



# OCD-UK

Supporting children and adults affected by Obsessive-Compulsive Disorder

by Ashley Fulwood, CEO OCD-UK

Whenever you read an article about Obsessive-Compulsive Disorder, it is usually accompanied with the image of a pair of hands being washed, it's almost become stuck in our consciousness, 'think OCD, think pair of hands being washed'. Yet every single image I have ever seen shows a pair of immaculate perfectly manicured hands. But let me tell you from personal experience, if your OCD focuses on a fear of contamination and involves compulsions about washing, your hands will look anything but perfectly manicured! My hands have looked old before their time since I was in my 20s and remain so now I am 39 (plus 24 months... sorry I can't bring myself to admit I am in my 40s having lost the last 20-years to OCD!). However I think the image that was circulated very recently of Emily graphically illustrates the impact of OCD far more than my words ever could.

Thankfully Emily tells me she is now well on the road to recovery, but the reason I wanted to show this image is to ensure that there are no misunderstanding that OCD is minor illness, that involves a little hand washing and a few funny pernickety traits.

In general mental health stigma is starting to change for the better but to quote a colleague, Lottie, "*OCD is the poor cousin of mental health*", it is still deemed ok to joke about OCD or use the



Emily

term 'Oh, I'm a bit OCD about that'. Let me tell you, it's not ok to do either!

Left untreated OCD can lead to disablement as serious as physical disability that impacts on education, careers and relationships, all of which is why the World Health Organisation once listed Obsessive Compulsive Disorder in the top ten most disabling illnesses in terms of loss of income and quality of life. Sadly, it does not just end there, sometimes OCD can lead to sad and tragic consequences.

As graphic as the image of Emily is, what the image does not show is the mental anguish, the mental torment Emily would have been going through, just as every single person with OCD is going through every single day. When talking about OCD people often focus on the compulsions, without realising it is the obsessions which drive the illness, which cause the mental torment and the OCD cycle (pictured on opposite page).

So for example in the case of someone that washes (the compulsion), for me my obsessive fear was the thought I might be contaminated by germs, and spread that around. At its worse, my OCD Cycle would take 3-5 hours just to use the toilet!

However, OCD goes far beyond that relatively well-known aspect of the illness. Many people with OCD don't have any obvious compulsions (other than reassurance seeking), they suffer with unwanted intrusive thoughts, thoughts of being gay, thoughts of wanting to hurt someone they love, thoughts of inappropriate sexual behaviour such as being a paedophile. All of which are common forms of OCD, but rarely talked about because of how they may be perceived.

Sadly even when people with those forms of OCD do pluck up the courage to speak to health professionals, uneducated health

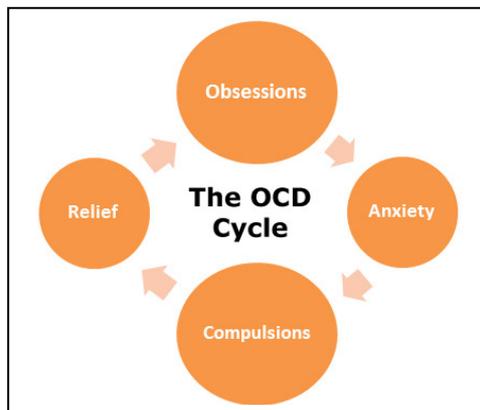
professionals often fail to recognise this is OCD and that their patient does not pose any more (less in fact) risk than you or I, and they over react and involve other agencies. This is absolutely unnecessary and potentially more damaging for the patient and their family. I am afraid some of the stories I have heard are shocking, and all could have been avoided had the health professional referred to the paper 'Risk assessment and management in obsessive-compulsive disorder' by Veale, Freeston, Krebs, Heyman and Salkovskis before they involve other agencies. I can send the paper to anyone that would like to review it.

