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

Transcript for interview

**C06**

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

**INT: So, before we talk about the photos, I wonder if you just give me a brief overview of the care that you provide for your husband, not just medications but more generally.**

C06: Everything, from the minute that we wake up in the morning to we go to bed (*laughing*). So, every- yeah, everything that entails. Yeah. So, it’s, you know, wash- not- I don’t actually do the washing because the carers come in to assist with that but, obviously, if one of them doesn’t turn up, which happens, then I just get on and you know, carry on. And, and, obviously, the- I do try to encourage that they do the, do the shaving and, and things that, you know, to- to help which is anything supposed to be with his personal care, but it, you do find it’s a bit difficult to- I don’t want to- ‘I don’t want to shave him because I’ll cut him’. ‘I don’t want to do this’, er yeah whatever. So, yeah, you have to literally specify everything that, but apparently, it’s supposed to be anything to do with his personal (*doorbell ringing and dog barking*) care while they’re here.

***Recording temporarily stopped then restarted.***

**INT: So, you were just talking around the care that you provide.**

C06: That’s right. Yes, right- right from the, the, the word go in the morning really. At the moment, we’ve got a bit of a problem because we’re not sleeping very well, so the nights are a bit drawn out. So, you’re basically getting up, you’re sorting out the tea, well, you’re trying to get yourself ready, that’s the, that’s the fastest bit, trying to get breakfast in you, yeah, so that you can do the rest of the day for everybody else. Yeah, and so, then you, you come in, you starting doing, you know, tea/breakfast, that sort of thing, then they come in to get him up and get him washed and dressed and that, so, you’re then sort of like sorting out the other bits and pieces, the washing, that sort of thing, getting ready for the day, and you come back in and you, you know, you’re sitting with them and keeping them occupied and that. If you’re lucky enough, you’ve got a sitter coming in, you know, weekends we don’t have them but during the week, I do tend to so that I can get on and do things. But I can’t really have a sitter here and not be here because it has to be two of us now so, I would have to employ two sitters (*sigh*). Yeah, one of them’s expensive enough. So, that basically, now that (*husband*) doesn’t do any walking to and back from the toilet, yeah, that means I can’t actually leave the house with the sitters unless I have two here so, I do tend to sort of like call on some people to come if I need to go anywhere. Yeah.

**INT: And how long have you been providing that level of care because that’s quite a lot of care, isn’t it? Roughly how long?**

C06: Well, since, since near enough day one, about six years really. Yeah, since, since this all started. Yeah, he hasn’t been left. You know, it’s always been that somebody has to be here. Yeah. Well, no I, I tell a lie, at the beginning, at the beginning, in the first year I would say, he would, he would go down to his brother, yeah, and he, he was, he was-, we were, we were a bit worried but we would let him, we’d watch him go across the road and that, and his brother would drop him back, but that was about it really. But I, I, I’ve always sort of like known, you know, from that point of view. We, we, we literally sort of- he would be able to walk up the stairs with my assistance and all that and, and then the progression. He was walking at the beginning, do you know what I mean, and the progression slowly over the six years. This, this year was the worse one because we literally got to the point that he couldn’t walk at all. COVID three years ago but we did manage to get him slightly walking and he would walk from the front door into here, you know, with the (*local*) rehab team and that and then unfortunately, once they left, nobody got- I haven’t seen a physio ‘til last Thursday. And no, you know, nobody got him walking so, of course, you don’t use it, you lose it. And I’ve tried and I’ve struggled, do you know what I mean, to try and get-, helping him but, you know, it’s hard because when he goes down, I, I haven’t got the strength, you know, and I do my best but I just feel that he, he could, you know, he could be walking if, if he was, you know, if he had people here that would help him to do that, you know. And, of course, when you have the (*local*) rehab team, their carers come in and they help walk him as well. But these girls from (*Name of domiciliary care provider)* and that, they’re, they’re not trained to do that, you know, and they, basically it’s not on their sheet to do it and that’s it, they don’t. They’re absolutely shocked when they see me do it, you know, and- because there’s nothing-, they can’t stop me doing it, yeah, whereas them it’s all their health and safety but I’ve got no health and safety rules in this house for me. No, that’s it. Yeah, we just pay her three-hundred-and-seven pounds a month, yeah, and don’t worry about health and safety because there’s not much you can do about that is there?

**INT: So, you’re obviously providing a lot of care which includes the medications. So, we asked you to take pictures of things that make you think about kind of managing his medications.**

C06: That’s it.

**INT: Can I just ask you before we talk through each photo, did you take these spontaneously or did you plan what you were going to take?**

C06: No, I just- I’d forgotten about that actually, you know, the, the thickener in the drinks. I sort of went into the kitchen and thought: “oh, yeah”. Of course, that’s all basically on the medical side, you know (*photo number 1*), I’ve been told I have to put two-, I have to put two teaspoons per 200ml so, I worked it out, yeah, if there’s 300ml in a cup then he has to have three, three teaspoons. So, yeah, as a thickener because it stops the choking. Yeah.

**INT: And that’s something you do every time he has a drink.**

C06: And I have to do it every time we have a drink. Yeah, and to be quite honest with you, when we were talking about medication, I didn’t even think about that. And then while I was there (*photo number two*), I picked that up and that is what I put all the daily stuff in for the medications.

