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

Transcript for interview

**C04**

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

**INT: So, I am going to start with a completely different question for you rather than just the photos.**

C04: Yeah.

**INT: If you can just tell me about the care that you provide more generally and the support that you provide more generally for (***P04***)?**

C04: Right. So, I would say just starting, again, we do have a fairly regular routine in the morning so, obviously, in the morning we usually, I make him a cup of tea and I persuade him to come and, because we do, to come and sit in my bedroom and have his cup of tea sitting with me, and then we come downstairs, we have breakfast. After breakfast, we do tablets and then we usually have a little sit for a bit, don’t we? Or have another drink together. Then it will be getting dressed, having, having a shower, and he doesn’t need support at the moment in the shower, but he does need support choosing his clothes. I do help him get dressed usually, don’t I? And then, depending what we’re doing with the day, we try to get out most days, don’t we? Because it can be tricky. If I’ve got things to do so like admin work or something like that, the telly does go on, doesn’t it, to find some sport or something for you, but we do try to get out. Lunchtime, again, food preparation is all, so, I will get his breakfast and put it in on the dining table and so, and I will and, again, up until fairly recently, you could make your own sandwiches and things, couldn’t you? You could do your own breakfast, you could do your own sandwiches, but it does need a bit more, well, I’m-he’s just a bit too shaky now so, I tend to do it, don’t I?

P04: It impinges on everything you do.

C04: Yeah.

P04: Fine preparation of food…

C04: Your fine motor skills are, you struggle now, don’t you?

P04: Motor skills are not absent but they’re a handicap because of the movement.

C04: Yeah, he trembles and things. So, again, that would always involve me. So, I would say, you know, I am very much involved in his personal hygiene, and things like that, making sure he’s got everything he needs if he goes to the shower, helping him dress. In terms of his meal preparations I’m very much, so that ...

P04: A review of the nights...

C04: Medication, I would say really on the whole if I didn’t remind him, I think, we’d, there’d be a lot of forgetting. At bedtime, it’s, I sort of help you to settle. We have quite a routine, don’t we, for settling at bedtime, and things like that.

P04: Yeah.

C04: So, I am basically involved with every aspect of his care really.

**INT: It sounds like that’s increasing over time.**

C04: Yeah, it is just steadily increasing up until even a couple of months ago, he could dress himself. He can more or less dress himself. If left to it, he can mostly do it, can’t you?

P04: I always took sticky clothes because the static between two different threads, threads of cloth is sufficient to put a resistance on the flow of your clothing.

C04: Yeah, and I I don’t think it’s that so much, it’s just it’s…

P04: It really can make it quite difficult.

C04: It’s difficult pulling things over.

P04: To move and dress. (*C04*) has lots of clever nursing moves that she does (*laughter*).

C04: But again, you know, any, any social activity would have to be arranged by me, you know, I think (*P04*) wouldn’t go out if we, if we didn’t arrange that, you know, as I say, shopping, remembering to, trying to persuade him to have a bit more fluids, you know, it, it, it does all require my input really. Yeah.

**INT: So, quite a lot of involvement really.**

C04: Yeah. Yeah. Yeah.

**INT: So, if we now talk through your photos around managing his medications, can I ask you the same question, were they spontaneous or were they planned?**

C04: For me, they were spontaneous. Yeah, I’d think: “oh, yes”, you know, as I saw something. I mean, for example, I did a meal where I thought, I didn’t bother doing every meal, the, the point is meals are a prompt, you know. Yeah.

**INT: So, shall we talk through them one by one?**

C04: Yeah.

**INT: And if you can just tell me about the photo and what it shows.**

C04: Yeah. So, the first one, as you can see, the medication, I have very deliberately sitting on the windowsill in the kitchen because then, of course, you’re in and out of the kitchen a lot, because I occasionally forget. You know, I’m not saying I’ve not ever forgotten to give him his tablets but that can be the prompt for me: “oh, tablets on the windowsill”, “bother, I didn’t give him his tablet”, you know so, that’s that prompt. And, again, for example, breakfast , that’s very much we have that meal and then there are tablets after.

**INT: Photo number two.**

C04: He doesn’t have any tablets after lunch, do you now? You did for a while, but you don’t now.

P04: Yeah.

C04: Evening meal we have earlier now so actually the tablets do come a bit later. The tablets, the evening meal, for the evening it, this isn’t, we’ll get to that one but that’s more a reminder.

