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

Transcript for interview

**C01**

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

**INT: So, if we start with the pictures, which I know that you took.**

C01: Yes (*laughing*).

**INT: And we talked a little bit about it on Tuesday with (*P01*).**

C01: Yeah.

**INT: So, if you talk them through to me in terms of what they tell from your perspective. So, your kind of story with the photos.**

C01: OK. Yes. So, I mean, I would start here with, I don’t know if you’re numbered or…

**INT: That’s fine, I can number that.**

C01: [Photo 2] And the biggest prompt in the morning is (*P01*) having breakfast. So, that, maybe he just gets everything out and that’s just a habit so, that, that’s sort of relatively easy to manage. And then once a week, he has to fill the pot. It’s a, obviously, a weekly pot, so then he gets all of his medication out of the cupboard and sits methodically putting, you know, one in each day or however many go in each day *[Photo 3 and Photo 4]*.

**INT: And he does that at breakfast time?**

C01: He does that again at breakfast time. Obviously, once the thing’s empty, whichever day that is, he gets everything out. So, again, that’s an at the table sort of breakfast activity (*laughing*). So, again, it’s easy to remember and easy to cope with. Evenings are a little bit more (*laughing*) challenging. So, he just has one tablet at night, or in, in the evening. So, it’s an evening pot which he then fills (*long* *pause*) I, I can’t say he fills it religiously like he does his breakfast one, he might do it in an evening, or he might sort of leave it on the table once it’s empty and do it the following morning, or something like that. So, that one is easily forgotten. He, again, he fills it once a week and it gets left in the living room by the television (*laughter*), evening activity, and it, it had been forgotten too many times which is why I set-up the Alexa alert because very often I forgot too *[Photo 1]*. So now, she shouts at ten and if it hasn’t been taken before then then he can go and take the tablet.

**INT: So, the evening medication was that a later medication that was added in after some of the other ones?**

C01: Yes, I think, but I--- don’t quote me on this, I think, that’s his dementia one.

P01: No, it’s not.

C01: It’s not?

P01: It’s one for settling your stomach.

C01: Lovely. So, yeah, it’s not dementia (*laughing*). That’s what I know. But, yeah, that was a definite later addition.

**INT: And so thus the routine ...**

C01: Had to, yeah, had to evolve, had to change a little bit because initially, although I, the pots came together, the morning and evening pot labelled, he was initially only using the morning one and the evening one was just sort of left and then this tablet got added so.

**INT: So, within all of that, what is your role in assisting (*P01*) with the medications?**

C01: a) especially in the evening reminding him to take it, or insisting that he take it, because often Alexa will shout and he’ll say: “oh, I’ll do it in a minute” and then that moment is gone so then, I have to remind him, and, I mean, morning really, I don’t, at the moment, I don’t need to get involved. He knows the pots are empty, he knows they need to be filled and equally, the breakfast routine is such that the pot just gets taken out and put down with the bowl and everything so, you know, it’s there and he does it, it’s in front of him and there’s nothing else really to distract him from doing it so. At the moment, yeah, mornings I don’t really get involved. I mean, later I will, I’ll have to put the tablets in the pots I imagine, and all the rest of it. It’s only the evening as a reminder.

**INT: And what about anything else to do with the medication? I know we talked on Tuesday about the ordering etc.**

C01: Yeah, at the moment, he orders it all online although that can be a bit problematic at times in that: “oh, I’ve only got…”, you know: “four tablets left (*laughing*)” and, but he’s, he does it, he still does it. I don’t want to take anything over that I don’t need to. If he can do it, let him do it. So, he does all that and then he goes to collect it. The issue we sometimes have at the pharmacy is they’ll say: “we don’t have all of this” and then that gets forgotten because obviously they’ll say: “well, we’ll get it in in a day or two, come back”. So, I think, it would be handy if they would either mark it on either the bag or the prescription, you know, that comes with the bag, put, I don’t know, a red star or something next to it so, I can see what needs picking up and then can give a reminder because that has, that, I mean, that does cause an issue and then sometimes it will be: “oh, well, I’ll, I’ll go to the chemist and see if they’ve got stuff that I haven’t picked up” so--- and very often they do. But, yeah, I mean, apart from that, he does it but that would be a handy reminder. Yeah.

