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

Transcript for interview

**C05**

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

**INT: So, although we’re going to talk primarily about medications today. I wanted to just start with a more general question about the type of care that you provide for your mum, how you support her?**

C05: So, I support her in that I do, I basically, it’s administratively. So, I do no hands-on personal care and I don’t do housework and cooking. So, I, I go, I, I try and sep- a little separate the sort of care bit and the being her daughter and going out bit. So, I take her out to lunch, I take her out to the cinema, I take her out to- I’ll take her out to buy clothes, go shopping, and then the care bit that I. I mean, I’ll, I’ll change a light bulb or something like that but I don’t do, do serious stuff in the house. And then I organise all her bills, electricity, council tax, all her, she has quite complicated tax so well, we organise that and I organise the carer. She has carers twice a day which I organise through a management company, I don’t, don’t book them individually. The management company runs the building that she lives in, so that’s easy. And and I deal with most of her- well, pretty much all of her appointments so, GP, blood tests, that kind of thing, and, and I organise her medication. I organise the delivery of the medication, I organise that carers give it to her so, if, if they have any questions, they come to me first. So, things like, like either should they use certain things or should they, you know, if they run out of something so, I do all of that.

**INT: And in terms of the appointments, do you go with mum?**

C05: Depends on what it is. So, if it’s a blood- if, if it, if I think it’s an appointment of consequence, or of understanding, then I try very hard to go. S, things like next Monday, she’s going, she has an annual review with the rheumatologist because she’s got a long-term vasculitis so, I’m going to the rheumatology appointment but if she goes for a blood test, I I would almost never go. I’d book her a taxi so, and she has, I book her a taxi on a taxi account so, somebody picks her up, takes her and brings her back but- so, I, I kind of pick and choose, well not pick and choose, decide on the level of (*laughing*) importance. Any any telephone consultation with the GP comes to me because she doesn’t make a lot of sense on the ‘phone. So, yeah.

**INT: So, how long have you been providing support for your mum?**

C05: I’ve been doing this for a- six years but progress-, well, I’ve been doing all the bills and accounts, and all the rest of it, for six years. The appointments and medication, probably for three or four. Yeah, it’s, it’s, it’s sort of gradually built up, you know. Yeah.

**INT: So, currently roughly how much time do you need to spend supporting mum?**

C05: (*pause*) Difficult to say because it varies, it’s it’s probably if if you’re realistic about it because some of it, some of the other stuff, it’s probably about four hours a week which as carers go, is very little, but (*laughing*), yeah. Yeah, it depends. Yeah, and and things like I can go on holiday, I can go away or- all that kind of thing, that doesn’t, it doesn’t- which- where an awful lot of carers are very limited on what they can do. Hers doesn’t affect that.

**INT: So, if you go away, does somebody else pick-up the background stuff that you’re doing like if there’s problems with medication?**

C05: Yeah, they just ring me (*laughing*).

**INT: Ring you wherever you are?**

C05: Yeah, ring me wherever I am (*laughter*). Yeah. Yeah. Yeah.

**INT: Let’s now take a look at the photos and you can probably remember what you took. So, if we talk through each photo in turn. So, can you just tell me a bit about photo number one and what is says about your role?**

C05: Well, the, the first photo is what do you call it? A- it used to be called a Dossett box, it’s got a new name now, isn’t it?

**INT: A nomad.**

C05: Nomad, it’s- so, it’s the, the pharmacy counts out the tablets, put them in sealed trays and the carer hands them out. So, mum cannot reliably use one of these boxes herself so, that, that’s been one of the progressions. She went from doing all her own medication to getting them muddled up to- so, the these it’s the those, those two really are the service that I get from pharmacy *(referring to photos 1 and 2)* and and from the GP. Our GP has a part- has a pharmacist as part of their staff so- who has been hugely helpful in finding someone that finding a chemist, because not all the chemists do all, do all these services, and, and then this particular dispensing chemist who is, it’s one of these small- it’s not part of a, a big chain, or whatever, and they- it’s taken a while but now they e-mail me, I e-mail them and, and so, it’s a combination of the the dispensing in the boxes and the deliveries because they, they deliver to her, and they deliver reliably which- and the current situation works really well. The previous one didn’t and we had very unreliable deliveries and it it’s it’s taken- that’s the grind, it’s taken a while to get to this. Now, the one we’ve got at the moment is working very well, and long may it continue, but we had a year or so of stuff- and eventually, I’d go around to the chemist and say: “why haven’t you delivered this?” and they- or say: “have you got it?” and they’d say: “oh, yes” so, you look at the dispensing list date and it was ten days ago, and and (*laughing*) things like that. So, it’s- so, we now have a system that works but it’s taken a while to get to it. Yeah.

