

### **Case Story 5: Clare's Story** (names of people, places and identifying features changed)

Clare has personal experience of using the mental health services in Ireland. She discusses her experience in private and public care.

Clare starts by describing what happened when she sought help with coming off her medication.

*"On a number of occasions as I was becoming stronger in myself and having ideas about my own recovery I felt I wasn't being listened to. I remember one occasion in particular, when I was going to an outpatient clinic and suggested to the psychiatrist that perhaps I didn't need to be on Lithium and that I could be tapered off of it. I mentioned this in a very passive way, following a long wait for the usual five minute interview where I'd only be asked the most basic of questions and without any kind of check in to see how I was really managing. The psychiatrist at the time came down on me very heavily and I remember the words he said. He said "You have a disease. You need to be on this medication for the rest of your life." Well here I am, nine months completely free of medication with no problems. I've never been happier or healthier in fact. I remember walking out of there and feeling like I was two inches tall."*

Clare describes her experience of poor communication between herself and her psychiatrist.

*"Most of the time you don't tell your psychiatrist anything at all because you're on your guard and end up withholding most of your information because you manage yourself...you might say something that will cause their [the service's] alarm bells to go off and inadvertently cause yourself more problems. They don't have a full picture of you or your life. They base their decisions on very scant information because they don't ask you any real questions. They just latch on to some unimportant aspect of what you say and make a mountain out of a molehill. There just isn't enough time with you for them to garner any idea of what's really going on with you."*

She describes what happened on one occasion when she approached her psychiatrist for help with sleeplessness.

*"I approached the psychiatrist to seek support in getting some sleep. I explained I was afraid of becoming unwell and thought I would benefit from getting some real rest through sedation to prevent any escalation of symptoms. I explained I needed to rest. The doctor said that they would take me into the hospital so that I could receive sedation and rest. I was voluntarily admitted into a psychiatric unit in 2010. I was very well overall but due to the stress of the new work project I had overextended myself and wasn't sleeping well.*

*I went into the hospital. I had to be voluntarily admitted and had to go through A&E so there was the whole rigmarole of blood tests and questions and interviews. Whatever existing stress you might be feeling gets magnified one hundred-fold in that scenario. For example, the doctor in the A&E didn't have a proper rubber band to take my bloods so he used a ripped plastic glove which really hurt my arm. Then because I was reacting to it, there was an assumption that it was symptom related – an "oh, she's a psychiatric case" attitude. In that kind of situation there's a real sense that your rights aren't being observed – no one should get their bloods done like that. So my stress levels were going up."*

She describes how she was coerced into taking medication while in hospital.

*“That particular night, they told me I had to take Zyprexa [an anti-psychotic] which I disagreed with. I explained I had been admitted on the understanding that I was to be sedated and to be just given an injection to sleep it off as I was in no danger of becoming psychotic. I explained I needed to sleep. However, it’s the last place to go to rest when you are in the viewing bay of a public ward with a nurse and two doctors either side of you and bullying you into taking Zyprexa against your will...They wouldn’t stop trying to coerce me into taking the drug. They were bullying me. I had no support and was completely disempowered and in the end I just relented and gave in and took it. Then the next day, they very sneakily gave it to me without telling me and I noticed because it’s the one that dissolves on your tongue. I couldn’t believe it.”*

Clare describes how she was unaware of how to make a complaint.

*“The times when I was most unwell were the times when I was not aware that I could make a complaint or I was never led to believe that my voice mattered at all.”*

She describes why she did not make a complaint during that hospital admission.

*“At the time I don’t remember feeling like I could complain about it because I was in pyjamas, I wasn’t allowed to leave the ward, I had family coming in and all sorts of other dramas to deal with in my personal life. So making a complaint was not in my interests at the time and was the last thing on my mind.”*

She describes how she felt unable to make a complaint due to being preoccupied with her condition, being unaware of how to make a complaint and lacking the support to do so.

*“At the time you are so engrossed in this problem that you have become that you can’t see beyond it and you don’t actually think about other avenues like complaining. You are also not aware of it. Nobody tells you about it. In fact, I was never approached by a social worker, not once. Surely a social worker would be helpful to explain your options and give you some support to get your needs met.”*

She describes how having some type of support person would have helped her deal with her dissatisfaction with the service at the time.