**INT: That’s useful to know. So, thinking more generally in terms of the kind of support that you give to (*name*). Are there any kind of specific things that you need to do?**

C01: (*long pause*) Not really at the moment. I mean, are we medication wise, or anything?

**INT: Anything really.**

C01: Anything. I mean, it’s, it’s all just constant reminders although sometimes reminding doesn’t work, for example, drinking, I’ll say: “you need to have a drink, why don’t you make a coffee?”. “I’ll do it in a minute” and then it doesn’t happen. So, if I don’t do it, it doesn’t happen, which is coming a bit more problematic because I still work in term time so, I’m obviously not here. I mean, our son has been here until now so, he would come down and remind, because I don’t think a ‘phone call anymore would be enough because as soon as you put the ‘phone down, you know, it wouldn’t happen. You, you’d, I honestly, I’d need internal surveillance or something (*laughter*) to work out what’s going on. So, that, I mean, that will become more of a problem, but we’ll have to just sort that one, but, I mean, at the moment, yeah, it’s just reminding, you know: “it’s one o’clock, it’s lunchtime, you need to eat something” but, yeah.

**INT: And you’re currently working full-time?**

C01: Well, it’s sort of, it, five days a week but term time so, it’s counted as part-time but it’s full-time when it’s happening (*laughter*), if that makes sense.

**INT: Yeah, that does make sense. A term time only role but over the year then equates to part-time working.**

C01: Yeah. Yeah. Yes.

**INT: So, in terms of managing medication, if we can go back to medication, how do you feel about the numbers of medications that he’s taking?**

C01: Well, I mean, he takes a lot but (*sigh*), I mean, I suppose, if he needs them, he needs them. There’s not a lot we can do about it. I don’t know what they do because I’ve left that to him. I will need to work out what they do and everything else sooner rather than later, I think. (*sigh*) Yeah, I mean, he takes a lot and he also, he takes two inhalers, but he doesn’t take them properly but (*pause*) what do I know (*laughter*)? It’s a bit like, you know, with a teenager and you’re saying: “I don’t think you’re…” but anyway. And he does occasionally go for, sort of lung clinic or an asthma clinic but whatever gets said there, I don’t know, so, and I don’t equally know what he’s telling them so, that is a bit of an issue as well.

**INT: So, in terms of that underlying chronic illness management.**

C01: Yeah. Yeah.

**INT: You’re not really sure?**

C01: No. No (*pause*), I mean (*sigh*), appointments never work for me (*dog barking*) because I’m at work. Sorry (*laughter*) *[apologising for the dog]*. Appointments don’t work for me because I’m at work and they’re not ... (*P01*), can you come and take the dog?

PO1: Yeah.

C01: And, I mean, I, I do know, I do understand why, but appointments out of the normal working day just don’t happen, you know, you can’t get an eight o’clock or you can’t get a, you know, half-past-six, or something so. Although work are really good, consider-, I mean, it’s not me that’s ill but they are very good and they will let me go but I just feel if I’m asking all the time, you know, that good will is probably going to run out (*laughing*). So, you know, I, I pick my appointments at the moment, the ones that--- or if we can get them in the holiday, fine, but, you know, if we can’t, then I have to pick.

**INT: And what sort of areas might you prioritise?**

C01: Well, if we ever had a dementia update, I would definitely prioritise that but that seems to have dropped off the radar totally. The blood one, he has a ‘phone call, I don’t know, every sort of six weeks or so, but that’s easy enough to manage because we get a letter although, and we get the, the letter of the discussion that was had although, I think, if there was anything urgent, I would make sure I was at home because it’s all very well me saying to (*P01*): “you need to tell them this, write it down”. I don’t know if it, you know, gets said or not. But, yeah, it’s more the management and me being involved (*sigh*), it’s just tricky sometimes.

**INT: So, you mentioned the blood clinic and them writing them down, that’s obviously something that’s helpful.**

C01: That is helpful. I mean, it’s just a letter. It’s just the letter that goes to the GP and obviously, (*P01*) gets copied in so then I can read it and I know, you know, roughly what’s gone on and what’s been said, and then I’ll know whether or not he’s got a venesection coming or, you know, however many times he needs to have blood taken, and that sort of thing, so I can, although I don’t necessarily do anything to it, I, you know, he sorts it (*pause*), I need, I feel I need to know otherwise I can’t remind or check that it’s happened or whatever. So, yeah, the blood correspondence, that, that is really handy. Yeah. Yeah.

