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

Transcript for interview

**C07**

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

C07: So, is it just about my experience with my husband because my, my mother had dementia as well so, I had a sort of-, looked after her as well.

**INT: I think, we’ll talk through a bit about your role with your husband but, yeah, if there’s experiences you’ve had from the past as well, that’s equally valid.**

C07: Yeah, fine.

**INT: So, if we start by talking about your husband, (*name*), can you tell me a bit about what support you provide for him?**

C07: (*sigh*) Well, I, I always give him his medication. He sometimes asks for help with what clothing to put on (*long pause*), gets very concerned about timing but, I think, he was a clock watcher in his working days (*laughter*), and taking him to and from appointments or carers together. We go to several things there during the month most of which, I think, (*husband*) enjoys now, initially, I think, he thought: “hmm, not so keen on that” but we’ve recently started, I’ve recently started taking him to a new art class because the ones he’s tried in the past they’ve-, none of them have been interesting enough, I think I would say. And the way I discovered that was because the second visit to this art class he does now he came home and as soon as he saw me, he said: “would you like to see what I did today?” and he’d never done that before with any other art class so, it made me feel great because obviously he’s enjoying that one. Whereas the others, didn’t enjoy for whatever reasons.

*Brief discussion between C07 and her husband (present in the room throughout the interview) about why the new art class is better (not transcribed).*

**INT: So, how much of your day does your caring support of (*husband*) take up?**

C07: I would say most of the day. He sleeps very well at night so, fortunate that he doesn’t get up or wander which, I know, is-, some-, it happens with some people, and he’s-, I do, I do another voluntary job so, when I do that-, it’s all local driving, taking people to appoint- hospital appointments and things and so, I’m usually only leave him for a couple of hours and so long as he knows what-, roughly what time I’m coming home, he seems to be OK with that, aren’t you? *(Husband indicates yes)* At the moment. You’re quite...

*Brief conversation between C07 and her husband about the benefits of her volunteering role (not transcribed).*

**INT: So, how long have you been providing support to (*husband*)?**

C07: Probably two to three years. I mean, I, I noticed a change in him and I thought that it was dementia because of my previous experience with my mother, but as always, it seems to be that the first-, at the initial test, which was done three times, is, I think, not a very successful test at all because it’s just-, I mean, I, I went with him for each test and I was doing it mentally myself, and it’s not easy to count backwards from-, in sevens from a hundred, and then there was the addresses that- to remember and things. But I didn’t feel that any of them really showed that he had got dementia and it wasn’t until he had a brain scan, and went to see a specialist, that-, we went up to (*hospital*) and she was so much more thorough with all sorts of questions asking him about his life from birth basically and what he did as a job, whereas none of the other questions-, none of those questions were asked with the other tests.

**INT: So, it took quite a while to get to the diagnosis.**

C07: It did. Yes. Yes, a good eighteen months, I would say, two years.

**INT: And you mentioned your mum.**

C07: Yes.

**INT: So, you had experience of someone with dementia.**

C07: I did, I did. Yes.