**INT: So, moving on to the next two photos** *(Photos 3 and 4)***.**

C05: The, the right, that’s- so, so, one of them is- my mother is is lucky, she is financially able to live in an assisted living flat so, she has her own flat, she’s not in a care home, but she- within the complex, there is a dining room so, she gets a, a decent three course- a very nice three course lunch every day with other people. So, she has company and food every single day and she and there are two or three activities, like a coffee morning, a film evening, something like that, there and the place is warm and if the boiler breaks, I have to organise somebody to fix it but somebody tells me so- and there are- she has carers that are from that establishment twice a day, but she- there are staff on the premises twenty-four-hours a day, and that makes it- so, that- she’s receiving care that I organise but it’s done by somebody else so- and that makes, that makes life very very much easier.

**INT: And what sort of level of care does she receive from the carers?**

C05: Really, she just- just medication and and somebody checking up on her. When she’s not well, they will prompt her to do things or or they might make her breakfast or something. She she gets- she gets dressed, she gets herself washed and dressed and gets her own breakfast which is cornflakes and tea, or something, and gets her- oh, they get her supper. She goes goes down the corridor for lunch, they get her supper which is like a sandwich or something. So, it’s- although it doesn’t sound like a lot, and at the moment they’re not- oh, and if if she’s having a sh- she has a shower, she showers herself, but she does it while they’re there doing something else. So, although it doesn’t sound like a lot, the big deal is the medication is- is that by having somebody go in twice a day and give her her tablets, then the- then she’s getting that correctly, because we discovered that she was either taking two or not taking them at all or (*laughing*)- yeah.

**INT: Actually knowing what she’s taken.**

C05: Yeah. Yeah.

**INT: So, what about the Charlie Bigham’s** *(referring to photo 4)***?**

C05: Oh, that’s that’s because the time I- so, if I’m down there in in (*town*) either visiting her or it’s- or or spending time on her and I get back late, I can buy- because because financially I’m able to do it and she’s able and she has the finance- basically saying that money makes her whole life- life a whole lot easier, you know. I can, I can sort of say: “right, well OK, I’ve spent all afternoon on her, I haven’t done my shopping, I haven’t done this, but I can have a takeaway or a ready meal or or something”. It’s basically looking after us at home rather than (*laughter*), that- that’s the, that’s the the balance is that- that various things have happened over the years and you really realise that the number one priority in your life is is the people in your own house which is me and my husband, and then there’s my kids who who are grown up with fam- well, a couple, one has got a family, and then mother is actually that far down the queue. Now, I know that sounds a bit brutal but that’s the way it is and the- all these things are ways of maintaining that.

**INT: Kind of keeping a balance of wellbeing?**

C05: Yeah. Yeah, because actually, some of the rest of the household will get- have the potential to get understandably quite hacked-off if I’ve spent all my time on her and not on anything else, and and they’re right.

**INT: So, that’s photo numbers three and four.**

C05: Yeah.

**INT: So, now moving on to the table.**

C05: These these are just- these are just things that, well, it was really an answer to your first question: “what do I do?” so, that-that that’s- and the one that I, the one I thought of after you’d gone is the things that I used to help so, like ‘phones, computers, internet, you know where, where, where places have internet bookings so, sort of like like like the blood test service around here has an internet booking system (*pause*), what I can use to make life as as, you know, can can I do it by e-mail rather than spending forty-five minutes on hold on the ‘phone? That that kind of thing.