**INT: So, in terms of the medication, say a medication was going to be stopped or reduced, how might that impact on the day-to-day management of medication?**

C01: Well (*sigh*), I mean, if they say, if they, somebody was to say to him: “stop this now”, I’d need to know because that wouldn’t get taken out of the pot, unless whoever it was was saying: “stop it” was in the room and saying: “right, we need to take these out”. It, it would just carry-on and then by the time he came to fill the pots at the end of the week, he’d have forgotten, and it would all just go back in again. So, unless, (*don’t lick the table*), unless (*laughter*) we, that’s not you, it’s my dog (*laughter*) unless we had some sort of written instruction or e-mail or, or I was involved on the appointment at the time, I would be concerned that it wouldn’t stop or the dose wouldn’t change maybe as quickly as, you know, whoever had asked for it thinks and equally if say the dose was reduced or increased, presumably if it was increased, the pharmacist would just add so we can carry-on using the original tablets but then I wouldn’t know. It, I mean, I’m talking myself into a corner (*laughter*) here, aren’t I?

**INT: No, that makes complete sense. It’s about the here and now. If a change needs to be made here and now.**

C01: Yeah, if they say: “don’t take that ever again”, I would need to know that but communication with me is minimal. Well, non-existent main, basically so, that would be a concern especially if they say: “you must instantly reduce this dose, go now to the chemist and get…”, you know: “a smaller tablet” or: “break them in half” or, you know, however they were going to manage it, I wouldn’t know that, until it’s probably too late (*laughter*).

**INT: So, thinking about stopping or reducing medication, what are your views around deprescribing, about stopping or reducing medication?**

C01: I mean, if it needs to be done. It would be nice to have an explanation as to why, you know, either what led up to it, what changes in (*P01*) means it’s got to be, you know, taken off or whatever. (*long pause*) Yeah, I mean, if, if it needs to happen, it needs to happen (*talking to dog*).

P01: (*talking to dog*)

C01: (*sigh*) Where was I?

**INT: We were just talking about it needing to happen and if you knew why.**

C01: Yeah. Yeah, I mean, you know, it’s absolutely fine. Obviously, the, you’d like to think the medical profession know what they’re doing (*laughing*) in which case, you know, they could put up their argument and say: “well…”, you know: “because of this, we’re doing that” which is fine, you know, if it’s got to be done, it’s got to be done.

**INT: So, would you see that as perhaps a normal part of managing medication or is it something that you’d consider a bit unusual?**

C01: I imagine it’s quite normal. I mean, things change (*pause*). I mean, like we had the statins episode, you know, suddenly he was at risk of having this heart attack so: “quick, give him statins” and then they just disappeared. They weren’t put, I don’t know if it was because they weren’t put on the repeat and now nobody knows that he was ever on them or, you know, we don’t know about that one, it just didn’t happen anymore after a certain amount of boxes of statins so, who knows (*laughing*)?

**INT: I know (*P01*) said before that he didn’t have the energy to kind of try and chase that to find out why.**

C01: No, that’s it, but also, if he then had tried the chances are he would have forgotten the explanation anyway and (*sigh*) (*pause*), yeah. I mean, really should the onus be on him to, you know, start digging around and try, trying to get hold of people and, because it’s, it’s, it’s the GP when all’s said and done, and you can’t get through can you so.

**INT: So, has there been any other time when a medication has been stopped other than the statins?**

C01: We did have--- when was it? I think, it was pre-pandemic, it was his blood thing, he’d been to the GP for, I, I can’t remember why and the GP, he came home with a prescription for iron and I said to him: “you must ring the hospital, don’t get that filled” because I do remember the very first appointment we had when the consultant said: “you’ve got polycythaemia” and she said: “you would imagine the treatment would be iron because you’ve got a low HB but…” she said: “that’s the worst thing you can take and don’t ever take it”. So, when he came home with this prescription of course he'd forgotten that, that had been said so, I said: “you need to ring the hospital before you fill that prescription”. I mean, hopefully the pharmacist would have perhaps picked it up but it depends how busy they were that day, I would imagine, and yeah, low and behold, a quick ‘phone call to the consultant, well, he got through to the secretary, and she rang back and said: “no, don’t, don’t fill it” and then she contacted the GP and said: “on no account prescribe iron” and that was, I think, written in his notes but that’s the only other one that. you know, thankfully (*laughter*) didn’t happen.