**INT: So, photo number three.**

C04: Three, again, is, is just that’s up to me, you know, giving him the tablets and making sure he takes them. Four, *(Referring to photo 4)* it, I do find because I just take calcium and Vitamin D every day and actually, that can be a prompt for me to think: “oh, right, (*P04*)’s tablets” because I take those, that’s, that’s…

**INT: So, that’s your medication.**

C04: That’s, that’s the only, that’s my medication. Again, I have, I’m not setting alarms at the moment *(Referring to photo 5)* but the one we had when we had that extra tablet in the afternoon was, that was the one I could forget because it was a recent one and I, so, I set, so, but I have, I do sometimes use my ‘phone alarm as a means of remembering that it’s, so, it will go off and that tells me his medications due.

**INT: So, that was because there was a new medication.**

C04: Yeah. Yeah. Yeah, and it was just because I was finding I wasn’t quite having it in my head every day so, that was to keep it in my head every day. And that isjust showing, I mean, at any time of day really, it’s a very useful clock to look at *(referring to photo 6)*.

**INT: So, photo six is the clock.**

C04: To remind, although it’s for (*P04*), it reminds me that his medication is due.

**INT: And you said that was more specifically the evening one.**

C04: Yeah, when we’re sitting watching TV and I’ll go: “oh, yeah eight/half-eight medication”. There again, the dosette box itself, you know, is very much…*(referring to photo 7)*

**INT: So, do you fill all the dosette boxes?**

C04: I fill it every week. Yeah.

**INT: So, you fill it once a week?**

C04: I fill it once a week. Yeah. So, he has his medication on Saturday night and then I always fill it before we go to bed, don’t we?

P04: Yeah.

C04: So, it’s ready for the morning. So, I do that once a week. And that one, I think, is just after half-eight there *(referring to photo 8)*. Again, I probably looked at that and gone in the kitchen and looked at the kitchen clock: “it, it’s time to take medication”. Yeah. So, a lot of it does in, is around actually observing what time (*laughing*) it is, but then there’s the prompts of meals and my ‘phone. Visually seeing the tablets themselves can be a prompt for me as well.

**INT: So, is there anything else that you do relating to medication?**

C04: Oh, I mean, I, I obviously do the the pres, you know, a repeat prescription, I suppose. You know, obviously that.

**INT: Tell me a little bit about that.**

C04: So, we actually now have it set-up with our local pharmacy. They actually, because he saw the pharmacist a little while ago, he set it up. That, he tried to, you know, to bring them altogether so that we are, have a, we’re getting that repeat prescription every two months as a, as a, you know, sort of, and they actually remind us, they actually send a rem, a reminder to (*P04*)’s ‘phone that his, but but I, I use his, I do...

P04: It should, ideally, it should come to your ‘phone but…

C04: Yeah, but it’s fine, I check your ‘phone all the time, don’t I?

P04: You, you need to be a bit of a computer buff to do all that.

C04: So, so, that has been better actually in that, you know, because obv- I, I, otherwise, I have to notice that: “OK, we’ve only got a week’s worth of that one left, I I need to order some of that” which does happen actually with the Sinemet. I’m having to be careful to remember to order that one, and the Sertraline but apparently, they are going to bring them together so that I, they are, if you like, just: “send me a note saying your prescription’s ready” rather than me having to rely on them which is what I do, sometimes have to do still. Yeah.

**INT: So, they notify you.**

C04: Yeah.

**INT: Do you have to order them before they notify you or do they do that routinely?**

C04: No, they do that, in theory now, they do that routinely. That’s just set-up to happen every two months but what I find is occasionally, I don’t get that reminder so I have to ring them to say: “oh, we are due the tablets” and I’m hoping it will be a bit more straight forward now, now we’ve got them set-up, I think. But yeah.

**INT: Anything else you do around medication?**

P04: No.

C04: (*sigh*) Not rea- I mean, we, we quite often talk them through, don’t we?

P04: Everything to do with medication is your nursing care and experience of nursing process makes an enormous difference because it, you don’t and are confident with it.

C04: Yeah, I think, if you weren’t confident handling this amount of drugs, it could be quite tricky.

P04: Yeah.

C04: Things like, so, for example, the Ramipril depending who’s, who’s, who’s manufactured it, the tablet looks different. It actually is the same shape but it, it can be white and red or white and green. One of the others, which one is it? Is it the Sertraline?

P04: Yeah.

C04: That’s, they change shape (*laughing*) so, again, I think, really I can see situations where if you weren’t on the ball, you could quite easily get, we’ve he’s got three, his tablets are yellow, different type yellows, slightly different shapes. It’s quite hard actually.

P04: There’s a lot in general practice about cutting down costs in medication by allowing pharmacists to shop around.