**INT: What sort of role did you have in your mum’s care?**

C07: Well, initially, she was living in-, near (*town*), and my father had died ten years before, and I, I noticed a few things. Because I was working, I could only go down there at weekends, and I have no siblings otherwise so, it was down to me. And that I noticed little things in the house like a, a plate of food had been put in the fridge with the knife and fork and the napkin on the top, and I thought that was a bit odd. And then I was the-, took her to the doctor and, I can’t remember whether she had those tests in fact, but I managed to find a couple of girls who lived locally who were absolutely wonderful with her and I’m sure they went beyond their duties, as it were. I used to take-, I used to do a load of shopping, food wise, and take it down and one of the girls would take most of the meat and stuff home and use it to cook her meals and then bring them back. And sharing her food as well with her, and then-, plus also they gave her her medication and things. But then a few alarming things started happening. One night she went into the kitchen and just emptied things out of the cupboards onto the floor and things, which was strange. But the last episode which in-, because of it, she ended up in hospital, was September, I remember- always remember the date, September 15th 2011, and I always watch the forecast, the forecast said that the temperature would drop ten degrees and early next morning, I had a ‘phone call from her neighbour to say that she’d found my mother in the woods half-dressed sitting in a bed of nettles and obviously, suffering from hypothermia. So, she’d called an ambulance, and I rang into work and said, you know, I couldn’t go into work and went over to-, by which time she was in (*hospital*), and I, when I got there, she was absolutely terrified about something, and bearing in mind that she had been quite agoraphobic the few months before, didn’t even go into the garden, and there were things in the garden that-, there’s no way that she could have moved it because it was heavy and it had been moved from one side of the garden, up some steps, down across the driveway so, somebody must have been in the garden and she must have seen them, I think and been disturbed by it which is probably why she went outside. And then from then on, she was actually in hospital for about five weeks, and they said she couldn’t go home so, I had to find a home for her which I did, and then there was the process of sorting out the house and everything. I actually rented it for quite a while, and then, luckily, I was able to sell it to the people that rented it which was helpful.

**INT: So, if we think about medication and your role in medication, you kindly took the photographs for us.**

C07: Uh huh.

**INT: Can I ask you first off, did you plan what photos you were going to take, or did you just spontaneously take them?**

C07: Well, because it was medication, I thought: “well, I’ll just go to the cupboard where we keep the medication” and, yeah.

**INT: You just took the photos there and then?**

C07: Yeah, I didn’t feel that there was-, anything else was necessary.

**INT: So, if we can go through each picture in turn, and I have numbered them. So, what does photo number one tell you about how you assist (*husband*) with managing medication?**

C07: Well, he has a-, I think, they call them Dossett boxes.

**INT: Yeah.**

C07: So, I take the ones out at-, let’s say Monday morning and put them in a pot and then the Pradaxa, he has two in the morning and one at night, and they come separately. So, that’s what those two tablets are sitting on the top *(photo number two)*, and this is the cupboard with both our medication, plus vitamins.

**INT: So, that’s photo number two.**

C07: Picture two, yeah, and, there’s, there’s been one or two- not recently but there have been one or two mix-up with medication because (*husband*) got, got a bit confused about things, and at the time, was trying to help himself. This was a good year or so ago and took the wrong ones so- which is when I decided-, and I’ve got a little green pot for him so, all of his medication goes into a green pot, mine goes into a red so (*laughter*)- and now we’ve got into the routine of it, so he’s quite happy.

**INT: So, the medications from the Dossett box, does he take them all in the morning?**

C07: No, he takes these five in the morning (photo number 1) and then there’s three to take at night.

**INT: So, you again pop them out into a green pot?**

C07: So, yes, I do. Yes.

**INT: So, if we can look at photo numbers three and four, anything else that they say about how you manage medication?**

C07: Sorry about the paw (*referring to cat*; *laughter*). Just wanted to get in on it (*laughter*). No, I just felt that maybe it would help knowing what vitamins he’s on as well.

**INT: So, he takes quite a few I can see.**

C07: Yeah, we both do. Take four-, five vitamins.

**INT: And they’re not prescribed.**

C07: No. No, they’re Omega, B6, B12 and D3, I think. And this fourth picture is the evening dose that he takes. This one.

**INT: And then photo number five.**

C07: Oh, that’s just showing the Dossett box really, and his medications are- plus the paracetamol which I should have turned around. So, that’s- yeah, that’s the Dossett box there.

**INT: So, he has just the two medications that aren’t in the Dossett box?**

C07: He has the- yeah, paracetamol when he needs it and the blood thinner.

**INT: And is there anything else that you do around medication to support (*husband*) other than getting his medications out day-to-day?**

C07: No, I don’t think so. If he’s-, he’s got an arthritic knee, if he’s complaining about it then I usually suggest he puts Voltarol gel on it.