**INT: So, that in essence is not starting a prescribed medication.**

C01: Yeah, it’s not a deprescription. Yeah, the only one was the, the statins. That’s the only one. Yes.

**INT: And did you notice any changes in his kind of general health when he stopped the statins?**

C01: Not that I’m aware. I mean, I don’t think he’d noticed a need to take it so, you know, once it stopped.

**INT: And you didn’t notice any changes?**

C01: No. No. No.

**INT: So, if we were thinking about a discussion that might go on with a healthcare professional about stopping or reducing medications that maybe they think are no longer of benefit or might be harmful, what questions would you need answering in order to think that that’s something that you would go along with?**

C01: Well, initially, it would be, you know: “what are the indications for this?”, “is it a change in (*P01*)’s health or is it just…”, you know: “somebody’s finally looked at all the tablets and thought: “oh, he shouldn’t be taking that one”. And then it would be: “what does it do?” and then: “what might be the causes of withdrawing it?” and: “should it be withdrawn slowly or can you just…”, you know: “not take it anymore?”. And then: “anything to look out for after it’s been withdrawn?”, you know, if his legs suddenly got really itchy or, I don’t know, something bizarre, just to keep an eye out for that and let them know. Yeah, it’s more around what does the tablet do and why doesn’t he need it anymore and what to look out for, you know, once it’s taken away.

**INT: And would you have any additional questions if it was in a situation when (*P01*) wasn’t able to make that decision for himself and you were needing to make that decision on his behalf?**

C01: (*long pause*) I mean, the only concern then would be, I don’t suppose that I’d have any more additional ques-, it would be (*pause*) (*sigh*) how to identify any not necessarily side-effects but any unwanted symptoms from, you know, taking the medication away. How could I spot them (‘*I’ stressed by intonation*)? It’s all very well if you’re taking the medicine and you say: “oh, no, I feel really sick every day now that I’ve stopped taking it” but if he wasn’t in that sort of state to say: “I feel sick every day” then how would I, you know, I’d need to know what to look for or what to mention to somebody that they might think: “OK, we better…”, you know: “put him back on or change the dose” or, or do whatever.

**INT: Would you have any concerns in either situation? In either supporting (*P01*) to make the decision or making the decision on his behalf, around stopping medications?**

C01: Not really. As long as, you know, we’d had an explanation and it makes sense then, you know, fine.

**INT: And in terms of having that discussion, let’s talk about the who, the what, the why, the when, any thoughts about what that discussion should look like?**

C01: (*sigh*) Well, either in person or preferably like a Zoom call rather than a ‘phone because, I think, you can gather a lot from sort of body language and, and also, it’s easier maybe sometimes if you can see let’s say like the box of tablets or, you know, and then they can say: “well, if you look…”, you know: “read that leaflet” or do this or do that. So, either in person or probably a Zoom (*sigh*).

**INT: Any thoughts on the professional who should be involved?**

C01: Well, personally, I’d prefer it to be a pharmacist but it, I mean, it could be a pharmacist in conjunction with some sort of clinical specialist be it a doctor or a, you know, a nurse, or whatever, running, you know, taking that role. (*pause*) I mean, it would be more important, I think, that everybody knew what had gone on so that if there was then a ‘phone say to the GP, they would know without having to trawl through the notes, they would know what was, happened, if that makes sense.

**INT: Yeah, and in terms of where that professional sits any thoughts about whether that should be primary care so, the GP, hospital setting when you have kind of multiple teams involved?**

C01: Yeah, that is the issue. (*long pause*) I don’t really know. I mean, a lot of it, a (*sigh*) does seem to be (*pause*) sort of handed over to the GP rightly or wrongly (*pause*) so, oh, yeah, but in (*P01*)’s case though, I think, it’s a bit, I mean, his Alzheimer’s stuff and his lung is all dealt with by the GP, his blood problem is very much hands on at the hospital. Although it’s only a ‘phone call, they are overseeing it and they would make any changes on the medication. So, it, I think, it would be difficult to know for, where a third party should sit because they’d need access to both sides. So, it would either need to be, (*sigh*) I don’t know, somebody that the hospital would know they need to contact or somebody that the GP would know they need to contact to be involved (*pause*). Yeah, that’s tricky, isn’t it (*laughing*), because neither, I couldn’t see either side doing that independently unless it was a system so ingrained that, you, you know, it was natural, but, yeah, whoever did it would need to see both sides because if there was, for example, an Alzheimer drug change whoever was overseeing that would need to know what else was going on and the interactions between everything else that’s happened. So, yeah, that would be a…

