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

Transcript for interview

**P09**

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

**INT: So, you kindly took some photos.**

P09: All of those.

**INT: Of your medication, which I’ve got here.**

P09: Yeah.

**INT: Can you tell me a bit about how you manage your medications on a day-to-day basis?**

P09: I’ve got two egg cups and on one, I got an: ‘M’ and the other one, I got an: ‘E’. So, I know if it’s not been tilted, I’ve not taken it.

**INT: So, that’s morning and evening?**

P09: Hmm.

**INT: So, do you pop the tablets out once a day?**

P09: No. I just look before I go bed if I’ve taken it or if I’ve not because as-, those kind of things don’t (*undecipherable*) for me, but I usually go in the evening because I know I’m not going to have a good night because I’m aching a lot, so I know I will have to tell this on that, but I try to take the minimum medication. I’ve cut down my Paracetamol. I’m supposed to take it five time a day, two tablets five time a day, I think is excessive, and-, but now, I got to take that one for the-, so I don’t wet myself. I forgot the name of it.

**INT: Don’t worry about the names of the drugs.**

P09: I, I, I take it in the evening. But, I think, there’s something I must do wrong or maybe something else it does something, because sometime, I’m, I’m up all night. It’s shocking.

**INT: So, in terms of the egg cups that you have marked: ‘M’ and ‘E’.**

P09: Yes. Yeah, I know I mentioned that I might have in the morning.

**INT: So, do you pop the pills out into the egg cup?**

P09: Yes. Yes, I do, but after that, I check if I done it right. Because I don’t remember the things.

**INT: So, you said that you don’t take everything that’s prescribed for you.**

P09: Only if I feel I’ve got to take it. The only thing I will take all the time is I will take-, oh, if I could see the names.

**INT: There you go** (*Hands P09 photos which includes pictures of her boxes of medication*)**.**

P09: I will take all the time-, I will take in the evening, the Montelukast and the Lipitor and-(*pause*) Montelukast, Lipitor, and I take twice a day I take the other one, the-, I forgot the name of it, Levetiracetam. Levetiracetam, that’s right. If I got a lot of pain, I will take the Zomorph, the continuous morphine with a (*undecipherable*), 5ml, and then I will take Amitriptyline in the evening, but I usually try not to take any Amitriptyline, ‘cause if I take that lot, it’s because I’m in a lot of pain, but the next day there’s nobody home. It knock me out, it really knock me out.

**INT: So, you would only take your pain relief in accordance with what your pain is like?**

P09: Yeah, because if I do what they say I do, well, I’ll just be a zombie. You know, it’s very easy to go that way, and I like to read, but if I take them, I will be at the same page over and over again because I won’t be able to take it in, you know. I think medicine is very dangerous. I’m anti-medicine. You would not think so, would you?

**INT: So, the ones that you said at the beginning, the three medications that you take regularly.**

P09: Yeah, you see in the morning, I take the Clopidogrel and Amol-, Amlodipine, and now, what’s the name of that-, Levetiracetam.

**INT: And what is the reason for you taking those?**

P09: Well, I, I, I take the Levetiracetam and the Clopidogrel because I had three strokes.

**INT: Three strokes?**

P09: Yeah. And the other one, the Omeprazole. I’m very frugal, I don’t have any excessive-, my favourite food is bread, butter and jam (*laughing*) or fresh mushroom in an omelette, or something like that. So, every so often, I will, I’ll cook myself some food, but then I make a big pot, then I eat it like for two or three days and I put the rest in the freezer which eventually goes in the bin, so- (*laughing*).

**INT: And that then impacts on the medication?**

P09: It, it does, it impacts. Sometime on then I will binge on something, I say something is wrong with me so, I will binge on, and I will have too many green stuff. I like salad. I like fruits. I like making tart with peaches, something like that, and then I binge on it because it’s naughty. Then I upset my intestine and I do the marathon, so I’ve got to take Imodium. Or other time, I will try to be good, have something but I do something wrong and then I got stuck, I need a corkscrew. So, I got to take the thing to go oopsie. It’s exciting, isn’t it?

**INT: So, that’s played by how your symptoms are, as to what you take?**

P09: Yes. Yes, it’s a blooming pain.

**INT: But those three medications in the morning you would take regularly come what may?**

P09: Yes. Yes, the Lipitor and statin. That’s for the fat, you know. So, I take that regularly as well in the evening, but the other one, I just seem to jingle with them because- and I take the Betmiga for the bladder thing every evening as well, ‘cause that’s very embarrassing. I just don’t know what caused that. It started last October when I fell down and all that, and they said-, the doctor says: “you’ve got to take that tablet” and I said: “I’m sure it’s affecting my kidney and my bladder” and I stopped taking it and (*friend*) went mad at me and all that, and-, and I cancel it and she went and bought it and all that. I don’t know if it got anything with it because apparently it does not do anything onto the body at all, that stuff, but at the moment, I’m not-, I took it this morning because last night-, I got some upstairs but I did not want to take it but this morning, I got up at five o’clock and I went downstairs to make-, the effort of moving and I-, I took it.