**INT: And is that prescribed?**

C07: (*pause*) It was prescribed for me actually, and I- so, because I have a chronic back problem, but I do find it works which is why I suggested he put that one. I think it-, it wasn’t specifically prescribed but when he saw somebody about his knee and had an injection, I did mention that uses Voltarol gel sometimes and they said that was fine.

**INT: And how about getting the medications here? So, what processes do you need to sort?**

C07: I go and fetch them from the surgery pharmacy which is down in town.

**INT: And do you need to order them?**

C07: Yes. Yup.

**INT: And how do you order them?**

C07: When I pick them up, I tick whatever I need for the next month. I do the same for both of us.

**INT: So, it’s once a month?**

C07: Yeah. Yeah.

**INT: How do you feel about the number of medications that (*husband*)’s taking? He’s obviously taking quite a few, how do you feel about the number he’s taking?**

C07: There are a couple I’m not sure whether he needs to take them really but then I’m not a hundred percent sure what they’re for because I have to keep looking up. I think, there is one that- for-, he get, he gets a bit anxious about things which he does occasionally but not very often, and I wonder whether it’s the right medication but the doctors should-, should know what they’re prescribing so. He hasn’t been checked with his medication for some time.

**INT: So, are you aware of any time when (*husband*)’s medication has been reviewed?**

C07: No, I can’t say I remember when-, (*asks her husband)* can you remember last-, when you last went to the doctor and had your medication reviewed? *(Husband cannot remember when except that it had been some time.)* Yes, it’s either very early last year or the year before.

**INT: And that was the GP who reviewed it a couple of years ago?**

C07: Yes. Yes.

**INT: And was that arranged as a specific appointment to review the medication or was it something that was done as part of something else? Do you remember?**

C07: No, I can’t remember actually (*pause*). I- I can’t recall whether it was specifically for his medication or whether he needed to see the doctor anyway about…*(Husband interjected to advise he had never been to a GP to specifically discuss medication.)*

**INT: So, thinking about that time when the medications were reviewed a couple of years ago.**

C07: Hmm.

**INT: Were any changes made at that point that you remember?**

C07: Oh, umm, I think, that might have been when he was put on the anxiety ones.

**INT: And you both attended that appointment together?**

C07: Yes, I always go with him to any appointments apart from his feet (*laughing*) but any doctors’ appointments.

**INT: So, thinking back again about medication so, sometimes it might be considered that a medication is not needed anymore, and you’ve alluded to a couple that perhaps you think: “OK that might be the case”.**

C07: Hmm.

**INT: What do you think about (*husband*)’s medication being stopped or reduced?**

C07: Well, if it wasn’t necessary for him to take whatever then, yeah, I’d be happy for it- anything to be stopped, but mostly, I mean, he’s been on blood pressure tablets since you were-, long before we knew each other. Thirty-five, or something, did you say, for your blood pressure? I think, that’s what you’ve said in the past. Yeah, and the blood thinners, he was put on because in 19- 2015, when we met, shortly after we met, he rang me one day and said he couldn’t breathe. He was living in (*town*) then, and so I drove over there, I said to him: “have you ‘phoned the doctor?”. “No”. “Have you ‘phoned an ambulance?”. “No”. So, I said: “right, ‘phone the doctor”. I ‘phoned- I illegally ‘phoned the ambulance whilst I was driving, and he ended up going into (*hospital*) with a bilateral lung clot. So, no idea how it had happened or why because until (*laughing*) he met me, he’d never been in hospital (*laughter*), and now he’s been in several times, haven’t you dear (*laughter*)?

**INT: So, what is it about a medication that would mean that you would support reducing or stopping it versus not supporting it?**

C07: No, I just-, if it doesn’t-, if it’s not necessary for him to take one that he’s been on, been on for some time, then that would be good if they could stop it, but if it’s nec- if it’s regarded as necessary by the GPs, then I’m happy to carry on. You know, they know better than I do.