**INT: So, somehow but you’re not sure how, it’s about including all sides.**

C01: All sides would need to be included. Yeah. I mean, alright the hospital do contact the GP and we, we know they do because the letter comes here so we know that it’s happened. So, I suppose, presumably the medication person could be attached to the, the GP surgery as long as, like communication remained good and you, you know, everybody knew what was going on. Tricky one that one (*laughing*).

**INT: And what about your role in that discussion?**

C01: (*sigh*) a) I’d need to be involved (*pause*) because, you know, in the end I’m the one that’s going to be overseeing it all, but at the moment, I mean, the hospital are pretty good about talking to me but the GP are rubbish, they won’t, they won’t entertain talking to me at all. Whereas the hospital are quite happy to ring me and pass on information about (*P01*) so that I can tell him, you know, if he needs to go and book a venesection, or whatever, they will say to me: “oh, this is what you need to do” or (*long pause*), well, it was a while ago now, the consultant rang, (*P01*), for whatever reason wasn’t here, so she had the conversation with me rather than with him, you know, which is fine, but the GP, that doesn’t happen. So, the blood thing I do feel that I’m actually involved in, the Alzheimer and lung, no, I’m not at all.

**INT: So, there’s something there about the discussions that happen in primary care, they need to involve you.**

C01: Yes. Yes. I mean, we’ve had, we’ve had, had this conversation. We met with, I’m not sure who she was (*laughing*) and we’ve never seen her again, and she said: “oh well, I’ll put a note on your notes to say that…”, you know: “anything obviously needs to include me” but that didn’t work so it, it still doesn’t. I can’t even remember when we saw her. It was after the pandemic. It was all still masks and everything so, yeah.

**INT: And it just didn’t happen.**

C01: No, it just doesn’t happen. No.

**INT: Thinking about the relationship with the professional who does the review, is there a need for that to have been an existing relationship? What do you feel about that?**

C01: No, not necessarily. I mean, as long as they, I mean, it would be nice if it was the same person each, I don’t know, year or six months, or whatever, but, you know, that’s not really going to happen. I mean, as long as they explain who they are, what their role is and they demonstrate that they understand, you know, everything that (*P01)* takes and what’s gone on around it and the whys and wherefores, as long as their, they can demonstrate that then that’s fine, you know.

**INT: So, it’s more about what they know than who they are?**

C01: Yes. Yeah. Yeah, you know, the fact that it’s been obvious that they have picked up the notes and read them rather than then they just say: “what can you tell me about yourself (*laughing*)?” Really? So, yeah, as long as they come into the appointment situation, whatever, with some background knowledge and can demonstrate that they’ve understood the situation then, you know, it would be fine. Yeah.

**INT: And thinking about medications that (*P01*)’s currently taking, are there any medications that you would be more concerned about stopping than others?**

C01: Well, on the blood side probably but having said that, I don’t know really what they do or how they work or how they work with each other. So (*clears throat*), I’d either need to try and find that information myself or get it from somebody. His Alzheimer medication (*pause*) we don’t really know if it works, don’t really know if it does anything. I mean, he was put on the dose when he got his diagnosis and that’s been the end of it so, I don’t know how they quantify that one at all. I mean, his puffer thing because he doesn’t do it right anyway (*laughter*). They’re never going to work properly (*clears throat*) but they manage it, so. Yeah, I mean, I probably should know more but I don’t but it would be the blood side, I think, that would be more of an issue because, I think, through that, you know, end up either having a stroke or, you know, some sort of brain haemorrhage, or whatever, so, it would be handy to (*laughing*) keep an eye on those (*clears throat*).

**INT: So, you’ve already said that you haven’t ever really had a discussion with a professional around stopping medication.**

C01: No.

