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

Transcript for interview

**C08**

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

**INT: So, before we look at your photos, could you tell me a little bit about the person you care for? So, about (*name*), and how you support her. What is it you do?**

C08: OK.

**INT: And not just specific to medicines.**

C08: General.

**INT: Yeah.**

C08: Yeah. So, (*name*)’s my partner’s mum, and they’ve got a really, really close relationship, the two of them, and they’re alike in quite a lot of ways, and so, I think, that helps me be able to look after (*partner’s mum*), if you see what I mean, because of how-, of my care for (*partner*), if you see what I mean, because of the way they are. They’ve got similar personalities and things that would annoy (*partner*) would annoy (*partner’s mum*) so, in some ways, that’s quite a good start. So, what-, (*partners mum*) has been diagnosed with dementia so, she’s got the Alzheimer’s and the vascular dementia. She also has a heart disease; she’s had valve replacement, but she’s still got some leaky valves. So, she’s-, she, she was a very robust lady but she’s probably a bit more frail. Well, she is a bit more frail than she was. She isn’t massively active or again though, she was previously. I guess, that’s been a bit of a gradual thing, and some of that’s due to aches and pains, and so- and last year, her husband, (*name*), died, they’d been married for like eleven years and so, he had bowel cancer and so they went through about fifteen months of being diagnosed to when we lost him. So, to begin with, he was not too bad on his chemo, very determined to have his chemo, and he was always a bright bubbly person, and very determined through it all he was, but it did all take a bit of a toll on both of them. (*Partner’s mum*) more, more- (*partner’s dad*) had to have a stoma and (*partner’s dad*) didn’t-, he didn’t get on-, also with his chemo, his fingertips were very numb and painful so, he had-, he man-, he had a job managing it. So, (*partner’s mum*) did help a bit with that although even at that stage, the things she did weren’t-, she didn’t actually-, like she would go and get the tea, but (*partner’s dad*) would tell her how long to put it on for and, and, and (*partner’s dad*) liked looking after her so, did everything for her. So, over the last few years, what (*partner’s mum*) actually does has got less and less, I guess, for two reasons: 1) that (*partner’s dad*) liked to do it and 2) that (*partner’s mum*) was actually finding it harder to do these things. So, the extent of the things that-, she likes to read although we have noticed that she’ll- she does lose her place in her books and things. She’s- I think, if you gave her the same magazine, sometimes she’d know she’d read it and sometimes she wouldn’t. I’m probably waffling on too much. So, so, there is a limit to what (*partner’s mum*) can do for herself although she dresses, she does-, she act-, she actually had the spell in hospital last year where the dementia seemed to worsen and that was where-, after that, she was diagnosed. We were seeing the memory clinic before that, but it was only after this episode that she had-, she was-, they said: “yes, she has got it now”. And (*pause*) when she come out of hospital, she could really do nothing, and she was very confused. She couldn’t really do anything for herself, but gradually she’s improved, and she is showering for herself, and she’ll microwave a dinner, and she will make a cup of tea and she gets- she can get dressed, she gets very breathless when she’s doing anything like that. So, we really do- she does come shopping, she’ll push the trolley, lean on the trolley.

**INT: And you’ll take her shopping?**

C08: Yeah. Yeah. So, I’ll-, we’ll take-, I take her shopping. So, it-, I do the housework but I’ve been doing the housework and things for a few years now for both of them. She can do a bit of washing. She’ll put it in the tumble dryer, it’s a bit hit and miss as to whether we get detergent or whether it actually does ever get into the tumble dryer or not, but she does-, she can do it, but generally I do her washing. Like I say-, so, her personal hygiene, generally she does herself except I apply a few creams for her that are a bit, you know, awkward to get to or…

**INT: And is that a daily...?**

C08: No, I don’t do it daily because she has carers come in-. If-, when she’s at home, she has carers come in morning and evening, and really the main reason for that is to make sure she has her meds because we (*coughs*)-, before (*partner’s dad*) died, and before she was in hospital because that was all very close together, she used to have before breakfast, after breakfast, four o’clock and evening meds. And originally (*partner’s dad*) used to pop those all out into one of those plastic trays for both of them so, he-, on a Sunday, he’d do it for two weeks sort of thing, and put them all in trays, but then as he wasn’t as-. Well, one time he was in hospital and none of us had a clue what was going on with the meds because (*partner’s dad*) had put them all out. (*Partner’s mum*) roughly knew what to take so that wasn’t too bad, but then he was in longer and someone needed to do the meds (*laughter*). Guess who (*laughing*)? It took me ages to work it all out, but we did get there. And then, I tried to persuade, persuade them to go onto the Nomads but (*partner’s dad*) was like: “no”. He would quite like going up to the chemist, getting the meds, and doing that. That was one of his little routines, but as he got poor- more poorly with the chemo, and his fingers were bad, he couldn’t pop the tablets out of the-, so, then I did manage to persuade them to go onto the Nomads. So, most of their medication, not all of (*partner’s dad*)’s because he had some diabetic stuff that was a bit ad-hoc and his chemo stuff was ad-hoc, but (*partner’s mum*)’s went into these four slots, but when she came out of hospital, she wasn’t taking them. Even if (*partner’s dad*) got them out for her, she wasn’t taking them. And then she wanted to have a go at doing them herself so, we used to just give her the Nomads and let her try and get them out. But she can’t get them out, she’ll put her fingers through other ones and can’t actually work out whether she’s got the morning or the- in the day and everything, she just used to get-, she got really muddled up. So, the, the, the carer-, that’s one of their main jobs, and they will do washing-up and things like that, empty the bins, things like that. Make sure she’s got enough pads and things. So, those sorts of things.

