CBT) is full of beautiful ideas and rules. One of the golden rules if you're an OCD sufferer is to "always do the opposite". That is, always to do the opposite of what your OCD tells you – because OCD is a liar.

I wanted to run away from this opportunity...so I did the opposite.

Albert Einstein said: "The most incomprehensible thing about the universe is that it *is* comprehensible."

What he meant by that, is that the most amazing thing about the world around us is that it *can* be understood. OCD *can* be understood. And it *can* be treated. The treatment that has been proven to be most effective so far in treating OCD is called Cognitive Behavioural Therapy. The first time you read a book about Cognitive Behavioural Therapy, it might seem very complicated. But actually, now that I've been through a course of Cognitive Behavioural Therapy, I can see that it isn't complicated at all. In fact, it's very simple. It boils down to this: by changing your behaviour, you can change the way that you see things. That's Cognitive Behavioural Therapy in a nutshell.

In my speech on Saturday I talked about the content of some of my own obsessions, and the nature of some of my compulsions. I started off by telling the audience about an exposure task that I'd done with my psychotherapist just a few days earlier. There were some gasps of horror as I described the task, and then people laughed, probably out of gratitude that their therapist had never made them do anything like that. (And, no, I didn't have to put my hands down any toilet bowls. I managed to avoid that one!)

I'm not going to discuss my own obsessions and compulsions here. That speech was delivered to an audience of fellow OCD sufferers (and professionals), and was for their ears only. I didn't show or read my speech to any of my friends or family members, as I have come to understand that it is not always a good idea to go into the details of your intrusive thoughts with non-sufferers. It's a personal choice, and

there are no hard and fast rules, but I have personally reached the conclusion that as a very general rule, it is fine – and good -- to reveal the fact that you have OCD with anyone that might need to know. Family members, partners, employers, colleagues...you need to make a personal decision about whether or not to reveal your disorder to each of them. In many cases, the best course of action *is* to disclose that you are suffering from Obsessive Compulsive Disorder.

However, I personally now feel that the *content* of your specific obsessions and compulsions should only be revealed to other people on a “need to know” basis. If someone doesn’t “need to know” the exact content of your obsessions and intrusive thoughts, then there is no need to tell them. Try to remember how *you* felt about your intrusive thoughts, before *you* learned that they are not really important. What did *you* think, when you started to have those thoughts? You wrongly thought that they were meaningful, or important. You have since learned that they aren’t important or meaningful at all. But you didn’t realize that straight away. So sometimes someone you love, or someone you know, might react in exactly the same way that *you* did, when you reveal a little bit too much detail about your thoughts. (Trust me, this has happened to me, and it can be yet another difficult hurdle to get over.)

For this reason, I am not going to go into my own specific obsessions in this piece.

What I *will* say is that I’ve had a huge number of different obsessions and compulsions over the years. I think that the sheer number and variety of the types of obsessions that I’ve had puts me in a good position to be able to see OCD for what it really is. And what I’ve learned is that the *content* of your obsessions, and the precise nature of your compulsions, is irrelevant. All types of obsessions, and all types of compulsions, are just different versions of the same problem. It’s like a song that’s been recorded by a hundred different singers. They might all sing it a hundred different ways, but it’s always the same song.

As a child, thoughts would get stuck in my head. Anything I’d done wrong, any tiny “crime” that I thought I might have committed, would go round and round in my head, making me feel sick with worry. I was a bright kid, but I can see now that I misunderstood a lot of basic things in life. During my teens and twenties, I developed more and more obsessions, and a truckload of compulsions (overt and covert) to try to cope with each of the obsessions.

I was still quite optimistic until I went to university. And then, in my first year as an undergraduate, it felt like my brain just blew up. The upsetting thoughts just seemed to multiply. Being at university seemed to overload my mind with obsessions and fears. Somehow I managed to get through university with a degree in Psychology. I don’t know how I did it.

I couldn’t understand what was happening to me, what all these thoughts meant. And I was too afraid to tell my GP or anyone else about what I was experiencing. I

couldn't even make sense of it. It seemed like I had fifty different problems, each one of them enough to ruin my life -- but together, it was just too much.

While I was at university, about a year after my OCD seemed to reach its peak, I started to experience depression for the first time. I struggled on through my twenties, and then through my thirties. I kept my obsessions to myself.

I avoided every opportunity that came along in my life. I avoided having children. I avoided getting married. I avoided any jobs that might have any kind of responsibility – because I knew that I couldn't cope with any of those things. I drifted in and out of one long depression after another. For far too many years, life just didn't seem to be worth living. But through all those years, to other people I appeared to be coping with life. No-one around me ever guessed at the secret torture that I was going through, every day, every week, year after year after year.