C04: Yeah, to get the cheapest at which they do, don’t they?

P04: And that that encourages the use of different colours and quite frequent changes and done purely for economic benefit of the practice concerned.

C04: Yeah. Yeah, but I do think for some, you know, they take a brown one, they take a yellow one, they take a. you know, it could be quite hard, I think. So, I, so I was going to say something else and I can’t think what it was.

P04: Dossett boxes?

C04: About, about, about medicine.

P04: Taste, the frequency?

C04: No, we but we do, we quite often, because, again, I think, this is your medical background, we quite often, as we’re having them we remind ourselves which one, what it’s for (*laughing*), don’t we? The only, I mean, I give him these every day and he looks at it and he goes (*laughing*) as if “what are you giving me?”, you know. So, we talk it through kind of thing so.

P04: Chuck it down you.

C04: And, and, and then you think but it just amuses me like, you know, and it’s the same every day but he will, you know, he’ll scrutinise it as if hmm (*laughing*).

**INT: So, particularly if one has changed colour.**

C04: Yeah. Yeah. Yeah (*laughing*).

**INT: Anything else?**

C04: I mean, I have to, I don’t think there’s anything else that specific. I can’t say, I can’t honestly say that I look at (*P04*) and I think: “oh, he’s getting a bit more shaky”, “he’s getting a bit more like…”, “he needs this”. I wouldn’t really say I’ve, I’ve had that sort of feeling of: “oh, you need your medication”, you know. I mean, obviously, we give it regularly so we haven’t got, maybe it’s that, we haven’t had that problem but, you know, yeah, I’d, I’d say I can’t think of anything else actually that’s particularly…

**INT: Any particular challenges that you face? You’ve mentioned, obviously, that you’ve resolved some of them with the pharmacy.**

C04: Yeah. Yeah, I do just have to be careful. Yeah, I’m aware when I, you know, am doing a week’s worth of tablets and I set them all out, you know, I have quite a routine of doing one tablet, putting that away, doing the next tablet, putting that to the side to make sure I don’t make any errors, you know. And also, doing it for long enough, I, I do recognise, you know, but even occasionally when I, I, I did put one in the wrong, it should have been there and I put it, and it was when (*name*) was looking after you, I’d gone out to the shops, this is one of my daughters, and she rang me up and I said: “oh…”, it was when you were having the Sinemet at, in the afternoon and I had put it in the wrong place and she and and…

P04: Easily done.

C04: And my reminder went off to take it and so, I rang (*name*), I mean, so, and she said: “oh, no I’ve not forgotten” and then she went: “oh, there’s nothing there (*laughter*)” and then and when I came back (*laughing*) in. So, you know, it is, it does happen even though you think you’re being really, really careful, you know, you can make mistakes. I do reflect on that really, you know, there is a potential there for, when there’s a lot of drugs, to making errors.

**INT: So, talking about the numbers of drugs, how do you feel about the number of drugs that (***P04***)’s taking?**

C04: Yeah, again, it makes me quite sad really that we’ve gone from this very, very healthy, you know, up until, towards sixty man who’s suddenly, and never dependent on any medication, suddenly is quite dependent. So, it does impact quite a lot, I think, that I, but, I again, I do think about the medication he’s taking and I don’t know, I, we do talk about whether we feel things could like, you know, could be stopped and I do agree that on the whole, I don’t think there’s anything at the moment I feel we could stop.

P04: And I and I could exercise.

C04: I mean, the Mirtazapine, I, I mean, that’s I do feel but I do feel it helps him a bit with his anxiety and and, if we’re honest, it helps you a little bit get off to sleep as well, doesn’t it, because it has a bit of a sedative effect.

P04: That and Sertraline.

C04: You know, but that in a way we’re quite grateful really so, we wouldn’t want to stop those. The Rivastigmine, you know, we are aware we would: “drop off a cliff”, they say, if you stop taking your Rivastigmine. I mean, I don’t know how true that is and we’re not going to try (*laughing*). You know, the Clopidogrel yeah, I, I see the necessity of that, the Ramipril, yeah, I see the necessity of that.

P04: The Ramipril.

C04: The Ramipril…

P04: Currently they’re, we said it…

C04: We’re, if that’s, well, maybe we’re a bit more on the fence about, aren’t we, because your blood pressure…

P04: It’s, it’s interacted a lot with other medicines in the in the box.

C04: I don’t know if it is. I don’t know.

P04: Well, Sertraline, it interacts with…

C04: Does it with Ramipril?

