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

**Transcript**

**HP15 (OPMH)**

INT:  
Can you tell me about your involvement in medicine management for older people with dementia or mild cognitive impairment, please?

Participant  
Yes. And my involvement is in terms of sort of the actual prescribing. I'm not, I'm nurse prescriber, so I don't do the actual prescribing.

But I do. I am involved quite closely in terms of the discussions I had with patients. So once I've given diagnosis, it's about having that discussion about medications that are available to them and also about, you know, discussing the potential side effects and all the information that you obviously want the patient to have.

So I'd say that that's my main.

Role per southeast with MCI and dementia.

In that I have those discussions.

Ask the patient if they've got any questions. Obviously, as we go and then if not I then ask obviously then link in with the medical team to get the prescriptions written up for them.

INT:  
OK. Thank you.

Thank you. Do you do you also have any involvement with their where appropriate with their family or a formal caregivers as well near?

Participant  
Absolutely, yeah. So I'd say probably actually about 99% of my conversations actually tend to be with the carers or relatives that I are their first point of contact when I see them in initial assessment.

That's usually, you know, my go to who I go, who iPhone as a, as a contact for diagnosis. And then I have the discussion with them. And then from that it's dependent on whether I see them in clinic face to face or whether actually the family are quite happy to kind of have that discussion.

It really depends on that that relationship really with between the family and the members that and what they feel comfortable doing as well. So but I say the majority of it is actually less with the patient unless they're MCI and they're able to hold that conversation.

Majority of it I'd say is with carers or relatives, yeah.

INT:  
OK. Thank you.

Participant  
That's fine.

That's fine, no worries.

Just to let you know, I'd just be taking some notes during the interviews, so just bear with me if I'm I am listening. I'm just trying to multitask. So yeah, thank you very much. Yeah. So what are your views regarding deprescribing of inappropriate medication among people living with dementia or mild cognitive impairment? What do you think about it?

Participant  
So obviously I feel if the medications are not useful or if they're, if you're concerned about sort of side effects that aren't suitable, then I'm absolutely all for. You know, we shouldn't keep people on medications that are absolutely not necessary.

Especially older people because it's quite easy for older people to get sort of GP meds thrown at them and then not necessarily have that review. So they end up on 12:15 medications that actually quite a lot of them, they don't need. So I think it in terms of.

The memory medication. If it's something that is actually really not tolerated or you know they feel as though they're getting no benefit from it at all and they don't want to take it then.

I absolutely, I don't feel let's find that an issue, I think that's absolutely fine as long as you know the patient's in agreement if they can, if they have capacity or you know as long as the relatives or the carers who are the next to kin, what have you.

Are also in agreement. Then? Yeah. If they said to me, no, we're stopping this. We don't want it. Or can we stop it then? Absolutely. As long as there's no sort of reasons significant reasons not to keep them on it.

INT:  
And how much are you involved in those decisions about deprescribing? I know we discussed it a little bit at the beginning, but how much would you say you're involved in the discussions around it?

Participant  
Quite often. So the people on my caseload, obviously, I'm their first point of contact. So if I always say to them, you know, when we start the medication, that if there's any problems at all, you come direct to us, don't go to the GP.

And they will always obviously speak to me because I've been their point of contact throughout the process really. So I tend to have that initial conversation with them.

Depending on what they're reporting, it's you, you know, it can usually often be straightforward, and I can say absolutely, I agree. Stop the medication. We'll have a holiday.

You know, sometimes even medication holiday or let's just stop it completely. It's not working, it's not suiting you.

In you know if you trick your circumstances, I might say to them, oh, you've only been on a few days. Can we? Are you happy to? To keep going, just to see if the if it's a physical thing.

And then obviously there's ones that I say, you know, that are a bit more complex and I'll say, well, do you know what I'll, I'll, I'll run this past the consultant and then come back to you. So it's a bit of.

There's several different options really, depending on what the patient's relatives are reporting at the time.

INT:  
Thank you very according to yeah.

Participant  
Yes, I can't. Yeah, they're individual sort of situation. Really. Yeah.

INT:  
Yeah. Thank you.

And who else is involved in decisions about deprescribing? You mentioned the consultant there and your kind of relations and so tell me a little bit more about how those relations and discussions work.

Participant  
So if.

If I can, sometimes I'll take discussions regarding medications to our weekly sort of memory supervision. So that's held once a week and that will be discussed as an MDT team. So there's, you know there's myself and then there's usually a couple of registrar FY2 doctor and then the consultants. And as a team we can then sort of have a chat and see what every everyone's opinion is.