**INT: But if you were to have a discussion, how do you think shared decision-making, so involving yourself and (*P01*) and the professional, can be facilitated?**

C01: (*long pause*) Well, it--- I mean, I, I think, preferably it would need to be a face to face or some sort of Zoom situation and, I think, at that time, whoever the professional was, would need to be ready to go through each medication, explain what they do and their relevance to (*P01*) but also, the interactions for all of them so that any changes (*long pause*) (*sigh*), so, if then we went to another appointment, or we went to see the GP or we went to see the, the hospital or they rang or whatever, and they then said: “oh, I think, we need to do this” if we had the information with the, you know, what they do, how they work, and the interactions then it might be for us then to say: “oh, it might be worth speaking back to the medication professional just to either let them know what’s going on or just check that that’s OK (*laughing*)” and it’s not going to make any of the situations worse. Does that make sense?

**INT: Yeah, it does. Thinking about how they present that information so, the language that’s used. Have you any thoughts on that?**

C01: Well, preferably words of one syllable and idiot proof (laughter) so, I’d have a, a chance of understanding. Well, I think, then if that, if that was done face to face or Zoom, you could say as the discussion goes on: “I don’t know what you’re talking about” or, you know: “can you explain that in a different way” or whatever, but then once you’ve got the explanation, I think, you need to then have something in writing, be it an e-mail or-, I mean, a letter in this day and age seems a great expense. I mean, if someone wasn’t on, online or whatever then fine, it would have to be a letter, but, I mean, we’d be quite happy with sort of e-mail correspondence or, you know, something like that.

**INT: Just some way of having it…**

C01: Some written back-up to say: “this is what we’ve discussed” and either: “this is what’s going to happen in the future” or: “there’ll be no change” or, you know: “we’ll review this again in six months” and even then if the onus was on us to ring for the six month appointment, that’s fine, but, I think, yeah, to have something in writing because, you know, if there was an appointment needed in six months’ time (*pause*), it probably would have gone out of everybody’s head by then so (*laughter*).

**INT: And any thoughts around timing? So, you’ve mentioned six months, do you feel it should be something that’s done regularly?**

C01: I think, it should be done regularly. I mean, whether, you know, it’s an annual thing or (*pause*) that really, I think, would be up for the sort of medication person to decide and, I suppose, you, you’d need possibly a review after, if there’d been a change or if there’d been a change say in (*P01*)’s symptoms, you know. You’d like to feel that you could go back to them and say: “oh, now we’re experiencing this”. “OK, well now maybe this is a chance to review” or, you know, somebody’s said we need to: take this tablet, “well, take it for a month and then we’ll review”. So that although the reviews, I think, should be fixed either annual or, I don’t know, six months, I suppose depends how many things people are on. I think, there should be the flexibility in the system to be able to change it if needed. So, for example: “OK, take that extra tablet for a month, we’ll then review it and then we’ll move…” so, then the six monthly or the annual review will be after that date rather than, you know, stuck back on the other date.

**INT: So, you mentioned within that around support, that follow-up support in terms of what you should be monitoring etc.**

C01: Hmm. Yeah. Yeah.

**INT: Thinking about the support that you would feel needs to be in place after something’s been stopped, are there any other things that you’d want to add to that?**

C01: (*pause*) No, I mean, it could be as simple as an e-mail. You know, if they say: “keep a look out for this” or: “tell us anything that changes”, you know, if he suddenly gets an itchy foot mention it, it might be rubbish, it might be part of it or if they would just say, you know: “we’ll make this change but then we’ll get back to you to re-evaluate”. I mean, I suppose, sometimes it would be difficult for them because they wouldn’t necessarily want to say: “if he suddenly…”, you know: “develops a green rash” and then people would be fixated on looking for this green rash, you know, or if they say (*short exchange between P01 and C01*)--- if they say: “here’s a list of symptoms he might experience”. well, is it a one-off?, is it six days in a row?, you know how are you going to look at that? So, they might prefer not to give you a list of symptoms so that you don’t then think: “oh, I’ve got that and I’ve, I’ve got that”. So, it may be easier from their side to come back and say: “how are you doing?”, “what’s gone on?” because they don’t want to plant in peoples’ heads (*laughter*).