**INT: Sorry, which medication was that?**

P09: The, the, the-, oh, what’s the name of it? That awful stuff, Paracetamol, which is supposed to be good for you. Anyway, why is it supposed to be good for me, all that c\*\*p. I should not have to do it.

**INT: So in terms of managing your medications, how do you get hold of the medications?**

P09: It’s delivered. Yeah.

**INT: Do you have to order it?**

P09: No, it comes every month.

**INT: All arrives once a month.**

P09: Yes, and then sometime, I, I, I don’t forget, and then all take out of the bag straight away and I give it back to the man like, you see, the, the puffer, you know, I don’t need it. So, if I know I got some-, I have too much, I did not take, I take it out and then you can give it back if-, straight away to him, if you do it straight away, otherwise, (*undecipherable*) and then-, then end up with in the bin which is shocking because as other people need it.

**INT: So, everything comes once a month and then you just hand back what you don’t need.**

P09: Yeah.

**INT: Is there anything else that you do to manage your medications?**

P09: No, because I hate to do it.

**INT: How do you feel about the numbers of medications that you’re taking?**

P09: Shocking.

**INT: Tell me a bit more about why you find it shocking.**

P09: Because a body is self-filling, you know, it’s supposed to be the mind over the matter, but it’s not happening (*laughter*).

**INT: So, does it worry you taking that many medications?**

P09: I’m in so much pain. At the moment, I can’t lift my, my shoulder, but the doctor has done the injection on my knee but, I think-, I don’t know if I can ‘phone and say: “please could I have a jab in my shoulder?”. I used to have it because they call that some name but, I think, you got to wait certain time and then it-, before that happen, I was about to have my one done in that ankle because it’s very painful, but I try not to do it. I try to move but-, you know, like the carer came yesterday and I couldn’t-, I got the lift. I sit on it, but I could not lift my leg in the bath. She got to do it. It’s very humiliating. It’s bloody shocking. Sorry, but not-, I got a body which need renewing (*laughter*).

**INT: And so, you worry about taking the medication?**

P09: Well, it may do a bit, but it destroys you at the same time. You know, there’s some of the thing in your body who are perishing and there’s-, some of the-, the quantity of it-, it’s abusing your body.

**INT: So, it’s got positives and negatives?**

P09: It is very so.

**INT: So, can you remember a time when a healthcare professional has reviewed your medications? So, looked at all your medications and done a review.**

P09: They don’t have the time. They cannot do this, that (*undecipherable*). They just did that instead of-.

**INT: So, you don’t think there’s been a time when they’ve looked at everything together?**

P09: No. No, they’re too busy making their wages.

**INT: So, sometimes healthcare professionals do decide that it might be beneficial to stop or to reduce a medication. How do you feel about the idea of stopping or reducing medications?**

P09: Well, I’m sure that some of the thing like the pain, that, the joint, I’m sure if there was some manipulation, something natural like massage, and things like that, but unfortunately, I don’t go because I can’t. My spine-, you know, I sit down but I suffer so much with it. I’m sitting on a chair and every so often, I’ve to get off because it’s killing me, but, as I say, if there was manipulation to move those joints, it would help more than medication, but they don’t have that kind of thing in this country. In some country, I could have gone, and I did have-, yeah, I had somebody who used to-, what do you call them? They plonk needle in you, the shiny thing.

**INT: Acupuncture?**

P09: Yes, and it worked, but he dropped dead so (*laughing*), it-, so that the-, that did not help. And then I got told there was no one else so, that was it.

**INT: So, alternatives to medication?**

P09: Alternatives to medication. Yeah, and I, I believe in plant a lot, and you go in any other country, you will have places where you can buy plant and make teas, and that helped a lot. Then you don’t have to take all those blimmin’ stuff.

**INT: So, of the medications that you’re currently on which ones would you be more concerned about if a doctor, or a nurse, was to say that you needed to start reducing, or stopping, them?**

P09: I would not want to get rid of the Betmiga because there’s a flood there, and I would not get rid of the Clopidogrel and the Levetiracetam and the Lipitor.