**INT: So, tell me about how you do that, how often do you do it?**

C06: Oh, once a week. Once a week, I’ll fill that up. I’ve got all the packs and I fill it up. And then in, in the, in the morning, ‘cause I’m- I’ve changed it around at the moment because trying to work out the behavioural, behavioural thing because we’re turning day into night, yeah, and night into day, and that is no good for me because I need to sleep. It’s alright for him, he can sleep all day if he wants, I can’t. So, the fact that he’s up all night is not doing me any favours at the moment so what I’ve done is I was giving him-, he has a 150ml Sertraline and I was giving it to him after his tea. ‘Cause it gives him acid reflux, you have to have something substantial at that point when you’re taking it otherwise he’s foaming at the mouth with it unfortunately. So, what I did is I’ve changed it now to the morning so, he has two Weetabix in the morning with his honey and his, his milk and that, and then I introduced it in the mornings. So, straight away into like jelly, I’ve managed to put it in with jelly and custard now to slip the jelly down so that he hasn’t got-, I don’t want him chewing it, and he has this problem swallowing it, yeah, and if it gets stuck-, so, I’ve worked out if I stick it in the jelly, the jelly’s a little bit harder, yeah, and I’ll say to him: “swallow” and, of course, the-, with the custardy bit, it, it swallows down so, we’ve got that off to a fine art. So, we’re doing that in the morning and then straight into the cereal and, and then after he’s had that then I’ll give him the Vitamin C tablet, which I’ve introduced since all his hands all swelled up, and since I’ve put him on Vitamin C every day, only a tiny little brown thing but no swelling.

**INT: So, do all of those pills go in your pots?**

C06: Hmm.

**INT: Yeah, and you that photo looks like they’ve got days of the weeks on.**

C06: That’s right. Yeah.

**INT: So, have you got one for different times of the day?**

C06: No. No. No, just I- those three there, those, those three there are all the Sertraline, OK? That one there’s the Tamsulosin, the orange and the green, that’s for the prostate, and that’s the Omeprazole because you’re taking all these (*laughing*).

**INT: So, does he take all of those at the same time?**

C06: No. No. No. So, the three Sertraline I’m doing in the morning, yeah, and then at the end of the breakfast, I’m adding in the Vitamin C, yeah. Then these two, he don’t have them until tea-time.

**INT: But they go all go in the same pot.**

C06: What, what I was doing, I was doing those two in the morning and the others at- and I swapped it around, a different time of day. Just trying to get him to sleep better and, you know.

**INT: And did you do that change in conjunction with a discussion with the doctor?**

C06: Doctors. Yeah.

**INT: So, then let’s look at photo number three. Tell me about that photo, did you take that spontaneously or did you plan it?**

C06: No, that--- that just happened to be that it was there at the time. Yeah. Then, when I came back into the, into the (*pause*). No, I wasn’t- ah, when I took these photographs, I wasn’t actually doing the, the Sertraline first thing in the morning as you can see. This is the breakfast, yeah, and I was doing the other-, other way around, I was doing the Tamsulosin, yeah, and the Omeprazole. No, no, tell a- yeah, Omeprazole, Tamsulosin and the Vitamin C still in the morning and not the Sertraline. So, I just thought: “oh, I’ll show you how I puts it in (*laughter*), in the cereal”.

**INT: So, that’s photo number four.**

C06: Yes, slip it down. Yeah. Yeah, that was spontaneous. Yeah.

**INT: And let’s look at photo numbers five and six. Tell me about those.**

C06: Right, this is, this is the Rivastigmine patch. Now, what it is, at the very very beginning when he was first diagnosed with the Alzheimer’s bit, they gave us Donepezil and some other ones, I’ve got all the boxes, three different types, he couldn’t tolerate them. So, he was never actually on any medication for, for it at all and then all of a sudden, I heard about this patch. There’s a Rivastigmine patch which you could have for memory and that, whether it-, because he’s always had a problem with taking tablets, now he’s been ta- taking tablets, and then, so, what we did is they introduced the Sertraline tablets and they introduced the, the patch, but we had to-, they start off on a low quantities and you have to come up and down, do you know what I mean, depending on getting the mood and everything right. So, we found that, or I found that, the Rivastigmine patch, the middle one, and the Sertraline at the 150mg, yeah, it, it seems to be a suitable combination because they do-, it does affect it, it does affect it because I’ve just had to come down from Sertraline onto a, a, a liquid, because he couldn’t swallow the tablets, onto a liquid and he couldn’t tolerate the liquid so, I had to quickly go back up again, and the doctor said: “well, we wouldn’t it that quick”. I said: “I’m not being funny, look, when you’re sitting on the other end of it you need to get them tablets in there as quickly and you need to get this stable again”. Because I, I was there six years ago and it ain’t funny. When these tablets, and, and, and the thing-, it all becomes unstable and he-, it’s, it’s, it’s horrible for him and it’s horrible for me.

**INT: So, thinking about the patches, how often do you (*doorbell ringing*. *Recording stopped*).**

***Recording temporarily stopped then restarted.***

**INT: So, we were just talking about photo numbers five and six.**

C06: The Rivastigmine patch. So, basically, they started with that. So, what I found on their paperwork, yeah, that you know where the spine is, if I put it to the right of the spine one day and to the left of the spine the next day so, that will be like the spine going down there so, there and there and that’s just showing you how it goes on there.

