



One conversation at a time

To coin a phrase from the *Time to Change* website, “There are no hard and fast rules for talking about your mental health” says OCD-UK project coordinator, **Beth Hemus** ▶

As project coordinator for OCD-UK's current mental health anti-stigma campaign I have observed and contributed to hundreds of mental health-themed conversations with the general public. And I have to agree with our funder: there are no hard and fast rules, and this is probably why it can feel like such a minefield at times. It's painfully obvious that OCD is still shrouded in a veil of misconception, trivialisation and poor taste jibes. "OCD is the poor cousin of mental health in that people tend to joke about it and trivialise the suffering of those living with it," says Ashley Fulwood, Chief Executive of OCD-UK. 'But it is a serious illness and it can lead to tragic consequences.'

The pioneering "Stigma Shout" survey carried out by Rethink on behalf of Time to Change, was an information-gathering exercise that would steer a 3-year mental health anti-stigma campaign, of which OCD-UK are an affiliate partner. It involved more than 3000 people with mental health problems, and starkly illustrated the volume and impacts of mental health stigma and discrimination nationwide. A startling 9 out of 10 sufferers consulted experienced stigma and discrimination that had a negative impact on their life and, in some instances, proved more difficult to deal with than their illness. Immediate and wider family, friends, neighbours, employers and GPs were identified as the most prolific discriminators. And stigma and discrimination were evidenced to lock people in a cycle of illness, with the effects of stigma and discrimination being contributing factors to mental illness. For example, barriers to employment are a common impact of stigma in the workplace and low income is a recognised contributing factor to mental illness. The full '**Stigma Shout**' survey report can be found at www.time-to-change.org.uk/sites/default/files/Stigma%20Shout.pdf

When examining these facts, I am left with no doubt that mental health stigma and discrimination are very real and serious issues that we all have a responsibility to challenge and eradicate. We are now approaching the end of Time to Change's 3-year anti-stigma project, and in that time, thousands of volunteers with lived experience of mental health

issues have been engaging the general public in anti-stigma themed discussions. I live in hope that these brave and important efforts have made a significant impact on this retrograde problem.

During the course of our project, my volunteer team and I have engaged people with every imaginable attitude towards OCD and mental health at large. Having been tasked with the responsibility of shifting negative or inaccurate attitudes towards OCD, we are consistently making efforts to engage people who present as 'cold' to mental health issues; that is to say that they are openly stigmatic or discriminatory. This can involve crossing the road to avoid us at events, making jokes in poor taste about OCD to a member of our volunteer team, and everything in between. Poisonous reactions are in the minority and we generally receive empathic attitudes from our audience, with most people expressing gratitude for the opportunity to learn more about what they come to understand as a serious issue. The wilfully ignorant and unsympathetic are far outnumbered by the curious and the kind.

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But negative responses we have had. Most commonly, people exhibit a trivialised and inaccurate perspective of the illness, with the vast majority of people claiming to have ‘a bit of OCD’ as they approach our stand. In this way, OCD-UK’s provocative choice of project title (‘Are you a little bit OCD?’) has served as a conversational bridge time and time again. This type of conversation can and does result in a positive shift of attitude in our audience members, usually because we share our personal stories and information about the illness in a digestible, clear and confident manner.

With this experience in mind, I have been asked to write an article about ‘talking OCD’ for the magazine, with a particular focus on how to manage negative and challenging reactions. The advice below has been generated by myself and my volunteer team and is based on our personal experiences as well as our experiences during OCD-UK’s anti-stigma project:

- **Make sure you are ready**

You are not under pressure to share information about your OCD with anyone if you don’t want to. Before you disclose anything to the individual or group in question, make sure that you feel comfortable with the idea of talking about your mental health issues with them and are prepared for the different reactions you might receive. My team and I all agreed that talking about your experiences in the right context can make you feel better and can be very cathartic as it liberates you from the need to hide your illness. Make sure that you have your conversation at a time and environment to suit both you and your listener.

- **Be empathic**

Fear of using clumsy language, or of reacting unhelpfully and making your situation worse, can often barrier people from talking to you about your OCD. Try to remember this when sharing information and be as patient and understanding as you can. You can signpost friends, relatives and colleagues to the following link, a guide developed by Time to Change to support talking about mental illness with sufferers: <http://www.time-to-change.org.uk/talk-about-mental-health/tips>.