**INT: So, what they think is necessary as opposed to what you think or (*husband*) thinks is necessary?**

C07: Yeah. Yeah. Yeah, I mean, he doesn’t have any objection taking them so.

**INT: And so, would you see stopping or reducing medication as a normal part of managing a health condition or do you see it as something that’s a bit unusual?**

C07: It’s not something I’ve come across before so-, yeah. Yeah. So, I would say probably a bit unusual.

**INT: And of the medications that (*husband*)’s currently having, which ones would you have more concerns if somebody was to say: “we think we should stop this”?**

C07: Well, presumably his blood pressure and the Pradaxa, the blood thinner. Oh, the other, other one he’s on is Omeprazole and I’m not sure why because he takes more Omeprazole than I do (*laughing*), and I’ve got the-, I’m the one with the hiatus hernia (*laughter*), which is a bit odd. So, yes, I’m not sure.

**INT: So, with the blood pressure and the blood thinning one, what are your concerns about stopping those?**

C07: Well, presumably if, if they stopped the, the blood pressure ones then his blood pressure would go high again. At the moment it’s around about 140 over 90, or something, I think, roughly. I haven’t taken it for quite some time. The- and certainly because he had the clot, I certainly wouldn’t feel it-, like to stop those because obviously, you know, it could lead to a stroke or anything like that and he’s got enough to deal with without having a stroke or anything.

**INT: And are you aware of a time, or can you remember a time, when one of (husband)’s medication has been stopped or reduced?**

C07: No. I don’t think so. No. I mean, he used to take his own medication ‘til what, about three years ago. So, I don’t know what happened before that and obviously, as I said, the blood pressure ones, he’s been on those for years, probably about sixty years (*laughter*). So, I don’t know whether that’s the normal for blood pressure tablets, you’d stay on it for life, I suppose. I don’t know, but presumably the doctors know what they’re doing so (*laughter*).

**INT: So, if the healthcare professionals were thinking about stopping or reducing a medication, how do you think decisions about that should be made? What’s the best way for those decisions to be made?**

C07: When you say a healthcare professional, you mean people at the university?

**INT: No, I mean, healthcare professionals involved in (*husband*)’s care.**

C07: Oh, right, OK. Well, if, it would be the doctors and if they thought it wasn’t necessary then, as I said earlier, they know better than me (*laughing*). So, yes, definitely, I’d go along.

**INT: So, you see as the role for a doctor rather than another professional?**

C07: Yes. Yes. Yeah.

**INT: Any reason why you see the role for a doctor rather than another professional group?**

C07: Well, the nurse prescribers have recent- only recently come in so, from my point of view, when I was nursing we never started anybody on medication, it was always the doctor that suggested it and wrote, wrote the prescription out, and I suppose being-, having been a nurse for forty plus years, I was-, I’m a bit old-fashioned in that way (*laughter*) (*coughs*).

**INT: And so, when those decisions are being made, how do you think that’s best discussed?**

C07: I would have thought patient, myself, and the doctor, rather than a doctor just crossing it off because without seeing (*husband*). Yeah, I think.

**INT: And would you have any questions that you wanted answering before those decisions were made?**

C07: Yes, if it was certain drugs, I probably would ask why he felt it necessary to come off it only ‘cause I’m curious (*laughing*) and sort of like to know the reasoning behind things so.

**INT: And would you expect (*husband*) to be involved in that decision-making as well?**

C07: Not involved in the decision but he would obviously be there with the doctor, you know, talking to him. Whether you would understand why a doctor stopped anything, I don’t know, you think you would, would you? *(Addressing husband.)* No, you just go along with whatever they say. They know best hopefully (*laughter*).