**INT: So, do you change the patch every day?**

C06: Every day it’s changed. Yeah, a twenty-four-hour patch. Yeah, but it certainly works, do you know what I mean? We’re quite pleased with it.

**INT: So, that’s photo numbers five and six. Now, let’s talk about photo numbers seven and eight.**

C06: Yes.

**INT: So, again, did you plan these?**

C06: No. No, again, I was, you know, when you have to do it every day and you’ve just got it and I thought: “oh, I tell you what, I’ll take a photograph of that”. Yeah, ‘cause you, as you can see, I’ve got the jelly and the custard (*laughing*) ready to go.

**INT: Yeah, that’s what you explained a bit earlier.**

C06: Yeah. Yeah. Yeah, stick it in the jelly and custard and it disappears and, and it goes (*laughing*). Yes, that’s just showing that that’s what’s happening there.

**INT: So, that’s photo number eight. Photo number nine and ten?**

C06: That’s similar again. Yeah, just thought to myself I would show you how I put the, the tablets within the jelly and custard.

**INT: So, all of the tablets you’re giving with jelly and custard?**

C06: Absolutely at the moment. Yeah. Yeah, it’s working so, if it works don’t change it. It keeps them whole, you see. I was crushing the Sertraline and, oh my gosh, it had a, a real bad detrimental affect on him. You can’t believe that, can you? But it did.

**INT: It did.**

C06: Hmm. Yeah.

**INT: Now, let’s talk about photo number eleven and twelve.**

C06: Now, unfort- now, unfortunately what’s happening here is these horrible Tamsulosin tablets, OK. Now, we have Tamsulosin tablets, and I have moaned, and I have moaned, and I have moaned, and this is the difference, and I’m glad I can show you. That is a Tamsulosin tablet. This is this week’s Tamsulosin tablet (*shows interviewer medication packet)*.

**INT: So, there’s a significant difference in size.**

C06: There is a big difference in size, and I keep on moaning that he can’t swallow those. He has a real bad job swallowing them so, when they come that size, yeah, what I do is I empty it within to the cereal and get it in that way, not in-, not, not asking him to swallow that sort of capacity, no.

**INT: So, that’s presumably about the difference in what the pharmacy provide rather than it being any difference in prescription.**

C06: Well, they say it’s what they can get so. No matter how much you moan. And then even now and again, oh, the normal one comes in (*laughter*).

**INT: So, let’s look at photo number thirteen and fourteen. Can you tell me about those?**

C06: Yes, because this is on prescription as well (*laughing*).

**INT: So, that’s his toothpaste?**

C06: Yeah. Yeah, it actually is because his, his teeth are, you know, so bad. When we go to the dentist, this one is a real high concentrated fluoride and…

**INT: So, it’s not in any way medicated other than extra fluoride.**

C06: Just extra fluoride. Yeah, five thousand ppm, whatever that means, compared to what we have. Yeah, just to put extra fluoride in the teeth. So, yeah, anything that had a prescription on because I’ve actually got a prescription sitting there waiting to go to the doctors somewhere. Yeah.

**INT: So, you’ve got all of these things on prescription.**

C06: Yeah.

**INT: Conveens *(photo number fourteen)*.**

C06: That’s it, Conveen. Yeah, then you have to ring them up. So, I didn’t know whether to put that in so, I just took a copy and I thought we could take it out if we need to.

**INT: So, is that the same for photo number fifteen and sixteen?**

C06: Yeah, then you’ve got dressings that you have on it. If they rip it-, rip it off of his thing and make him sore, hmm, yeah, and the Dermol lotion, again, is for, you know, on medication for his dry skin.

**INT: So, that is photo number sixteen.**

C06: Hmm, and…

**INT: I think, this is a continuation, isn’t it?**

C06: Yeah.

**INT: Photo number seventeen.**

C06: Yeah, these, yeah, these are the bags, the bags that you have with the wee.

**INT: That’s photo number eighteen.**

C06: And that’s to get it off the, the thing.

**INT: Get the dressing off.**

C06: The sheath off.

**INT: Oh, the sheath off.**

C06: No, they put the sheath on.

**INT: That’s photo number seventeen.**

C06: I mean, it’s brilliant because you haven’t got to get him up in the night. Oh, oh, fabulous. Fabulous., whoever invented them.

**INT: And photo numbers nineteen and twenty.**

C06: Yes, the Carmellose drops.

**INT: So, they’re eye drops?**

C06: Yes, they’re eye drops and he has to-, and, no, you see, I forgot about things like this, and he has to have his eye drops in because he had a-, an operation many many years ago when he had the cataracts done and the lenses put in, and they all tend to end up with dry eye. Yeah. Yeah.

**INT: So, are they medicated eye drops?**

C06: They are. Yeah.

**INT: So, actually, when we’re looking at deprescribing we’re looking at anything that’s got a medication in it rather than anything that’s prescribed per se.**

C06: Yeah.

**INT: So, that would definitely be included. Now, you mentioned before about having your prescription ready to go to the GP. Tell me about how you get hold of his medications, what do you have to do there?**

C06: Oh, so, all different things because, you see, now, I’ll go to the dentist, he gives me the prescription for, for, for that one. I ‘phone up Coloplast and they give me the prescription for the night bags and the spray, those sort of plasters if, if they mess up. Let’s see, you’ve got night bag, yeah, and the spray, and the sheets.