Alternatively, if it's not, you know if someone's phoning on a Wednesday and they've got a problem with medication, and I know it's not till the next Tuesday that I'm going to meet with the team.

Then I will. I'll e-mail one of the consultants and say that this is this is it will pop down and see them depending if they're around and say this is the situation. What? What would you what's your recommendation?

That's if I haven't already said to the patient. Actually, I'm in agreement. Stop the meds. You're not tolerating them. If it's clear cut and they're really not, they're really suffering with side effects. I wouldn't kind of make them carry on taking it and say, oh, well, give me a few days to talk to the consultant.

But I guess that's come with experience.

In terms of being feeling confident to do that.

INT:  
OK.

Participant  
Yeah.

INT:  
Thank you.

Participant  
OK.

INT:  
Thank you and.

And the advantages or disadvantages in terms of those?

Deep prescribing of inappropriate medications for those patients living with dementia, mild cognitive impairment, any maybe if we look at the advantages first.

Participant  
Umm.

To the advantages of so of deprescribing.

INT:  
Those patients, yeah.

Participant  
So again, I think it comes down to what they're reporting in terms of. For example, if they're having side effects. And I'm just thinking of someone recently actually that we gave them…They really didn't get on well with it at all. They got significant sickness and diarrhoea and for them they said they absolutely felt terrible. So you know the advantage in that situation is actually the side effects are very, very clear and.

The patient themselves said. You know, I'd I feel terrible. I felt a lot better without them. So in that instance, the advantages we take them away, actually we don't have to, we don't have to slowly take them away. ..I could literally just say that's fine, that's just not manageable. Let's stop it. You don't need to be put through that really.

So in that way that deprescribing in that situation is an advantage.

A disadvantage of deprescribing I think is more when you have maybe a behavioural element with like bpsd in dementia because obviously if you if you've got that some of those behaviours need to be kind of managed per SE. If they're really tricky. And I'm thinking about memantine here that you know, if you if you were to deposit a, that usually is enough to take the edge off someone's.

Certain behaviours, but if you're having to take that away because of, I don't know potential side effects or what have you, that then becomes very difficult for the, the carers or the family that are involved because you're taking away something that is actually.

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Participant  
Potentially gonna really help those behaviours and then obviously the alternative is maybe an antipsychotic which you don't really want to do unless you absolutely have to.

You know, last resort. So I think that's the negative in terms of or disadvantage of deprescribing because all if they don't tolerate it, then actually you're not going to keep them on it just because it's calming them down because the side effects potentially are just too significant.

INT:  
Thank you.

Thank you. And any challenges as well in in addition to the disadvantages, anything that that makes it difficult to actually deposit for those patients?

Participant  
Umm.

No, I think that goes back to what I was just saying really. I think the challenge is more unfortunately for the carers or the family or the relatives that are living in that situation.

But in terms of physically depressing them?

It's not really a challenge, you know, it's all run through me. So it's like we have that telephone discussion and I say well, actually, you know, this isn't, they're not tolerating it. So we're going to have to potentially look at an alternative. So for me, it's not, it's not a challenge.

It's more of a concern about how the family and the relatives are going to get on when the patients really sort of may be agitated and unsettled.

INT:  
Yeah.

After effects, but yeah, the impact of decision.

Participant  
Yeah. So the actual deprescribing for me is really actually the easy part and unfortunately that's the family or the relatives that are going to potentially suffer trying to manage their relative with dementia.

INT:  
Thank you.

And any thoughts about how those challenges, potential challenges be resolved at all?

Participant  
Umm.

So I think what we would do is if someone had, for example, been on memantine and they weren't tolerating it for any particular reason, we would give them what we call like a medication holiday.

Potentially up to a month without the medication to see. Actually, if those side effects they're reporting are from the mountain.

So at the end of that point, it's then about obviously open and honest discussion with the relatives or the family that are involved and saying, look, we can either retrial the memantine.

And see how it goes.

And we can do it slower. So we you know, although we've got titration pack, if I was quite concerned I'll speak to the consultant and say actually can we rather than 5101520 over the course of the month can we take this really slow, can we give a month of fives and just really see how they get on.

If that's not an option, then obviously dependent on the behaviours. If they're really significant and impacting on family and the patient, then that's kind of moving on a discussion away from the dementia drugs really onto anxiolytics or antipsychotics really.

Participant  
So I think that's a challenge. If you have to go from a dementia drug to an to like an antipsychotic, I think that's it's quite significant difference.