P04: With, with Sinemet because that changes blood pressure as does the Ramipril and Sertraline also interferes with the blood pressure, I think.

C04: So, we do keep an eye on your blood pressure which, to be honest, goes up and down a bit, doesn’t it?

P04: It goes up, goes up and down a bit.

C04: It can be fine.

P04: It’s tending to be a bit low.

C04: Yeah. Well, we think, we think that was the Sinemet, don’t we, was making it, was making it go a bit low so, we’re just keeping an eye on that. So, no, it (*pause*), the Sinemet, do we feel the Sinemet is really making a difference? I mean, this is only the recent ones, it was…

P04: I think, I think it is. It’s, it’s Sinemet.

C04: You do, don’t you, and then, and it and I…

P04: It’s long tried and tested.

C04: And I do sometimes feel, you know, like with a small child and, sorry (*P04*), and they can’t quite explain to you, like well, like they’re fitting their shoes, and you say: “how do they feel?” and as mum, you you can see if it seems to fit alright but actually, that’s as far as you can go. It’s how, does it feel comfortable on your child’s foot and, I sometimes feel a bit like that with (*P04*). It’s you’re the only one who can really say if this actually is benefiting you or: “does this make it better?”, “does this make it worse?”. I kind of, it, I feel a little bit, you know, I can’t really con confidently say…

P04: Problems with sensation in my feet.

C04: You know, I have to, it has to come from him really, the lead has to come from him on this with all his pills and I I’m not seeing anything that makes me say: “oh, no, you need to stop that” or: “oh…”, you know: “we really can’t…”.

**INT: So, at the moment, it kind of seems about right.**

C04: Yeah, I think so.

**INT: But it sounds like you’re keeping a really close eye on what you do.**

C04: Yeah. Yeah, we do, I think, we do. We do. Yeah.

**INT: So, with (***P04***), we talked through about the medication review, and you said that you’d had a review recently with a pharmacist and you’re clearly having regular reviews with a GP.**

C04: Yeah. Yeah.

**INT: Is there anything that you want to add to that beyond what we discussed with (***P04***) around the review process?**

C04: The only thing with the review when we go (*laughing*), because I because he is on very good form when he goes to see the GP and we, you know, I the GP walks in the room and he goes: “oh, your walking’s better”, you know, and, I think and I think: “hmm? Yeah (*laughter*)”, you know.

P04: I thought to myself when that, when that comes to me, I thought: “well, surely you knew that this…”.

C04: But this is a known fact with the, with, you know, that they, you, he can put on quite a good show. We had some friends here on, (*P04*)’s niece was here on Sunday with their two little boys which was lovely and although when you chat you do get a little, you do get a little bit lost occasionally, he was very good (*laughter*) really, you know, but that’s a known. I remember my grandma doing this to with mum, she she would, we had a granny flat and and unfortunately, my grandma developed dementia and, you know, obviously mum was the carer, main carer, but, but her brother would come- and (*name*) would come and she’d put on this amazing performance. And then mum would be like, when they’d gone, would be going (*laughter*), you know, and kind of say: “oh, she’s back”. We had a lot of that when you, not so much now because it’s a little bit more visible now, but when you first started, people would see you and they’d say: “oh, he’s fine, isn’t he?” and you think: “no, he really isn’t”, you know.

P04: Was it: “oh, he’s fine” as in: “I don’t want to talk about it”?

C04: No, I don’t think it was even that. You you put on quite a good performance and, in fairness to them: “I think, well, actually, yeah, you’re right, he was fine today”, you know, but, but obviously I have it all day every day.

**INT: Yeah, you’re seeing everything.**

C04: That is not how it is (*laughter*).

**INT: So, in terms of the medication review with the pharmacist, were you involved with that?**

C04: Yes. Yeah, that was…

**INT: And were there any changes made by the pharmacist?**

C04: Really he didn’t make any changes…

P04: He changed, changed the Ramipril.

C04: Ramipril? Er...

P04: And Sertraline.

C04: ... I don’t know if he did. Certainly, he was on, he kind of set it up so that, hopefully we, the medication comes automatically every two months rather than me having to always chase them up and, you know, the Clopidogrel finishes then so I’ve got to, you know, order a repeat of that but then, and then the Ramipril then, you know, almost week to week sometimes, there’s another medication I was having to arrange the repeat of, he’s sort of consolidated that and brought that together. Did he change anything? Oh, sorry, I should, I should have highlighted when he came, when we went to see him (*shuffling papers*) because he might have done. Do you think, do you feel like…

P04: It is the community pharmacy, community mental health care, was where most, most of the, the initial changes took place.