**INT: What about the medications?**

C06: The other medications, that’s all done on the NHS website. Yes, apart from the one that I’ve just had to call in this morning (*pause*), this is an ointment that I-. He has an eye condition, yeah, and I have-, every now and again, I have to, I have to-, it’s gone a bit sore again. It gets-, oh, I can’t remember what they told me he’s got wrong with him, but it’s quite-, it seems quite a common thing in older people to be quite honest with you, it’s like a little duct type thing and it goes red, and he has to keep on putting that stuff in until it clears up but it never really clears up.

**INT: So, you had to get that as kind of an extra prescription?**

C06: Yeah, that’s an extra prescription because it only lasts twenty-eight days, you see. Yeah.

**INT: And how often do you usually get your medications for?**

C06: Oh, those ones, it comes in every month, twenty-eight-, normally about twenty-eight days, I think, it always says on the prescriptions in there.

**INT: So, you order it on the NHS app?**

C06: Yes.

**INT: And then…**

C06: They just come through from the pharmacist.

**INT: The pharmacy deliver it.**

C06: They deliver it. He just delivered one this morning. Yeah. Oh, they’re really good. They are good.

**INT: So, other than what we’ve talked about and what the photos show us, is there anything else that you do to help your husband with his medications on a day-to-day basis?**

C06: Um, it’s- my honest opinion, most of it is, is like reviewing it, yeah, because this is where I’ve got the problem with the doctors at the moment. Now, like I said before, we’ve just had to come-, they (*sigh*)- I’m, I’m fuming over it, if I’m perfectly honest. Now, they put him on-, he’s got dementia, and I don’t like to mention it in front of him as you can imagine, he’s got Alzheimer’s dementia and he’s got Parkinson’s. If ever I talk about it, I say Parkinson’s because he doesn’t-, it doesn’t sound-, everybody who knew Alzheimer’s dementia, everybody was scared about getting Alzheimer’s dementia. So, if somebody doesn’t understand, you don’t really want to keep telling them that that’s what they’ve got, you know, and I do notice he does get a bit agitated when you do mention the word. So, I talk about Parkinson’s because he doesn’t know what Parkinson’s is. Yeah. So, that’s how I get over it and it stops his stress levels, you know. But, you see, what they’ve done is they- and it’s good, it’s good they’ve got him stable, yeah. They’ve got him stable with the patches and the Sertraline, OK. But when all went wrong, yeah, we-, what have we come down to? They tell me now that the last thing that’s going to happen is he’s going to lose his swallowing ability, he’s going to choke to death. So, why are you giving somebody who’s actually going to be losing the swallowing ability, tablets? And they’re not going to be-, when you get to that point, he’s not going to be able to take the tablet.

**INT: And have you had an opportunity to talk that through with anybody?**

C06: Yeah. Yeah, so, I was crushing the tablets and obviously, it wasn’t working, it was making it all go haywire, and I know this looks bad (*laughing*) *(referring to cupboard she has opened full of medication),* I just had a-, some more come in. Oh, what are they called? I kept it because I know it’s not out of date, but I don’t know why-, I kept it, I do tend to keep the packets so that I know what, what works and what doesn’t work, do you know what I mean? *(Talking whilst searching through cupboard.)* I write down things on things, for myself as well, what works and what doesn’t work (*long pause*). Ah, there it is. Fluoxetine, yeah? So, anyway, I’ve, I’ve got him off of that, put him on that, oh, terrible. Nearly as bad as the Donepezil and his Memantine and, oh, I thought: “here we go”. So, yeah, agitation, agitation, he’s really agitated he was, so, I had to quickly get him back on-, fortunately, his, his (*long pause*). He was-, fortunately, he was getting better and his swallowing was im-, improving and that so, I managed to sort of just do half a tablet to swallow with-, and then I found the jelly and that and, hey-presto, we managed to get em down. So, went back up, but I said to the doctor: “so, what are we going to do then?” ‘Cause this is where we’re going to end up, yeah? As I’m finding out, I’m learning all this. “What are we going to do?”. “Oh, we’ll cross that bridge when we come to it”. “Oh, no, we won’t cross that bridge when we come to it, love, I’m going to be going to see the old people mental health people and then we’re going to have a plan”, “we need a plan”.

**INT: So, you mentioned the Fluoxetine and the Sertraline.**

C06: Hmm.

**INT: Was that something that was proposed by the GP?**

C06: Well, I had a (*laughing*)-, somebody else has got a new job now and he’s called a, a mental health pharmacist, OK.

**INT: And that’s at the GP surgery?**

C06: Someone’s got-, yeah, yeah, someone’s got another title. Oh, you’ll be surprised how many titles they all got now and, yeah, he ‘phoned up, ‘phoned- (*name*) his name is, and he said to me, he said: “yeah, we’re going to go from the, that to that” and I went: “no, we’re not”. He went: “what?”. I went-, no, no, tell a lie, let’s start again. Right, what happened with-, I said: “right, can you supply the Sertraline in the liquid form?”, I said: “because I read all about it and the Sertraline does come in a liquid form, you need 7½ml of that for a 150mgs”, I’ve done my research. So, anyway: “can’t”, “we can’t get it”. Right. No, no, no, they don’t-, that was it, they don’t do it. I said: “we’re going to start again and you’re going to stop lying”, I said: “now then, they do do it but you obviously, in the NHS, are not willing to supply it probably, maybe the cost”. I said: “but don’t lie to me and tell me that they don’t do it when I know that they do it. You can get it on Amazon pharmacy, love”. Anyway, he went: “oh, I hope we can start again” he said: “we’ll-, you can get it”, he said: “but we can’t get it at the moment”, he said: “on prescription”. I said: “OK, fine, I’ll accept that”. He said: “we tried to put it in-, into that one over there but it’s-, for some unknown reason, it’s not about”. I said: “well, I’m hoping I don’t have to prove you wrong” but there you go. So, anyway, that’s why we went onto the Fluxotine, OK?

