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

Transcript for interview

**C09**

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

**INT: So, to start, a very general question about your role as a carer and the sorts of things that you do for your wife.**

C09: Yeah.

**INT: What your role involves and how you support your wife.**

C09: OK.

**INT: So, if you could just tell me a little bit about how you support your wife.**

C09: Well, it is just twenty-four-seven. I get her up in the morning, breakfast, tablets and (*wife*) washes, she washes-still washes herself, I get her clothes out and I help her dress. If I’m out, she is normally out with me, and if I’m in, she’s in. So, I find it difficult to entertain her in the day if I’ve got my stuff to do, my jobs, if you like. I don’t know really know what else to say.

**INT: Do you get any assistance at home?**

C09: No. No.

**INT: So, we’ll talk about the tablets and how you’re involved in the tablets.**

C09: OK.

**INT: Before we do that, can you just tell me, those photos, did you plan what you were going to take, or did you take them spontaneously?**

C09: Just took ‘em. I didn’t really know what you wanted so. I order tablets online. All tablets that we both take, because I have still got mine to sort out as well. I try to order to- together. They are all on-, on repeat prescription. So, anything the doctor decides to prescribe new, they always put it on repeat, and I pick ‘em up, the-, we get two months supply and I order both mine and (*wife*)’s. I bring ‘em home, I try to get rid of as much of the packaging as I can and take the names off, recycle what I can, bin what I can-, what-, what I don’t-, you know, bits of whatever that’s not needed. Then they’re put in the cupboard in a-, in a box and Saturdays is our tablet day. So, I get the box out, it's in a running order so that I can remember because (*wife*) takes about eight or nine tablets. So, I took a photo of number three which is the blue one. Sunday to Saturday is the one I use upstairs. OK.

**INT: So, that’s photo number three.**

C09: That’s why I took that photo because that’s got (*wife*)’s two tablets that she takes at night, cholesterol and another one, but I can’t remember the name of it, and one for the first thing in the morning, half-an-hour before her breakfast, which is for thyroid. So, that’s the three tablets that go in the blue box that goes next to my bed so that I can do the two at night and the one in the morning. Then it is breakfast.

**INT: So, what picture number is that?**

C09: Well, there’s no-, there’s no picture of breakfast. And then after breakfast, we-, oh, number two is a good one for the-, so, number two and number three is upstairs. OK? Number two is open. Then after breakfast, in a weekday, number four is the box we use with- and the puffer. So, in there is two for calcium, one for (*wife*)’s head/brain, an aspirin, oh, and one for her stomach because she takes so many tablets, and the puffer. She has two--that’s on picture four.

**INT: So, they’re all in a box that you use during the day, are they?**

C09: Yeah. Yeah, that’s what we have every weekday in the morning after breakfast, or (*wife*) has. She takes the one for her stomach before, before breakfast. She takes a calcium, one for her brain and the aspirin. I-, that is dissolvable. She takes them after breakfast, and one calcium is saved for after lunch, and she also has two puffs of the puffer. That’s for her throat. Then I‘ll-, so that is basically what I use the boxes for that I’ve taken the photos. The other box in picture one, it shows the empty boxes and all the tablets, well, not all but near, near enough, what I put in the boxes every Saturday morning. That’s our once-a-week day, and then I use the boxes-, so, number four, every morning, and number two which is open, it’s a better picture, is the night ones. And the little one in there is for half-an-hour before her cup of tea. OK? So, she has that and can have another half-hour in bed (*laughter*) so. Then the picture six is the sticker on the cupboard where the tablets are and picture seven is the sticker on the front door, which I suspect you’ve seen, which is-, which is part of Prince’s Trust, I think, which if anything happens to me, that should indicate that there is information in the fridge and also, indicates which cupboard the tablets are in.

**INT: So, the two match-up, don’t they?**

C09: Yeah. So, in the fridge is a jar, or a little bottle, with what tablets she takes and what order etc, except it’s slightly out-of-date now, it’s got one missing. And that’s it really. So, it is-, I order them online, I coll-, collect them from the chemist. That is two month’s supply. I bring them home. I box them up in order in a box and then once a week on a Saturday, I fill the weekly boxes up and the blue one’s upstairs and the white one is down. So, one’s for at night and one’s for after the breakfast basically.