C04: (*turning papers*) June, no, I think it was after that. It was definitely after that. I will be with you in a minute.

**INT: No, carry on.**

C04: (*turning pages*) It was before that.

P04: It’s been quite a long wait, hasn’t it, to get to a point where we, a more regular…

C04: Why can’t I find it? As soon as you go, I’ll find it, won’t I?

**INT: Don’t worry too much.**

C04: Yeah, that’s annoying though.

**INT: But it’s not anything that stands out that it was stopped?**

C04: No. No (*turning pages*) (*long pause*). I didn’t think it went that far back. I definitely wrote it down. Oh, sorry, I’m going to have to, that I can’t find it. So, I’m aware that…

P04: So, I think, that more reflects that you got things fairly regularly ...

C04: Yeah, it’s definitely written down. No, I definitely wrote it down.

**INT: You’ve just got so much there (*laughter*). So much to remember.**

C04: I’m-I’m scanning it and not finding it but but so, I can’t remember if we changed anything, any dosage, did we? We talked about…

P04: It was initially a question between…

C04: No, I think, it all stayed the same, it was more just getting it more organised. Yeah.

P04: Sertraline was a concern along with the…

C04: He, we we didn’t have that then. When we saw him, you weren’t on the Sinemet or the Sertraline.

P04: And there’s there’s the other one. Which one do we take at night?

C04: Mirtazapine?

P04: Mirtazapine, that was probably the main thing that to start with because concerned about getting the right dose there.

C04: Yeah, but that was with (*doctor*) we sorted that one out. That was (*doctor*). Anyway.

**INT: Don’t start worrying.**

C04: No, it’s annoying me though (*laughter*).

**INT: No. So, in terms of that review with the pharmacist. You were involved. And did you feel that that was shared decision-making? How did that feel?**

C04: Yeah. No, it did feel, it did feel like a shared decision and and I do feel (*P04*) was included as well, you know, it was, yeah. No, I, I was quite happy with with how that went, to be honest, and I got the impression that’s going to be an annual thing. Yeah, from when...

**INT: And is that helpful?**

C04: Yeah. Yeah, definitely. Yeah.

**INT: So, in terms of thinking about stopping or reducing medication and obviously, from our discussions there’s been a few things that have been either reduced, stopped, increased, added., lots of changes. Do you see that as a normal part of managing a health condition?**

C04: I do. I--- I think, it’s an important part really. I feel it should be, you know, managed like that, like you just--- there’s a con--- an ongoing discussion about is a medication needed, dosages are right. I feel--- yeah, definitely.

**INT: So, that’s important?**

C04: Yeah.

**INT: What would encourage you to support a medication being stopped versus feeling like: “actually, I don’t support that”? What is it that helps make that decision?**

C04: Well, I think, perhaps if we, you know, if I didn’t, if I wasn’t really feeling there were any benefits at all. If I didn’t feel there’s any changes or if I felt it was giving him perhaps side effects, you know, that that were actually almost more of a problem than the the thing we were trying to to treat. That’s why I’m a bit on the on the (*pause*) on the fence with the Sinemet because I’m not absolutely sure that I’m seeing any real change in that but in fairness to (*P04*), he feels it is, you know. So, its things like that really. I think, if I really saw…

P04: It’s taking a while. It tends to interact with the sort of movement disorders, and they take longer to sort of present themselves.

C04: Yeah. I mean, the Ramipril, I’m aware that we really shouldn’t stop that one. The anti-platelet, obviously, I think, I would be concerned to stop that in in case, you know, it did cause any further problems in terms of strokes and things.

P04: Yeah.

C04: No, I wouldn’t, I think, we do, so, we go through each of the drugs fairly regularly really and discuss whether we feel they’re, are they needed.

P04: We take blood pressure and temperature and…

C04: Yeah, we keep an eye on blood pressure and things, don’t we, and we do your your sats as well. We do occasionally.

P04: We do all of this.

C04: Yeah, we sort of keep a fairly close eye on things. Yeah.

**INT: So, in terms of any medication that was stopped, I can’t remember which one we said had been stopped.**

C04: The statins.

**INT: The statin. Can you tell me from your perspective how that came about and your involvement?**

C04: I think, that was when we went to see the GP and he felt that that was impacting on his blood pressure to a certain extent, and obviously, you know, things like his cholesterol levels have been fine, things like that. So, he felt that wasn’t really necessary and, yeah, I I agreed with him (*laughing*). Yeah. So, and, I think, you agreed with him as well, didn’t you really?

