

Lived experience of stigma and recovery

Dr Jo Barber, service user



On 21st April this year I was privileged to speak at the conference 'Silent Prejudice: Stigma, spirituality and mental health', held by the Spirituality Special Interest Group at the Royal College of Psychiatrists. My talk was entitled 'Lived Experience of Stigma and Recovery' and it included description of all the different sorts of stigma I have experienced as a long term mental health service user over many years.

I once had the experience of being hospitalized for several years, and more recently have been supported on many occasions by the Home Treatment Crisis Team. As a qualified medical doctor and a religious person, I have been particularly vulnerable to stigma. I identified four distinct ways in which I have been stigmatized. The first, amongst any friends that I did have, was stigma against mental illness in general, especially when I received a diagnosis of schizophrenia. The second was concerning the fact that I was a doctor with a mental health problem. Some of the clinical staff in the hospital where I was a patient commented that I had a good job and must be intelligent and therefore should not have succumbed to a mental illness. The third experience of stigma occurred within the church I attended, where my religious problems were thought to indicate possession and I had deliverance ministry. Unfortunately, this was unsuccessful and I left the church feeling disgraced. The fourth experience was in the hospital, where it was assumed that my difficulties were purely the result of illness and I should have been cured by medication. Unfortunately, although medication was partially helpful, it was by no means a total cure. Again I felt blamed and I was confused by the conflicting messages I received from the ministers at the church and the hospital staff.

Spiritual care has helped me to overcome many of these difficulties. Spiritual care assumes a spiritual dimension to mental health problems and seeks to help people find positive meaning and purpose through their religious or spiritual experiences. It involves firstly making a trusting therapeutic relationship with the care provider so that a spiritual assessment can be made. Referral to the appropriate faith chaplain can be made if desired by the service user. In my talk I described the difficulties I had trusting anyone with the details of my experiences and how eventually I came to trust a particular psychiatrist who helped me faithfully over many years. He referred me to a Christian chaplain. The job of the chaplain is to use their expert discernment to disentangle religious experiences from symptoms of illness and help the person to address their difficulties in a way acceptable to them.

Crucially, spiritual care is a holistic intervention, validating and respecting peoples' experiences without any stigma or judgement. For me personally, this was life changing. I now have rejected some of my misconceptions about religious doctrine, and have much better acceptance, understanding and control over my experiences. I have an active life, living on my own with my cat and doing some mental health research. Most importantly, I have found a church where I receive understanding and care. I no longer feel stigmatized for having mental health problems and I am very grateful to all the people who have helped me along the way. It is only when you feel accepted and valued by others that you can begin to accept and value yourself.