**INT: And when should those discussions and decisions be made? As part of an appointment just to discuss that or as part of something else?**

C07: Well, because apart from his knee and his dementia, he’s a, an exceedingly very healthy person. He has no other illnesses or chronic problems, so, it would probably just be a, a medication review because he hasn’t seen a doctor for… Apart from your knee, you haven’t seen anybody for ages, have you? *(Addressing husband, who said no except for a time when he had a stomach problem.)*

Oh, well that, that was different because you ended up in hospital then because you had some-, a very severe bug, and it started on a Friday night (*laughing*) so, I coped with it all weekend and on the Monday morning, I rang the surgery and said, you know: “it’s getting worse” and he was becoming hydrated because he’s a devil for drink-, not drinking fluids, and some doctor that we- no idea who he was from outside, he came in and immediately called an ambulance and he was in hospital for about five or six days. Yeah.

**INT: So, in terms of reviewing medication it kind of needs to be planned.**

C07: Yeah, I think so.

**INT: And would you see that as needing to be face-to-face or could it be done over the telephone, or virtually?**

C07: I think, probably face-to-face would be better because he’d need to take his blood pressure and- or she. You know, I don’t-, I feel really, I know the doctors are hugely overworked but, I think, if you’re reviewing something like somebody’s medication, they should really see the patient, I think, but that’s my feeling.

**INT: And so, we talk a bit about shared decision-making these days.**

C07: Hmm.

**INT: Have you had any experiences of being involved in shared decision-making around (*husband*)’s care?**

C07: (*pause*) I suppose-, I can’t remember her name unfortunately, the, the dementia specialist that we saw but, as I say, I go to every appointment with him, so, if I’m concerned about something, or a query, then, you know, I can ask there and then. I don’t think she’ll knock it off, she’s very, very careful (*laughter*).

**INT: No, that’s fine (*laughter*). So, how do you think those worries or concerns that you might have about stopping a medication should be addressed by those healthcare professionals? So, if you raised a concern with the doctor, how do you think that should be addressed?**

C07: Well, if, if they suddenly sent me a message and said: “(*husband*) needs to stop taking whatever” then I would ask: “why”. Yes. Yeah, I’d want to know why because I haven’t, obviously haven’t got the knowledge that they have, but I have some having worked as a nurse and worked in a dispensary as well. So, yeah, I think, patients should always be involved and if the patient needs back-up, as it were, then the back-up person should be there as well, I feel.

**INT: So, thinking ahead to hopefully something that will not happen too soon, if (*husband*) was unable to make decisions for himself, would you have any extra questions if you were having to make that decision on his behalf?**

C07: If it was to do with-, do you mean just to do with medication?

**INT: Yeah, just to do with medication.**

C07: Yes, I think so. I would double-check that, you know, this is the right thing and ask why they-, probably ask why they want to reduce it, or stop it, just out of interest as much as anything.

**INT: Would you challenge it if you weren’t sure?**

C07: Well, if-, for instance, if the blood thinners or the blood pressure were stopped then I would because, I mean, those two, I think, are the most necessary ones that he needs to be on, I think. So, yes, I, I would challenge that, but-, and I might also ask: “why is he still on Omeprazole?” because he gets the-, very occasionally gets a bit of indigestion but it’s so infrequent, isn’t it? *(Question directed to her husband.)* I mean-, but-, and he takes two a day, I think. So, yes, I’m not sure why he’s on that one. The other ones, I can’t think what they are.

**INT: Don’t worry.**

C07: I can go and get them.

**INT: No, that’s absolutely fine.**

**What do you think should happen after that medication has stopped? So, you’ve had a discussion with the GP, the GP has suggested one medication is stopped, what do you think should happen after that?**

C07: I think, there should be a review after about a month/six weeks of not taking it. See if there’s any benefit-, beneficial change or anything like that.

**INT: Would you want any information to support you?**

C07: Well, no, I would, I would trust the doctor to obviously know what they’re doing, but mostly out of interest from my point of view because that’s my-, you know, I was-, because I’ve been a nurse all my life so, I would be interested to know why he wants to stop them or lower the dose, or whatever.