**INT: And you mentioned previously that (*partner’s mum*) is between her place and your place.**

C08: Yes. Yes.

**INT: How often does she come to you?**

C08: (*pause*) Definitely sort of the weekends, but lately those, those days have extended a bit. So, it isn’t quite a-, I mean, recently, I would say it’s been probably more than half and half. If you looked at a six-week period, she’s probably been with us for-, lately, but prior to that, it was more weekends and she’d go home for three or four days in the week. So, when she’s here, I do do a bit more again ‘cause I will help her get dressed and undressed because it is really hard work for her, but then that’s hard ‘cause you don’t know whether you’re making it worse because you’re helping, and when she goes back, she has to do it herself, but I find it hard just to leave her to struggle. So, I try to just dip in and out and let her do certain things and-.

**INT: Shall we talk a bit more about your role within the medication? So, I’ve got the photos that you kindly took for us.**

C08: And we do all her paperwork and everything as well, she can’t do any of that now. We’ve just applied for Power of Attorney, and we’ve got delegated third party on the banks and things.

**INT: I am going to spread these photos out. I’ve numbered them so that if we refer to a photo we can give the number for the purposes of the tape. So, first question: did you take these spontaneously or did you kind of plan what you were going to take?**

C08: It was really very spontaneous particularly-, not long after you’d given me the camera, the new batch of Nomads, or medication, arrived. So, what happens is-, oh, did I take them spontaneously? No, I didn’t plan them actually but now-, but I thought about it a bit. So, after I’d done these- and one morning, I was give-, putting her tablets out ready and I thought: “oh, well, I might as well take a picture of- of what we do”, “how we-, roughly, how we do it” and then I thought: “oh, but I haven’t actually taken a picture of the Nomads” because I just assumed you’d know exactly what they look like, but then I thought: “I expect they all look a bit different, I don’t expect they all look the same”. So, I-, that was why I took this (photo number 7). Hmm.

**INT: So, shall we talk through each photo in turn, and you just tell me a bit about the photo and what it says about the medication and how you manage it?**

C08: Yes. Yeah. So, this first one, this is actually at our house because we’d been and picked (*partner’s mum*) up and just collected those off the table. So, what happens is that every four weeks, the pharmacy comes, and they’ve actually got the keycode so, they actually bring the medication into the house and leave it on the table so, (*partner’s mum*) just leaves a, the bag there, and that will contain (*coughs*)-, generally speaking, that will contain four weeks of Nomads, oh, there you go (*points to photo number 3*), and other loose things that are not daily-, but they might be daily but they’re not-, they don’t fit in quite to the routine of the Nomads. So, paracetamol she can have up to four lots a day. That’s an Alendronic, that’s one day a week, and then that’s her cream, the Voltarol cream, but she also has magnesium hydroxide and there is a cream that she puts on her bottom that comes in with that sometimes as well. Oh, and cream she washes in.

**INT: So, how often does she take the magnesium hydroxide?**

C08: Every night. Well, unless she’s had the day where she’s been more regularly than normal. She has diverticulitis so, she suffered with-, she’s managed that pretty much through her life really. So, she’s very set on whether she’s taking magnesium hydroxide and whether she needs more or less, you know, so. Well, she thinks she knows but she- now, she’s getting muddled up as to which day it was that she actually went to the loo and didn’t go to the loo so, even that is getting a little bit more complicated.

**INT: So, photo number one is the bag of medication.**

C08: Arriving.

**INT: So, what about photo number two?**

C08: So, picture two-, oh, so, in this one on-, here they actually pinned it on the front, they put what wasn’t in that bag because quite often-, no, quite often isn’t fair, over the years there’s been times where things like magnesium hydroxide was almost impossible to get and sometimes her cream for her bottom is, is-, doesn’t-, they can’t get for some reason. So, I’m sure it’s the same with various peoples’ medications, I’ve heard it on the news and things. So, then you have a slip of things that are owing to you.