And again, it's down to that open and honest conversation with the family because the side effects from them are can be quite unpleasant.

Time.

INT:  
Thank you and.

What types of medications would you feel most comfortable depressing for people living with dementia or mild cognitive impairment, and why?

Participant  
Umm.

So I'd feel quite happy depressing antipsychotics. So obviously if they're on those, they're on them for a reason. Whether it'd be, you know, mainly probably a behavioural reason or they're getting, maybe hallucinations is part of their dementia.

But obviously the risks and the potential side effects from those antipsychotics, especially in older people, is significant. So I'd be sort of I'd, I wouldn't feel particularly.

Upset if I had to take someone off an antipsychotic, for example.

If obviously, if the clinical picture indicated that actually it wasn't doing them any good, I'd you know I wouldn't. It wouldn't upset me if I was taking them off an antipsychotic, for example.

INT:  
Thank you.

And what would encourage you to support reducing or stopping a medication?

Participant  
What would encourage me to what, sorry.

INT:  
Yeah, to stop or reduce the medication, is there anything that would help you in that decision making about stopping or reducing a medication?

Participant  
So yeah, I mean it. It's obviously down to if someone's getting significant side effects that would support in stopping that medication. I think if they're getting increasing.

I can't think of the terminology right now. I'm having a blank, but when medications do the opposite to what they're meant to be doing, what's that word?

Oh.

INT:  
Not con. Not Contra. No, no different.

Participant  
No, it's. It's like an opposite effect. I can't think of the word. I'm a brain moment. So for example, if I'm giving a cognitive enhancer to someone that's meant to be giving them a bit of clarity and hopefully making them feel a little bit less muddled and less confused. But actually when we start that medication, they're significantly more confused and more muddled and just not getting on with it at all. Then obviously, that would be a reason that would be quite happy to, to stop that medication as well.

There's a terminology for it and I've gone completely blank.

It'll come back to me.

INT:  
We'll come back to you after the interview for sure.

Participant  
Yeah, well, I don't need it.

So obviously, yeah, I think the main ones for me, I'd be more than happy to support someone coming off the meds if it if the significant the side effects were significant.

If they were getting the opposite effect to how they should be, and potentially also if we had someone at end of life, it's about weighing up those benefits of, you know, if they're potentially palliative care stage.

You know what? What good is our medication doing at that point? Possibly. Absolutely nothing. So is that a point to consider, then actually taking it away so that they're having less in their system that they don't necessarily need or not benefiting from?

INT:  
And on the other hand, what medications would you be reluctant to depress scribe and why?

Participant  
What is this in terms of just dementia or yeah?

INT:  
Yes, sorry for those patients with dementia and mild cognitive impairment, which ones would be more reluctant?

Participant  
Do you know what? I don't think I'll be reluctant to deprescribe any of them, because again, it comes back down to the patients, how they're presenting so.

You know, if they're significantly impacted by this medication in a negative way, I wouldn't feel bad about taking it away.

Because the whole point in that medication is to try and make things easier and help them, and it's not no help to them at all if I'm giving them something that's making them feel worse or making them not be able to leave the house because they can't leave the toilet or.

Making them withdrawing to themselves or, you know, just any of those types of things.

I wouldn't feel particularly upset taking it away unless the family were saying, oh, oh, we, you know, we have had a really good effect from it, but the side effects are just not manageable. I might feel a bit sort of like, I know it's really unfortunate, but actually it's weighing up. Do you want your family member to be a little bit cognitively clearer, but then they can't physically leave the house because they've got an upset stomach?

Do you know again, it's having that open discussion with family about the risks versus the benefits, the medication.

INT:  
Thank you.

And what would be the reasons for you to not support reducing or stopping a medication for patients within that group?

With dementia or Mal cognitive impairment.

Participant  
So the reasons for not just deprescribing.

INT:  
Yes.

Participant  
I think if someone is.

Reasons for not depressing. I think the mate that would come down maybe to behaviour again I think if.

The.

If the medication is kind of like if it's very evident that actually it's helping with maybe BPSD symptoms or things like that.

Then I think that's a reason potentially in itself, not to describe depressive them unless there's obviously a physical significant physical impact of that medication staying in place like you, e.g. Fr Has gone really poor or you know, your bloods are showing up, that there's a concern or ECG and pulse rate have gone completely skew if.

I think.

I don't really. I think unless there is a significant reason for deprescribing you, you wouldn't necessarily need to.