This is one of the key problems we have realised is faced in treatment of OCD, and one area that we feel health professionals need help and guidance about, so it will form part of our OCD Conference for Health Professionals in Nottingham on Friday 31<sup>st</sup> Oct. The following day (Saturday 1<sup>st</sup> Nov.) is our annual conference specifically for people affected by OCD and their families. To book either day, or for further information please visit [www.ocduk.org/nottingham2014](http://www.ocduk.org/nottingham2014)

Incidentally, the obsessive intrusive thoughts I refer to above may sound strange, but are actually very common. Think about it for a moment, how many of you have stood on a crowded train platform with someone annoying you and had the thought, oh I could so push that person off the platform? I would hazard a guess the majority of you, the difference is your thought is a one-off in and out that is gone within seconds, or at least once the annoying person is out of view. For someone with OCD their intrusive thoughts don't go, they remain and grow. Research conducted in Canada a few years ago with several hundred university students, none

of whom had any mental health problem diagnosis, showed that a large proportion of them all admitted having the same thoughts I described above. But it is not OCD because they don't obsess over the thought, their thoughts were not impacting on their life.

What this shows us is the intrusive thoughts themselves are not the problem, it is the way the person with OCD deals (or perhaps interprets) the thoughts, that is the problem, and that is where the Cognitive part of the treatment (Cognitive Behavioural Therapy) can be so beneficial.



For those working with patients affected by OCD, one piece of advice I would offer is to remember, every person with OCD will be different. For example, two people may be exhibiting the same OCD compulsions, but doing so for very different obsessive fears.

Understanding your patient is vital and knowing the facts about OCD is only half the key, the other is understanding the 'feeling' of what OCD is like is the other. Over the years there have been many films about OCD, Hollywood blockbusters like *The Aviator* and *As Good As it Gets* but nothing in my opinion has captured the 'feeling' of OCD better than this short six-minute film called '*Locked*' produced by one of the OCD-UK trustees, Claire Gellard. You can view it at [www.ocduk.org/locked](http://www.ocduk.org/locked)

## So what else makes a good therapy experience?

I recently made a short presentation to a group of therapists in Maidstone, and I decided to involve patients within my presentation by inviting them to help me compile ten therapy tips for therapists. Ironically I met some resistance with some of them with excuses ranging from service restrictions don't allow it, to not wanting to be recorded. However the fact remains, all ten of these would improve the therapy experience for the patient, so less excuses and more action on these please!

### 1 – Introduce yourself

Sounds obvious hey? But some patients are several sessions into therapy and the therapist is yet to give their name. Giving your name improves trust. Use the badge template shown.

# **hello** my name is...

### 2 – STOP IT!

Don't tell a patient to just stop having their thoughts, or stop doing their compulsions. If it was that easy they would not be sat in front of you! Again, it should be obvious but therapists still do it. To see how unhelpfully ridiculous this is, watch this sketch - <https://www.youtube.com/watch?v=Ow0lr63y4Mw>

### 3 – Don't tell your patient you know nothing about OCD

My therapist (IAPT) admitted she did not know anything about OCD. Whilst this was honest, and better than someone bluffing their way through therapy, it did not fill me with confidence, so the therapeutic relationship ended at that very moment she admitted she did not know anything.

#### 4 – Too little, too late

Often patients wait weeks, months, or even years to seek help, or to get to the top of the waiting list. Don't limit therapy sessions to just 6, it puts pressure on the patient before therapy even starts. Obviously it cannot be unlimited therapy, but be sure that the patient knows they won't just be thrown back to their own devices after 'x' sessions.

#### 5 – Treatment on location

For some, OCD is specific to certain places, so it makes sense to get out on location and do some of the therapy where the problem occurs. Don't be afraid to get from behind your desk.

#### 6 – Risk assessment in OCD

Discussed above.

#### 7 - B without the C is like fish without the chips!

Some patients report their therapists only do behavioural (ERP) exercises, and no cognitive work, or vice-versa. We know CBT works, and for most patients it needs the C and B part.

#### 8 – Homework – Set it, check it!

Therapists rightly set homework, but patients often report the therapist never follows that up with the patients at the subsequent sessions. Set it, check it!

#### 9 – Audio record sessions

Therapy can be emotional and it's amazing how much is discussed in therapy, but the patient forgets due to the emotions of the session. So invite patients to audio record the sessions, and to play them back after therapy. Invite them to use their mobile phone or buy a Dictaphone. Get your service to buy some to loan to patients.

#### 10 – Involve loved ones

Loved ones often get sucked into the OCD, so it is important family

members know what they should and should not do to help the person with OCD. Even if they are not present at therapy, with the patient's permission you can write a letter/report to them with some advice and instructions.