**INT: And how does that impact you?**

C08: Well, I’ve been very lucky in the last-, since (*partner’s dad*) died really, I’ve been very lucky in that sometimes there is stuff owing but generally, it will turn-up without me having to chase it. What it does mean is I do need to keep it in the back of my mind which tends to happen quite naturally because you’re using the meds quite regularly. If (*partner’s mum*) wasn’t coming to stay and only the carers were doing it, I think, that would be a bit more of a- like a job I’d have to list down and make sure I did because it would be easy to get to the stage-, if they haven’t-, still haven’t got it, they just don’t deliver so then you could be in a stage where you haven’t-, I haven’t got any magnesium hydroxide and (*partner’s mum*)’s going: “I need my medicine” (*laughter*). So, because I do it regularly, I think, you automatically monitor it and luckily, things have turned-up within time. There was one time recently-, it’s not that one, one time recently, they just delivered two trays so, I thought: “right, I’m guessing they’re waiting for something to come in” so, I thought: “I’ll leave it for now because it will probably turn-up” and we’d got to using the second tray, that the week that we were using the second tray and nothing had come. So then I did ring the pharmacy and ask what had happened to it, and it was because something was missing, but it did seem like they hadn’t quite twigged-, oh, that’s right, because it was a Friday actually, I’d meant to do it earlier in the week and it was Friday when it was due to come, and they hadn’t realised so, it wasn’t out for delivery so, we-, on the Monday, we wouldn’t have had any meds for (*partner’s mum*). They were very good, they said: “we have got it here, the pharmacist will drop it into (*partner’s mum*)’s house on his way home” (*laughter*), and we said: “it’s OK, we’re picking up (*partner’s mum*), if you just have it ready, we’ll come in and get it”. And I ha- have to say that the people in (*pharmacy*) generally that I’ve spoken to, are really lovely and very helpful, very understanding and are-, they do seem to get to recognise you a little bit, but they’ve been excellent generally. A couple haven’t quite seemed to quite grasp what’s going on, but, I guess, it’s just that they don’t deal so much with the way we have it, but most of them are excellent. Can’t complain about them at all.

**INT: So, tell me a little bit about photo number four.**

C08: So, picture four, that’s if (*partner’s mum*)’s staying here, in the mornings that one actually is. I just-, when we’re getting- putting the- the stuff out for breakfast, I just get them- the daily Nomad ones out, and I count them to make sure there’s six, and that one makes seven, and then leave the paracetamol…

**INT: And that one is?**

C08: This is just a calcium. I leave that separately because she just has that afterwards, whereas these, she just tends to gradually get through them with her breakfast sort of thing. She hates that one as well (laughter). And lately, she has been saying: “I don’t know if I really need all of these tablets”, “I wonder what would happen if I didn’t take all of these tablets?”. So, we have-, when we saw the memory clinic nurse and she signed her off because she’d got to the max-, to the level that they were going to give her of Memantine, they suggested that she could reduce-, I can never quite remember the name of it, Sertraline, I think it is, for the (*tapping table*) anti-depressant that is, because they did increase that quite a lot when (*partner’s dad*) was on his sort of journey through chemo because it did-, sorry, got a little fly there, seem a little- obviously, it was putting a strain on (*partner’s mum*) so, they did increase that quite- and they wondered if that was affecting her memory. So, I do wonder if that could be reduced, but you never know, you know, how much what’s going on now is affecting her and isn’t. Anyway, and they also-, Am--is it Amitriptyline? I think, she has one in the morning and one at night, and they suggested that she might be able to reduce the Amitriptyline, but (*partner’s mum*) does sleep generally very well, which is really nice because there’s nothing worse, is it, if you don’t get a good night’s sleep. She sleeps a lot actually, and that-, I think, they were thinking that some of these might be confusing her a little bit more and making her sleep more than she really needed to. At the time they spoke to her, she said: “oh, well, these- I feel OK on what I’ve got so, I’ll just- don’t think- I’ll stick with what I’ve got”.

**INT: And when was that when she was seen?**

C08: August that was. I can’t remember what you asked me now.

**INT: So, we were just talking through the medications and how you give them out.**

C08: Oh, what it- yeah, how I give them, yeah. So, she just helps herself and she does-, sometimes she’ll, we’ll be nattering and looking at the birds or something and, you know, even though they’re there, she’ll keep drinking her tea and forget she’s got those to take. So, it-.

**INT: And then you’ve got the Paracetamol.**

C08: Yeah. So, I just always give that as an option because it isn’t-, you know, she knows her pain. I think, she doesn’t really quite get the gist that if she had regular Paracetamol, it’s more likely to be better for her than one now, one in- tomorrow, you know (*laughing*). But I just feel like it-, if she was in a lot of pain and I could see she was, and one time earlier in the week, I said: “I think, we better do the Paracetamol for-, regularly for a few days and see how we go then” and sometimes she will and some times she won’t, but I just think: “well (*laughing*), it’s up to her in the end”.

**INT: So, moving onto photo number five then.**

C08: So, that’s just the Nomads pack as it arrives which is quite handy because it does specify which week. When we first had them delivered, I didn’t realise it had a week number on it so, I was just doing them-, you know, whatever one I picked out that’s the one I’d start, and, and then the carers got a bit confused, they’d start- they’d go into the bottom drawer and take a new Nomads, like ev-, on a Thursday, even though these tablets were still in there, they’d start one (*laughing*) and so then, I wri- I thought: “right, I’m going to have to write the date that-, of the week- which week this is relevant for so that they don’t do that” because it gets confusing having-, not confusing, but it’s- we don’t need-, I like things straightforward, I don’t want two Nomads going at the same time (*laughing*). So, I looked, and I suddenly thought: “oh, it has got the week on there”. So, it says it’s week one, two, three or four, and it does say on there somewhere (*partner’s mum*)’s date of birth. I think, it says her health number as well.

**INT: Yeah, I went through and blocked it out on the photos.**

C08: I understand why it’s on there for them to make sure they’re giving it to the right people, but in some ways I’m like: “I don’t really like all that being on there” because obviously, the carers will come in and when I need to get rid of it, I have to make sure I don’t-, you know, that I shred it. So, I-, whether there is anything that could be done about that because that is personal information that’s just left- and I wonder how many other elderly people just throw that away. So, generally, that seems OK really, and then this (*points to photo number 7*) is just the inside-, that’s just come out of the lid that’s just down there, which is quite straightforward because it is just morning and afternoon.