- **Beware your own projections**

Evidence indicates that the level of stigma sufferers expect at the point of disclosure vastly exceeds the actual stigma experienced. Indeed this is something that everyone I spoke to about this article resonated with. We have all hidden our illness from friends, family and employers at some point for fear of judgement and/or rejection. Sometimes you will experience a negative initial reaction, but these usually shift overtime. And if this is not the case, heed the piece of advice below.

- **Share information about your mental health unconditionally**

When unpacking this piece of advice, my volunteer team and I identified the inherent contradiction in the statement; i.e. expectation will surround every disclosure made to those that play an important role in our life. But managing expectations



and an unconditional approach will minimise the hurt and disappointment that a negative reaction can incur. We cannot control the thoughts and actions of others and we should not, in turn, be controlled by them. Being honest about our mental illness and talking about it openly is an important step in everybody’s recovery journey. If someone close to you reacts to your sharing in a toxic way then do not mirror their fear-based, intolerant reaction. Try to remember that being honest about your illness will ultimately serve you and everyone around you.

- **Be informed**

People will probably ask you a lot of questions about your OCD as they try to reconcile their perception of you with their (sometimes stigmatic) perception of your illness. The more information you can give them about your OCD, how it impacts on you, and how they can support your treatment and recovery, the better equipped they will be to react in a helpful way.

- **Stand up to stigma and discrimination in a constructive way**

Winston Churchill is quoted as saying ‘You have enemies? Good. That means you’ve stood up for something, sometime in your life.’ For whatever reason, some people may respond to OCD in a stigmatic or discriminatory way. Try not to react in a way that clouds the issue. This is sometimes easier said than done, but reacting with clarity instead of anger will keep the situation on point. Make it clear that this kind of reaction is evidenced to lock people in a cycle of illness and explain why you have a problem with what has been said or done.

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Through talking to the general public we have identified that the majority of misunderstanding about the illness has its origins in something watched on TV, read in the newspaper or heard on the radio. Don't be afraid to respond to examples of stigma and discrimination in public forums or the media; by sending a constructive letter or email you are helping to challenge the issue and it will give you an enormous sense of empowerment. Standing up to stigma in a productive way ultimately strips it of its power.

- **Ignore the trolls**

Rise above thoughtless negative comments and do not waste your energy engaging in conversation with people who are seeking to rile or provoke a reaction. Let's be honest; if reacting to this kind of wilful ignorance in a negative way solved anything, the problem wouldn't exist anymore. As the famous prayer goes *'God, grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.'*

- **Know your rights**

The Equality Act 2010 makes it illegal to discriminate directly or indirectly against people with mental health problems in public services and functions, access to premises, work, education, associations and transport. Advice on how to manage unfair discrimination can be found at: www.gov.uk/discrimination-your-rights/what-you-can-do.

In summary, communicating honestly about OCD may not be easy but it will support your recovery, it can shift perceptions and is absolutely vital if we are to eradicate the misrepresentation that surrounds this illness.

Every conversation matters. Even conversations that feel ineffective at the time can go on to shift personal, and eventually public, attitudes. As someone who has been openly disclosing their mental health history to complete strangers for several months now, I cannot extol the virtues enough. The personal catharsis is beneficial, but knowing that I am doing my bit to end the stigma and discrimination that surrounds OCD and other mental illnesses is incredibly rewarding.

Wishing you the very best mental health and happy talking. Beth (beth@ocduk.org) ■

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STUDENTS CHANGING ATTITUDES

OCD-UK member and teacher **Julie Wainwright** (pictured far right) recently spoke about OCD to her students in 11Jervaulx at St. Francis Xavier School, Richmond, who subsequently collected £110 in loose change over Christmas for OCD-UK.

After talking to her students about OCD, Julie shared this fantastic story with us.

"I think actually educating students about the challenges that sufferers face, especially over Christmas, is what actually encouraged them to help with our Christmas

donation. It was lovely to hear one of my students sternly correct a younger student in the corridor who made a flippant OCD comment today. This student actually explained why the student was wrong to make the comment and informed the student about the debilitating nature of OCD. I was so proud of her. Education really does work."

Julie is so right, as we have found with our 'Little bit OCD' project, talking really is a great way to educate.

Thank you Julie and 11Jervaulx!