**INT: And that follow-up in a month/six weeks that you’ve suggested, how should that take place?**

C07: Well, again, I think, the doctor should see the patient, because certain things you can talk about on the telephone but, again, if for instance, if it was his blood pressure, I have got a blood pressure machine and I do know how to take it, but I don’t think that Mrs General Public would know necessarily how to take it properly because if you haven’t got the cuff in the right place or what-, you know, and why should they know anyway because it’s not their field. So, for the-, in general, I think, it should be discussed as a review.

**INT: And that should be face-to-face so that they can monitor the blood pressure?**

C07: I think so. Yes. Yeah.

**INT: If it was a different medication so, say it was the Omeprazole, do you still think that should be face-to-face or is there any differences depending on the medication?**

C07: No, not-, because you can ask questions about, you know, the results of: “have you had any effects not taking the Omeprazole?” sort of thing, whereas I don’t know because I-, I’ve got very low blood pressure but I presume somebody with high blood pressure, wouldn’t necessarily notice that their blood pressure has gone up. Would they? I don’t know. Yeah. So, I think, for certain things, definitely see the doctor but for other things, not so necessary, you can talk over the ‘phone.

**INT: And so, if a medication was to be stopped, how would that impact on how you manage the medications day-to-day?**

C07: Well, if I just collected a month’s worth (*laughing*) of medication and brought it home then they would be wasted. What I do is I check when I go to the-, get the medication, I check what’s in there and if he’s got plenty of that particular one already at home, i.e. paracetamol, then I don’t take another box because I know that if it leaves the surgery, they throw them away, whereas if you give it back to them, they can put it back on the shelf and, you know, I think, it’s a terrific waste of money more than anything but-.

**INT: And what about the medications in the Dossett box? How would that work if a medication was to be stopped?**

C07: Well, again, if, if it was changed, I would have to make sure that it-, if I’d got the Dossett boxes at home when it was changed, I would have to make sure that I was taking the right one away and- because they, they some-, two of them particularly look very very similar and I found that with an awful lot of medication (*laughing*) I’ve done. It looks-, or even some medications, one week it’s- or one month it’s one colour, the next month it’s a completely different colour (*laughter*).

**INT: And often a lot of them are little white tablets, aren’t they?**

C07: Yes. Yes, they are (*laughter*). All so tiny, I can’t even see the writing on some of them, or the indentation, or whatever (*laughing*).

**INT: So, that could be quite challenging potentially?**

C07: For some-, certainly for some people. Definitely. Yeah, because, as I say, they, they-, that person would know nothing about medication or health, how it would affect their health, or anything. They just accept what the doctor says and don’t query it whereas me, I’d query it because I (*laughter*).

**INT: You like to know what’s going on.**

C07: Well, yes, that and also if I know what I’m talking about and I-, and I don’t with a lot of things medically, but-, yeah, certain things, I would say: “why?” or: “what’s the reason behind that?”, just to confirm, you know, my understanding, I suppose.

**INT: So, that’s all of my questions. Is there anything else you would like to add to what you’ve already said? Anything from your experience with your mum that maybe we haven’t touched on around medication?**

C07: Umm, it was so long ago that-, I mean, she went into hospital in 2011 and then went from there to a home where it was obviously dished-out by the nurses there. So, no, I can’t really think of anything. It was with my mother, it was more the odd things that she did because her-, when she was at home, the girls that were looking after her, they’d come in-, one would come in in the morning and give her her medication and make sure she took it and-, you know, I’ve had experience with patients pretending to take their medication which some people, you know, do, and then they’ll spit it out when the nurse has gone (*laughing*). Yes. Yeah, so.

**INT: So, thank you very much. I’m going to switch off the machine now.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

C07 Respondent

***Audio* file: 47.11 minutes**