**INT: So, you mentioned previously that she was taking medications four times a day.**

C08: Yeah. So, it-, it was four.

**INT: So, obviously, at some point it’s been simplified.**

C08: Yes, when she came out of hospital, I-, we just talked to the GP then about whether any of the meds really- or was there a particular reason that the meds were spread out for four sessions in the day, or was it just that (*partner’s mum*) found it easier to, you know, take them at different times. I mean, in honesty, I think, some did say before food and after food, but when we talk-, when I talked to the GP about it, she said: “the best thing is we’ll just consolidate them to morning and evening, and then in terms of, you know, making sure she’s taking them, then it’s easier because you’ve just got the two times to do it, and the-”, she said: “the most important thing really is that-” I think, it’s the heart tablet should have twelve hours between it, which it doesn’t quite because she gets up at nine and- nine’ish, and they come at about seven-thirty so, that isn’t quite right, but that was as best as we could do. When she’s here, it’s more like twelve hours because we will (*pause*)-, it’s not quite twelve, but we’ll just give her them during the evening, it doesn’t have to be at seven or seven-thirty.

**INT: Yeah, but obviously the carers are restricted to the time of their visit.**

C08: That’s right. So, that was what the, the doctor had said that it-, the GP had said, that the most important thing is that there is- that one is spaced out as evenly as possible. It’s not-, it doesn’t really matter that she takes all of them in the morning and then all of them in the evening.

**INT: And then photo number eight?**

C08: Yeah, and that’s just the list of what the actual medication is that’s in there, which is quite useful in terms of recognising. So, for example, if (*partner’s mum*) dropped one of them, we haven’t got spares so-, and generally, if it’s one we won’t worry, but if you- if we knew that she’d missed the same one then I probably would speak to the pharmacy or the GP to say: “we’ve missed this one a few days” and at least here, I can see which ones it would be because they describe the shape and colour of them and that changes, it’s not always consistent. That was- used to be really annoying when you were popping them all out into the pots. I still find that quite annoying why they’re changed, but it, it doesn’t-, it matters less now because I- you do get to recognise them, but I don’t take so much notice of that now, I just accept what’s in there is what’s she’s meant to be having (*laughter*). Yeah. So, that-, but it doesn’t say what she takes it for, and there are some of these that are historical that I’m not absolutely sure why she takes them, but that’s fine because, I think, I mentioned to you we’d been talking to the GP ‘cause she’d had some pain in her breast, and we went and saw the GP and she examined her and then did some blood tests. The blood tests all actually came back as (*partner’s mum*)’s normally are, and so she’s just ringing me probably within the next week or so now. So, nothing changed with her meds, she thought she might be anaemic because she’s a bit itchy as well (pause), but she’s at her normal level. So, nothing actually changed with her meds because then if something changes, you either have to wait until the next lot of new Nomads to start the new course or they can deliver them separately and she- they can be administered, administered separately which is fine as long as they’re not outside of the times of this, then if they are, then that adds in another little conundrum (*laughter*).

**INT: So, beyond what we’ve talked through in terms of the photos, is there anything else that you do to assist (*partner’s mum*) with her medications?**

C08: Oh, so, I suppose-, it’s funny how you take it all for granted. So, she does have creams. She has the Voltarol which is really for her back and shoulders so, I apply-, sometimes I’ll apply that even if she’s not here because all of it’s a bit of an effort for her, to be honest, and I can understand that. So, sometimes when she gets up she’s- and the carers are there, she just can’t be bothered to let them do it so, I’ll put some Voltarol on her. And the same, she has like a moist-, I can’t remember what it’s called. Do you need to know what it is because I have got it written down?

**INT: No, don’t worry.**

C08: That we put on her legs because her legs get quite dry and go a bit of a funny colour sometimes, and then she does get-, she wears the incontinence pants and so her-, the tops of her legs sometimes get really sore so, we just use like a barrier cream there and it’s just a bit awkward for her to get to that.

**INT: So, do you find yourself visiting most days when she’s at home?**

C08: Well, I-, we try and do every other day, (*partner*) and I, between us. So, the days that I don’t go, the Voltarol she’ll get the carers to put on and sometimes, they do her legs, and she doesn’t actually need the leg cream every day, but- and the sore bits are sort of a bit periodical and (pause)- and, again, we seem to be able to keep those at bay with just me doing it, you know, when I’m there. You know, it’s not like if I don’t do it every day it gets horrendous, at the moment, so, we’re managing it like that. And she-, push comes to shove, if (*partner’s mum*) was really uncomfortable, she can apply it herself but, again, it’s just all effort and it’s just a bit awkward to do, isn’t it?

**INT: Yeah.**

C08: So, creams, magnesium hydroxide, that’s it, I think, there’s no other.

