

**Kate's Story** (names of people, places and identifying features changed)

Kate has been a carer and supporter to her son who has long-term poor mental health. She discusses her experiences of the last six years. She begins with what happened when she wanted to change consultant.

Kate wanted a new consultant for her son because their consultant refused to change her son's medication without a hospital admission. When they asked the Clinical Director for a new consultant they were referred to their current consultant to solve the problem.

*"I had problems with the consultant who practically refused to put him on new medication because he wouldn't go into hospital, but she didn't seem to me to do anything about persuading him to go in, or helping us in any way to get him in or cooperating with us...I wrote to the Director of the Hospital and I asked to have a change of consultant. So what happened then was I got a letter from the consultant, from the original consultant, to go in and speak with her...We wrote to the Director again and said no, we wanted a new consultant, full stop. We didn't get one, but he [her son] was moved sideways into the rehab team, so we got a new consultant in that sense. And I talked to her [the new consultant] about the medication and she put him [on it]. She said it was no problem whatsoever. She even persuaded him to go into hospital for three days."*

Kate discusses her dissatisfaction with the Clinical Director's actions.

*"I was very annoyed about it, that the Director had left us to deal with it, that he should have brought us in and asked us what was our complaint and dealt with it, you know? So I was upset about it. And I was going to write to him again and then I said, "ah, I can't be bothered," you know? And then in the meantime, the Clinical Director has changed."*

Kate was upset that the consultant did not listen to her opinion.

*"She [the consultant] wasn't going to give us what we wanted, I suppose, that was the nub of it. Which I, and it's very arrogant of me to say this, but I've been dealing with [my son] now for over forty years, but I knew the medication wasn't working, that was my gut instinct around it, you know, and for that not to be heard, you know, or taken into account, that I would have some idea [whether or not the medication was working]."*

Kate would like to see more protection for families.

*"[There] isn't any protection for families. And I know if they physically threaten you, you can take out protection orders and things like that. Anybody can deal with the big stuff, the big threats, you know, like if you're really in danger, but it's the small, niggling, you know, feeling frightened...If you feel frightened in the house and you're terrified of upsetting the air for them, in case they go off on a bender, or you precipitate them into a breakdown, or that, you know."*

Kate would like information to be readily available about what can help her and her son, particularly information on the range of therapies and supports on offer.

*“But they don’t do anything else with him until I actually go and ask for something else, you know. Now I discovered, in a very roundabout way, that the social worker actually does a little gardening program with them every week, you know? So eventually I got [my son] to go to that. But you see that’s a useful thing because the social worker there, the guy there who’s doing it, in that way he can observe [my son], he can see how he’s getting on, he can talk to him, you know, he can draw him out a bit. But that was only a fluke, I found that out myself and made sure he went to the class, you know. And then there’s a day centre there for him, but he’s never gone to it, you know. You just feel like you’re asking all the time, you know, and that sometimes what you’d love is for somebody to say “This is what you’re entitled to. What can we do for you?”*”

She would like more information on how best to look after her son and what to do when he is becoming unwell.

*“We need to have the knowledge of how to look after them and what makes things easier for them and what to look out for if they’re breaking down again, what to do in that case and also, how do we have a life, without precipitating them into a breakdown again.”*

Kate feels that there is not enough therapeutic activity in the hospital.

*“They would tell you there were a certain number of day activities, but it doesn’t seem to be an awful lot.”*

Kate draws attention to the difficulty that catchment area boundaries can cause when trying to get someone into hospital.

*“Another thing too about the psychiatric hospitals - there’s no A&E in them. Well there is, if you live there, you know, if you’re in that area... I had a boy in my house now, a number of years ago, a neighbour from [a different part of] Ireland and he had mental health problems. And he was staying with me and he was quite unwell. And I rang [the doctor]] because it was at night time you know, and I said, “If he gets bad during the night, can I bring him over without calling the GP?”...and they said, “Where’s his catchment area?” And I said [my local hospital]. [And they said], “Well, you’d be better off to bring him to [his local hospital].”*

She draws attention to the fact that attending A&E is distressing for the service user, the carer and the other people in casualty.

*“If [my son] became unwell during the night, I think he’d probably be ok to go to [their preferred hospital] because he’s a known patient there but I mean most people would have to go to casualty in the ordinary hospital. Can you imagine how distressing that is? And how distressing it is for the people in casualty? With someone sitting there. ...they have to sit and wait for hours and hours and hours and get a psychiatric doctor down to see them. So these are all the areas where carers are not supported in any sense. Can you imagine what it’s like, that your whole life is on hold all the time, because of what they do, you know what I mean?”*

Kate describes the impact that being a carer has had on herself and her family. She describes the stress of being a carer as well as increased isolation from her friends.

*“It’s like you’re lying in bed awake waiting for them to come back, maybe, you can’t go out because they might set fire to the house, you know, not intentionally, just cooking. You can’t have people in. Because I used to love having people over, you know, at dinner parties and things like that, and all that had to go because it was just too stressful to do it, you know, with him in the house. And you’re upset then for the brothers and sisters as well, because their friends can’t be in casually or easily, because the whole atmosphere is disrupted. None of that is taken into account.”*

Kate explains how the situation affected her mental health to the point where she was hospitalised herself.

*“Well it was just that I was absolutely, absolutely exhausted. My mother was very ill at the time too and I was trying to get help for him and get him treated and all of that. And I just went under. I was very lucky, there was a nurse that was in our group and I called him, and he said yes ... so instead of sending me to the GP he got me to one of the consultants in the hospital and she said, “Look, I’ll take you in for a week, and just have a rest.”*

Kate stresses that she feels service users with a mental health problem need an outreach programme and readily accessible mental health care.

*“If we can campaign for outreach teams ... that’s our biggest, biggest need, I’d say. What I’d like to see [is] a recognition of when people ask for help, you know, that it would be there, you know, that you can see a GP, that you can see a psychiatrist, that there could be outreach help, that somebody can come to a home. If you have a child or a brother or sister or somebody, who’s clearly not well – now it could be an alcohol problem, it could be mental health, anything – that somebody from a psychiatric team could come out, you know, like a social worker. You know the way you have it on the medical teams, they come out, the nurse comes out and does the dressings and things like that for you. If there was that kind of outreach team on mental health, it’s what we desperately need ... That’s the biggest need we have, that somebody can come out to the house. They can observe the family, they can observe the person, they can see what kind of people we are. You know? ...and [they should be] getting help, like in the early stages, not waiting until it reaches crisis point, which is always what happens, you know, it has to go to crisis.”*

Kate feels that the attitude of the mental health services could be improved.

*“Well the attitude would be, to look you in the eye, to speak to you and not to, all these times, I don’t know, have to have the patient’s permission to speak to you. You should be entitled to speak to the consultant about the care of the person, about what it’s like for you at home with them, you know? Sometimes the person, that is the service user might accuse you of things [like] abuse, anything, and I think the consultant has a duty of care to have a look at you and the family situation and see is this true or not.”*

Kate feels that mental health professionals can put family members at ease through their manner.

*“Also, sometimes if they just greet you, if they even offer you a cup of tea, and they explain things to you.”*

Finally, Kate describes the positive experience for her son when he was taken on a group holiday.

*“One of the regional development officers [from voluntary service provider], he took a group, they’re people with the illness and he brought them on a holiday. And he brought them to a four star hotel, got a deal and they used the jacuzzi and the gym and all that. And he was saying, what a treat it was for them, to go to somewhere where everybody goes to, somewhere normal and nice and that wasn’t just a hostel or that.”*