**INT: Any particular reasons?**

P09: Because, I think, they are more important because, I think, it’s all those started to get involved with that after my-, my stroke and then seizures so that’s got to be something right about it, but the rest- well, I, I tell you something, since I get the Montelukast and I take-, it’s not in there. Oh, I missed one. And another one I’m taking that’s not there. No, it is there. I think, it’s called (*shuffling papers with photographs of packets of medications*)- yeah, it’s called-, I can’t spell it. Carbo-something, it’s for the-, the lungs, asthmatic, so that I breathe like a young girl. I don’t-, with a puff.

**INT: So, that makes a big difference?**

P09: Yeah, and that Montelukast, that’s when the doctor-, they send me to see a doctor at the-, at the hospital and she was a wonderful lady, and I saw her twice. The second time I say: “did I see you last time?”, “was it you?”. I say: “you look so much younger”. She said: “no, it was me, but I changed my hair colour”. So, no, that it must be good because, ooh, asthma is horrible, but my puffer, I don’t use it that much.

**INT: So, from what you’re saying, it sounds like if you can feel that the medications are having an impact then they’re more…**

P09: I’m positive with it, but the rest-, and there’s quite a bit of it, like that blimmin’- whatever, urgh.

**INT: So, some of them you would be less bothered?**

P09: I would rather, rather have herbal stuff and mobility, you know, action on the joints.

**INT: So, you mentioned before that you don’t take them all as prescribed.**

P09: No, I don’t.

**INT: Are there any medications there that you never take?**

P09: No. No, I do take them now and then. It depend on- don’t forget, I used to be a doctor, and they’re really corny those people, you know, doctors (*laughter*).

**INT: So, can you remember a time in the past when a medication has been stopped by a health professional?**

P09: No, I’ve been on medication from long time. Don’t forget that I had a car crash. I was paralysed and then my spine went, and ever since, I’ve been on blimmin’ doctor’s stuff for one thing or another.

**INT: So, an individual medication has never been stopped?**

P09: I stopped it many times, but eventually I had to go back for it because you can do so much and eventually, the pain is so much that- and really, I tell you something, I’m a tough cookie. I really. I really have a lot of pain every day, even when I take it. I’m in pain now. It’s always somewhere. In one corner it’s horrible, but most of it is my, my spine. You could put a boomerang stick instead it may work better (*laughter*). I like a joke because other way, you cry.

**INT: Now, I know you haven’t had an experience of this, but if you were to think in an ideal situation and a healthcare professional was thinking about stopping, or reducing, a medication, how do you think that should happen?**

P09: I don’t think I would trust anybody. (Pause).

**INT: Not any professional?**

P09: What kind of professional you have to refer?

**INT: Well, which professional would you think would be best placed?**

P09: (*laughing*) They’re humans (*laughter*). You know how I feel about those. I don’t think the time we’re living at the moment is time for that, you’ve just got to live with what you’ve got. Everybody is up the creek. I don’t think anybody can really concentrate. There’s so much going on. The world is very black, and they got other thing to do is probably more important than looking after an old biddy.

**INT: But in an ideal world if they did have that time, and it was considered important, who would you feel would be the best person to do that?**

P09: A very knowledgeable-, I would go back for the needles.

**INT: So, you wouldn’t be looking for a…**

P09: Medication.

**INT: But if they were talking about stopping the medication, which professional do you think is best placed to discuss with you stopping medication?**

P09: (*laughing*) I don’t have a clue.

**INT: Who would you feel most comfortable with?**

P09: No one. Sorry. I can’t trust no one because everybody take the p\*\*s out of me.

**INT: So, no particular professional group or individual professional?**

P09: No, because everybody I’ve met, they have always taken advantage of me. Every single one, even when they have promised they would not. Unbelievable.

**INT: Including professionals?**

P09: Yeah (*shouts*), I had a, a psychiatrist-, well, no, I had two psychiatrists. I had one who was lovely lady. The way to really- a sorrow was to sing, and she ended up singing at the-, something funny in the-, you know, the round thing in (*city*). What’s the name of that? And they were singing. And the other one, he was married, he had children, and he was not happy at all so, he tell me his life stories. People tell me their life so how can you trust people like that when they’ve got their own problem they can’t sort it out?

**INT: So, you haven’t met any professional recently that you felt you could trust?**

P09: Well, the world being the way it is, nobody’s perfect. That’s mission impossible. The only friend you’ve got is yourself, and I don’t really trust myself either (*laughter*). Well, you don’t do you?

**INT: So, let’s say it was one of the doctors at the GP surgery who was having that discussion with you.**

P09: I would not because I don’t even have my own doctor there.

**INT: Is that a problem not having your own doctor?**

P09: I’m very old-fashioned. If I’m not being what I was, and suppose I would have been a doctor to, you know, a GP-, I don’t think I would have been a good GP because I don’t glue- I don’t gel with people. I’m very critical with people and I get done by it. Doesn’t matter. But no. I forgot what I was talking about.