**INT: Do you need to do anything in relation to ordering medication?**

C08: Not really because all the ones that she uses regularly, they very-, I mean, originally, we did. All these separate ones we had to order those separately. The Nomads came regularly, and these didn’t. But I’ve got a feeling-, I don’t exactly know how it happened, and even her creams-, oh, and she showers in a part- in Epimax--- is it Epimax that she showers in? She uses a cream thing to shower in. I’ve got a feeling it was (*name of GP*) that just decided to put them on a regular repeat and so, because they’re on the regular then the chemist just bring them. So, she has got a Sumatriptan, or something, for migraines which, touch wood, she hasn’t had anything of. So, I would have to order that sort of thing. And, I must admit, there is a few things now that we’re beginning to build up a little bit of a stock of and I don’t really want to end up having tons of it so, I have spoken to the chemist to say not to send anymore of the shower cream for the time being, and we’re just-, they’re going to keep it on the prescription but not fulfil it. So that I can just say: “oh…”, when we get down to a couple, I can ring them and say: “can you pop it on for a while”. So, I’m very lucky in that respect. If it had been (*partner’s dad*)’s, I think, I would have had to have done more ordering myself because (*coughs*), I think, some of the stuff he used to have, I can’t exactly remember now, used to come at different-, he’d need it at different times because it wasn’t a regular consumption of it, but I’m lucky with (*partner’s mum*) really in that respect.

**INT: So, looking at the photos, she’s obviously taking a lot of medications because there’s about seven or eight of them just in the morning there in photo number four.**

C08: Yeah, it’s the same actually: seven in the morning and seven at night, nine (*tapping on the picture of the box in photo 3*) if she takes this and then the one that’s (*tapping on the picture of the box in photo 3*) one a week, that one.

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

C08: To be honest, I hadn’t-, she’s always said: “oh, I’ve got so many tablets”, for years and years (*pause*), you know: “oh, I’ll ratt- I’ll rattle. I’ve got so many tablets” so, I’ve never really thought too much about it because she says: “I’ve got so many tablets”. And then like my sister and brother-in-law are in their eighties and they’re all-, you know, they’ve got various tablets that they’ve taken- they take as well so, I suppose, I haven’t really thought too much about it. It’s only been these last (*pause*), well, eight months, I suppose, really that I’ve started to think about it. Probably because of the, the memory clinic nurse saying that she had-, she could reduce them, and over time, I’ve thought to myself: “how many of these were-“, oh, it’s hard to explain what I mean exactly. Like, for example, her heart, whichever is her heart tablet, I would never question it because I think to myself: “well- well, I, I think, if she’s not taking it then she’ll have an earlier death”. So, I think: “well, she needs to have it”, but any of the others, I’m not quite sure. I think, there is one for kidney function, or some- something like that so, I’m thinking: “hmm, she probably does need that one as well”, her legs do swell every so often, so sometimes we have to have water tablets. We haven’t had that for a while. So, I think: “well, I wonder if she could reduce them?” and like I say, she has said lately that she wouldn’t mind reducing them, but then she was on the ‘phone to her cousin and she said (*laughing*), she said: “I don’t seem to take as many tablets now, I wonder if they are giving me all my tablets”. She didn’t mean me she meant the medics: “whether they are giving me all the tablets that I should have”. I’m like (*laughing*), the night before she said: “I’d really like to reduce the tablets that I’m taking”. So, I say to her, every time I say to her: “when we speak to (*name of GP*) next, we’ll ask (*name of GP*) if she thinks there are any there that you could have a go at reducing”. (*pause*) And, I suppose, that’s where I am really. I think there’s no point taking tablets-, what’s a-, what-, for example, (*partner’s dad*) was clearly at the end of his life and, you know, he’s taking tablets for his diabetes. Well, what was the point (*laughing*)? So, that I definitely think: “yeah, it’s time to stop” whereas (*partner’s mum*)’s, you know, for all we know, she might live another ten years, and if these help her do that then fair enough.

**INT: So, you obviously would be OK with her stopping medications but what information might you need to understand whether you would support it or not support it?**

C08: Yeah. So, I think, all I’d need to really-, I suppose, like the ones that I-, the other ones I’m not too sure but, but, I think, it’s those two are the- Sertraline. So, I know those are to do with anti-depressants so, if they said: “well, let’s try reducing the anti-depressants” then I’d be happy to do that, and I just really need them to make me aware of any side-effects or things to look out for. I’d be happy to do that. The Amitriptyline, because I don’t exactly understand what that’s for, and it does concern me about her sleep ‘cause I really think it benefits everybody that she has a good night’s sleep. What I would hate to see happen is that she doesn’t sleep as well, or she’s restless, or- and the same with anti-depressants, if she starts to get anxious, then it’s not worth it. I’d much rather she had a reasonably calm existence even if it means taking those. So, I just think I would need- and I would obviously talk to (*partner*) about it just in case he had a different-, we would all talk about it anyway, but he-, if he has a different view to me. At this stage, we haven’t because we’re not at a stage of talking to anyone about-, when-, I am waiting for (*name of GP*) to ring and I am going to say to (*partner*): “shall I mention to (*name of GP*) about whether (*partner’s mum*) could reduce any, if (*partner’s mum*) wants me to?”. If on that day, she says: “no, I don’t want you to” then I won’t. Even though the next day she might say she does (*laughter*). So, it’s difficult to balance (*pause*), I think to myself: “is that the right approach doing what (*partner’s mum*)’s asked me to because it- might she be a bit better, less sleepy, might she be a bit less sleepy if she did, did reduce them?” and I’m not even asking if she could. But then I think: “if the doctor’s doing a review, she does usually ask-”, if she’s doing like an annual review, she would usually say to (*partner’s mum*): “are you breathless?” and things like that.