P04: Yeah. Cholesterol takes two years or so to really have a long-term…

C04: Your your cholesterol’s always been fine actually, hasn’t it?

P04: The cholesterol has always been no problem.

C04: I think, that was given initially post his TIA and the strokes that he had. It was given very much as a stat thing to have because of what had happened, you know, and a sort of year or so down, you know, down the line, do we really need that one? So, no, we hadn’t thought of stopping it, to be honest, had we? But the GP suggested it, and actually we did agree, you know.

**INT: And that was very much a shared decision?**

C04: Yeah. Yeah.

**INT: And did you have any follow-up after that?**

C04: No (*laughter*). I mean, other than us taking his blood p... but then we haven’t had, you haven’t had your cholesterol recently or anything, have you?

P04: Not, not the cholesterol. No.

C04: No. In fact, you’ve not had any blood tests recently. Not that you’ve needed them but but, no, we haven’t had any but I must admit, there hasn’t been any particular follow-up from that. And, again, the…

P04: (*Daughter*)’s getting a little bit concerned about uric acid and concentration. That and stuff.

C04: Yeah, quite rightly.

P04: But that’s more to do with…

C04: That’s to do with drinking pal (*laughs)*.

P04: Drinking. Yes (*laughter*). Drinking enough, but and, of course, too much of that also impinges on sleep pattern at night.

C04: Well, I think, the, that what we’ve got is if, if he drinks more then he needs to get up in the night, and so, we tend to, you know, yeah, getting fluids in is, as as often is, is a, is a tricky one (*laughter*).

**INT: So, in terms of any future decisions about stopping or reducing medication, how do you think the best way for that to happen is?**

C04: Well, it, it would always be to discuss it obviously between ourselves but also with a health professional so, with our GP.

**INT: And the GP specifically?**

C04: Yeah, I think, well, again, it’s our best port of call really, isn’t it, it has to be. We, we actually don’t have, again he’s no longer, he was discharged from elderly mental, elderly what is it? Elderly person’s mental health team (*laughter*). So, and she did say if you have any problems in future come back to us but, I think, again, she felt at that stage there wasn’t really much more they could do in terms of medication. It was, it was just a matter of monitoring medication and how it went sort of thing. I’m not sure how I felt about that. I thought maybe an annual review at least from that team might have been beneficial because she’s an expert in that field, you know. I mean, I get it. I get that in a way we didn’t need to go back to her but I was a little bit surprised at the same time because even for her an annual review, she would be able to see how his, how he was and check that she was happy with his medications as well because, you know, in all fairness, the GP hasn’t got that ex extensive knowledge that the consultant has.

**INT: So, it’s sounding like you feel that her involvement should be there to some extent around some of the decisions.**

C04: Yeah, I think, so. I, I would, I mean, it…

P04: Just, just to let you know that you’re being seen by someone.

C04: Yeah. I mean, we’re both medical background and, I think, that maybe had something to do with it that, you know, we would know to seek advice if, if things were deteriorating, but I kind of was surprised perhaps we didn’t just maybe have an annual face-to-face with her, but I know, again, it’s all about the pressure, isn’t it, and the, they’re so busy, and relative to probably many of her patients you were quite good, you know.

P04: Hmm.

C04: I think. Yeah.

**INT: And so, the GP has now given you the oversight on that medication?**

C04: Yes. Yeah.

**INT: So, if you were to be having a discussion with the GP around stopping any of the medications relating to the dementia, how do you think that should best happen?**

C04: Yeah. Well, I, I think, we’d be quite nervous about that if he were to suggest that we stopped specifically taking…

P04: For a yearly review, I’d sort of--- a fairly clear idea of what the purpose of the drug was and the side effects from the pharmaceutical point of view would help particularly for patients who are more, more proactive about chasing up results because it’s a complex area with lots of different drugs used and the, the balance between using this drug or that drug is not always clear even to the medical profession and that leads to a sense of, you know, is everything happening here that needs to happen?

C04: But, I think, we are going to get that sort of pharmaceutical review once a year now. I got the impression that, that, that will be an annual thing, and I do feel each time we’ve been the GP looked at what you’re taking and reflected on it and, you know, I feel he’s sort of been quite supportive in that area.

**INT: Are there any specific questions you would want answering if it was proposed that a medication was stopped?**

C04: I don’t know, it would depend on what, I’m not sure, to be honest, I think, it would be an in-the-moment thing almost, to be honest. I can’t think of anything, I mean, I would always say: “why?”, you know, or I’d always want to know: “why are you saying that?”, you know: “what’s the…”, you know: “your reasoning behind that?”. I wouldn’t just say: “oh, right, OK” but, I think, that’s probably and as long as I was happy with that and that I felt it was the best solution for (*P04*) as well, I think, I would be happy with that.