**INT: So, have you faced any challenges in helping to manage the medications?**

C09: Well, now it’s just gone ov- added to as time’s gone on. Like I say, there’s one not, not on the list in the fridge because it’s just been recently given, so, and that, and that is a night one, but I haven’t got round to adding it.

**INT: So, it’s more the changes in the medication that potentially cause the challenges?**

C09: Yeah, I suppose so. Yeah. Yeah, I, I, I am used to what I do, and it has built up over the years. (*wifee*) was diagnosed with cognitive impairment 2017 so-, so, six/seven years down the line and several added tablets, I’ve just done it as I’ve gone along. Yeah, there is-, one’s added this, this month and then three month’s time, something else is added. You just learn to adapt.

**INT: So, how do you feel about the number of medications that she’s taking? You mentioned eight or nine tablets.**

C09: Yeah, I’m not happy. I’ve had her in front of the doctors three times now over three or four years period to have her tablets reviewed, but they reluctantly don’t take anything off. The only one I got off- and (*wife*) fell down the stairs in 2018 and broke her back, T3, which the doctor said she shouldn’t have broke. Whatever she breaks, it shouldn’t be that one. She can break an arm, a leg, or whatever, but not that. So, that started the density on the bones and started her on tablets for bones which is the two calcium, but there was also once-a-week tablet, an acid something. I-, yeah, I can’t- I’m not good on names and all that.

**INT: No, that’s fine.**

C09: And that one I have got stopped because her bones-, she’s been on tablets since 2018 so, by now, they’re back to what they should be. They’ve left her on the calcium but the other-, the once-a-week one which is another half-an-hour before her cup of tea, and you can’t lie down. So, she was having the thyroid one, having half-an-hour extra in bed, then she had to get up, take a tablet for her bones and then she couldn’t lie down, and she couldn’t have a cup of tea for another half-an-hour, but that one I managed to get stopped, but that’s a very rare occasion.

**INT: So, you talked there about reviewing of medication. Was that all initiated by you?**

C09: By me. Yeah.

**INT: So, you’ve never been invited for a review of medication?**

C09: No. No. I mean, for something else for (*wife*), and I’ve gone, you know: “can’t we get rid of some of these?”, you know. She’s on a stomach tablet because she takes so many tablets. Well, get her off of some of them (*laughter*) and then that’s another one that can be stopped, but they don’t, you know.

**INT: So, how did that medication review happen? Did they talk you through all of the medications?**

C09: They get-, they do sit there and they-, they are quite good. They will sit there and go through ‘em with me and-, and one quite recently, and he’s not our doctor, but he did sit and go through ‘em, said what they are, and: “ooh, I don’t think we can take that away” and so on and so on (*laughing*). So, like I say, they never take anything away except for the one.

**INT: So, if you were looking at (*wife*)’s medication which medications do you feel she needs more than others?**

C09: I would, I would say her important one is for her brain which is quite, quite late in being given because she was originally diagnosed cognitive impairment, that’s the veins. They said the veins in the brain-, brain and aspirin, and that’s when she started the aspirin, and nothing else. Although she had had an MRI scan, I think, at that time. That was 20-, late 2016 and it come back January/February 2017 so, early 2017, and that was the aspirin. Well, you know, four or five years down the line they diagnosed dementia and it’s mixed. So, (*wife*) has Alzheimer’s and- (*pause*) my brain’s freezing. She has Alzheimer’s and (*pause*).

**INT: Shall I go through some of the other types?**

C09: Yeah.

**INT: So, there’s vascular dementia.**

C09: Vascular. Alzheimer’s and vascular, and she’s got-, she’s given a different tablet which I call her brain tablet. Alright? I don’t-, I don’t-, I’m not very good on names on the tablets.