**INT: Yeah.**

C06: And I tried, and I tried, but you believe me, it was, it was not good so, I quickly got him back and, and stabilised him but, I’m not kidding you. You’ve, you’ve got to have nerves of steel doing this, you really have, ‘cause when they’re all over the place and they’re, they’re ratty and you’re, you’re, you’re not getting your sleep and they’re not getting their sleep, I tell you honestly, how you-, how anyone stays sane, I don’t know (*laughing*). And I mean, at the moment, you can see my condition’s not good because they’ve got me down to one of these Salofalks and I’ve noticed I’m starting to get shaky and I’m starting to ween on it. I took three.

**INT: So, thinking about the numbers of medications that your husband takes.**

C06: Hmm.

**INT: How do you feel about that number?**

C06: I’m quite happy about it. I tell you for why, because he’s not actually (*laughing*)-, everybody says to me: “I can’t believe he’s not taking any medication for Parkinson’s”. I says: “well, to be quite honest with you, I don’t think he has got Parkinson’s so, why would he be on medication for it?”. Even though they say he’s got Parkinson’s, I think, he’s got Lewy body dementia but there’s only two types, two ways of finding out that he’s got that and one’s an autopsy and the other one’s a lumbar puncture and I’m not going to put him through it to find out. But he’s, he’s had two, two cousins that have-, are dead now who had Parkinson’s and you can (*laughing*) really tell the difference between Parkinson’s and Lewy Body dementia.

**INT: So, it would be of a concern to you, would it, if he was on extra medication?**

C06: Not so much a concern, I’m pleased he hasn’t got it because let’s face it, all his medication’s going in his belly, yeah, and it don’t do you any good going in your belly. I-, that- one good reason, one of them’s a patch. The Sertraline, I’m not too worried about that because you can take sort of like a 100mg tablet and a 50mg, yeah. The fact that there’s three is because we’re breaking it down into the small ones, OK, so, it would only be two, yeah?

**INT: Yeah.**

C06: And an Omeprazole, like I say, the Omeprazole is because he’s taking all the other tablets for acid reflux. With no disrespect, you know, you, you, I don’t know if you’ve ever seen the tee-shirts, you take that tablet because you take-, yeah (*laughing*).

**INT: Yeah.**

C06: The Vitamin D is only a new thing because the fact that we didn’t, he didn’t go in the sun much this year and that, that’s a new thing so, I’m not too worried, and it’s such a tiny little tablet, I’m not worried about it. And the Tamsulosin is a preventive of prostate cancer, and it’s done well so far so. Yeah, and the Rivas-Rivastigmine patch, yes, whether it, whether it helps the memory or not, who knows? But as long as it keeps the mood right with his-, yeah, with the other ones, yeah, because don’t forget, they’re supposed to be a anxiety, erm what is it? Anxiety-, depression tablet, that’s all they are, they’re not anything to do with the condition, they’re just ‘cause he gets depressed. Let’s face it, he’s sat there all day long, do you know what I mean?

**INT: Yeah.**

C06: Wouldn’t you be? I mean, what are you supposed to do, you’re going to fiddle, aren’t you? Yeah? You can’t get up. Everything has to come to you. Oh, and he gets frustrated, he wants to come to you.

**INT: So, other than that conversation that you had with the mental health pharmacist around whether you could change the medication from tablet form to another form, are you aware of any other time when all of your husband’s medication has been reviewed kind of as a whole?**

C06: Oh, no. You used to go in the doctors and have (*laughing*) all that done, didn’t you? Yeah. I mean, every now and again that-, they stop-, you know, because you, you can get so many issues, don’t you, on, on a prescriptions, yeah, and then you run out of issues and then you say: “well, you need to put that back on prescription”. But really, I mean, he’s, he’s got-, well, I, I’ve got about three or four pages really and there’s stuff that needs to come off. Somebody really does need to do a review because a lot has changed since our last review. He was on those drinks to thicken up-, to, to put on weight but I don’t even need him on them at the moment but then who’s to say he’s not going to go downhill again, and he won’t be able to eat and I’m going to have to rely on them again. So, this is an ongoing situation that’s, you know, the end result is the end result and, I mean, at the moment, do you know what I mean, going back a little while, in there is all his end-of-life care treatment. All sitting in the cupboard there. They thought he was a goner so... Manuka honey put that one to bed (*laughter*).

**INT: So, you mentioned when it was last reviewed, do you know roughly when his medication was last reviewed?**

C06: No, no, not off-hand, not off-hand. I mean, I, I do talk to the, the doctors on the ‘phone but we don’t go down to the surgery very often. He is sort of classed as a, a at home patient, you know. I mean, we do get like the doctor guy comes in, I say doctor guy, he’s not actually a doctor but he’s sort of taken over. He used to be (*pause*)- another one’s that’s got a job in a different position that we never knew about, you used to get like the paramedics. Now, he is like senior to the paramedics but, again, he comes under the doctors so, when they need people to go out for visit patients instead of the doctors going, he goes. Yeah, because he’s quite high up as a paramedic type thing but not quite a doctor, but he can do prescriptions so, his- one of his colleagues was telling me. Yeah. So, he comes and he, he, he was the one that came Monday to see if he had a chest infection, a water infection, and that. He went: “well, this has changed since I’ve been in here last”. I said: “yeah”. Getting him walking, getting him up. Hmm, doing me best.

