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

**Transcript**

**HP05**

INT:   
And can you just tell me about the care you provide to people with dementia or mild cognitive impairment, please?

HP05:  
Yes, I guess obviously I come at it from a medicines point of view being a pharmacist. I work with patients with dementia or with the carers to try, and I would use the harm associated with medicines in this group of people as there sort of particularly at risk of, umm, inappropriate medicines use which can cause harm and they might struggle to identify where things are causing side effects and harm. So I guess that's where I the angle I come at it from, but if that answers the question.

INT:   
Thank you. And how much of your workload is the kind of care you provide to people with dementia or mild cognitive impairment?

HP05:  
Tricky to say? relative impairment probably more at the moment. I work in chronic pain and we have a lot of older people. It's difficult to put a number on it, to be honest. Umm, I'd say probably somewhere in the region of five to 10% have mild cognitive impairment and probably a little bit less have dementia. Umm, but historically I've worked with a lot of dementia. I've worked with lots of people with dementia and care homes and things probably more like 50% of my patients had dementia going back a year ago. But the moment maybe a little bit less, let's say, maybe 10% of people fall within that bracket.

INT:   
Thank you. And what involvement do you have in their medication management?

HP05:  
Umm, I guess … adjust medicines and might stop medicines?

Possibly liaising with their GP, depending on what they are in terms of the practical medicines management aspect, as in ordering and things I may not have masses of involvement.

I may try and support where there's problems with liaising with pharmacies.

HP05:  
Umm, but in terms of the true medicines management aspect in terms of the simple stuff, the ordering of medicines and quantities and things like that, I don't to all that much. I do more of the clinical medicines optimization aspect.

INT:   
And what are your views regarding deprescribing of inappropriate medication among people living with dementia or mild cognitive impairment?

HP05:  
Though I think this is something we don't do enough. Umm, it's something that I think pretty much all healthcare professionals, regardless of sort of prescriber status, should be thinking about and looking at when we see patients with dementia or impairment. I think maybe there's a lack of knowledge among all professions, you know, all health care professions around the risks with certain medicines, the risk of harm and probably the lack of evidence and the lack of benefit in people who maybe quite frail and have cognitive impairment, and also the sort of additional risks that's come. So medicines where patients with cognitive impairment might not be able to tell or inform someone if they're having a problem aside effect. So I think it's something we should all do at every opportunity we have rather than it being a reactive approach, which is what we do at the moment, it should. So it should be more proactive rather than reactive.

We're doing it to kind of at the moment we talk about reducing harm with medicines and people with dementia and doing searches on our clinical systems, identifying people on anticholinergic medicines and things like that and being reactive because they have to. And sure, I'm not trying to claw back some quality of life for them, but actually we should be far more proactive.

And I guess that's what we're working towards in that we should be thinking 10 years before they diagnosed with dementia, picking up the risk factors taking people off their anticholinergics or not putting them on it in the 1st place. And identifying the people who are at the greatest risk and trying to take action earlier. But I guess we're a long way off that.

INT:   
Right.

INT:   
And any other kind of advantages or disadvantages or deprescribing that that you kind of observed?

HP05:  
May I guess I don't see the disadvantages in a way. I guess the advantages of deprescribing are that when you do it well, the patient and all their carer generally tend to be more well informed about their medicines, whether they're medicines that you're continuing or not. Umm, they tend to get and on medicines which are working for them and not on medicines which are not working for them all causing them harm. The antibiotic is we reduce harm associated with medicines. We reduce risk of hospitalization, we reduce risk of death, we potentially improve quality of life.

The disadvantages? I guess it's time consuming of doing it. It's not a one. It's often not a one stop, you know, one intervention and you walk away and you're done. It's time consuming for those who do it. It requires follow up.

INT:   
Mm-hmm.

HP05:  
It requires sort of some understanding from the patient or the career so often it can be that you need to kind of provide information in order for them to understand why you're stopping it in a way and justify yourself it might go in contravention to, you know, a neurologist who prescribed certain medicine 10 years ago and you're not telling them. I don't think it's appropriate and that can be tricky.

INT:   
Umm.

HP05:  
Sometimes can be a barrier more than a disadvantageous pose. Yeah.

INT:   
But thank you that those kind of barrier you mentioned in terms of maybe another professional prescribing and then you're deprescribing to be witnessed anything in primary care mentioned about secondary primary care or is it yeah?