**INT: So, is that something that happens, a regular annual review?**

C08: She has done that. Yeah, because I’ve taken (*partner’s mum*) the last few years, I’ve taken (*partner’s mum*) to it so-. I can’t remember when in the year that is and, to be honest, because she- we’ve sort of been speaking to her about things, and when (*partner’s mum*) came out of hospital, she was ringing us every-, to begin with every week and then gradually knocked it off. So, we’ve had quite a lot of conversation, but when it was after the hospital, you don’t think about reducing them, do you, because you just think: “oh, they’ve got what they need”.

**INT: And so, at that annual review is medication one of the things that you would talk about?**

C08: I don’t think she asks us if, if we want to reduce- ask (*partner’s mum*) if she wants to reduce the med- medication. I don’t think she does ask that question.

**INT: You mentioned when she came out of hospital there was a look at her medications to simply the regimes.**

C08: Yes. Yes.

**INT: There was a medication review then. Was the medication discussed with you?**

C08: And in honesty, I don’t know then whether they did change any (*long pause*). I don’t-, I didn’t have a conversation-, there was a couple of doctors that came to the house as well because she’d-, she broke some vertebrae in her back so, she- it was hard for her to go anywhere. So, they came to the house, and it was then that we discussed doing this, and I don’t remember them discussing whether we change any of the medication or take her on or off anything. So, they might have done it then, but I don’t remember discussing it with them. There was a lot going on at-, the hospital bed in the lounge and (*partner’s mum*) didn’t know where she was and (*laughing*)-, so, I’m not saying they didn’t, but I don’t recall it.

**INT: So, do you recall any time when a medication has been stopped or reduced?**

C08: There was, there was a time-, I mean-, I think, it was actually when COVID was on that she probably would have been due to go for a heart review but they couldn’t-, they weren’t going to do the heart review, and some nurses came out (*pause*). No, that’s not quite true, she did go and do something with the heart people, I didn’t go, (*partner’s dad*) went with her, but then some nurses came out to look at her medication and they did adjust her medication so-, but it was quite a long time ago. They did adjust it, and I’ve just got this thought in my mind that they might have taken her off of Amitriptyline but then the GP later put, put her back on it, and at one stage a while ago, I can’t why that was (*pause*), they- I think, it was the Amitriptyline that they doubled but (*partner’s mum*) said it didn’t really have any affect (*long pause*). And I actually can’t remember what that was, why they did that, and I can’t exactly remember when that happened. But the nurses coming out to review was quite a while ago, it might have been-, there was definitely a, a review that happened during COVID and I’m fairly sure there was a review prior to that as well about her meds.

**INT: And so, when any medication changes are made, is there any follow-up?**

C08: The nurses did keep in touch and like when-, and it was (*name*) who issued the-, gradually increased the Sert- Sertraline. And we were going back to see her and, I think, it was every couple of months we went back to see her.

**INT: So, at the memory clinic?**

C08: Yeah. Yeah, the memory clinic. Yeah. So, that was all done through the memory clinic and they refer it apparently to a consultant that decides whether it’s OK, looked at her other meds and said: “yes, OK” and that’s, that was what happened with the Memantine. He would review all of it, her meds, and said: “we can’t increase that anymore based on her-“ (*talking quietly*) I get muddled up with liver and kidney, I know that’s stupid, but one of, one of those functions and her heart medication, they felt that was, you know, her limit.

**INT: So, if a medication review was going to happen. How do you think that’s best done? Who, when, where?**

C08: Well, it is a difficult one, isn’t it, because the-, you know, the, the GP is the general practitioner and she’s the one that will have, probably have the most contact with (*partner’s mum*), probably (*long pause*). But I suppose, there is a bit of you that-, I’ve-, a bit of me that feels con-, you know, they’re not-, she’s not an expert in heart conditions, she’s not an expert in memory loss. She probably knows pretty well how the drugs respond with each other, and what they’re for (*pause*)-.What did you ask me? Sorry.

**INT: Just about how-**

C08: How would it be best to do it?

**INT: Yeah.**

C08: And who would do it. Yeah (*long pause*). I think, probably the GP although, you know, if the heart department did it in consultation with any other team-, because these days, it doesn’t seem that any one person does all of the things. It was the same with (*partner’s dad*), you know, he had various things going on, but they all had to try (*laughing*) and communicate with each other (*pause*). And I-, selfishly, I think, (*partner’s mum*) (*pause*)-, she’s used to (*name of GP*) and, I think, she would res-, respect-, no, respect’s not the right word. I think, she’s used to talking to (*name of GP*) about things and remembers her from previously. So, probably the G-, I would say, for (*partner’s mum*), probably the GP.

**INT: And so, is it always (*name of GP*)?**

C08: Well, it has been lately. Yeah, it has been. We’ve been very luck-, whether they’ve made a decision that for some of the elderly peop- patients they stick to their GP, or whether (*name of GP*) just gets asked and says: “oh, yes, I’ll speak to her”. I don’t know how it-, how it is, but we do seem to manage to talk to the one person, and it usually is (*name of GP*), and (*partner’s mum*) remembers her when she first joined the practice, and when she had her children and things so. So, for (*partner’s mum*), that’s quite a comfortable feeling. The heart people, I-, she might remember some of them if it was the same consultant, but we haven’t seen a consultant at all for quite a while. She went and had the echo, the one where you have to sort of go on your side and everything, she did have that, I’m going to say last year. Last year or late the year before, but then didn’t see anyone, they just wrote out to say that there wasn’t any particular changes, and she could continue with her meds and they’d let the GP know.