**INT: So, sometimes with medication it can be decided that it’s not needed anymore, and it might not be replaced, it might be reduced, or it might be stopped.**

C06: Hmm.

**INT: What do you think about medication being stopped or reduced? What are your general feelings about it?**

C06: Well, the, the- my honest opinion, the, the least amount of medication you can have, the better, you know. I’ve, I’ve, I’ve always thought that I’ve done well with getting away with just the Omeprazole all my life. That- if I’m sixty-five years of age and all I-, well, sixty-four I was, and I-, the only thing I-, anything I took was Omeprazole and that was before this condition I’ve got, and now I’m on Salofalk tablets and Omeprazole and in a right state.

**INT: So, the fewer tablets the better from your perspective.**

C06: Hmm.

**INT: So, if, for example, one of the tablets they decided wasn’t needed anymore, you’ve kind of talked through them all, are there any tablets you would be happier being stopped than others?**

C06: Yes, I would-, you know the, the antidepressant ones because I, I actually went down to 50mg. When-, well I had to, I didn’t have no choice. So, you, you start off at 150, right, and then you have to come down to 100 and then you have to come down to 50. Now, you’ve got to ween ‘em down ‘cause when you, when you first go on ‘em, you have to go up with ‘em so, you have to start-, like the patch, you have to start off on the lower dose, yeah. You have to do that for maybe a month before you go up to the next dose, yeah, and then see-, and then he was not good on the high dose so, I brought him back down again, and then we stayed mediocre. And the same with the Sertraline, we took him up to the 200, no, no, no, no, no, bring him back to the 150 and then you find this mediocre that we-, you think he’s settled down with and that’s brilliant. But when you come off it, you’ve got to go-, step back the same way, that’s what I told the man. He went: “oh, we’re going to come…”. I said: “no, we’re not (*laughing*)”, you know: “we’re going to step back down”, yeah, and then ‘cause I told them that now it’s: “oh, yeah, well you got…”. I said: “yeah, look I, I know”, but he didn’t know that. He was quite happy to go from a 150 to 5ml.

**INT: So, in terms of reducing any of the medication he’s currently taking, are there any medications that you would be happier to be stopped? You’ve obviously talked a lot about the Sertraline and the impact that that has if it is stopped.**

C06: Yeah. Well, I, I just wonder-, I just wonder whether it would be worthwhile, now we’ve got it stabilised, as I call it, yeah, I was going to talk to the doctors and say to ‘em: “look, what do you reckon on…” We don’t want to go more, I-, I can’t see the point in more but then they, they, they come back and explained to me why it might-, it should be more, yeah, and I could say: “look, why- what about now?”, “and see if we can reduce it, but we need to…”--- it’s what I need to explain to them: “we need to reduce the patch at the same time as the Sertraline”. Yeah, ‘cause, I think, what they went wrong, even though they were listening to me, and we red-, we reduced the Sertraline, what we should have done is we should have reduced the patch at the same time we were coming down but, of course, nobody thought of that. I must admit, I didn’t think of it either until it all went haywire, and I thought: “what’s going on?” “What’s going on, he’s turning day into night”, you know, it-, hon- honestly, it was-, it was a horrendous like last month, and now, as I say, it’s all settled down again and I’m thinking: “so, what on earth is happening here?” But one good thing, he, he, he was alert. All of a sudden it was like the receptors all woke up in his brain, and I was watching this, and everybody was noticing it as well: “wow, he’s more talkative today, what, what you done?”, “oh, I’ve changed- I’ve knocked off the medication”. So, I’m wondering. Yeah.

**INT: So, in terms of having those discussions around making changes to medication, who…**

C06: Makes the decision.

**INT: Who do you think is the best and the most appropriate person to talk to?**

C06: (*pause*) I’ve got no faith in any of ‘em (*laughing*), I’m sorry. I mean (*sigh*) (*pause*), I’ve-, you go to (*specialist mental health*) place, OK, and this is, this my last encounter, sitting there and watching the other couple, it’s a man and a wife. He’s clearly got it, she hasn’t. So, in comes the like nursey, you know you’re going to see the doctor, she’s sitting in the room at the other end there, they do all the fussing and all the weighing, and all that goes on, and I’m watching this. So, in she comes. So, she says to the-, because he’s the patient, now, don’t forget he’s the patient, so, she says to him: “right, do you want your wife to come in and see the doctor with ya?”. So, the wife (*laughing*), and very rightly so, she said: “well, if I ain’t going in to see the doctor with him, there ain’t no point him even be-, him even being here because he ain’t even going to remember he was here”. Well, she was fuming, and I thought: do you know what? She’s flipping right, you know. I get that you’re-, they’re dealing with the patient, I get that, but come on. Seriously. That and you want me to have faith in them (*laughter*). So, what did I do? Yeah, watching this, I went and spoke to one of the nurses and I said: “could you do me a favour?”, I said: “could you ask the-, the doctor if I could have five/ten minutes with her before I go in with my husband please?” and she, she did arrange for me to do that. Yeah.