*“It would have been nice to have someone to hear my side of the story for a change but part of it is so complicated because for me at that point I just took it all as some kind of joke. I was going around the hospital messing, saying things like “Uh oh, watch out – I’m in danger of becoming psychotic!”*

Clare describes getting a poor response when she raised a question about her experience at a public forum.

*“I was attending a public educational lecture about bipolar disorder and a very eminent psychiatrist was discussing the do’s and don’ts of bipolar disorder...[I explained that] I had approached my psychiatrist for help with sleep, was taken into a public hospital on the basis of my request to be sedated and instead, was put on an anti-psychotic tablet. The doctor’s*

*response to this, in front of a few hundred people in the audience at this 'informational' lecture was just, "shop around." You can't really "shop around" when you're put through experiences like that. You can't "shop around" when you're unwell and living in fear that you're only going to get worse or "cracked". You're made to believe that you're not in your right mind, that there's something wrong with you, that you're living with a disease, that you're never going to change, that you're never going to get better. That is the attitude you get."*

Claire also describes another incident which made her feel like making a complaint. She describes not being listened to by her psychiatrist and not being supported to make the changes to her treatment that she preferred. During this time she wanted to access counselling and wanted to stop taking medication, but her psychiatrist failed to give her support for either of these changes.

*"I had an ok relationship with this [other] doctor although I found him to be rather arrogant. In general and because it was so early in my diagnosis I was living in fear of becoming unwell and so listened and did everything they said. I think it really retarded my development by quite a few years. I was always managing the condition and didn't do anything that might put me at risk like working. I was on edge constantly trying to avoid 'relapse' and did what I was told.*

*I remember asking if I should get some counselling and being told that my mood had been "so severely disturbed" that it wouldn't be much use. Later on I asked about it again and was told that it wasn't really necessary because "this is just the way you are". Basically the line is take the drugs and shut up. After requesting wanting to come off the medication several times, I just kept getting fobbed off and told to come back in a few months time to discuss it which never happened."*

She describes another occasion when she asked questions about a possible pregnancy and she felt that her psychiatrist responded in a patronising way towards her that added to her anxiety.

*"The psychiatrist seemed to think it was reasonable to question me about [my boyfriend], our relationship and whether my family were approving of it or not. Regardless as to whether he might have been a bad influence or not, it was a very inappropriate way to speak in front of him and in front of me. I was in a very nervous state as it was. I was becoming unwell but was also concerned about possible pregnancy and asked the doctor about this. Instead of being supportive and informative, I remember him really taking advantage of that moment to scaremonger me and in a heavy handed, patronising fashion warned me of all the dangers associated with my medication and pregnancy which further added to my anxiety and distress."*

She describes what happened when she tried to get help during a crisis and could not get help from her doctor after normal office hours.

*"I remember becoming very unwell and calling him and getting no answer, he wasn't available. It was a big problem for me that there was no after hours service available rather than having to contemplate the commotion of A&E."*

When asked to reflect on all of the occasions when she was dissatisfied with the mental health services, she describes the reason for not making a complaint in terms of the negative effect it would have on her recovery.

*“The biggest factor that stopped me from making any kind of formal complaint was that I needed to focus my energy on getting myself well. I was so determined to free myself from the system that any formal complaint procedure would just bring it all back to me. My main priority is to be well and stay well and not have to ever go near those people again.”*

She describes how she feels about the mental health system now. She talks about the shift into community-based services as being ‘superficial’ and that the system for getting into hospital is stressful for service users.

*“The shift into the community is superficial. As far as I can see they are just going to replicate the existing model and culture out in the community. People are very vulnerable. They are seen as being in danger of becoming manic or suicidal or self harming and the only option considered to deal with this is by admitting people to psychiatric facilities which can sometimes add more stress in itself. For example going through A&E or being admitted the first time when there’s no sense of calm or peace there. There are too many questions and procedures and pressure on the person in distress. I think some form of safe houses would be more useful, a place where you could go to feel safe ... I believe the psychiatrists working within the current medical model don’t spend enough time researching how to reduce people off the drugs.”*

Claire concludes by describing where she is now in her recovery.

*“I disengaged myself from the services and moved to a private psychiatrist who was interested and willing to work with me in reducing my own medication in a very careful way over time.”*