**INT: So, the things relating to medication that you might do on e-mail or online.**

C05: Yeah. So, the the pharmacist, now if- so, things like they ran out of something she she- it’s all in the, in the pre-dose box except she has paracetamol as as needed, they ran out and they ran- they rang me when they had one tablet left, they didn’t rang me when they had one packet because she’s got half-a-dozen packets, didn’t really have one package left, they only had one tablet left, and I can organise more of it by e-mail to the pharmacist. So- and actually, the pharmacist answers the ‘phone but it’s the ones that- and the GP I do probably most of my consul- my my things with the GP by e-Consult and then they’ll either e-mail me back or ring me back, but that’s a big, that’s a big difference because if you ring a GP, you can be on the ‘phone for forty-five- you can be on hold for forty-five minutes (*laughing*) whereas if you- because most of the stuff that- I don’t need an answer in half-an-hour, I need an answer in in the next day or two, and to do it by e-mail, it makes makes a a- by e-Consult, or- and services that send out appointment confirmation by text or e-mail because then you know exactly what the appointment is. The down- the ones that are more difficult are things like the hospital send all appointments or letters to her which creates considerable anxiety. She’s got an appointment next Monday, she got the letter about three weeks ago and she’s she’s copied part of it out and and, you know, which which corridor, you you know, department six, floor four, something which is in the letter well, she’s written it out three times in long hand and she doesn’t know why she’s going although she goes every year, and it creates a certain amount of anxiety. Now, I make- I’ve- on that one, it’s the ‘phone to the secretary, the secretary has actually been really helpful, and has now started sending me copies of the appointment but it’s only that particular consultant. There is not a mechanism, as far as I can tell, that that sends- and I don’t want them spending money on stamps, you know, send me a a- and it doesn’t even have to be the letter, just the appointment reminder, because one hospital, every single appointment you get an e-mail- get a text confirmation, another hospital, like (*hospital*), do not do text under any circumstances, and it it it makes it a lot easier and and I I mean, she- there was an appointment I should have gone to but by the- she- it had got changed and she got a letter about four or five day be- and I never saw the letter, and I never went. She did but I I didn’t and that was was a waste of an appointment and stuff like that. So, it’s where they can tell me what’s happening as well as- and that makes- it makes a big difference. It doesn’t sound like a lot but yeah.

**INT: So, do you actually have a list like that that you tick off** *(referring to photo five)***?**

C05: Oh, I I did- oh, I just did this for the- instead of a photograph. Yeah, it was just- so, this this actually, doesn’t have, this doesn’t have anything to do with the prescribing on it, it’s- it’s the stuff that…

**INT: All the other stuff.**

C05: All the other stuff. It was really in answer to, in fact, in fact, it turns out to be a- an answer to your first question. Yeah, and the one that I I should have done was take a a picture of ‘phones and computers and laptops, and stuff like that.

**INT: So, what about that final picture?**

C05: And that final picture, well, that- that’s the- that the prio- that’s the one I just said, that’s the priority is is is well well, first my husband and then the rest. And and my husband has health issues as well so, he had a, he he had a stroke.

***[Section of transcription removed by researcher as participant sharing personal information relating to her husband’s health irrelevant to the study.]***

Yeah. Yeah, but I mean, that’s, you know. So, there’s always that niggling away (*laughing*). Yeah. Yeah.

**INT: So, that’s the photos that you’ve taken and the photos that you remembered that you should have taken (*laughing*).**

C05: Yeah. Yeah.

**INT: Is there anything else that you do to assist mum manage her medication that we haven’t already talked through?**

C05: Umm, I talk to her about it. I try and explain, you know, if she, if she gets something- she went on some sort of patch the other week and I sort of say: “right, you’re taking it on this…”- well, I think, she’s coming off that patch but- pretty rapidly but that- so, I’ll I’ll- if there’s a change in it, I’ll explain. Particularly a change that she’d notice, if the- if something changed in there, she wouldn’t notice. Sorry, in there, pointing to the picture *(Picture 1)*. Yeah, the the Dossett box, and and- but also, I’ll say- I’ll ask her if she’s well or or things like if I go and see her, if she’s walking/pushing her trolley down the- pushing her walker down the corridor and she’s limping, which that happened recently, and then you sort of say: “oh…”, you know, and she says: “oh, I’ve been sitting awkwardly” and then the next week, she’s still doing it and- and then you you get in touch with the GP and say: “she’s got this lower back pain”. So, you’re initiating stuff and actually, that’s that’s the one we’re on at the moment because they’ve given her a patch but it- instead of paracetamol but it’s the patch- I’ve forgotten what it’s called, something- something that everybody’s on, but it’s opioid and you just sort of think: “actually, if she’s doing OK with paracetamol, let’s- let’s stick with that”. I can see no point in, you know, the the GP- and that that was one where it worked, i.e. I did e-Consult, he rang me back and sort of explained the side-effects which I don’t think she’s particularly getting, but she’s- it’s not- she’s she’s OK so, let’s go back to the paracetamol. Let’s- let’s stick away from (*laughing*) the opioids. So, I’m making decisions. Yeah. Yeah, I mean, I’m lucky I’ve got- I was a dentist so, I’ve got- I don’t have a background- well, I do have a background in dementia because I used to do dementia dentistry, but (*laughing*) but I’ve got, you know, the medication and the painkill- I’ve got some knowledge of it. Yeah.

**INT: So, you spoke about the fact that the carers assist with medication.**

C05: Yes.

**INT: So, you’ve mentioned that they dispense it from the Dossett box.**

C05: Yes.