**INT: So, some sort of follow-up ‘phone call or ...?**

C01: Yeah. Yeah, or even just an e-mail, you know: “what’s gone on?” or: “how’s it going?” because, I mean, it’s far easier for somebody sitting somewhere to send out fifty e-mails than to do fifty follow-up ‘phone calls, and I would imagine in the great majority of cases, it would just be an e-mail coming back saying: “no, it’s fine” or, you know: “yeah, he’s got…”, you know, don’t know: “yellow feet” or, you know, something in which case then that could be followed up again. Yeah, so just some sort of follow-up but it could be, you know, quite vague just so you feel that there’s somebody there and somebody’s actually bothered, you know, and it hasn’t just dropped into a big abyss, and no one really cares anyway (*laughter*).

**INT: So, around the timing of having these reviews. We’re talking about having them regularly. But is there a time at which that should start? Should that be something for everybody on medication or at certain points?**

C01: To be honest, I think, an annual review. If you’re (*interrupted by researcher’s diabetes alarm*). Yeah, I think, if you’re on lots of medication, I mean, I don’t know what the cut-off point would be whether it would be, you know, three, four or more, or whatever. I think, I think, an annual review would be sensible for everybody and then, I think, depending on certain situations you might then want to like up the annual review to, you know, six-monthly or, I suppose, it depends on how dynamic the disease or whatever that somebody’s got, you know, if it’s constantly, you know, up, down, changing, then they would obviously need more reviews than somebody else but, I think, as a bare minimum (*sigh – kettle boiling in background*), an annual (*laughing*), an annual review, I think, would be the ideal (*pause*). Yeah, because it, you know, over the course of the year, things do come up and you do think: “well, does this need to be increased and how do we know if it needs to be increased or decreased?”. Yeah, it’s just, even if it was as simple e-mail: “how are you?”. “No, we’re absolutely fine, it’s all well”, you know, leave it at that but, yeah, I think…

**INT: Just thinking about this discussion, we’ve talked about what you might need in terms of involvement in a discussion.**

C01: Yeah.

**INT: Thinking about what (*P01*) might need to support him to be able to take a full part in the decision-making, is there anything?**

C01: (*long pause*) At the moment, it would be time. So (*long pause*) (*sigh*), you wouldn’t want to feel that this review was going to be done in two minutes, or five minutes. You’d want to go into it feeling that you could ask all of the questions that you need to ask (*dog barking*) and, you know, get the answers that you need and in a format that you need them. I mean, sometimes the conversation has gone on but it’s quite obvious that (*P01*) hasn’t either understood it or, you know, got it, so, that would be the point, you know, to stop and, you know, go back a bit and try and explain, you know, what is needed. So, I think, at the moment with us it would be a time thing. Later, I don’t know, I suppose, it just depends, you know, how, how he is and what he needs really. So, I suppose, it all boils down to time, doesn’t it, when all’s said and done. You just need time to get the explanation that everybody’s happy with and everyone can understand so, that would be the one.

**INT: So, that’s covered all of the questions that I’ve got. there anything else that you want to add? Anything that came out of listening in on Tuesday?**

C01: To be honest, I’ve forgotten most of it (*laughter*) on Tuesday. (*long pause*) No, I think (*long pause*), as far as sort of creating a system for sharing information over medication with, you know, professionals and the patients (*pause*). I mean, I suppose, it can’t be too bespoke because it just would be too expensive but you would really need some sort of named person that you could go back to (*pause*) so that, you know, for example, if three months down the line you think: “oh, maybe this isn’t right”, you’d need to be able to feel that you could get in touch with them and (*pause*) you’d get some sort of timely reply. I mean, it wouldn’t have to be the same day but, you know, in a couple of days or whatever, depending on how urgent, I suppose. (*pause*) Yeah (*speaking to P01*). Sorry.

**INT: That’s alright (*laughing*).**

C01: Yeah, I think, it’s mostly a) that whoever, you know, whichever professional needed to can get hold of the medicines person but equally, we can too, you know, so there is, you know, a bit to and fro on all sides.

**INT: And in terms of deprescribing generally something that you’re relatively happy ...?**

C01: That’s fine. As long as, you know, you get a bit of an explanation, you know what’s changed to cause it or, I don’t know a, a new tablet’s come on the market and it’s better, you know. As long as there is a suitable or a sensible explanation then absolutely fine. Go with it.

**INT: OK. I will switch off the recorder now.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

C01 Respondent

P01 Respondent 2

***Audio* file: 43.27 minutes**