**INT: Medication names are difficult to remember.**

C09: So, I felt at that stage, they could have dropped her aspirin, but I-, like I say, I’ve had it reviewed several times. It’s like this one, that’s calcium and Vitamin D. Well, Vitamin D’s out in the sun which she will go out there when it’s (*laughter*) sunny, and her bones are back to more or less what they should be so-, and she’s not running around. If-, if she walks, she holds onto me so, it-, you know, I felt that the bones could have gone, the aspirin could have gone and the, the stomach, she’s never really had an upset stomach over tablets, I don’t think. So, you know, all stuff that could have-, stuff that-, some of it could have gone but, I think, the brain one’s important, the thyroid one’s important. I think, her new one’s important.

**INT: Do you know what that one’s for?**

C09: That’s for-, it was pro- protein-, protein in the wee so, kidneys, Ram-, Rama-something.

**INT: Ramipril?**

C09: Yeah, something like that, for kidneys. Right. So, I think, that’s important. Cholesterol I wasn’t so sure about. She’s been on that cholesterol since her brother had a heart attack at forty-two, and he is now nearly seventy, so about thirty years, and I just think you end up on cholesterol tablet and they leave you on it. That’s it, you know, and I, I don’t think her cholesterol-, her diet’s pretty good and I don’t see the point of that one. That’s another one so.

**INT: So, it’s mainly the brain, the thyroid, and the kidney tablets that would be the ones you would be reluctant to see stopped.**

C09: Yes. Definitely. Yeah. So, I think, the-, I keep calling it the brain one, I ought to get the name.

**INT: No. No, please don’t worry.**

C09: Are you sure?

**INT: Yeah.**

C09: I-, you know, I think, that’s holding (*wife*) Alzheimer to where it-, you know, maybe a little bit worse but-, so I think that’s important. So-, but, yeah. So.

**INT: So, sometimes doctors do decide to stop medications, other than the one that you talked about, the once a week one, have you ever known any other medication be stopped?**

C09: No, nothing. And, like I say, I’ve had it reviewed three times by three different doctors.

**INT: And nothing else has ever been stopped?**

C09: Nothing ever stopped. Only that one tablet.

**INT: So, when that was stopped, were you involved in the decision-making to stop it other than asking it to be reviewed? Did they discuss it with you and (*wife*)?**

C09: No, the-, the doctor I was talking to, she is new’ish up there and, I think, not training but still under someone’s wings sort of thing, and she went through it, and I don’t know if she text me on that, she said: “I will discuss it further” and then come back to me. I think, it was possibly a text and said that we can stop that one, but that’s the only one anybody ever stopped.

**INT: So, if we think about in the future when maybe doctors are discussing with you stopping medications, or any healthcare professional, it doesn’t have to be a doctor, how do you think those decisions should be made? Who do you think should be involved? How do you think it should happen? What are your thoughts around that?**

C09: I don’t really know. I would have just said that it’s-, it’s just something that the-, they’re, they’re., the doctors keep prescribing this stuff and, to me, they don’t look at what else is being taken. They just go: “oh, well, we’ve now got this so, we’re going to have that”. They never look back anytime unless I ask them to, they just carry on, prescribe something else, and to me, and I’m only an ordinary person, but do one table affect another? That’s what I, you know, feel or worry about, and to me, they don’t-, they never seem to look back, but I suppose they do, it’s on the screen. I don’t know, but-.

**INT: But you feel that that’s something that should happen?**

C09: Of-, it-, yeah, I-, you know, I suppose, the doctor’s surgery is the place. I-, you know, I don’t know.

**INT: Is (*wife*) seeing any other doctors or just under the GP?**

C09: Just under the GP. Yeah, she has a regular blood test, annual MOT, if you like. Like we all do as we’ve got older, so some stuff’s picked-up on that and that was the latest which was protein. Protein in the wee so. And, like I say, they just call you in, add something else on, and that’s another tablet I’ve got to remember but, you know, they’re added on over the years so-, and as long as I put them in the box in order, and I get my little weekly boxes out and put them there, and I go: “right” duh duh duh: “right, that’s the night ones”, “that’s the day ones” and whatever, but I assume the doctor to-, should check or review.

