I was first diagnosed over 10 years ago, but until last year I don't think I had ever said these words out loud to a group of people...even many of my friends don't know what my actual diagnosis is, they simply know that I have “a mental illness” that effects my ability to function in various ways. They know I take medication, they know I am regularly under the CMHT (community mental health team), some of them even know about the times I've ended up in hospital. But the actual name of what I have, or the actual specifics of my symptoms, I tend to keep that quiet.

“Many of my friends don't know what my actual diagnosis is, they simply know that I have ‘a mental illness’.”

It's hard to explain why I try to keep my illness vague, I know many would try to hide that they had a mental illness at all rather than only hiding its name. But as I can't do things like hold down a job or attend many social functions I find the fact that I am ill has become essential knowledge for some people to help them understand that I am not being lazy or awkward. Also, to be honest, at times it's impossible to fully hide my illness anyway when I am acting erratically, looking for signs and clues to some unknown mission, or staying up for days at a time frantically writing in notebooks. Obsessively watching a politician on TV and recording his blinks looking for a secret coded message (true story, I did this for several weeks in 2020). I used to try to fully hide my illness, but the stress or doing this only made things worse.

So why do I still hide my diagnosis so much?

Honestly, fear. Very few people have even heard of schizoaffective disorder, let alone actually know what it is. And when people google it many of the search results are often not exactly positive in nature – or even accurate. Some people may go to reputable sites for information, and that's ok, the charity Mind for example has a section aimed at friends/family of those with schizoaffective, and Rethink’s factsheet is fairly accurate (both linked at the end of this blog). Other people though may end up seeing alarmist headlines, overly negative or dangerous portrayals, or they may just see the word “psychosis” and panic...

“In short they associate psychosis with dangerous, and I just can't face losing any more friends to this misconception.”
I have had this happen before, friends who have learnt that I hear and see things that others don't and have panicked, never to speak to me again. Sometimes it may be because they don't know how to act, but often it's because they now see me as someone who is potentially violent, unpredictable, and just not a safe person to know. In short they associate psychosis with dangerous, and I just can't face losing any more friends to this misconception.

“I'm a person with normal wants and needs. I'm no more dangerous than anyone else and when people make assumptions it hurts. I am human and I do have feelings”

I have schizoaffective disorder, I experience the world in a very different way to many. I hear voices on a regular basis, and I often have delusions of grandeur wherein I am not human and I exist solely to save humanity, I have blunted affect and so often don’t show emotions, I get paranoid and feel like people are watching, following, tracking, or trying to hurt me, I have strange distortions in my vision and sometimes see shadowy figures following me. Stress and lack of sleep can make my more ill, and historically I can't hold down a job for more than a few months at a time. But I am also a person with normal wants and needs, I am no more dangerous than anyone else and when people make assumptions based on my diagnosis it hurts, because regardless of what I believe when I am in a delusion I am human and I do have feelings.

I have schizoaffective disorder, and that shouldn't be a scary thing to say or hear.

Resources in England

- Rethink - https://www.rethink.org/advice-and-information/about-mental-illness/learn-more-about-conditions/schizoaffective-disorder/

York Ending Stigma

To find out more about all our work and to join us to end mental health stigma in York, please refer to our website https://www.yorkcvs.org.uk/york-ending-stigma/ or email us on yes@yorkcvs.org.uk