**STOP-DEM – Deprescribing for People with   
Cognitive Impairment**

Transcript for interview

**C02**

***Please refer to the key to abbreviations on the last page of this transcription***

**INT: So, first of all, just thinking broader than medication, can you tell me a bit about how you assist (*name of husband*) on a day-to-day basis? What support do you need to provide for him?**

C02: Everything really from (*laughing*), you know, going, the time everything’s got to be done to, to actually doing it. I shower him, I, I soap him and then he rinses himself. He starts to dry himself while I’m cleaning the shower down and then I get out and I finish drying him. Because he’s incontinent, I have to keep an eye on the time and change him at the appropriate times. He needs help with dressing. He starts to do some of it on his own but I mean, for instance, he can put the tee-shirt over his head but it’s difficult to pull it back, right the way down so, you know, and then trousers, he needs help to put his trousers on, so. And basically, he needs help with most things (*laughing*).

**INT: So, you spend quite a bit of time supporting (*name of husband*)?**

C02: Yes.

**INT: And how long have you needed to provide support for?**

C02: Since December 2017.

**INT: So, quite a few years?**

C02: Yeah.

**INT: And had you had any experience of caring for anyone prior to that?**

C02: Yeah. Yeah, donkeys’ years of it (*laughing*). I worked in care of the elderly (*laughter*). I worked in care of the elderly so, as a physiotherapy so, yeah, I had, and, I think, that has helped me without a doubt.

**INT: So, if we think about the photos that you took. First of all, were the photos that you took planned photos or were any of them spontaneous?**

C02: Planned.

**INT: So, they kind of tell a story of how the medications are managed on a day-by-day basis. So, shall we start and go through each picture in turn and if you can just tell me a bit about the picture and how it relates to your role?**

C02: So, number one, I did that the lunchtime after you left. So, we started straight away basically. I don’t why he puts them on the spoon because then he, he takes them off the spoon and pops them in his mouth with a, with a, he, he has a, a special cup with a straw so, he, he, for some reason, he puts them on the spoon but then he takes them off and.

**INT: And is that just the lunchtime ones?**

C02: Those are the lunchtime ones. Yes.

**INT: Does he put any of the others on a spoon?**

C02: No.

**INT: Just at lunchtime.**

C02: Yeah.

**INT: What about photo number two?**

C02: Number two is the evening one and it’s convenient because they’re going to be lying around all day to put them in a, a little case like that.

**INT: So, do you put them out earlier in the day?**

C02: They’re, I put all the tablets, set them all out at night. So, that is. is what I do late at night. So, the, the evening ones go into that [points to left hand pot in picture six], and it sits over there [points to work surface to side of kitchen], then lunchtime ones go into that [points to right hand pot in picture six] and it’s sitting on the surface over there and then these [points to loose tablets in picture six], I put on the breakfast table, and the significance of the knife [picture seven] was they’re on the breakfast table next to his knife and fork.

**INT: So, we’re looking at photo number six, the evening ones are the larger tin, the lunchtime one is the smaller tin and then the breakfast ones are just loose.**

C02: Yeah.

**INT: And the breakfast ones, you get those out at breakfast time?**

C02: No, I get them out, in actual fact, I, I think, they are left out (*laughing*) overnight.

**INT: So, you put them out on the side overnight. So, you get them out in the evening.**

C02: I set the table and, and put the tablets on the table the, the night before.

**INT: And then that’s the significance of the knife in photo number seven.**

C02: Yeah.

**INT: And so, if we go back to photo number three, when I was talking to (*name of husband*) we were talking about it looked like a cushion potentially in the lounge. Can you tell me a bit more about that?**

C02: Yeah, we always have our evening tea, I, I cook at lunchtime so it’s easier to have that in here [we were sat at the table in the kitchen], and then in the evening, (*name of husband*) sits in his armchair and he, he takes the tablet sitting in the armchair, and we usually watch television while we eat our tea.

**INT: So, the medication is at breakfast, lunch and evening, three times a day?**

C02: Yeah.