**INT: So, obviously, your role in that decision-making is important?**

C06: Oh, absolutely because you’re the one that’s dealing with it every day, day in, day out, you know, and I get that they’re, they’re trained and I’m not. I do get that, yeah, but they don’t see it on a daily basis and every patient must be different. We’re all different, we’re all individuals. We don’t all react to the same thing. I mean, it’s like my, my cousin on the tablets I’m on, she’s on 150 er 1.5g, me, I need 9, and her condition is worse than mine, if you please, in medic-, medical terms (*laughing*).

**INT: So, in terms of your experience then, because obviously you’re managing lots for your husband, I’ve seen that, and you’re obviously involved in the decision-making around his medication, what’s your experience of making those decisions jointly with professionals? Can you talk me through your experience?**

C06: I can’t because I haven’t got power of attorney over his-, I didn’t realise, when, when the- up- man at the OPMH told me to go and get power of attorney, he didn’t explain to me that there was two.

**INT: So, therefore you…**

C06: I’ve only got power of attorney over the finances and apparently there’s one over the medication as well. Only-, honestly, this whole journey, nobody explains anything to you. I haven’t got no say in it really.

**INT: So, do they involve you?**

C06: They do involve me, they do involve me, but I have to do as I’m told. I have to do as I’m told because I haven’t got it-, and that’s fine.

**INT: And you’ve been told that by the professionals?**

C06: And I get picked-up if I don’t do something right. Hmm, hence, I gave-, I had- this paramedic bloke came in and I, I gave him-, he was sitting there, my husband was sitting there and he looked a bit dry and I (*demonstrates tipping water from a water bottle into mouth*), that’s all I did. I just gave him a drop of water out of my bottle, and he said: “you shouldn’t be doing that”, “you have to give everything with that *(points to thickener)*”. “Good job the doctor never saw you do that” he said. Just down to a mouthful of water (*laughing*).

**INT: So, how do you feel about being involved in decisions (*kettle boiling*) about medication?**

C06: Well, I, I, I honestly think that it’s, it’s not much good if, if you’re not involved in it because you’re the one that-, you’re the one that sees how, how they are on the medication, yeah, and, of course, his, his- you’re dealing with mind-bending tablets ‘cause I’m not being funny, that’s exactly what de- anti-depressants are. They’re mind-bending tablets, they make-, they bend- bending the mind to try and make you think that if it’s a miserable day, he’s happy (*laughing*), and I try and make it happy for him so (*undecipherable due to kettle boiling*) (*laughing*). Don’t rely on the tablet, you know, (*undecipherable due to kettle boiling*).

**INT: So, if a healthcare professional was to discuss with you and you agree that a medication should be stopped.**

C06: Yeah.

**INT: What do you think should happen after that medication has been stopped? So, if they say to you tomorrow: “we want to stop this medication, this is what we’re going to do”.**

C06: Yeah.

**INT: What do you think should happen subsequent to that medication being stopped?**

C06: So, are you asking me do you think that, that all should automatically come off his prescription?

**INT: Well, I’m asking you what you think should happen?**

C06: Well, in, in an ideal world, yes, yes, that should come off the prescription but if they change their minds, yeah, then it’s got to go back on and (*making a cup of tea*) or, or be altered whether it was still there to be pulled off. But you’ve got to be careful with it because you’ve got people that would pull-off medications willy-nilly so, they’ve really got to look after it. I mean, yeah, it-, it’s, it’s a hard one.

**INT: And what might you be looking for, or would you be looking for, in terms of support following that medication being stopped?**

C06: Well, there ain’t none (*laughing*). Well, they, they normally, they normally say: “oh, we’ll, we’ll follow- follow-up in a couple of weeks” and that’s what the doctors said to me last time. Well, that couple of weeks was too long, I- I couldn’t wait for her to ring me in a couple of weeks (*teaspoon stirring noise*), and I just ‘phoned ‘em and told ‘em: “I’ve- I’ve added it up, I was on 150, we, we, we did say that we were going to do it over two weeks” and I said: “look, it was getting bad, I had to speed it up a bit faster than that”, and don’t forget, he’d been on this Sertraline for quite a few years so, it was already in his system, it wasn’t as if it had left his system completely, you know, and I just got it back up again and then, you know, wait for the slap on the wrist sort of thing. It didn’t, it didn’t come because they knew that-, you know, what I’d done was- urgh, OK, not correct-, it was correct, but it could have, it could have benefitted from taking longer, but I mean I was sitting in a crisis, trust me.

**INT: So, in an ideal world, should that plan for follow-up have been sooner?**

C06: Yeah.

**INT: So, what sort of timeframe would you think would be acceptable?**

C06: Every day. It was a changing picture every day. Yeah. Especially when you’re dealing with this, you see, because, like I said, you, you take Wednesday, you know, you can get one week, you- or one day you can get him walking, next, his legs have gone, and he’s right over like that, and you’ve- and the core muscle’s completely gone, you know.

**INT: So, in terms of that access to that support, how is that best achieved if you need the regular access?**

C06: Well, you-, you don’t. This is the thing, you don’t need it all the time, you know, you don’t need it all the time because you just-, you know, it’s just on these one occasions like that that you need those doctor’s support, and they ain’t, they ain’t got the time, have they? Let’s face it. They haven’t got the time (*tap turned on*).

