

Supplement 8. Experiences of usual care.

"I'm on antidepressants and I sort of go through good periods and bad periods and when I'm in a good period I try to come off the tablets, because I don't want to be dependent on them. But I realise that by coming off the tablets, I needed them. And I had to go back onto them. And because I'm so worried about being dependent on them, you know... there doesn't seem to be any help out there, other than some tablets that will just keep me on an even keel. And sometimes the tablets even when I'm happy don't even allow me to be as happy as I should be... Yeah, it's like you're just sort of on one level all the time. Yeah, you're not depressed and you're not anxious, but you just don't get any excitement or, you know, at times when you should really. And it's really weird. A weird thing really. It's really hard to describe. You just can't seem to muster up any enthusiasm... I was more concerned about my anxiety. I asked if there was any kind of drug that I could have just to control my anxiousness, you know. Something instantly, you know, when I could feel myself getting anxious. But there was nothing that they could prescribe for me... at the moment I just feel like I've reached a dead end. There's nowhere else for me to go and nobody's going to make me any better, other than continually giving me these drugs. There's no treatment for me. There's no treatment for me unless I pay for it." (p50,F,uc)

"It's kind of got to a stalemate really. I think that's the way of it. I was trying to think about this, really. I think one of the things for me that kind of was a problem, if you'd want to call it that, was now everything's on the repeat prescription thing, normally with my former doctor, you'd go once a month or whatever, just to get a repeat prescription. And that 10 minutes was kind of just enough to almost keep you going. And my old doctor I'd known for a long time. The new one, maybe only six years or so, but now because everything's on repeat, I don't think I saw her at all last year, because you just don't need to... I normally do try and see her because obviously, you know, it's easier in a way if you do see the same person, for them as well... the GPs just don't have time, I mean, you're there 10 minutes; there's nothing much you can say, really. But I think that certainly for me, that not going regularly hasn't helped... But unfortunately now, whatever care there is out there, it's rationed – not rationed, it's just that the time and the cost and you know – I think that's just one of those things, isn't it, really." (p52,F,uc)

"I've got fluoxetine tablets and they seem to have helped a bit, because I mean before I started taking them I was suicidal – I used to think about it quite a lot... supposed to take one a day, but I take one every other day. And it seems to have taken the edge off the panic. I don't pace around the house as much as I used to do... I worry about side effects. I'm on loads of other medication as well for... various other bits and pieces... It's not that I'm worried about getting addicted to them. I just don't want to be – I don't want to take the edge off too much, you know what I mean... I'm still really depressed and I still think about suicide a lot. The mess I'm in at the moment is just unbelievable. It would take me all day to explain the mess I'm in... it's just the people that it would upset if I did, you know. Like my son. And my dad. My dad's not well and I don't want to upset him either." (p54,M,uc)

"What he wanted to do was refer me to this, I think it was a link worker was what he said, and I went, and he said it will take a few months and you'll get your appointment... I have to be honest, the doctor that I saw... he's amazing. He is a particularly good doctor. He was actually the one that helped me with my fibre intolerance. It was always brushed off by other doctors and he realized that it was a real struggle for me and I was in a lot of pain. And with this as well, he was – he actually sat and listened and understood. And then he said, look I'll recommend you, but there is a long wait. And I'll put you on these tablets to tide you over, but I don't think it's for you. And I said, well neither do I, but I can't – and I don't know if it would have happened with any other doctor. How long I would have to have waited." (p55,F,uc)

"I have seen a counsellor but I didn't really find it beneficial... but I decided there and then that I didn't want to pursue it. You know, I find sometimes that they talk in like, clichés. Do you know what I mean?... I think she was fairly experienced. She had like lots of candles and she had lots of alternative things, you know. Yeah, but I just felt, oh, I think we're talking in clichés here. And it's not really helping." (p56,F,uc)

"I was referred to a counsellor last August, and it took six months for me to get the appointment through... And I had two sessions with this counsellor (link worker) and I was starting to feel a lot better and she said that I didn't need to see her any-more and that I was managing to cope on my own, so it was really quick, but I did feel really good actually at the time... I had a couple of sessions with her. And I did feel really good. I felt really in control and everything... It just took an awfully long time to come through. And I could really have done with it at the time, rather than having to wait six months... You really need somebody to help you, well more or less straight away. A couple of weeks really. That was the problem with it." (p57,F,uc)

"The GP was very, very good. Recognised quite early on what was happening and basically put me on some antidepressants which were nominal. They didn't really stop a downward slide but as she progressed – I mean she couldn't actually refer me to anything straight away – she just wanted to make sure she was right... But she eventually said, you know exactly what you're doing so you can regulate your own medication – it's there, whatever you need at the time. Obviously if I need a review I go every six months or whatever for a complete review. And I can't change medication myself, I can't kind of prescribe myself something new, but the medication that I do take is available. It's there on the... I can just go, I need some of that, and if it's there I can have it. She trusts me to actually look after myself as it were. To draw up my own strategies for survival, if you like." (p59,M,uc)