**INT: And is there anything else that you do around the medications so, thinking about getting medications etc? How do you get your tablets?**

C02: Online but I have patient access. They can all be got at the same time except the (*name of medication*) which they will only give you a month’s supply at a time so, I have to order those in-between.

**INT: And then that goes direct to a pharmacy?**

C02: It goes direct to the GP surgery and then the GP surgery send it over to the pharmacy which is on the opposite side of the road (*clears throat*).

**INT: And then you pick them up?**

C02: We go together. We walk round there, (*name of husband*) with his walker, and we walk up there, around the corner to get them.

**INT: So, what do you do that kind of helps you to overcome any problems with managing medication? Have you encountered any problems?**

C02: No. I was aware that he was becoming much slower so, I did ‘phone for an extra appointment with the consultant to get extra (*name of medication*). Unfortunately, wasn’t, it wasn’t quite as (*long pause*) it wasn’t as helpful as I was hoping it was going to be. He did up it, but it hasn’t made, he, once before when (*name of husband*) was very stiff, he upped the dose of (*name of medication*) and it was like, it was like a magic bullet. So, when he became really slow again, I ‘phoned and said: “can we see you early?” and we did, and he upped the medication, but it wasn’t as good as the time he’d upped it before.

**INT: So, that’s disappointing, isn’t it?**

C02: It was disappointing. Yeah.

**INT: So, if one of the medications, or more than one of the medications, was to be stopped or reduced, how do you think that might impact on you in assisting with the medications?**

C02: (*clears throat*) Well, I personally can’t see how you could stop any of them. I would hate for you to stop that [points to one of the round tablets] because we’d be immobile.

**INT: Well, I’m not stopping anything (*laughter*), I can reassure you there. But, yeah, just kind of thinking if it was to be offered, not that it is going to happen but if it happened, how might that impact on what you do?**

C02: (*long pause*) Well, I, it, I mean, we wouldn’t be able to do as many things as we do. I think, they all have a job to do and…[pause].

**INT: But in terms of that day-to-day management of them, would you see having a pill removed having any impact on that?**

C02: No, not really. I mean, if, if it was removed then, you know, I’d, I’d clock-up. I, that’s one less to sort out.

**INT: And so, how do you feel about the number of medications that (*name of husband*) is taking?**

C02: It’s a lot (*pause*) but we do, I do know what they all do (*pause*). I, that one, in actual fact, is put in by me, that’s Vitamin D and that’s not a prescribed one.

**INT: And that’s an evening one, isn’t it?**

C02: No, it’s a morning one. That’s the only one that’s not prescribed.

**INT: Is that the little black one?**

C02: The little brown, brown one.

**INT: So, in terms of the positives of the medications that he’s taking, you can see they’ve all got a purpose you said. Any negatives about taking that many medications?**

C02: (*pause*) Not really because they’re all, they’re all doing a specific job. I mean, we, we were taking an extra one, we were taking (*name of one medication*) as well as (*pause*) I can never remember, that’s the one pill I can’t remember the name of, (*part of a 2nd medication name*) something or other, but it is, it is to do with blood pressure and we were taking (*name of first medication*) and his blood pressure did drop too low so, we had an appointment with the GP and discussed it and we took that away and monitored his blood pressure. It, it was fine so, that one did go but we, we’ve hung onto that one and that just about keeps him on a level.

**INT: So, you’ve just given an example of when a medication has been stopped, can you tell me a bit more about that discussion and how it happened and what led up to it?**

C02: I, I, I, do you know, I’m struggling to, to remember that. Except we went through a period when his legs were very swollen and that’s when we went onto the water tablet but the water tablet plus the (*medication discussed above that was stopped*) seemed to lower his blood pressure too much and I do monitor his, I monitor both our blood pressures and thought: “oh, I think, the blood pressure is a bit on the low side now we’ve got the water pill as well so, that…(pause).

**INT: So, you then made the appointment with the GP.**

C02: Yeah, and said, you know: “I can see why we need that but I’m wondering whether we still need the other one” and it was taken away and, you know, he seemed to be, on a level now.