Even though you're not necessarily, and I often say to people patients that you know, we can start you on this medication. And I I'm very open and honest with them and say I get a handful of patients, it will start on it in fields. Some noticeable difference. I get people that will start on it and don't notice any difference at all and that's not uncommon. Doesn't mean it's not working or doing something. And I get a handful of people that will start on them and not notice any difference but family will.

So.

And if we were to stop everyone's medications, that didn't feel a difference. A lot of people wouldn't stay on it. To be fair, because often they don't notice the difference or feel the difference. But actually sometimes the family members pick up that actually they do seem a little bit clearer, or they seem a little bit more sort of less muddled, a little bit more with it. But the patient themselves don't necessarily recognise that. So I think there's many reasons for not depressing. But on the other hand, there is. There's also many reasons why you would deprescribe.

INT:  
Thank you.

Participant  
So it sound vague, but it's all really for me. It's all very patient dependent and on what they're reporting at the time as well.

INT:  
Thank you.

Thank you. And we'll see you much about the role of the family and their observations of.

Yeah.

Participant  
Yeah, yeah. And that's quite I find probably the majority, like I said earlier, the majority of my contact tends to be more sober family who came to the initial assessment.

Maybe then with the patient themselves, unless they're very early stages, for example, or MCI, and they're able to have that discussion and take on what you're saying. Otherwise a lot of the time it's done through next to kin, make it as long as they power of attorney and things and decisions are sometimes made.

In that way.

INT:  
OK. Thank you.

And what are the main things that you think need to be in place for successful depositing for someone with dementia? Mal cognitive impairment sort of. The main things that need to be in place for successful deprescribing for patients with dementia, mild cognitive impairment.

Participant  
So I think you need to have a very clear and open communication with the patient if they're able to do that or with the family members.

Kind of manage their expectations, I guess in terms of what may happen or what may not happen.

Obviously, if you're deprescribing something, you need to make sure that you're doing it safely so you know you wouldn't necessarily you. Potentially you would need to decrease the level of medication that you're giving.

Over a period of time, rather than just saying, just stop this completely right now, so it's about rather than titration, you're doing the opposite and taking it down slower.

Obviously, running as a nurse, I wouldn't make those decisions necessarily myself. It would be so for me that'd be about running it past the medical team and the consultants who ultimately are the are the ones that are prescribing it. So although I'm doing all the discussions and the conversations around it, it's not my name on the script at the end of the day. So they potentially they would need to be involved in sort of the successful deprescribing of it. So they need to be known, need to be aware.

INT:  
And how much you involved in or do support decision making around deprescribing that takes place in primary care so.

Participant  
So in primary care, well as in GP.

INT:  
Yeah, or your interactions with primary care.

Participant  
I we don't really have any. Well, I say none, I say very minimal. So obviously whilst you're going through the memory assessment service, it's very specific. You're coming through us for memory assessment, then we're scanning you, then medicating you. Potentially if someone's out in the community under their GP and they're being prescribed these medications, it's then down to the GP.

Very rarely, occasionally we may get a sort of referral from AGP asking for advice and guidance on medication related to dementia drugs.

But I would say very barely, not often at all. So our actual contribution to.

That in terms of primary care, say GP services or primary care nurses is very minimal.

INT:  
OK. Thank you.

And how do you feel about engaging patients with dementia, mild cognitive impairment and shared decision making as part of the deprescribing process?

Participant  
Yeah, I feel that's absolutely fine. I think they should be absolutely well informed.

You know, again it comes down to capacity. So if you got someone who is not capacitors, then it's about having that that discussion with the next occur and the relatives that are involved and have taken that decision that actually they don't want the medication anymore. So

But yeah, in terms of having that conversation, I think as long as you're open and honest, it's.

It's fine and a lot of relatives or early stage patients.

Have already kind of made that decision themselves. You know, if they if they feel the meds aren't working or they're not being tolerated.

Often they will say well, actually, can we stop these? It's just not working for us. And then it's about how obviously having that discussion that if we stop them then you know some of the cognition may deteriorate slightly or if we have to restart them again in the future.

If things deteriorate in between, you're not going to get back to where you are now. Potentially you're going to have to start from where they are at that point. So again, it's for me, it's about making all of those things very clear so that they're fully informed.

And they can make a valid decision.

INT:  
Thank you.

And any thoughts around what would help?

Their involvement, patients with dementia, mild cognitive impairment in shared decision making, so anything that particularly help involve them in that shared decision making any observations or reflections.

Participant  
I think if your early stage is dementia or MCI.

Think you're able if you're able to capacities, you know, to have that conversation, you've got capacity.

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Participant  
Then that's helpful because they feel they feel empowered. They feel able to make those decisions for themselves.