I sank into a deep depression about two years ago, and I couldn't get out of it. Earlier this year, I got signed off work and went on sick leave, as I just wasn't able to function any more. (When I read about the Equality Act (2010), and I read the definition of a disability as “a long-term physical or mental illness that affects a person's ability to carry out their normal day-to-day activities”, I knew exactly what that meant. And, yes, OCD *does* meet the definition of a disability, under the Equality Act.) I'd reached rock bottom again, and I couldn't go on. I was tormented by a thousand different obsessions, and the depression went hand in hand with all that mental torture.

I saw a number of different therapists and counsellors over the years. I was glad to have someone to talk to, but I felt like I wasn't getting the breakthrough that I was hoping for. The therapists kept recommending books that didn't seem to relate to my own problems, and giving me advice that seemed hopelessly inadequate.

I finally managed to find out that I could refer myself to the NHS Oxleas Trust mental health department in my area. By this time, I'd read “Overcoming Obsessive Compulsive Disorder” by David Veale and Rob Willson. I couldn't believe what I was reading. They were describing some of my obsessions and compulsions word for word. It was like someone had stuck a camera inside my brain, and had been filming my life for the last twenty or thirty years.

By the time I got to see a properly trained Cognitive Behavioural Psychotherapist, I was ready to get to work. I was ready to believe that the fears I had were nothing but lies I'd been telling myself out of ignorance. I was a good person who'd been suffering from a number of problems, including Obsessive Compulsive Disorder, since I was a child. For the first time in twenty years, I was able to let go of the burning self-hatred that had consumed me and ruined my life. I was ready to forgive myself, and embrace the idea that I was not a bad person; I just had an illness, and that illness was called OCD.

The psychotherapist that I happened to get allocated to on the NHS was fantastic. He didn't talk down to me; he didn't laugh at my theories; he was like a collaborator. He made it clear that I would have to do all the work, in order to get rid of my OCD. He wasn't going to do the work for me. He would open the door – but I had to walk through it.

With his help, and with all of the OCD books that I read by myself, I managed to start turning things around. For me, the exposure tasks played an important part in my recovery. But the *cognitive* part of the therapy was just as important. Understanding the *meaning* of my thoughts. Week by week, little by little, I came to understand some incredibly important things that I'd never quite got my head around before. Some of my breakthroughs were obvious, simple things, but somehow I'd never quite understood them in the past.

I learned that a thought is not the same as an action. Thoughts and actions are two totally different things. No matter how horrific a thought is, it's only a thought. It doesn't mean anything about you, that you had the thought. It isn't important – unless you *make* it important.

While I was looking for some inspiration for my speech, I started to read an article about Mahatma Gandhi. And I learned that: "...in the struggle against the British, Gandhi employed non-cooperation, non-violence, and peaceful resistance as his weapons..."

Now, I can really relate to those ideas, because I think that's a good description of some of the techniques that you need to use against your OCD. Non-cooperation...non-violence...and peaceful resistance. That describes it perfectly.

In my opinion, you can't defeat your OCD by fighting against it. Fighting will only make the problem worse. But you *can* choose *not to co-operate*.

Over the last few months, I've started to see myself as being part of a minority group. That group is made up of everyone who is suffering from OCD, or has suffered from OCD at some time in their lives. I'm told that there could be somewhere in the region of one million people within that group in the UK alone. That's a lot of people.

Now, if I want to make life better for people like me, people who have suffered – or are suffering – from Obsessive Compulsive Disorder, then I need to do something about it. So what can I do? What can anybody do?

On my own...not much. But maybe if I get together with other people who've been affected by OCD, together we *can* do something.

Because of my OCD, I found that I reached a point where I couldn't cope with my life any more. I couldn't cope with my job; I couldn't cope with anything. Now that I've managed to get the appropriate help and treatment for my OCD, I've started to make some plans for the future. And those plans include getting involved with OCD Action,

and getting involved in the fight to improve the lives of everyone in this country who's affected by this crippling, horrible illness.

OCD made my life a living Hell, for too many years. Now I've got my life back, and I intend to keep hold of it.

If you have OCD, then there are two fights that you need to be aware of. The first fight is the one against your own OCD. In my opinion, the only way to win that fight is by *not fighting*. Non-cooperation; passive resistance. Choosing *not* to co-operate with your OCD.

But if you want to get involved in a *real* fight, then get involved with the charity. Get involved with OCD Action. Call up the charity, and tell them that you want to get involved. Tell them what you'd like to do. Tell them what you're *able* to do. If you think there's something that the charity *could* be doing, and isn't doing it already, then phone up OCD Action, or email them, and tell them what you think they *should* be doing. And ask them what *you* can do to help.

If there really are a million of us out there, all around the UK, living in our own private, secret Hells, then imagine what we can do if we all stand up together and demand to be listened to.

If you have OCD, then you've suffered long enough. Stop suffering, and start fighting. Get involved with OCD Action today.

To steal blatantly from President John F. Kennedy, ask not what the OCD Community can do for *you* – but what *you* can do for the OCD Community! (Or, as Jerry Springer always used to say, "Look after yourselves...and each other.")