**INT: And how was that followed-up? So, after it was stopped, did you have a review appointment with the GP?**

C02: No, he just trusted (*laughing*) me to, to get in touch if I was worried (*laughing*).

**INT: And you monitored that at home?**

C02: Yeah.

**INT: And did you notice any changes? Were things better without it?**

C02: Yeah. Yeah.

**INT: So, in terms of your views then about a medication being stopped or reduced if a healthcare professional decided that it wasn’t needed or in that situation you decided that it wasn’t needed, do you see that as a normal part of managing health conditions that sometimes they need to be stopped, sometimes they don’t, or do you see that as something that is quite unusual?**

C02: I think, it’s something where you would have to have a discussion about it.

**INT: So, would you have any concerns about any medication being stopped at some point in the future? You’ve already pointed out the Parkinson’s one.**

C02: I, I mean, we would be at a standstill. In fact, I nearly ran out last week and I was: “oh, just hope that prescription’s round there when we get round there”. I don’t normally, I, I’m usually pretty hot on it but I only gave them a week instead of a fortnight and … (pause)

**INT: Got a bit tight.**

C02: Yeah.

**INT: So, you’ve said about the other medications, are there any other medications that you would have particular concerns about stopping if it was advised at any point?**

C02: Well, the (*name of medication*) is stopping him having another stroke (*pause*). The (*dementia medication*), I think, does help with, with the thinking, the cognitive processes, and then (*pause*), that’s (*name of medication*) [points to it in picture]. The water pill, his legs seem to be fine and that little one just keeps the blood pressure down. The (*name of medication*) I’d be worried if he didn’t take those that he might fall and fracture. So, I think, oh, and the (*name of statin medication*) is again, that’s (*long pause*) (*sigh*), it, that’s the, the one that, oh, help me (*laughter*), I have a mental blank (*laughter*).

**INT: That’s the statin, isn’t it?**

C02: That’s the statin. Thank you. Yeah. So, he’s not taking any that aren’t doing a, a job. So, yeah, I would be concerned if, if they did say they wanted to stop some. I know that the (*dementia medication*) is, is expensive because the consultant suggested it and the GP said: “ahh, that’s an expensive one” (*laughing*). But thinking back to how (*name of husband*) was right at the beginning when he didn’t know who I was and quite often thought I was his mother and (*pause*) you know and didn’t know where he was and it, it, after he went on that, a lot of things did seem to improve so, yeah, I’d be worried if that one went (*laughing*).

**INT: So, it’s kind of the ones for the specific health conditions that you would have concerns about?**

C02: Yeah.

**INT: What about the Vitamin D?**

C02: Well, I suppose, we could get rid of that (*laughing*).

**INT: So, if somebody was to suggest stopping that, you’ve said before you would be looking for information. Can you expand a bit more about what sort of information?**

C02: Well, I mean, I have Googled whether, who should be taking it and, you know.

**INT: I mentioned the Vitamin D, but any medication, because you talked about information. What sort of information would you be particularly looking for? What questions would you want answering?**

C02: (*pause*) Is it doing the job that I think it’s doing? I mean, we don’t, (*name of husband*) wilts in the sunshine so, I mean, we’ll sit outside this afternoon but we’ll be in the shade because luckily this house is wonderful in that in the morning, the sun’s there but by twelve o’clock, it’s, it will be really nice to sit in the garden but we won’t be getting sun on us. So, hopefully, that Vitamin D is doing the job.

**INT: I’m sure it is but I’m not commenting on the Vitamin D, I’m just thinking more in general about what would support you with that decision-making. So, if a healthcare professional was to say that any one particular medication they thought that maybe it should be stopped, what information might you be looking for? What questions might you have?**

C02: Well, I, I’d be saying: “are you going to say it was the (*part of* *medication name*), whatever it is?”, I’d be saying: “are you going to monitor his blood pressure if,if you take that away?”.

**INT: So, you’d want that follow-up?**

C02: Yeah, and, I mean, I keep an eye on his, the legs as to whether they’re swollen so, I wouldn’t want the (*pause*), the water pill taken away. So, yeah, I, in theo-, I mean, I’d want, and certainly, we wouldn’t want the, the (*name of medication*) because I’d then be worried he was going to have another stroke which would make him even more difficult to look after (*laughing*).

