

Interviewer: What we call 'person centered care', means that the care is implemented because of what the person says their needs are. All right. Your experience with both in-home situation and the residential facilities. Do you think that was how it was presented? Or do you think they just told you what care was going to be given?

Ed: Well, at the beginning, they'd tell me what care they were giving and so on. But if we had any doubts about it, it could be improved, or something could be done different. We had the opportunity to speak to the carers but mostly speak to the, to the organisation. Someone there we could speak to.

Interviewer: So it was sort of coming sideways rather than..very.... [sic]. Did anyone sit down with a piece of paper and say, "What do you want, what does Mary want?"

Ed: I guess not, no. Not to that extent, no. But we would have to let them know what the situation was before you...Mary went into Respite care and so forth.

Interviewer: And as Mary said before, part of that was that you didn't feel they were listening to you. Do you think? Or did you ever feel that they couldn't, weren't taking as good as care of her as you did? [sic]

Ed: Aw, well, I'd, you know, yeah..

Interviewer: Its ok to say.

Ed: In my mind, they didn't, you know. They should have checked on her and so on and more. At that time, she got up and went to the toilet and I don't know how long she was there, they didn't find her until the early morning, and I thought that's not the way to care for people. Should be checking during the night. But yeah, that was the first time, the second time wasn't so bad. She'd had her lunch and so on sitting in the lounge and then she got up, you know how you try to help me. People, you know, it's no one there to say you know Mary, we're getting up now would you like me to take you. Do you want to go to your room? But no, I didn't feel like...I feel like they ignore people.

Interviewer: Do you think...Apart from asking you more about the things that you did all the time for Mary. This is from the respite care, potentially. What sort of other things, do you think they should have asked, or should have known? Or you would have, or you think would have helped them understand better? Well, I just thought that.

Ed: They had the information about Mary. Going into Respite, but they should have had... they should have known what her situation was, and they should have, ah been, kept an eye on her more than anything.

Interviewer: So, do you think that there was an element of, we understand what dementia is, we both know how to care for dementia person [sic] as a broad thing rather than look at Mary as an individual?

Ed: I think so, when she went the first time there was a dementia place for everyone. The second time, she was in a home with people, you know, not a lot were permanently there. But the first place she went to the people sort of permanently there in a way, but they were all on Respite sort of thing. So ah, no, I don't...I just thought they could have been more careful. I prefer to have her at home.

Interviewer: So, I suppose what we quite often find, I'll just put a bit of background to this, is that we don't often take your intimate knowledge of the situation in consideration.

Ed: Oh yes. We are more theoretical and professional stuff.

Interviewer: Yes. That you have that really rare [sic] knowledge that fits in.

Ed: No two people are the same sort of thing. Yes, know that knowledge of the person.

Interviewer: So that would have helped, do you think?

Ed: Yes, it would have. Yes, definitely.

Interviewer: So, following on from that, out of all the help you had across Mary's journey who provided the most valuable support, the most effective?

Ed: Well, I think the carers had a lot to do. Because they're the ones that who saw Mary often. And ah, you know, they knew what her condition was, and ah, they'd cater for me, and because they were here all the time, they're the ones who supplied the best care that she could have got. The other people like, GP, and specialist and so on. At the time, when Mary had to go to them, they were good too. But ah, just thought the carers were used to make a day, you know.

Interviewer: Did the carers provide support for you, as well when they came to care for Mary during their visits? What did you get? What did you as the influencer take away from it, did they offer you any support, apart from, you know, half an hour of respite?

Ed: Oh yes, look, the carers who came, and of course they got along so well with Mary, so they became like part of the family, that was great for me to, you know. In the... I appreciated what they did for Mary and what they do for Mary. Things for me too. And ah, that was helpful to me, yes.