**INT: So, you saw a copy of that letter.**

C08: Yeah.

**INT: So, if there was a discussion going on with say (*name of GP*) around medications, would you wish to be involved in that?**

C08: Yes (*laughter*), simply because-, I mean, in, in the end, at the moment, we are sort of whatever (*partner’s mum*) says she wants, within reason as long as it’s not any damage to her, then we’ll go with what she wants (*long pause*). So, in some ways, to- I’d just be there for knowledge.

**INT: For your knowledge.**

C08: Yes, because if (*partner’s mum*) said: “no, I don’t want to reduce them” or (*partner’s mum*) said: “I don’t really want to take any of them” so, (*name of GP*) then explained: “if you-“ and (*partner’s mum*) went: “alright, I’ll take those”” then that’s, that’s fine, but I would like to know. And like she might sort of say-, say, for example, she said: “oh, no, I’ll just carry on as I am”, I might say her to: “well, a few times recently, you’ve said to me that you don’t know whether you really need to take all of these and you’d quite like not to take them”. I’d have that conversation with her to see whether it made any difference to what she or (*name of GP*) said.

**INT: And so, in terms of shared decision-making so, sharing that decision-making with the professionals. Have you had any experience of that happening?**

C08: Specifically about the medication?

**INT: Or anything generally.**

C08: Well, when she was in hospital, it was-, to be honest, it was the complete opposite, they just told us what they were doing (*laughing*).

**INT: And how did you feel about that?**

C08: Well, when it came to discharging her, very worried. But, again, there was more than one thing at play in that (*partner’s dad*) was so ill and there was a bit of us that was worried that he might-, well, not-, we weren’t sure how (*partner’s mum*) would cope if she didn’t-, if she wasn’t there, you know, if she hadn’t seen him. So, there was more than one thing at play. Whilst we didn’t think she was fit to come out of hospital, they said to us: “she’s reached her baseline”. We said: “what do you mean she’s reached her baseline?”. “Well, she’s the same as she was when she came in”. “She certainly isn’t, she doesn’t know where she is, she could-”, you know, she was helping (*partner’s dad*), doing things with his stoma and things when she went in, she couldn’t have done that then. She couldn’t-, you know, she- and then, you know, they did assign care for her so, to-, looking back on it, I suppose I can sort of see that maybe she didn’t need hospital care. I can sort of see that looking back on it, but at the time, we felt like we just weren’t listened to.

**INT: So, your impression was they made the decision?**

C08: They did. They rung and told us. Whether they spoke to (*partner’s mum*) about it, they may well have done, but she-, she didn’t-, she wasn’t capable of making her own decisions at that time, she really was not herself at all. Thank goodness she has recovered a lot from that. So, that was awful, that was horrible. Even to the stage where like sending- and I understand they’ve all got jobs to do, but sending her home, we’d literally got the hospital bed in the lounge the day before (*long pause*), and so stuff was everywhere (*laughing*), and they just rung up and said: “right, we’re discharging her, she’s-, our driver (*name*) is going to bring her home”. “What (*laughter*)?”, “there’s no-where for her to sit (*laughter*)” and that-, you know, we explained, but they were like: “well, we’re not a-”, what was it they said: “we’re not a (*pause*)-“, I can’t remember what words they used but like, you know, like a reception where they could just stay because they sent her to somewhere so that she could go home, and they were saying that they couldn’t keep her. So, it-, that was all, that was all horrible. Whilst it wasn’t her medica- and they did- oh, and that was the thing then: “will you send her medication with her?” and: “will it tell us what you’re sending?”. So, then they told us what the medication, you know, what her medication was when she came out, I don’t think it was particularly different. Oh, no, there was some extra medication, and that-, that’s right, there was. They just told us-, when we asked, they told us what it was, and I said: “what happens when that finishes if she’s still in as much pain?”. “Well, just go and see the GP”. And when we went to see the GP, the GP couldn’t prescribe what the hospital had prescribed because it’s only prescribable by the hospital apparently. So, there was all those sorts of things. It’s amazing how you forget (*coughs*). Sorry, that might not be relevant.

**INT: No, it’s interesting to hear whether that shared decision-making happens or not.**

C08: And even like a frame, she’d been- she had used a frame in the ward, and we said: “well, will she-, will you send her home with a frame at least?”. “Oh, hmm, OK, we’ll make sure she gets a frame”. No frame.

**INT: So, if at a point in the future where maybe (*partner’s mum*)’s less able to make decisions for herself, how might you feel about being more involved in the decision-making?**

C08: I think, I, I think, I would feel OK about it (*pause*). I, I’m not sure if (*partner*) might struggle a bit more (*pause*). Because, I think, if I understand what the likely impacts of doing it are, and like I said to you, there is a bit of me that I feel like if there’s not really much point in them having that now, then don’t. I think, he probably will feel the same but, I think, that will be hard for his mum.