**INT: Is there anything else that they do?**

C05: They- they will also give her paracetamol PR-, as as needed, PRN. So, they- when they go in in the morning, they give her the Dossett box stuff and then they say, you know: “how are you feeling?”, “do you want one of your painkillers?” or: “do you want one of your--- do you want a paracetamol?” or or something like that. Having been there once or twice when they’ve done it, and it was in the evening, if I’ve been there for a cup of tea, and this is being picky, they’ll sort of call from the kitchen: “do you want a Panadol today?” or: “do you want a paracetamol today?”. There’s not much assessment (*laughing*) or anything. However, what we’re talking about is plus or minus one or two paracetamols, and and it appears to work so, live with it (*laughter*).

**INT: So, it’s literally the administration of the medication that they get involved with?**

C05: Yes, they they are doing the administration of it. Yes. Yes.

**INT: And then they tell you when they’ve got one paracetamol left (*laughing*).**

C05: Yeah. Yeah. Yeah, and the things like when she got the patches, I, you know, I’m saying that: “this- these patches will be delivered and the doctor says do do this and…”, you know, what- what to do with it sort- I mean, it’ll say on the box, but it’s things like the box says use a patch once a week, it doesn’t say stop the paracetamol. It was the doctor who said: “stop the paracetamol” so, you’re you’re filling in the- because because she’ll have it in her box, there’ll be patches saying: “change this once a week” and there’ll be paracetamols saying: “up to four times a day” and it- there’s nothing that says: “one or the other”. Yeah. Yeah.

**INT: So, you are kind of filling in those gaps for them?**

C05: Yeah, filling in the gaps. That’s that’s, so, that’s a good word. Yes. Stopping her- what was the one the other week, because I do her online shopping: “I want Lemsip” and she’s actually banned from any medication in her flat that isn’t in a locked box because because she’ll take too much of it or something like that: “oh, dear, have you got a cold?”, “no, no, it’s a lovely hot drink”, “what (*laughing*)?”, “oh, I see”. She said: “I really like hot lemon and it saves squeezing lemons” so, I said: “well, you don’t want to be taking Lemsip because that’s got medicine in it, the same as the other tablets you take” and she doesn’t understand that concept. Anyway, substitute lemon squash for LemSip, and she’s now not taking truckloads of paracetamol (*laughter*). So, it’s it’s monitoring but, you- it’s- you have to ask- it’s a bit of detective work. Yeah. Yeah.

**INT: Yeah, it sounds like it. So, mum’s obviously on quite a few medications.**

C05: Yeah.

**INT: How do you feel about the number of medications that she’s taking?**

C05: I’m- this is one of the questions I’ve got for the rheumatologist next week. She’s on- have you got the list? Did I give you the list?

**INT: No, I haven’t got a list.**

C05: No. Oh, OK. She’s not on any psychotics or- or mood changing or anything like that. She is on- she has, or had, question mark whether she’s still got it, an auto-immune inflammatory condition of vasculitis which has been really well managed for twenty odd years. For years and years under some very shiny private consultant in (*city*) because my father worked for that sort of job where he had that kind of insurance, and now- so, she takes Methotrexate once a week so, they’re going to manage to get- do the once a week thing which is- as well as every day, that throws the system (*laughing*) and she takes steroids every day, and- and then she takes a couple of other things like vitamin D and folic acid which are because she’s on the other tablets, and Omeprazole, or whatever you call it, Omeprazole, Omeprazole. All those words you see written down and you don’t (*laughter*) know how to say it out loud. So, three or four other things that are- because you take one, you’re taking the other. She was in hospital earlier this year with a- she cracked her pelvis and actually, somebody did a bit of a review and she’s on slightly fewer than she was so, that’s good. I question whether she still needs to be on on on this- on this much Methotrexate and- or any at all, Methotrexate, and a couple of years ago, the rheumatologist said it may well have burnt out, it may well be not a feature, but the system seems to work. Now, whether that’s still the case. She she has for years said she’d rather not take so many tablets. She- I I don’t think she’s got enormous side-effects; I just wonder what the benefits of being on all this if you’re ninety-three with osteoporosis (*laughing*) are so (*pause*)- and that’s that’s one of the ones that where I’m I’m definitely not pursuing the opioid painkiller at the moment. The the carers reckon that she didn’t have any side-effects, only over a week, the potential side-effects are constipation and being more muddled. Quite frankly, since her muddle-ness varies from day-to-day, unless it was spectacularly different, it would be difficult to tell whether- I I reckon, on the ‘phone, she’s slightly more, but it’s difficult to put your finger on it especially over one week, and heaven knows about the constipation but it just seems (*laughing*)- it just seems why bother if you can do it with paracetamol. So, I think, we’re going to- I would like to stop the patch experiment and- but you can argue it the other way, it’s one patch a week rather than tablets every day so- and, as far as I know, she’s she’s not got particular side-effects from all these tablets, they’re the same ones she’s been taking for twenty years, some of them, but when when you’re older and frailer and your- you tend to take doses down anyway and how much of this stuff she’s taking because it’s always been like that and how much of it she really needs to take. So, we’ll see what the rheumatologist has to say on Monday, but …

**INT: So, you mentioned that when she was in hospital somebody reviewed her medication.**

C05: I’m not sure whether it was when she was in hospital or when- or when she- or whether it was the GP when she came out because I don’t think- I’m pretty certain- no, she’s not, she’s no longer on mini-aspirin and something else she’s no longer on, I can’t remember what it was. I think, she used to be on two blood pressure tablets and she’s now on one so.