But despite the problems the OCD brings those that suffer, despite the problems accessing treatment and some of the actual therapy problems listed above, I think the biggest challenge OCD sufferers (or OCD survivors as I like to call them) face is the stigma that the trivialisation and misconceptions of OCD cause, not helped by the pathetic Channel 4 programme, Obsessive Compulsive Cleaners. The stigma makes a person feel isolated and alone, and we can all do something to change that. We are doing our bit with OCD Awareness Week in October (13-19<sup>th</sup>)

So next time someone uses the term 'Oh, I'm a bit OCD about that', pull them up on it, challenge their words, point out unless it causes them to be anxious or impacts on their life it is not OCD, help them understand there is no such thing as 'a bit OCD'!

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**OCD-UK is the leading charity working for children and adults affected by Obsessive Compulsive Disorder.**

[www.ocduk.org](http://www.ocduk.org)

## OCD and Work

by Catherine Mills

I have suffered from OCD and Tourette Syndrome since the age of 9 years, yet only received a diagnosis age 36, having previously received treatment over the years for depression and an eating disorder.

Unfortunately I was unable to confide in anyone about my OCD for fear of being 'locked away', such were the distressing nature of my intrusive thoughts. I have been through the gambit of rituals over the years such as checking and contamination although in the main I'd managed to hold down responsible jobs and achieved professional qualifications.

By the age of 36 life had become pretty unbearable; the Tourettes was distressing and exhausting and the OCD just ground me down to the point where I contemplated taking my own life.

I became very depressed and reached the stage where I was barely able to function or get out of the house. Eventually I broke down and was signed off work for a year. It was a very difficult year although I tried to convince myself that I was doing OK, having been started on a regime of medication and receiving therapy.

I'd had a spell in hospital and then attended the day hospital and felt morally obliged to return to work. Despite having wonderful employers at the time, I was simply not well enough to go back to my management role and after about 2 months I had to go off sick again.

That was 16 years ago and the prognosis was not good, with neither myself nor others believing I would ever be able to return to work again.

So the years rolled by and I returned to the safety of hospital and the day hospital where I felt as secure as I could. After about 3 years of this, I took a big step and started volunteering with OCD-UK, Mersey Care NHS Trust and Sefton Carers. I was pretty terrified of returning to a work-like role although I had the safety net that the work was voluntary. However, I felt very committed to my work and treated it as seriously as I would a paid job. Very, very slowly my confidence started to pick up although the progression was over years rather than weeks or months.

During this period I was referred to specialists around the country in OCD and Tourettes and this helped a lot. Although I received excellent care from my local NHS Trust, they didn't have the necessary expertise to help me in the way I needed. What my Trust did offer me though was a psychiatrist and psychologist, neither of whom ever gave up on me or lost faith in my ability to lead a productive life again.

Three and a half years ago I was offered the opportunity to do some temporary part time work with my local NHS mental health Trust. This proved to be a huge step in my recovery and it was with great trepidation that I applied for the opportunity and was successful. They were to all intents and purposes offering me a work trial. I was able to stay on my DWP benefits as I earned only the amount I was allowed to earn under the permitted earnings rule. So the Trust that had cared for me over the years was now offering me an opportunity to test out the world of employment, what a statement of faith!

I stayed in this role for 12 months and towards the end of that period a permanent part time job

was advertised which I now had the confidence to apply for and was successful. That was two and a half years ago and I have loved every minute of my work since. My employers are very supportive, especially my manager who understands if I have any particular requirements around my mental health. Although I don't broadcast my difficulties, a lot of my colleagues are aware that I am also a patient with the Trust and accommodate my sometimes eccentric little ways!

Life is not a bed of roses and each and every day I have to battle against the bully that is OCD. It is always trying to play silly games with my head and sometimes it wins and that gets me down. Sometimes the job presents challenges and pressures and they are not always easy to deal with as my symptoms do exacerbate. But I'm more than holding my own and being surrounded by good colleagues helps a lot.

My life is restricted in a lot of ways due to the OCD but I am conquering the work challenge which helps build my confidence. After years of depression, that is now in remission. I still receive therapy and see my psychiatrist on a regular basis but that is helping to keep me well. I am now 52 and my journey has been a long one, but I hope it gives hope to others who are just starting off on theirs.



*Our sincere thanks to Ashley and Catherine for sharing their experiences and knowledge of OCD with us.*

*Ed*

Institute of Welfare 2014