**INT: And would you have any additional questions if you were more involved in the decision-making that you might not have now?**

C08: No, I think, I’d ask some now even- even with, you know, so (*partner’s mum*) could hear as well, to be honest, because, I think, well if there is a question to be answered that might make a different decision, then it’s good she hears it, whether it changes her mind or not.

**INT: And you touched on the answer to this last question a bit earlier around what do you think should happen after a medication has been stopped? So, you mentioned about knowing what you would need to look out for. Is there anything else that you think should happen after a medication has stopped?**

C08: I guess, if, if stopping it might mean her blood pressure will go up, then I would say that she- regular. So, if there is a med-, I use that as an example, but if there is something that you could tell whether stopping it has had a detrimental effect then the measurement of that. So, I guess, really I’m saying some sort of follow-up with the people that made the decision, whether it’s just a conversation about how she’s been or whether it’s actually a check, a blood test or a monitor (pause). And, I think-, yeah, I think, that’s it.

**INT: So, in terms of making the decisions about stopping medications, follow-up conversations, how do they best take place? Telephone? Face-to-face?**

C08: Yeah (*laughter*) (*long pause*). I don’t mind a telephone conversation in the event of, you know, as (*partner’s mum*), as she is, in some ways it’s easier to see someone because you can just have a little chat about it whereas on the ‘phone, she’s never really-, you know, in her day, they didn’t ever do medical appointments over the ‘phone. I don’t mind it because, you know, some of it I don’t mind because you can get it done so much quicker and easier, can’t you? But it’s not her cup of tea really and, you know, when (*name of GP*) rings if we’re with (*partner’s mum*), I say: “oh, it’s (*name of GP*)” and, you know, I’ll ask-, sometimes she’ll have a little chat with her, or I might just ask (*partner’s mum*) and (*name of GP*) can hear the reply. So, for (*partner’s mum*), I think definitely face-to-face. For me, I don’t mind so much on the ‘phone. I think, (*partner*) would probably prefer face-to-face. So, it’s a bit of a varied answer.

**INT: And so, coming back to these photos and the process that you have for managing medications, if (*name of GP*) decided to stop a medication, how might that impact on what you do?**

C08: I don’t think it would really change it, we’d just probably have to wait ‘til the end of the four-week cycle and then the new boxes that come through would just not have it in. Sometimes I think (*pause*)-, I’m just trying to think when they increased the Sertraline and when they increased-, ‘cause the Memantine started off smaller as well. But they did just do that, we didn’t have to have a separate one. I’ve got a feeling with that one (*long pause*)-, it would be much easier for us if they could go into the boxes because if it, if anything changed-, no, you’re saying reduced it so, that would be fine.

**INT: So, it would just appear at the end of…**

C08: Yeah, because obviously, it just came out of the boxes because you can’t ask carers to take one of them out and not give it so, we would just wait to the-, and, to be honest, doesn’t-, as far as I’m aware, there’s nothing in there that they’re urgently going to want to take out. It’s, it’s just a matter of- and I’m assuming with Sertraline or Amitriptyline, they’d probably do it gradually. I wouldn’t-, I’m fairly sure they won’t just stop it. I hope they do it grad-, I would hope.

**INT: So, that’s all of my questions. Is there anything else you would like to add that we haven’t discussed?**

C08: (*long pause*) Because you were saying when-, I think, when you first brought the camera about the-, it hopefully would be something that you-, the outcome would be something that would help GPs, or whoever it might be (*long pause*). I don’t know what I was going to say now (*laughter*) (*long pause*). No, I don’t know what I was going to say. I had a train of thought and it’s just gone completely. Oh, yes, I know what it was. It was more around the annual review because we had definitely had an annual review with (*name of GP*), but I can’t-, I don’t feel like it really particularly covered the med- the meds, but I don’t know whether she-, the question she asked and the answers gave made her think: “right, we’ll leave (*name*) as she is on her meds”. So, she wouldn’t have direct-, might not have directly, and I might not have remembered that she did directly say: “how are you getting on with your medication?”.

**INT: So, do you feel an annual review of medication would be helpful?**

C08: I do really. I do really. I do. I’m thinking back to a few years ago, like when (*partner’s mum*) used to have her certain medications arrive, like there might be some that she wasn’t taking for now, but she wanted to keep them on the list because if she needed them, she could just order them. So, I do think there might be an element of that with people that they don’t want to get-, take something off because then it’s hard to get it put back on if they feel they need it (*pause*). And I can see that to a certain extent, but I haven’t had that experience. Like I say, since I’ve been directly involved with (*name of GP*) and the surgery have been very good, well, and the chemist, so, I’ve been able to get an appointment and get meds if we’ve needed them, you know, like water infect-, you know, not water infection, if her ankles are swollen. So, I do think it probably would be a good thing to have an annual review of them, for people-, I think, some people will want to keep them on their list because they are like a safety net for them. And I can understand that, but I also think it is better not to have lots of meds around and not lots that you can dip into if you think you can. So, yeah, I do think it probably would be a good thing.

**INT: Anything else you wish to add?**

C08: I don’t think so.

**INT: Thank you very much. I’ll turn the recorder off.**

**END OF INTERVIEW**

**Key to abbreviations**

**INT Interviewer**

C08 Respondent

***Audio* file: 57.40 minutes**