**INT: We were just talking about having a discussion with a GP.**

P09: That must be bloody interesting. I forgot what I was talking about.

**INT: You don’t have a regular doctor.**

P09: They don’t have the time, they don’t have the number of doctor they should have at the thingy, and I believe you have-, like in the old days, one doctor, the family doctor, the one who follow you, the poor bu\*\*er, they got too many people to their name to cope with.

**INT: So, why is it important to just have the one doctor, the family doctor?**

P09: I believe in follow-up in everything, in every job, there’s a continuation and even if it’s when you went to another, it’s like that. That’s how the strikes go. That’s how the- you live a lot- the goodness or the badness.

**INT: And going back to this big ‘if’ because I know you think it won’t happen, but if a doctor was to talk to you about stopping a medication, what questions would you want answered by the doctor before that happened?**

P09: Well, I would have to say: “why is this medication? What it does it really does to the system?”. I can’t tell you what I would ask because I’m not with that person now, I’ve not had the conversation. Does that make sense?

**INT: Yeah. Have you had any experience of being involved in shared decision-making where you’ve truly felt that decision has been shared between you and a healthcare professional?**

P09: That’s never happened. I’ve consented to have an injection in my foot because it was unbearable. Yeah, I can’t say I can say: ‘yes’ but I did- it’s not a long thing, it’s what’s said: “can have it three times a year”. I only had it once, because I don’t want to abuse the system and I don’t want to abuse myself, and a little bit of pain-, if you’ve got pain, you’re alive (*laughing*). Simple enough, isn’t it?

**INT: Yeah. So, going back to the that idea of decision-making not being shared and having no experience of sharing that decision-making, is that because you think that it’s led by the professional, or is it led by you?**

P09: It’s not led by me. Willing to listen because that’s all I will commit to it. It does not mean that I would like it. So, I’m bit of a waste of space because I probably would not do what I’m told. They would have to give me very blimmin’ good answer.

**INT: And if you were to have a discussion about stopping medication, how do you think that should happen? So, where, when, any thoughts around how it should happen?**

P09: The day I got no quality of life, I will decide about the medication, and I will stop the clock ticking. It’s simple enough. I don’t think there is a problem at all.

**INT: So, after a healthcare professional had a discussion and decided you should stop one of those tablets, what would you want to happen after that medication had been stopped? So, again, we’re talking about an ideal situation.**

P09: Yes, but why would I stop that medication? Why would I stop it? What would it do? How would it help me?

**INT: So, you’d want to know…**

P09: I want to know why.

**INT: You’d want to know why it was being stopped?**

P09: Yes, and I want to know all the consequences of not taking it. What is it going to do to my body? How am I going to cope with the pain if it’s one with a pain? OK, if you take the one who do the thing about the bladder, you take it away and you say: “I got not take it”, that would be terrible because I’d be sitting on a toilet all day. So, I-, each medication, there’s a reason.

**INT: So, if they were to say reduce one of the medications .And you’d said you’d want to know what the consequences are, what would you want the healthcare professional to do after you’ve stopped it?**

P09: Oh, just bloody put me to sleep. I can’t cope without it. I want to. Some day I try not to have it and it’s hell so, I’ve try many time to get off of it. Do you know, one-, there was (*name of doctor*), she put me on three- is it 20mg a day? She just wanted me to be converted into a, a banana or something, you know, and, and there was nobody home, and, and it’s not fair to push on old people that get (*undecipherable*) and become a vegetable. I think that’s abusive. You know, I won’t get into that trap anymore. I mean, sometimes I think I take too much as it is, but my back has been very bad since October, has got worse, so, in- instead of taking the, the, the Zomorph with, is it 10ml, yeah, 10ml, I take 15ml once a day, and I’m not even happy with that. I would like to take only 10 but then if I take 10, I have to take the Amitriptyline and, and then that always work, and- but I take only 15 and I can do without the Amitriptyline but if it’s really a bad day where my back, I just like bend like an old witch, then I will take them, and when the next day there is no point getting awake because really (*makes being sick noise*).

**INT: That makes sense because what you’re doing is balancing it.**

P09: Yes, I’m trying to balance it permanently.

**INT: And you’re making those decisions about what you’re taking.**

P09: Yes, and I’m not particularly happy with it, of course.

**INT: So, that’s all the questions I had around stopping medication.**

P09: Yeah.

**INT: Is there anything else that you want to add that we haven’t covered?**

P09: No.

**INT: I’m going to switch the recorder off.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

P09 Respondent

***Audio* file: 30.55 minutes**