**INT: So, I’m assuming from that you weren’t involved in any discussion about reviewing medication.**

C05: No, I wasn’t. No. No. No, I- I’m- because there was an awful lot going on because we were- because while- when she came out of hospital, she had carers four times a day, and this kind of thing, so, there was a a bit when when I said the four hours a week, at that stage, it was three days a week (*laughter*), and (*pause*) I- I’m- I can’t remember whether I e- sent an e-Consult saying: “should we look at her list of medication?” or whether, you know, there were so many discussions going on, I can’t remember, but- so, it might have been me, it might not have been.

**INT: Are you aware of any other time when her medication as a whole has been reviewed?**

C05: No. No, because aren’t they- theoretically, isn’t the pharmacist supposed to review it every year or something?

**INT: I think, it can vary from practice to practice.**

C05: It varies. Yeah. Yeah. Yeah.

**INT: So, as you’ve already kind of alluded to, sometimes it can be decided that a medication should be stopped for whatever reason, it’s not needed anymore. So, it might be stopped, or it might be reduced and then stopped. So, do you see that as a normal part of managing health conditions or do you see it as something unusual?**

C05: What? Stopping medication?

**INT: Yeah.**

C05: No, that should be a normal part of it. You don’t put something on something for- and then do it until they die (*laughter*), you review it (*laughing*). Even long-term medication, you- I mean, somebody who’s got diabetes, or asthma, should should be reviewed on a fairly regular basis (*laughing*). Even if it’s working, you should review it. Even if- even if the review says: “no change” it’s still- it still means you’ve- “no change” doesn’t mean you’ve done nothing, it means you’ve thought about it, and not changed it which is completely different to doing nothing. Yeah.

**INT: So, in terms of mum’s medication, what would encourage you to stop something? You’ve already talked a bit around the rheumatology medication.**

C05: What would encourage me to stop something?

**INT: Yeah.**

C05: If if if there was- if there was an obvious side-effect, then you’d have the discussion: “is the side-effect worth it?”. I mean, depending on what it was, a side-effect may well be worth it (*pause*). There’s a bit of just people- or or she doesn’t like the idea of taking loads of tab- and hasn’t for a long time, even before she was less less muddled, when she was less muddled, and there’s this idea: “why am I on all this stuff?”, I just- particularly as you get older and frailer, the whole interaction thing and the dose thing becomes more of an issue, you know, what you- truckloads of stuff you can throw at fifty year olds are not the same as what you throw at ninety year olds (*laughter*), and- and there’s the sort of the risk/benefit, you know: “is is this- is this stuff actually doing her any good?” and if it is, then fine, and and and, I think, it needs to be doing her good rather than not doing her any harm. Yeah. It’s diff- it’s difficult to put your finger on it, but but, I think, it needs looking at especially as she’s on stuff that’s prescribed by a hospital consultant, this is the Methotrexate, and and that does get- it kind of gets reviewed. Yeah. Yeah.

**INT: So, you’ve mentioned obviously her rheumatology medication, are there any other medications that you think she might not need any more?**

C05: Probably not because basically they’re all rheumatology ones (*laughing*). She she- the one- the only one that she- is not a rheumatology one is a blood pressure one. Yeah, and I suspect she probably needs that. Yeah. It’s diff- yeah yeah, it’s it’s it’s difficult to to monitor, she has blood tests four times a year which- so, that she’s OK and she doesn’t need things changing, but what they don’t say is she, you know, if if you actually came off it for a bit and then did the the test. Now, would she- is it too much of a risk, would she be seriously ill if she did, and actually, what does seriously ill mean? You’re ninety-three, think about it (*laughing*). Yeah, that sounds really harsh but but it’s actually something that she has said over years and years and years: “I don’t ever want to be…”, you know: “I never want to be- I don’t big interventions” or- you know, I’m not trying to (*laughing*) withdraw all her tablets, and have her curl up in a corner, but, yeah, it’s it’s the, you know: “why am I taking all this?” is something that she said when she was a lot less muddled and and we’ve always said: “because it keeps you well and it’s working” which, you know, yeah. If- with- because with the more getting more muddled, if anybody came up with the idea of anti-psychotics or- you’d have an open-mind on it because it would depend on what she was doing, you know, if she started wandering or something and you could stop it with sensible- sensible medication, but, I think, I would ask a lot of questions about anything like that.