**INT: But if you’d had access to them by telephone, would that have been helpful?**

C06: Oh, yes. Yes. Well, we-, when I ‘phoned up-, here I’ll give you an example. Well, I ‘phoned up to tell her: “oh, she’s not in ‘til Monday”, “she-, I see on her notes she’s going to ring you Monday (*laughing*)”. OK, it ain’t going to help me, is it?

**INT: So, what happened then?**

C06: She went and referred it to another bloke and the bloke told me I got it wrong. I went: “yeah, I did, didn’t I?”. When she came back, she said to me: “you-, you gave them to him early?”. I said: “that’s correct”. “And how is he?”. I said: “fine”. She said: “well done”. Now, she didn’t say to me: “you, you gave- you didn’t…”, yeah (*teaspoon stirring noise*).

**INT: And so, when a medication like that is stopped, how does that impact on what you do in terms of managing his medication?**

C06: Well, because then I had, I had to say to her: “right, now, what are we going to do now because I’m back to the 150 and I need to have the 150 going in in small amounts”. So, she said: “what I’m going to do now is I’ll put that prescription in for 3…”. So, where we were having like the 100 and the 50, now we’ve got three boxes of 50, yeah. So, that changed the medication and the prescription at that point. OK (*teaspoon stirring noise*)?

**INT: Yeah. So, that’s probably all of the questions that I had for you. Is there anything else you want to tell me? Anything you want to add about stopping medications?**

C06: No, I think, I think, we’ve covered it all. I, I, I do worry, do you know what I mean, at what-, where we are with the medication by the simple fact of what I’ve explained to you about the swallowing. I- where’s this going to end? Well, I know- seem to know where it’s going to end (*mumbles*)- what’s it’s name, where it’s going to end, I’m quite aware of that now, but it does worry me that, you know (*tap running*), at what point is-, that this is just going to become more and more distressful for him and it’s going to become more and more distressful for me because I’m going to be trying to go back to where we were, and he’s not going to be able to swallow these tablets, yeah, and he’s going to be choking on it, like he was. On everything he was choking, on everything.

**INT: So, you wanted a plan in place for that?**

C06: I need a plan. I need. I need.

**INT: And you haven’t got any further forward with that?**

C06: Well, no, she just said: “we’ll deal with that when the times comes”. I went “no, we won’t”. No, we won’t. You might want to shelve it love, but it ain’t going to be shelved.

**INT: And nobody has offered you an opportunity...**

C06: No. No, my next plan, my next plan-, because they said to me: “what are you going to do now?” and I said: “well…”-, oh, I found that prescription. What I’m going to do is that I’m going to-, I’ve got an appointment with the OPMH coming, I think, I’ve got it-, oh, I’m going to check where it is, I’m sure it was January, but I’ve got a feeling something happened there where I changed it and they were going to come back to me. Something’s in my brain, I’m not sure what. I’ve, I’ve got to double-check. So, I looked the other day for the letter and I thought to myself- is it in that-, I think that-, I didn’t see it (*shuffling papers*) (*pause*). I keep everything like for next year in this pile, you know.

**INT: So, your plan is at that appointment to pick it up there?**

C06: That, that is where we, we, we need to be deciding. Oh, here we go, it was there. Yeah, the 24th January, nine o’clock. Now, that-, when we see this consultant, right, that is when I should do exactly what I did last time, I said like: “I need to speak, to speak to the consultant”, yeah: “about this medication”. I don’t want to talk to him about it because it’s going to be talking about end-of-life care, yeah, and what are we going to do so, I don’t want to be discussing that in front of him. So, where do we go from here? But what I can do, in the meantime, now I know that’s the 24th, I can do this, I can find out-, I can go to (*pause*) Amazon, I haven’t tried it yet, but Amazon Pharmacy and see if I got a private prescription because you wouldn’t be able to get it on NHS anyway, yeah. I would have to get a private prescription and I don’t know whether you can pay your doctor to write a private prescription. I don’t know.

**INT: That will be things you will need to discuss with the consultant.**

C06: Yeah. Yeah.

**INT: So, is your reason for choosing OPMH over your GP because…**

C06: Oh, no, because the doctors told me. Yes, they, they- actual- actual fact, it wasn’t OPMH, it was (*name*), (*name*) centre. The (*name*) centre gave him the Sertraline and the doctors passed the butt. So, I said to them, I said: “look, what am I going to do?”, “I’m crushing this tablet and he’s going haywire, what am I going to do?” “Oh, we can’t deal with it, you’ve got to go back to the (*name*) centre”.

**INT: So, tell me about why you’ve decided that it’s best to talk about the kind of end-of-life care plan with OPMH rather than with your GP, for example.**

C06: Because they’re, they’re not, they’re not (*laughing*), they’re not going to give me the tablets, yeah. They told me they can’t do anything I’ve got to go back to them because the Sertraline tablets were actually given by them. So, it’s out of their hands, yeah. So, now, apparently all his medication which is to do with Parkinson’s, to do with Alzheimer’s, comes always from them. So, you’re not allowed to talk to your doctor about it at all. The doctor administers all the future medical repeats, but that’s it. Yeah.

**INT: So, anything else you want to add?**

C06: No. No. No, hopefully that will all be sorted.

**INT: Let me switch the recorder off.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

**C06** Respondent

***Audio* file: 53.50 minutes**