**INT: So, thinking maybe not in the immediate future but maybe in a longer term future when maybe medications sometimes become less necessary, what would encourage you at that point to maybe stop or reduce a medication?**

C02: I can’t see that they’re going to become less necessary. I can only see that we’re going to need possibly difficult Parkinson’s ones or, I don’t think we’d up those, I think, he would probably say: “well, let’s try giving you something different”. And now, whether that would work, inter-work with one of the others, I don’t know.

**INT: And so, you would have questions about: “does it interfere with other medications?”?**

C02: Yeah. Yeah.

**INT: And how do you think that can be addressed by health professionals helping you to understand?**

C02: Well, me asking lots of questions (*laughing*) which I always do.

**INT: And if, for example, a medication was stopped, you talk about follow-up, is there any particular way you would see that follow-up needed to happen?**

C02: Well, going to the surgery.

**INT: So, you’d want that to happen at the general practice?**

C02: Yeah. Yeah.

**INT: Any particular healthcare professional?**

C02: It could be done by a nurse.

**INT: So, just one of the professionals at the surgery.**

C02: Yeah, because she, if, if there was a problem, she would report it to the GPs so, it could be done by a nurse.

**INT: Yeah, but you would just be looking for some sort of monitoring.**

C02: Yeah.

**INT: Anything that might help you at home between those kind of follow-up visits to support that? What sort of information might you need to support you?**

C02: I don’t know (*laughing*).

**INT: It’s difficult, isn’t it, because we don’t know that it’s going to happen so, we don’t know what that might look like. So, in terms of having those discussions and making decisions jointly with a healthcare professional, have you had any experience of making decisions joint with professionals in the past in your role?**

C02: Oh, yeah, I mean, , I’ve referred people (*laughing*) in because they were taking too much medication.

**INT: Yeah, but not in your professional role, in your role with (*name of husband*). Have you had any experience where you’ve made decisions jointly about something with the professional?**

C02: Well, he had polymyalgia and (*pause*), I mean, it, probably it was me who pushed to see a consultant privately rather than wait because he was in so much pain so, I pushed him to have a private appointment rather than hang about in the ordinary, so, I don’t know whether that answers your question.

**INT: So, I’m thinking more about if a decision was to be made about some aspect of care where you’ve weighed-up the kind of benefits and the burdens jointly with a professional. Have you had any experience of doing that as (*name of husband*)’s wife?**

C02: (*long pause*) Well, I, I mean, it, it was discussed with the consultant that the (*name of Parkinson’s medication*) was, was discussed, you know: “do you think if we up the dose…”, you know: “that would help you?” and, you know, I could have gone back to him if it hadn’t helped but it was so miraculous the first time.

**INT: And so, you’ve talked about asking questions and having your questions answered by the healthcare professional, would you have any additional questions if you were needing to make a decision on (*name of husband*)’s behalf? So, (*name of husband*), at that point in time wasn’t able to make the decisions for himself and therefore you needed to make a decision on his behalf, would you at that point feel that you needed any additional information?**

C02: (*long pause*) Probably not.

**INT: So, the same amount of information you would need if you were just supporting?**

C02: Yeah, but, I mean, I, I do, I do read the leaflets and I do Google and what have you (*laughing*) so.

**INT: And in terms of how the information and the answers to your questions is shared with you, how is that best achieved?**

C02: Verbally, I think. A discussion.

**INT: So, face-to-face and verbally.**

C02: Or on the telephone.

**INT: So, you’re happy to talk on the telephone?**

C02: Alternate appointments are on the telephone unless I ask for them to be otherwise.

**INT: So, you would speak to the professional on (*name of husband*)’s behalf?**

C02: Yeah.

**INT: And does that apply to all professionals whether they be primary care or hospital services?**

C02: Both. Yes. The consultant is twice a year unless, and I did say to him: “it’s all very well me speaking to you and (*pause*) saying: “yes, we’re fine when three weeks later we might not be” and he said: “well, if you’re not in three weeks’ time, you ‘phone up and you, and you ask for another appointment and I will squeeze you in” which he, in fact, he does, he’s good. And the, the GP is as and when except he does have a once yearly review.

