



Exploring the medicine experiences and needs of patients from under-served communities

Transcript for Sue

Listen to Sue's narrative

I'm 25 years old and I suffer with chronic illnesses and also mental illness. They have given me a diagnosis of ME or chronic fatigue syndrome, fibromyalgia, underactive thyroid and also anxiety. Because of the nature of my illness it means I can't work, unfortunately. A lot of the time I'm housebound and sometimes bedbound so I don't get out much.

What does it feel like to be homebound?

It can be really lonely and it can be really hard because it feels like you're the only person in the world who isn't out there with other people and who can't join in. Yeah, it's very difficult.

Problems with medicines

I suffer from a lot of side effects, things like constipation, nausea, dizziness and headaches. Sometimes I end up not taking those medicines when the side effects actually get too much for me. I do also have some concerns about my medicines interacting with one another. I think that some of them do have strengthening or weakening effect on each other and sometimes I try and guess which ones the problematic medicines are so I can stop taking them, or I will take more or less of one or the other.

Relationship with pharmacy staff

There's no real communication there between me and the pharmacy and in the past when I have spoken to the pharmacy workers, occasionally I've felt a little bit shamed by them with regard to some of my more stigmatised medicines, my anti-depressants in particular and also my strong pain medication like codeine. There's been a time when I think she kind of was implying I was a junkie which was actually really hurtful, really hard, to feel like you're fighting for your own medications. And because I rely on them so much to have a good quality of life it's a bit scary talking to pharmacy workers sometimes.

Medicines Use Review?

No, I had no idea what a Medicines Use Review was and I didn't know that there was actually help that the pharmacy teams could be giving me as well. I think I was quite surprised to learn that really, that there was any extra information or help I could get. I thought that maybe you either get it from the doctor or nothing. But with a pharmacist you have the

advantage of maybe seeing the same person regularly, seeing them every two to three weeks, whenever you go and pick up your medicines. I think that I would quiet benefit from having a more consistent base to touch home with every now and then with my medicines, but yeah I'd never heard of one before.

Identifying people who are homebound

Asking people who come in to collect that person's medication. Also I think there is a certain amount that you can infer from the medicine. So obviously you shouldn't make assumptions, but actually if you have bed sore dressings for example, that might be an indication that that person maybe has to stay in bed a lot, can't get out as easily as most people can, has problems with mobility. Those sorts of things can be an indication to pharmacists.

Engaging with individuals who are homebound

I think I would really benefit from something like a Medicines Use Review and even if I maybe said no the first time it was offered to me from anxiety, to be offered it again would be really helpful. I think, you know, don't give up trying if someone's turned it down once that doesn't mean they definitely don't want to do it. I think it means that maybe they're too shy or too anxious or they don't know what it is. I think if pharmacists can explain what it's for, that they're actually there to help you, not to take your medicines away or punish you I think that would be a really useful service for people like me.