**INT: So, you’re talking about the doctor. Is there any other healthcare professional that you have ever been involved with, or (*wife*)’s been involved with, that you think would be able to do that perhaps instead?**

C09: Well, we’ve not really been involved with anybody else.

**INT: So, you see it as the role of the doctor?**

C09: Yes. Yeah.

**INT: So, in an ideal situation, if you went to the doctor or the doctor called you in to review the medication and suggested stopping one of the tablets that (*wife*)’s on, what questions might you have for the doctor? I know it’s very hypothetical, but if a doctor suggested one of the tablets should be stopped, what would you want to know?**

C09: Well, you know, obviously what she’s taking it for and like the one that springs to mind with me is Aspirin. That I understand thins the blood, I understand that part of it, but if she don’t need that thinning anymore, you know, why is she taking it? So, yeah, I would ask the questions if I thought I was concerned on something being stopped. Like if they said her brain one, they’re going to stop that then I would go-, well, you know, that to me, is a complete: “no, no”. I’m not-, to me, that slowed down or held it, the problem for now, you know. So, I, I would obviously be very concerned if they said we’re going to stop that, but some stuff I, I don’t see the point of, to be honest, and I, I would go-, if they said: “we’re going to stop the calcium tablets”, I would go: “yes, thank you”. Get rid of them.

**INT: And so, any discussion around medication would you both be involved or is it primarily yourself?**

C09: Primarily me, I would say. (*wife*)’s- no, not.

**INT: But would you want them to try and involve (*wife*) as much as possible?**

C09: Yeah, they-, I think, they do when we’re there, you know, but (*wife*)’s quite quiet, sits and takes it in, I think. But most decisions stuff is left to me.

**INT: And how do you feel about making decisions on (*wife*)’s behalf?**

C09: I just feel that, you know, I’ve got to do it and that’s it. It’s-, that’s how it’s evolved, and someone’s got to do it. So, for better or worse, and that’s it. So, that’s, that’s how I feel on that.

**INT: Have you had any experiences where you’ve felt that it’s really shared decision-making? So, you’ve been sharing that decision-making with the professionals. Not necessarily relating to medication, relating to anything. Any experience of feeling that the decision has truly been as a joint decision?**

C09: No, I would say I feel that they’ve made the decision, they might have explained it to me but, I think, you know, it’s-, the, the decision’s been taken, it’s not up for discussion whether-, whether or not the tablets, or whatever is being taken, it’s- (*pause*)

**INT: And how do you feel about that?**

C09: Well, I feel they are the professionals and if that’s what their advice is, then that’s what you’re left with, you know, and that’s like the reviews, I’ve asked for reviews, and they come back and say: “well…”. She stayed on everything. That’s the advice that’s given to me and that’s what I’ve got to accept, I think, you know. I don’t think I’m that clever (*laughter*).

**INT: So, for example, if a medication stops, and we said the one for the bones was stopped, what do you think should happen after a medication has stopped? What do you think a professional should do after the medication has been stopped?**

C09: Well, obviously, it-, I’m not saying they will, but if they stopped say cholesterol then I, I would like to think that a few months down the line they would check her (*pause*) levels in her blood, what I’m trying to think of.

**INT: The lipids? The fats?**

C09: Yes, the fats. Yeah. Yes. So, yes, I, I would like to think they would check that or keep an eye on it, on her once a year MOT, and go: “oh, well, maybe we was wrong there”, “we-, we’ll put her back on it”, you know. I don’t know. They upped it once to 80ml, from 40 to 80, and it give her a lot of grief. I can’t remember what it was. I think, it might have been with the- going to the loo and stuff. And I got it- got back down to 40 but, you know, they don’t- they won’t stop it for whatever, so.

**INT: And any of the other medications where you think it would be something specific that they’d need to follow-up?**

C09: Well, you know, there’s, there’s the-, the, the ones for the bone, I’m not-, not-, you know, I think that could go. Cholesterol, I think, there is a chance that could go. But I understand that- I suppose, they feel, you know, keep the heart going and all that. I don’t know. Yeah, you know. But any-, anything that could go, I would like to have seen gone, but I can’t-, they won’t do that and-, but it- and if they did, then I would expect that on her MOT type thing when they’re doing her blood tests, they would check: “well, we stopped that, we better have a quick look at that and make sure it’s-, her levels is alright” or whatever, I-, you know.