**INT: So, you mentioned that the aspirin and possibly a blood pressure had been stopped before. You weren’t involved in any of the discussions around that?**

C05: No. No.

**INT: What happened after it stopped? Was there any follow-up?**

C05: No. Not that I know of. No (*laughing*).

**INT: Did you notice any changes?**

C05: No (*laughing*). No, none at all. The only thing I noticed was the list on the repeat was shorter (*laughing*). Yeah. Yeah.

**INT: Is that something that you feel you would like to have been involved in?**

C05: (*long pause*) (*sigh*) In theory, yes, be- because- yes, but on the other hand, it was a good thing to do so, yeah, I I guess, I’d feel differently if it has been- if I’d not agreed with it (*laughing*). Yeah, because I very much agreed with it. So (*pause*) so, yes, it would have been nice. I can’t put my hand on my heart and say I wasn’t asked. Also, my sister was staying at the time and it’s perfectly possible that that somebody spoke to her so- but, yes. But it was- it was withdrawing two quite ordinary- OK, you can say it’s put her to bigger risk of clots but I- on on that one, again, you know, there comes a point when you think: “how many risks do you want to reduce (*laughing*)?”. That is the gastric bleed thing so.

**INT: So, thinking about how decisions should be made about stopping medications. Who do you think should lead the decision-making? Which professional is best placed to do that?**

C05: Well, I think- I think, the- in theory, the the GP should be the middle of it because they’re- the problem with all the others is they’re all kind of in little silos, and- as is a GP, but i- idea- because ideally, the GP should have an overview of this and probably look at it say once a year or something and and say, you know: “do you- do you still need to be on all this?”, “do you need to go on anything else?”, “has anything changed?” and: “do we just carry-or or do we change anything?” and it would be ideally you’d have somebody kind of in the middle who had- you know, who’d actually read the letters from the hospital and looked at the blood tests, or whatever, and and and I don’t expect them to do this every month or anything but, you know, maybe once a year or something like that, and- and then if if there is anything that they propose to change, then they can talk, ‘phone, e-mail or whatever. I mean, it’s the kind of- that kind of conversation you can have on the ‘phone, it doesn’t need to be a face-to-face one, and if necessary, see her and get a- get some sort of feedback about how she is on all this and, you know, is is she--- is she not getting out of bed because everything hurts too much or: is she really plodding around quite cheerfully and does she need to be be on this. But, as I say, some- somebody who in- who actually has a a bit of an overview, either either the GP or possibly, a a a good practice nurse. Yeah, just- but somebody who looks at the the whole picture rather…

**INT: So, probably somebody from primary care?**

C05: Primary. Yes. Yes, because if you say to the rheumatologist something about- I mean, the things like when she first started getting muddled, I said to the rheumatologist something like: “oh, I think…”- act- actually, the label around the neck of the rheumatologist- is (*doctor*) says: ‘rheumatologist and medicine for the elderly (*laughter*)’. OK. So, I said: “she’s starting to get…”- but she said: “talk to your GP”. Yeah, this this is not a a- OK: “yeah, I’m- you’re here for your rheumatology appointment, talk to your GP” so- which that, you know, and fair enough, but it’s the joined-up thinking that’s the tricky bit and actually, a a practice nurse or- or somebody like that could could equally, but it doesn’t have to be the GP in person, but somebody in prim- that’s a good phrase, is somebody in primary care who has- who has, you know, who’s got eyes on the computer and can see all the bit- all the letters. Yeah.

**INT: And you would want to be involved in that?**

C05: If there were changes, yes, I would utterly want to be. I have power of attorney for health and welfare as well as for- as well as for finance so (long *pause*)- and she is not capable of making- now. I think, they should talk to her, ideally- because quite often sometimes on the ‘phone they’ll say: “I’ll leave you to talk to your mother about that” and I said: “no (*laughing*)”, I mean, it depends what it is, but it’s- sometimes it’s a default thing: “I’ll leave you to talk to your mother about this” or (*pause*) when when she was going- when she fell and, you know, she had to go into hospital because they thought she’d broken her hip, but- it- it’s: “well, you explain it to your mother” and and you can understand, there’s a paramedic there who’d never met her or me, but- and then- but- and if you say: “no, I want you to say it” even if I end up repeating it because then it’s not all coming from me who- and she’s a bit suspicious of everything that comes from me whereas if it comes from doctor somebody or other, or nurse somebody or other, quite rightly, because because she sees them as the professionals. So so so, yes, but she- although she she needs to be slightly involved- and again, it will depend what it is, like this patch-less business she’s not involved in at all, but she hasn’t a clue so- whereas if if she had to have some treatment, if she had some physio or something like that, but.