Like I said, quite a large proportion of mine is done by the relatives and the carers or what have you, because actually the patient, although they may say yes, I'll have the medication, they don't necessarily fully understand what they are saying. You know what for all because some of them have insights, some don't.

Some of them have fluctuating insights so you can see them one minute and they'll go. Yes. I'll take this meds. I know my mum is poor. And then the next minute they that's gone.

In terms of that stage, what would help involve them?

I think even though potentially you might find that they won't recall the conversation you've had, I think it's still important to have the conversation about the medication with them, because often you get on the phone with some family same. Oh well I you can tell them they've got dementia, but they're not going to remember that. I'm like yes, but it's still their diagnosis.

So I think it's still important to have that discussion whether they're going to remember it or not. I'm not sure really what.

What would help to involve them or not?

I can't really think of anything.

INT:  
Yeah. Thank you. And any thoughts around any communication or?

Like tools or information that that may help.

Participant  
So in terms of communication, obviously the main our main communication is verbal. So having those open discussions with people, the other things I tend to do in terms of medication. So when I'm looking to actually prescribe the medications, they get sent out information leaflets about what they are and the potential side effects. So again, they're fully informed before they turn around and say, yes, I want to start this medication.

If someone struggles to with verbal communication, whether it be because of their dementia or hearing or what have you.

Then I'm more than happy to usually send information in other ways so I can pop information on an e-mail or like I said, the information sheet.

If they're able to read.

This that's really the only ways we do it. If there's someone who's.

I suppose if they got hearing deficits, then hopefully they can read.

I think if you got dual hearing and eye problems, I think that's quite tricky and I don't think that's something I've really, really had to come across to be fair.

It would be about at that point I think I'd be liaising with the family and saying, well, how do you communicate with your family member and then look to adapt? Maybe doing it how they do it, because there's obviously some communication that can get through.

It's asking about what suits that individual and doing it in their in that way.

INT:  
Thank you.

And what are the barriers to people with patients with dementia, more cognitive impairment in involvement in shared decision making? So what, what, what are the barriers to involving them in shared decision making?

Participant  
So I think we've already just touched on that really in terms of sensory deficits that they may have. So whether that be a visual deficit or hearing or both.

So I think that's definitely a barrier at times in terms of discussions that you have with the actual patient themselves.

Participant  
I often liaise. Like I said, I liaise with family but.

Some family will say actually I'm not happy to kind of have these discussions with my relatives. So at that point, then I bring them in face to face and I will have the diagnosis, discussion and the medication discussions. So again, I think it's all very much about.

The inflexible in terms of what your patient needs, not just having one set way of working.

INT:  
Some flexibility, yeah.

Participant  
Yeah, flexibility in terms of, you know, again, it comes down to, I guess doesn't it that, that holistic view of your patient, you know, not assuming that they call it all, hear you or they can all read or you know trying to adapt.

Adapt how you give and take information due to those certain barriers, and obviously there's also that potential of that language barrier in terms of if they're dysphasic or they're having comprehension difficulties, but also in terms of if they are not, say, don't speak English. So it's about trying to adapt.

Get through that so you know the barrier in itself can sometimes be a language barrier cause they don't speak English, but then on top of that, you've got the barrier that actually they've got dementia. So they're not one they can't really understand you at the best of times. And then this disease process as well as making that understanding a lot more tricky. So then it's about trying to, you know, if you have to get an interpreter or actually trying to work a way around that with the family and saying, well, how can you know, can I talk through you? Can you bring them into clinic? Can I talk to you and you give them the information in your in your language.

So yeah, I say physical barriers and actual.

Ethnicity sometimes can be not ethnicity.

That's about their nationality. Sorry can still be difficult.

INT:  
Sure. Thank you.

And.

What language should be used in communicating information about medications with people with dementia or mild cognitive impairment and their formal caregivers?

Participant  
Umm.

INT:  
So what language?

Participant  
What language? So I.

I think sometimes you again I keep saying this, but it's all very down to who you're talking to. I think so. You know, I've had careers come in that have been family, so that have been carers in care homes. So they're very much like, I know what meds you're offering. I know what they are so.

The terminology in that that I use with them may be slightly different to someone who doesn't know anything about dementia at all, so it's really about again, knowing your patient or the family.

But obviously trying not to throw in too much, too much medical terminology really because that because that just confuses people more. Really. So we're trying to make keep it quite plain and simple and just.

Informative, but without throwing in. You know I don't sit there and go into detail about.