**INT: So, some sort of monitoring.**

C09: After. Yes. Yeah.

**INT: So, if they stopped medication, is there anything that you would like to know as (*wife*)’s carer in terms of what you might need to do after a medication has stopped?**

C09: Well, yeah, if there was anything that I had to know then, yes, I would expect that to be explained, but-, I mean, I just see (*wife*) on a daily basis and if stuff don’t seem right then she ends up, up at the doctors so.

**INT: So, you would report it back?**

C09: Yeah. Yes. So-, but, yeah.

**INT: So, in terms of everything we discussed right at the beginning around how you manage the medication, and we talked then about medications being added, what impact might it have if a medication was stopped?**

C09: What, to me?

**INT: Yeah, to how you manage the medications.**

C09: Well, it will be less-, one less that I got to think about, wouldn’t it really, you know. Like, like I say, they’re, they’re set in the box in order. I go round the box, that goes into our weekly boxes and then I, I know whether I’ve missed anything out, but I just use--, I do it from memory, and that’s it.

**INT: So, if they were to stop the statin tomorrow, you’d be able to just pick it out?**

C09: Yeah. Yeah. Yes, that’s it, it would just come out of my running order. It’s a bit hard to explain but-, so, in my box of tablets, and that-, mine’s in there as well, there is a running order. So, that’s how I take them out of the-, out of the bulk and put them in for the week and- and if there was one taken out, it wouldn’t worry me, you know.

**INT: Just one less to do.**

C09: One less to do. Yeah.

**INT: So, that’s all the questions I had. Is there anything else you want to add about stopping medication, medication generally?**

C09: No. I mean, I’m, I’m stuck with the doctor really, and that’s it. And I understand that, but-, I, I mean, my mum, a few years ago, she had Alzheimer’s and she was on a blister pack so, all hers was popped-out and that-, and what got me was-, on that was my mum took one for her thyroid but that was just in with all the others, so it was just taken as a big-, a bulk. But when they reviewed her tablets, when she was bedridden, the blister pack went down to about three tablets a day from, I don’t know how many, to three tablets. So, they did get rid, rid of them all. Like I say, she was hoisted from bed- bed to chair and chair back to bed. Was no good worrying about ‘em falling over, or anything like that, is there? That sort of side of it goes, you know. It’s like (*wife*), they don’t-, she don’t walk up the shop on her own, she walks to the car, I normally help her in the car or I help her out of the car, she holds into me if we walk anywhere. She don’t walk far anyway. What are they worried about her falling down for? That-, that sort of thing, you know. So, yeah. And, like I say, she fell from the top to the bottom of the stairs and the only bone she broke was up here, her T3, and they never noticed that on the-, it took the ambulance people an hour to get her out of the house and at the hospital, they never noticed. They didn’t notice it on the x-ray, and three weeks later we got a letter asking her to go back and they said: “you broke T3, but we didn’t notice it” because I was putting cream on her back because she said it was not very-, hurting, it was hurting. And so-, but she didn’t really break anything. Like she didn’t have two arms broken or anything like that. Yet, she ended up on tablets for-, well, still on ‘em, for quite-, you know, that once a week one that they stopped, they’ve only just stopped it. So, you know. Quite recent, very recent. So, she took those tablets and she’s hardly walking anywhere anyway. I’ve now got a gate guard at the top of the stairs so, if she’s wondering at night, she don’t fall down the stairs, you know, but the tablets just kept going and you can’t stop them. So, you can mention it, and I-, like I say, I have several times, but they just go-, I think, it’s just easier for them to go: “well, you’re on cholesterol”, “you was on the cholesterol for a reason” but is that thirty years down the line, is that reason still there, you know. So, I don’t know. Alright?

**INT: Yeah. Thank you very much. Let’s switch-off the recorder.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

C09 Respondent

***Audio* file: 39.07 minutes**