**INT: So, in terms of thinking about the rheumatology appointment and discussing that medication. Mum will be involved?**

C05: She’ll be there. Yeah. She’ll she’ll be there (*laughter*). She- to what extent she’ll be involved is is- she- basically, she won’t understand and I- probably, I don’t know, but probably after a couple of minutes she’ll- because because I suspect the the rheumatologist will do the standard rheumatology sort of thing and then they’ll say: “is there anything you want to talk about?” and and, at that point, she’ll just probably zone out. Yeah. Yeah.

**INT: So, in essence, she might be able to answer some of the more basic questions but can’t make the overall decision is what you’re saying.**

C05: Yes. Yeah. Yes, that’s very good, she can answer some basic questions, but she can’t make decisions. Yes. Yes.

**INT: So, if somebody said to her: “are you taking too many medications?”.**

C05: She’d probably say: “I take far too many pills”, but she wouldn’t…

**INT: But actually, in terms of what the individual ones are.**

C05: She wouldn’t. Yeah. I mean, she’s very- she’s perfectly capable of choosing lunch from a menu but she’s not capable of making decisions that she needs to understand the implications of.

**INT: And how do you feel about being involved in those decisions on your mum’s behalf?**

C05: I I much prefer that I am because I know what’s going on. In an ideal world, she’d be well enough to do all this herself. OK, she’s not, so so, if it’s- if- we are where we are, she can’t make decisions (*pause*) so as I say, I’d rather be in a situation where it wasn’t necessary but since since we are where we need it, then I would much rather be at least informed and preferably a bit involved. I don’t- I mean, if I say- I don’t expect them to do as they’re told by me, total- absolutely not, but a bit of dialogue of what the implications are or- because it- I mean, sometimes like the the person who prescribed whatever this was the other day, had no idea whether she does her own medicine, or whether they’re in Dossett boxes, or they’re- or somebody gives it, you know, they just write the prescription how they- they have no idea how it actually gets gets (*laughing*) into the patient’s mouth. So, that’s where the- sometimes having the dialogue with- having a- being involved just purely on a practical level as well- that’s- so, there’s the practical level of it and then there’s the, you know, yes yes, I think, somebody to to tell me what the side-effects are and what the pros and cons are briefly. Yeah, I’d rather have that than not have that.

**INT: So, what are your thoughts around sharing the decision-making with the professional?**

C05: I’m quite happy to share it. Yes. Yes. Yes, part- particularly where where the- and where the professional is- I don’t expect them to have a case conference every time they change it, but but but where there’s- where there’s some evidence they’re looking at the bigger picture. Yeah.

**INT: So, if they were doing a review of all of the medications?**

C05: Yeah. Yeah. I mean, we could get to the really meaty one which I have no idea whether it will ever happen or not, if she gets a really bad chest infection, do we or don’t we give antibiotics? And obviously, that one would be a shared decision, but anyway.

**INT: What’s your experience about shared decision-making with professionals thus far?**

C05: I have to ask for it and- but but some things (*pause*), yeah, I have to- it doesn’t happen automatically. Yeah, when I ring the GP, ring or e- e-mail them, or whatever, and- as- if- if I get through on the ‘phone- when I get through on the ‘phone and I say who I am and I’m ringing on behalf of (*name*) and I have power of attorney, and they’ve obviously got something on their computer that says that I have power of attorney, and they ask me one or two questions about postcodes just to check who I am, that’s fine, and then they will- they’ll totally talk to me. Yeah, and that works well, but- and, of course, every- you know, if you’re talking to different GPs then you have to explain the situation, but I haven’t- I haven’t had any- I haven’t had an experience where anybody’s been awkward or difficult or refused, or anything. Yeah, I’ve- generally, we’ve had to ask for it but but but it- if we’ve asked for it, we’ve got it. Sorry, I’m rambling.

**INT: No, not at all. So, if a medication was stopped, what do you think should happen? In an ideal world, after a medication has stopped, what do you think should happen?**

C05: Yes, some sort of review of the situ- I mean, it depends why it’s stopped but say it’s something that she’s been on for a long term and then not sure that she needs it or not, after- depending on what it is, a month or two months, or something, say, you know: “has this made any difference?”, “has it made her better?”, “has it made it worse?”, is there nothing at all, no- nothing to see and depending on what it was, you might need a blood pressure monitor or a- or a blood test or-,you know, I’m not talking MRIs, or anything like that, but sort of- but some kind of review. I mean, the review might be a verbal review or depending on what it is, it might be say a blood pressure test or a blood test, or something, but that level of it and, again, a sensible practice nurse could do that kind of thing, and possibly even with me over the ‘phone.