Backs and tangles. And you know all of that, unless they specifically ask and they want to know certain things, you know, and obviously about the different proteins. And that might be contributing to things because they don't necessarily want to know that or would understand that. But I give it in a in a way that.

That's suitable for them. So if they ask absolutely, I'm more than happy to have that in more in depth conversation with them.

But if it's very clear that actually their cognitive impairment or dementia is quite not going to be able to understand that, then I would change the way I communicate with them in terms of my language and the words I use.

INT:  
Thank you.

Participant  
Hmm.

INT:  
And just reflecting back again with primary care colleagues, what would assist engagement with primary care colleagues to support shared decision making? Have you had any observations or thoughts in the past?

Participant  
So what was the system in?

Shared decisions.

INT:  
Just. Yeah. Can we talk to? Yeah. Engagement. Yeah. With yourselves to support shared decision making.

Participant  
I don't know because ultimately as a standalone service, so you have the memory assessment service in a way so that those decisions don't have to be made by primary care. That's the whole purpose of it. So that they don't have to do the assessments and then obviously have those discussions about diagnosis and medications. So really those.

That shared decision is then taken away from them because they've come through to like, you know, a specialist service for their memory assessment.

And in all honesty, I don't think they necessarily need to be involved in a shared decision unless I had, for example, a patient that was significantly had significant physical ailments.

That, you know, may be contraindicating to the medication then obviously that's when we would go back to the GP and say we'd like to prescribe this, but actually, can you check ECG? Can you check this? That and the other before we prescribe.

But otherwise, in all honesty, I sounds awful. I try not to get the GP involved because they.

They actually sometimes have a habit of interfering when you're giving the medication and then it kind of gets very confusing. So it's like if I just keep them out that they get told by a letter, you know, they get told where we're at. They've got diagnosis. We're going to look at medications we've started such and such, but actually.

Participant  
I often say there's no action for you at this time. At the bottom of the letters because I don't want them to do anything. I don't want them to interfere because then it can get really confusing. There's too many people trying to action things and then I don't know where we're at.

INT:  
OK. Thank you and thank you. That's helpful. And how do you feel about engaging in formal caregivers of patients with dementia, mild cognitive impairment and shared decision making as part of the deprescribing process, so the informal caregivers, the.

Participant  
Informal, but so like family and things.

INT:  
Yes, a family. Yeah. A family members, yeah.

Participant  
Sorry again, I think it comes down to knowing the family and the patients. So from that initial assessment, which is you know is usually a good hour and a half. So you kind of get the gist of.

What's going on in terms of family dynamics sometimes?

And it's. Yeah, I don't think my discussions with informal family members are really any much different really to that of, like a care agencies or practise nurses or things like that, because I'm still giving them the same information. I'm still giving them the opportunity to ask questions.

Maybe a little bit less term medical terminology if it's, if it's a family member. But again, like I said, if they ask you know well, what is dementia, how do you get it and what have you then I will give them some information regarding that.

And everyone that goes through diagnosis here, they always get sent out. A dementia guide book anyway. So in terms of what dementia is and how that might.

How you know how that might present?

So I don't. I don't think my engagement with informal family members or have you is really any different to anyone else. Really. Yeah.

INT:  
OK. Thank you. And any thoughts around again things that have helped involving family members and shared decision making?

Participant  
Just information to be fair.

Like I said, so on diagnosis, they're sent out a dementia guide so they can. And I say to people again, I say some people want to know the insurance and outs of everything. Some people don't want to know anything at all. And that's absolutely fine. But this is the dementia guide. You can read it if you want to, otherwise deal with it as you will. And again. So it's about making sure they're fully informed and have all the information at hand to make an informed decision.

INT:  
Thank you. And on the other hand, any barriers to their involvement in shared decision making?

Participant  
Yeah, sometimes accessibility. Sometimes the carers aren't particularly.

Very good at answering phone calls or coming back to messages or responding to emails.

There might be a family member that came with them to initial assessment and they said that their first point of contact, but then you find out they actually live abroad. So the contact with them is really hard to get hold of. So they are then trying to find an alternative point of contact that the first one would be happy for you to liaise with.

What was the question? Sorry, what was?

OK.

INT:  
Yeah, it was. It was about the barriers to involving informal caregivers, family members of patients with dementia. So

Participant  
I say mainly that's probably the main barrier to be fair in terms of sometimes just being able to get hold of them is can be really tricky. You know, some of them work still. Some of them don't.

And then, sometimes quite often, you're playing telephone tennis because you leave a message, then they phone you, then you're in clinic and such. And this could go on for sometimes a couple of days, depending on what days you work. So I'd say that's probably one of the main barriers.