HP05:  
Yeah, yeah, yeah. I mean, you know, ten years ago GPs would put everyone on asphalt, maybe not 10 years ago, maybe like 15 years ago, the GPs would put a lot of people on aspirin as primary prevention for cardiovascular disease and their GP might have said to them, right, you're gonna be on this for life. And then ten years down the line and telling them no, it's not appropriate. You've never had a heart attack. Never had a stroke. There's no indication you're high bleeding risk. There's no good reason to give you this, and that's exactly in contravention to what their GP said a long time ago. And so I do sometimes spend time explaining about, you know, research changes, what we understand about these conditions changes. What we understand about the risks of medicines change. So yeah, that we come across those kind of things that quite often and even just simple things like statins where it was appropriate five years ago or 10 years ago. And when you're 90 and you have to dementia, it becomes less relevant and less important.   
So yeah, very often we start stopping medicines that were used as chronic disease management or primary prevention and for other conditions and those things kind of fall by the wayside and their priority is quality of life. So very, in fact, it probably almost all. Umm deprescribing sort of opportunities. There will be something that's been initiated in primary care.

INT:   
And then then also the you mentioned the awareness of those particular drugs as well.  
  
INT:   
And what types of medication would you feel most comfortable deprescribing for people living with dementia or mild cognitive impairment and why?

HP05:  
Umm to tricky question, think everyone's bit different, aren't they? What do I need prescribe sort of most of, I think diabetes drugs. I'm quite like comfortable and confident with deprescribing, where it's appropriate. Umm, statin sort of things for prevention, where they're probably isn't great evidence for use things where you know, like statins you're talking about, you know, reducing their ten year cardiovascular risk when someone has dementia. They don't generally don't have 10 years, says judging based on the severity of their dementia. I guess whether it's appropriate to stop in conjunction with discussing with them what other things do I stop a lot of blood pressure? Things I cut back on to call in Energix I'm quite happy to cut back on umm to things that insulin. I'm very keen to get people off if they're Type 2's, talked about diabetes…Umm things that might be Umm, you know less of a problem now. You know things like you know often. See drugs for like restless legs and stuff like that, and stuff people suffered with ten years ago and taking people off of these. Kind of quinine and stuff like that, where the evidence for use is very, umm low level and not sort of long term. And often these conditions kind of become less noticeable as they get older, or particularly as they have cognitive impairment.

HP05:  
The restless legs becomes less of an issue.

HP05:  
This other issues crop up.

HP05:  
Yeah, I think that's probably more, but that's all I can think of.

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

HP05:  
I think the ones that I always found a bit tricky are anticoagulants for stroke prevention AF. Umm, it's a bit grey. I think a lot of the other stuff, but I feel like you it's a tricky one in that there's no sort of hard boundary where you cross and say the risks that weigh the benefits, you have some of the scoring systems, but it's not. And I want to go out ways the other and so it's a judgment call after having a discussion. With the patient or friends or family or carers or whoever it is I'm so often I try and almost leave the judgment down to the family, discuss the risks and benefits of stopping versus not stopping, but that's always a tricky one. I always feel like should I be discussing this with the GP before stopping it and I probably generally do. Umm. What else? Umm, I guess some of the specialist stuff like Parkinson's medicines, where I see that maybe they're having adverse effect, they're hallucinating with them because of the specialist nature of them. I'm often even if I know it's probably the right thing to do. I'm reluctant to actually make the change myself. I might go and have a speak to a specialist nurse or whoever's involved before making the change. You know anything where the specialist involvement really like epilepsy and stuff like that. I probably wouldn't meddle. Umm, I think I'm probably quite happy to meddle with most other things.

INT:   
And what are the main things that you think need to be in place for successful deprescribing for someone with dementia or mild cognitive impairment?

HP05:  
So you need to have someone with you if the if the cognitive impairment is to a degree where you're the patients are not gonna be able to give very good history, they're not gonna be able to report side effects or adverse effects or, you know, problems they might be having like dizziness or falls or that kind of thing, you.