**INT: So, over the ‘phone would be fine?**

C05: Yes. Yeah.

**INT: That was going to be my next question.**

C05: Yeah, but it depends- it depends what it was but- but generally, you know, some- if somebody rang me up and said, you know: “is she better”, “worse” or whatever it is, and- or: “here’s a blood form, organise a blood test” or something like that then…

**INT: So, some form of follow-up?**

C05: Yes. Yeah. Yes, not not just stop it (*laughing*). Some kind of…

**INT: And how might stopping a medication impact on some of these processes that you’ve got in place?**

C05: Fortunately, very little. Tell the- tell the pharmacist, they change the delivery, and that will be it (*laughing*). Yeah. Yeah, glory hallelujah (*laughter*).

**INT: So, if they wanted it changed straight away.**

C05: Well, if it- it- as long as you’re doing it at a week’s notice the- because the boxes are for a week. Yeah, so so, you could do it for next week. Yeah. Yeah.

**INT: So, are the boxes delivered one week at a time?**

C05: Yeah. Yeah. Yeah. No. So, that’s- yes.

**INT: So, that’s fairly straightforward.**

C05: Well done that that pharm- that pharmacist at the-, it was the pharmacist at the GP who said: “oh, I’ve- we’ve tracked down a couple of pharmacies that will do this”, “we- if it’s alright with you, we’ll change from…” whatever pharmacy she was using at the time which was next door to the doctors: “we’ll change it to one- it’s further away but since she gets deliveries it doesn’t make any difference” and so so, you know, it was very proactive of that pharmacist to come up with this sort of plan.

**INT: So, that’s all of the questions that I’ve got.**

C05: Yeah.

**INT: Is there anything else you want to tell me about medications? I see you have a little list there.**

C05: No, these- these were just things I should have taken photographs of, one of which was things like computers, ‘phones and e-mail, and stuff like that, because- in other words- and appointment reminders, the the electronics, and the more you can- a bit- a bit like your telemed, not telemedicine but, you know. And and the other one which I I told you about last time but there’s- having had a couple of very sensible friends with very bad experiences, there’s- you start to get this slight anxiety that somebody will report you to social services and you’ll be up for a safeguarding thing so- which is horribly easy to happen. There was something on the radio the other day…

***[Note from transcriber: Did not transcribe section of recording. Researcher confirmed: irrelevant information unrelated to the study.]***

**INT: So, is that particularly around medications?**

C05: Well, just in gen- just look- looking after somebody in general. Yeah. Yeah, I mean, ev- thing- I mean, nothing to do with medication but things like every financial transaction I do for her like, you know, trans- I mean, I do big trans- seriously big trans- because her peculiar tax thing, but things like paying- she has paper delivery and so on, I do it all through BACS or credit cards, or something, so, everything appears on a statement. I have a a a petty cash thing of, you know, sweeties and that that level, but it- it is literally that that sort of level, any- anything that’s- anything that I can possibly put through, something that comes out in a statement I always do, and such like, but you just sort of think somebody- is that…

**INT: It sounds like you’re sort of covering your back.**

C05: Yeah. Yeah, and- and and this is- it’s this sort of- I’m not lying awake worrying about it, but it’s an anxiety that- as I say, the the two people who I know very well who got really caught out by this who really haven’t done anything wrong at all, one of them was a disgruntled …

***[Note from transcriber: Did not transcribe next section of the recording. Researcher confirmed: irrelevant information containing personal details unrelated to the study.]***

**INT: Is there anything else that you want to add around the medication?**

C05: Medication. Sorry, I- I seemed to have talked about everything except medication.

**INT: No, that’s fine. It’s all context, isn’t it?**

C05: Yeah, it’s- it’s context and- but, as I say, the the real- the thing that’s made the the the sort of big difference is having somebody- having carers that will- that will do- that will- I’ve forgotten what they call it, do they call it prompting or- there’s some- there’s some word that they- because they can’t actually make- if she refuses to take it, they can’t make her. Anyway, she’s quite happy, you know, they put them out in a little glass and a glass of water, and she takes them. So, it's having somebody supervise it, and having the well organised deliveries, and that’s what’s making it- as I say, it’s taken a while to get there (*laughing*). Yeah.

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

C05 Respondent

- Interrupted sentence

***Audio* file: 50.22 minutes**