I suppose other barriers could be that actually.

You do get some.

Family or carers that come in that don't necessarily, there's never been a particularly good relationship, but they're still doing that role. And then obviously you're trying to give them as much information as you can to be informed, but actually they just don't really want it. They don't. They're kind of, it's almost like they don't really care, they they're going through the process because they know that that's how they feel they should do it.

So then, it's obviously about sometimes there's difficulties there. cause you're trying to give them information and they're like, OK, yeah.

Yeah. OK. And then not really forthcoming and giving you information.

So that can be a barrier sometimes, but I'd say that's infrequent. It's not like obviously a regular thing.

INT:  
Hi, thank you.

And what tools or resources are needed to facilitate shared decision making in relation to deeper scribing for patients living with dementia, mild cognitive impairment?

Participant  
Tools or resources for deep scribing?

INT:  
And the shared decision making could be in terms of healthcare colleagues firstly. So any things that would help?

And if, if and when those circumstances come up.

Participant  
I suppose in terms of shared discussion decisions about E prescribing if.

So I'm just trying to think of someone I've had recently that has had we started on, on medication and then the blood pressure went.

Quite high, but then we we've had to access all her past kind of blood pressure readings. See if actually, that's quite normal first. So we have had to do quite a lot of linking in with the primary care GP and saying.

There's concerns about the blood pressure, but actually can you manage this in primary care? We don't want to stop the medication because actually the family are reporting that it's had a really good effect in terms of distress.

So in that case, we obviously want to keep that in place because it's helping her in terms of day-to-day. But on the other side of things, the BP is just going sort of up and down.

So that the shared decisions there in terms of we've been liaising with the GP and saying, well actually we're not stopping the meds. So can you manage the BP and if you can't then you're going to have to let us know because actually we may then have to take the medication away. But we don't really want to do that. So if you can manage the fluctuations and make sure there's no.

Problems in terms of what the BP levels are.

But in terms of tools and resources, I don't.

I don't know. We don't tend to use tools or resources for deprescribing. Again it comes down to.

That kind of that communication with patient and the relatives and the same is shared decision. So it's.

The only tool we use, I guess is our documentation to say that we've had that verbal discussion.

Or potentially you back it up with the letter to say you've had the discussion and the decisions been this and then that obviously you make it clear that it's been a shared decision between primary care and us or between the family and us or but as tools, medical.

Healthcare tools.

I don't know. We don't tend to.

INT:  
Yeah. OK.

Participant  
Use any. I don't think I can think of.

INT:  
Yeah, is it is, is there anything that you think might be useful that you've observed in other?

Areas that could have crossover or.

Participant  
Well, deep, deep swinging and shared decision.

INT:  
Yeah, resort resources or tools, yeah.

With healthcare colleagues.

Participant  
No, I haven't. No, I haven't. I'm not aware of any others.

No.

INT:  
Right. And in terms of patients in formal caregivers again the same question, are there any tools or resources which would be needed or could help that shared decision making?

Participant  
Umm.

Tools help share decision.

No, I don't think there is because a lot of the time it's done verbally. So between families, obviously they would communicate with one another.

Again, all the art teams work quite differently, so if you were to have this conversation with the nurse prescriber over on the West, she potentially they may have tools that they use. But because the tool the teams are so kind of different in in how they work, they might ultimately reach the same goal at the end. But the process of getting there is not necessarily the same.

There's no tools that I would give to a family member, for example, to then discuss that other than you know, I'll send out a dementia guide to my first initial point of contact, along with medication information, and then if they say, oh, I need to discuss it for my brother. But he lives in Timbuktu and I'll they, I might say, well, actually, do you want me to just send his own copy to him so that he's also got the information and you can then sit down as family have this discussion and then come back to me.  
Once you decide what you want to do  
But other than that.  
There's no sort of sort of sets.

Thing that I would necessarily send out or use.

INT:  
Yeah. Thank you. And how best would patients living with dementia, mild cognitive impairment and their formal caregivers being be supported during the prescribing process?

Participant  
So sometimes I think a little bit more contact from us in terms of checking in and seeing how they're doing whilst the medications are being reduced. So I think sometimes carers and patients find that quite useful.

Because it gives them an opportunity to tell me if there's any concerns or you know, or things have actually improved or not.

So I think maybe more contact if that's what's kind of deemed necessary at that point in time. I think it's quite useful.

INT:  
OK. Thank you. And in terms of following up patients with patients with living with dementia or mild cognitive impairment, who should be following up patients do you think?