**INT: So, tell me a bit about that review. What sort of things are addressed during those reviews?**

C02: Well, he, he generally asks how (*name of husband*) is, how we’ve been, takes his blood pressure, has a look at how well he’s moving. That sort of, that sort of thing. Or he asks me, no, the yearly review, we do usually see him.

**INT: And you both go together?**

C02: Oh, yes. Yeah.

**INT: And does that give you an opportunity to ask questions?**

C02: Yes. Yeah. (*name of husband*)’s been going to the same GP for a very long time.

**INT: And is that important?**

C02: I think it is. Yeah. In, in fact, he’s partially retired but he said: “I’m going to keep people like (*name of husband*) on because I want to…”, you know: “follow them up”.

**INT: So, what is it that makes that easier to have a discussion with him rather than with another GP?**

C02: (*pause*) I suppose, it’s because he’s always known (*name of husband*). He knows how high-flying (*name of husband*) was before this all happened. You know, whereas a new, a new GP has no idea of (*name of husband*)’s previous life.

**INT: Yeah, and that sounds important.**

C02: Yeah.

**INT: So, thinking about those reviews with your GP, those appointments with the consultant, what helps you to share the decisions that are made at the end of that? What helps that?**

C02: (*long pause*) Knowing that they’re there and being able to discuss things with them.

**INT: So, is there anything that helps you to be able to discuss things?**

C02: Probably my medical background (*laughter*).

**INT: So, that’s really helpful?**

C02: Yes, I definitely think the fact that I took care of people with Parkinson’s, and what have you, before this happened to (*name of husband*) has made a big difference to…

**INT: Why do you think that is?**

C02: (*pause*) I think, I mean, for instance, (*name of husband*) and I play, used to play, and we still do play in groups but not as a couple because it, it’s different when you play as a couple, the adding up and what have you, but we used to play a lot of canasta and I used to look across the table and look at (*name of husband*)’s facial features as he was thinking and thinking: “I’ve got a nasty feeling we’re heading towards Parkinson’s” but I don’t think I would have noticed that if I hadn’t seen so many people with it in the past.

**INT: So, what is it about that kind of medical knowledge that you’ve got that makes the interactions with healthcare professionals perhaps easier which is what you were saying?**

C02: I think, for starters, we went through the system quite quickly because we knew what we were entitled to and how to ask for it. Whereas I, I mean, I’m always talking to other people and discovering that they have no idea how to talk about different things.

**INT: So, is there something there about language?**

C02: Probably and, I think, probably if, if you’re using certain, I mean, I, I don’t, I don’t arrive at the consultants or didn’t arrive at the consultants: “I’m a physiotherapist so, I expect you…”. I never said that but in actual fact you know, as well as I do, you use different words, and the consultant looks at you and says: “what did you do for a job?”. So, you’re sort of, you know, you, you don’t have to go in there and throw your weight around (*laughing*).

**INT: And do you think that then means that they treat you differently perhaps?**

C02: I think they might look at you slightly differently, yes. I’m not sure about the one that, the, the consultant that we have because he’s, I think, he’s, he’s superb and, I think, he probably treats everybody much the same, but we’ve had two previous consultants and, I think, it definitely made a difference there.

**INT: So, something about having that medical background and then also you mentioned before about having a professional that you know and trust because of that relationship and makes that difference.**

C02: Yeah.

**INT: To be able to make decisions together.**

C02: Yeah.

**INT: So, that’s all the questions I’ve got but is there anything else that you want to tell me? Anything that you want to add around deprescribing, shared decision-making?**

C02: Not, not really because, I think, we’ve de, deprescribed as much (*laughing*) as we can which was the (*name of medication*) and I, I don’t see how we could deprescribe any of the others.

**INT: No, okay. That’s great. Let’s switch the machine off.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

C02 Respondent

***Audio* file: 30.59 minutes**