**INT: And you’d want to be involved in that decision-making? As well as (*P04*).**

C04: Yeah, I would really.

P04: Yeah.

C04: Yeah. Yeah.

**INT: What’s been your experience, so not professionally but as (*P04*)’s family member, of being involved in shared decision-making?**

C04: Very positive actually. I feel very much people have taken on-board that, you know, I do have to be quite involved and it is a shared decisions, you know. I don’t feel... I think, they’ve understood that they can’t really expect (*P04*) to always be able to even articulate sometimes exactly what he wants to, how he feels, what you want to say about...

P04: Yeah, particularly articulation because you start on a subject and start, start with, you know, one thing and very quickly find that you, you can’t keep more than one ball up in the air...

C04: Yeah. Yeah.

P04: ... so to speak.

C04: So, no, I think, people have been very good about underst appreciating that actually I’ve got to be quite involved really. Yeah, it’s a necessity.

**INT: And if things progressed and say (*P04*) wasn’t able to contribute so much would you have any additional questions?**

C04: Well, it, it’s-tricky at that stage because I, you know, you feel very much you’re…

P04: Consent.

C04: ... making, yeah, it’s about consent, isn’t it? And if I’m making unilateral decisions, at the moment, I feel any decisions we make are al-... you know, I know you have some difficulty sometimes, but I do feel, you know, there is capacity there, he understands. You know so, but that, that yeah, when it gets to, when I’m having to make decisions for him, I mean, that’s, that’s OK, I’ll, you know, I am happy to take that on, but I will be aware, I think, it’s…

P04: You’ve already, well, we’ve already, we’ve already been through a lot of that between each other but the people we haven’t really been, been is about making decisions, joint decisions is actual joint decisions itself, we haven’t, other than outlining what we think is the necessary treatment plan, there isn’t somebody who tells you, or aids you, what’s immediately there at the time.

C04: Yeah.

P04: I’m probably not making sense.

C04: I’m not sure.

**INT: So, I think, from what you’re saying that perhaps that will be a little bit more worrying for you making decisions.**

C04: Yeah. Yeah, that’s right.

**INT: Is there anything specific?**

P04: Who’s in charge, that’s the question, isn’t it? Yeah

C04: I can’t think of anything specific at the moment. Not really. Again, I think, it will be (*laughing*) sadly, it will probably be more of a reactive thing as, you know, we talk long-term about how we will manage at home in terms of if if he starts to need more care, in terms of feeding, you know, actual need need personal hygiene.

P04: Bed.

C04: Would we need to have a bed downstairs, you know, we talk more about that sort of thing when it would come down probably to my decisions really about that because it will get to a point where you perhaps can’t be a part of that decision. Obviously, the fear that he might need to go into a home at some point, you know, where, how far down the line do do you go before you make that decision. Do I how much am I able to cope and care for (*P04*) at home before we get to that sort of decision, and what sort of support would I get to enable that. You know, we do…

P04: How to choose a care home*.*

C04: We talk about that sort of thing, don’t we, long-term as well.

**INT: So, in terms of making those decisions around medication ...**

C04: It would probably be down to me really.

**INT: In conjunction with the healthcare professionals?**

C04: Yeah. Yeah, that’s right. Yeah, we need the healthcare professionals, but it would be very much probably down to me, I think.

**INT: So, is there anything else you’d want to know from the healthcare professionals to support you in that situation?**

C04: Possibly. No, it’s hard at this stage, it’s really hard. It’s really, you know, you, you, we do think about it, and we do talk about it but, I think, it’s sometimes those things until you’re in them. You know, you’ll probably ask me this question in a year’s time, I’d probably say: “oh”, you know: “have…” but, yeah, I do find it hard actually to project…

P04: I, I can foresee a a question when it comes to the point of needing input from district nursing care if that becomes an issue.

C04: Yeah, but if we can, I think, we both feel if we can manage that with some, if it gets to that point, then that’s what we would rather do than have you in a home. I feel a home’s a last resort. Yeah?

P04: I think, if you choose, one chooses the right home and it goes on alright, it can be quite…

C04: I don’t know, maybe I’ll get to the point where (*laughter*) I’m thinking…

**INT: That’s a conversation for the future, isn’t it?**

C04: Yeah (*laughter*), that’s a conversation for the future.