Participant  
So is that whilst they're under our team?

OK.

INT:  
It's just a general question, but I guess how you want to interpret it. If you want to. Yeah, consider within your team.

Participant  
So within our team we work that you've got your caseload that's kind of your responsibility. So you know if someone needed following up, that would be me that would be following them up. And if I wasn't sure or if I needed some advice and obviously I'll speak to the medics.

If they're in the community in terms of not under us and under primary care.

Then.

That should be follow up should be done through primary care in terms of the GP.

Whether that be like a, you know, an annual review or more than that.

And also, we're quite lucky here that we've got quite good. Admiral nurse team. So actually they will more often than not will refer to them at point of diagnosis and then they'll be, they'll get involved. So actually when you're at the point of diagnosis, you know that actually there's already someone there kind of ready to take your spot.

So that when they can't really phone you and say I'm struggling a bit or I've got a question, you know that the Admiral nurse is going to step in at that point because they can contact them.

INT:  
Thank you. And it would be the GP within primary care, is that right or was anyone else do you think?

Participant  
Yeah, if they weren't under us, I well, actually, I suppose it could be the they now have primary care and mental health nurses. So again, in terms of their roles, I don't know if that would be part of their role or whether it would still be under the GP.

INT:  
OK. Thank you. And how often should patients medication be reviewed those specific patients with dementia, more cognitive impairment?

Participant  
Are we talking dementia drugs or just drugs generally?

INT:  
I think, yeah, just drugs generally. But for those patients with dementia or mild cognitive impairment.

Participant  
I don't think it should be any different to how most people really should have reviews, but unfortunately we know that that doesn't happen.

Necessarily, because primary Care's not able to manage that. Particularly you know they've got their own, they've got more stuff that needs to be done.

I don't think A6 monthly review would hurt in any case, and obviously for those people that are needing a little bit more support or if they're having any problems and obviously those reviews need to be brought forward or managed accordingly to how they're presenting at the time.

So I think it again, it's very patient specific.

INT:  
OK, thank you. And just finally, can you identify any training or educational needs for you or your colleagues to enable you to safely stop unnecessary medications for someone with dementia or mild cognitive impairment?

Participant  
I think not, not at the moment, as the team that we have 'cause, obviously the team that I work with at the moment are quite well established. So they're all you know, none of them are sort of quite newly qualified nurses or anything like that. So they've all been in the role managing dementia patients for a very long time.

And more often than not, if they've got a query, they might ask me and then I can advise. But if I don't know then I'm I just say, speak to a medic because I don't know.

Other than that, in terms of training needs, a lot of the.

Actual CPNs that I work with, they're not overly.

Involved in deprescribing.

Dementia drugs, because usually by that point they've even been through us and they're discharged or they may have been through us and then they've been passed on to a CPN, for example, because they have a mood element. But by that point that you're transferring them on, they've either come off the meds because they haven't tolerated them at all or they're very stable at that point. And you're like, we're happy with them on the donepezil now you need to look at the mood or you now need to look at whatever.

The other problems are so they don't necessarily. I don't think they really come across that much.

So yeah, they'd either ask me, and if I don't know, I'd be like, speak to a medic in terms of the training needs.

I think no at the moment, but if we had a team full of newly qualified nurses, I think yeah, there'd always be a training need in terms of what dementia, you know, just even the basics of what dementia is, what you can expect from that, what medications are available, what side effects you may not get, what the contraindications are, what physical elements you need to be looking out for prior to prescribing.

Like I said, my team's very like, they're very well established and been qualified a long time. So a lot of them kind of know that already.

So when that changes when people retire or nurses leave, I think that, yeah. Then that's the time that we're going to need to look at identifying those like those training needs really.

INT:  
Thank you. Sorry, just to check you said mentioned CP ends, is that right? Yeah.

Participant  
CPN yeah. So Community psychiatric nurse, yeah.

INT:  
Thank you I thought that probably was the case, but I didn't want to make the wrong assumption there, so thank you, that's great and.

Yeah. Is there anything else that you think's important to say when you've been taking part in the interview that you haven't had the opportunity to, which I think might help with the research topic?

Participant  
Not that I can think of. I'm sorry if I haven't answered any questions in the right way.

INT:  
Oh, no, no. They speak extremely helpful. Yeah. No. Yeah.

Participant  
I can't. No, I can't think of anything at the moment, no.

OK, OK.

INT:  
OK. Well, we've come to the end of the interview now, so I'll just stop the transcription. It's rolling on. Just bear with me.