**INT: What do you think as (*P04*)’s family member should happen after a medication has been stopped?**

C04: Well, I mean, obviously, you’re going to monitor how you feel that’s, what effect that’s had, has it had a beneficial effect or, or an. you know, a negative effect, and I would hope that, you know, I would get support from the GP in, in that.

**INT: What might that support look like? What might you want it to look like?**

C04: Well, it, I, I think, realistically, it would either be a face-to-face consultation or, or if it was myself wanting to, you know, needing support, I think then it could be a separate conversation, you know, initially at least, you know, but then depending what we discussed, you know, it might be useful for the GP to see (*P04*) face-to-face as well. Yeah.

**INT: And coming back to the processes we talked about at the beginning, the practical stuff that you do day-to-day, how does stopping a medication impact you that way?**

C04: Yeah. Well, it’s great, it makes it easier (*laughter*). It makes it, because, one, for example, the Sinemet, having started that and then there was the afternoon dose and again, I, because we also quite like is we have breakfast and we do medication and then that’s it then, there’s no more medication until after he’s had supper and we settle down for the evening. Again, very easy to get that prompt. Again, third lot of tablets he has is just before we go to bed, very easy. So, I, you know, I it actually stopping even just one medi- dose of that medication actually made my life a little bit easier (*laughing*), you know, and I appreciated that: “right, I haven’t got to remember the afternoon one anymore”. I mean, I’m sure it would have become habit but it’s, you know, and I do sometimes think: “oh, there’s an awful lot of medication here”, “there’s an awful lot of tab-…”. Every Saturday night, I’m thinking: “there’s a lot”, you know.

**INT: Yeah. How about if it was stopped and it needed to be stopped immediately, how might that impact?**

C04: Well, that’s OK because we have, we have done that, we did do that with the statin, didn’t we?

P04: Yeah.

C04: We did just stop that, and I didn’t worry about that actually. You know, if I felt it was appropriate to stop it suddenly, so, particularly if it seemed to be really having an adverse effect then actually, no, I would be fine about that. Yeah.

**INT: And it wouldn’t impact on any of your processes?**

C04: I don’t think so. No, because there’s lots of other processes (*laughter*). It’s not, so, no, no, I think…

P04: You would see at the time as to what you wanted to, to do with the medical profession, with the medical…

C04: Yeah. Yeah.

P04: ... doctor in charge of your case one would hope would be making contact.

C04: Well, again, I think on the whole, they probably rely on you to contact them generally.

P04: Yeah. Yeah.

C04: Don’t they really, they don’t often say: “I’ll ring you in a couple of weeks and see how stopping that drug’s gone”. It’s much more of a: “you contact us if you’re having a problem with that medication”, you know, it’s, it’s generally that way around, isn’t it?

P04: Yeah. Yeah.

C04: They don’t, I don’t think we’ve ever had a ‘phone call from a doctor after any other additional medicine or stopping medicine and they’ve said: “oh, I’ll give you a ring in a couple of weeks to see how it’s going (*laughter*)”.

**INT: So, the onus is on you to report it if any problems?**

C04: It, it is on us. It is on me really, I think, to report which I’m OK with, to be honest, because I’m, you know, but, again, I do reflect is that partly because I have that medical background in the first place because I think so. It must be hard for people if you’re not got any medical knowledge at all to kind of take all this on. It’s quite a lot, I think.

P04: I--- I think, an awful lot goes on that we don’t really know about.

C04: Well, I always remember when dad was looking after, my mum had dementia and so, my dad was, you know, being the main carer for a while. And I, I don’t think he remembered to give her her tablets. I mean, she did go into a home after a while and she actually improved for a while and, I think, it’s because she was getting medication regularly because she was eating regularly and being and having fluids. I think, my dad just couldn’t cope, you know. So, I do think, you know, it’s yeah, important.

P04: It is, it’s often more positive than people expect it to be in my experience.

C04: What’s that? Sorry.

P04: Changing medication, you know, having to be reliant on a doctor to tell you what to do and it being or going into a home, you know, the act- the going into a home is a-milestone which represents a, a part of the development whereas going into a home and being cared for is an outcome in other situations where a patient needs additional care and the care home can provide it.

C04: Yeah.

**INT: So, that’s all the questions I have for you. Is there anything that you would like to add that you haven’t already said relating to medication deprescribing?**

C04: I don’t think so. No. No, I think, again, if we think of anything, I can always contact you and let you know, but I, I can’t think of anything specific at the moment.

**INT: Great. I will now turn the recorder off.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

C04 Respondent

P04 2nd Respondent

***Audio* file: 41.19 minutes**