HP05:  
Need someone who knows them well, who can give you that information and also you might be able to help make that decision with them. What else do we need? Time. You can't do this in 10 minutes. You need time. You need space to do that, and you need more than one opportunity. It's not a single intervention. You need time to follow things up in support from others to do this, because sometimes it can be seen as sort of making work for yourself. You do prescribe you have to follow them up, make sure you have adverse effects and stopping. And it's almost like you're generating work for yourself. And yes, you are, but in the long run it's saving yourself, saving the NHS time and money and the patient, you know, improving their life. On your side to doing this work into appreciating the benefit and to supporting you when you have questions and not sure about what to do. Umm, what else would you need? So there's lots more things. May I think we need, you know it's, you know, you're coming out from the research angle and having more research of the understanding of the best way of doing this. We're doing this off sort of instinct in some ways. Obviously we're promoting shared decision making, but understanding how we do this to give the patient the best outcomes, wouldn't it? We know is helpful and I guess we're learning lots. You know, the last few years we've learned a lot more best way to go about. This. Yeah, we need access to the secondary care. You know? Kind of not on call, but easy access to your expressions.

For further information for further advice, what we're not sure what to do and that's not always easy and I know parts of the country where there is good access to geriatrician, sort of, you know, quick response as it were. As shown to improve outcomes? Umm, that's what I can think of I think.

INT:   
Thank you very much and please describe your experience of having deprescribing discussions with people living with dementia or mild cognitive impairment or their informal caregivers such as family members.

HP05:  
So sometimes it can be difficult to get a proper history of. More often than not, if I'm not in a care home and you've gotta patient in front of you and it's very informal carers. Often their partner isn't it, and they may be of advanced age and often not in fabulous health themselves. So it can be challenging to sometimes get the history that you need in order to make the decisions. So sometimes you have to gather some of that information yourself, which can be more time consuming. So like an example might be. So there's lots of blood pressure medicines and you know, you ask about do you ever feel dizzy or, you know, do you ever fall and you might not get a good history on that. So it might be that you have to do a bit more digging in terms of there. They're their blood pressure control. Whether it drops when they stand up, FELS Diaries, that kind of a thing, or speaking to falls clinic and getting a bit more history. So it can be difficult, it can sometimes be really good and you get a lot from the partners or what the carers, you know particularly I guess their formal care as you get a lot you can often get a lot more there. Sometimes partners can know, you know, they've known their partner for 50 odd years and can give you so much information. And what how different they are as a person at the moment? And some of the difficulties they're having with their medicines. So I think there's a massive range essentially and you might only get one angle or they might focus in on one particular problem or two particular problems which, umm, are often really important and really relevant, but are often sort of, you know, you go in with the mentality of I'm gonna look at XY and Z and they come with a completely different angle or a completely different issue, which you might not have been expecting. So, because often these people have lots of other health problems.

Umm, I know on lots of medicines they can come with a massive variety of kind of a cute problems along the way and that can sometimes be difficult to manage when you're going in with the angle to try and cut down on their medicines.

INT:   
And on the other hand, anything you've observed that works well.

HP05:  
Umm, I mean, I think broadly speaking, having and a carer there is really, really helpful and really important. And I think this goes along with a lot of other conditions as well. Sometimes it's helpful almost outside of the diabetes, it's helpful to have someone there who can give insight into how the patient experiences. I guess particularly in the dementia angle, people with mild cognitive impairment may not necessarily had knowledge or remember some of the key things that have happened to them, like a fall, you know, and their partner might go. And simple things like that, whereas I think obviously people with so did the latter stages of dementia will rely more wholly on their career so they can bring a lot of benefits by having that them there.

INT:   
Yeah, but round your experiences of describing your experiences of having deprescribing discussions with people living with dementia or mild cognitive impairment or their informal caregivers, and about what challenges and-

HP05:

So particularly from the angle of the caregivers then being there, yeah. Yeah, yeah, I think I think broadly speaking is definitely beneficial to have them there.

I guess there is a risk that they you lose, you lose the patients voice in it if they sort of speak up the whole time and say ohh they wouldn't remember this and they won't be able to tell you this and they can kind of speak over them.

So I guess there is that risk so often when I start the consultation side, regardless of what the notes say about the level of dementia that they have and what goes on. And I'll always speak to the patient directly, at least to begin with and talk about what I'm doing and say, you know, it's really helpful. Your husband's here and they might be able to help you. And generally I try and direct the questions that the patient see what response I get first before then kind of asking the partner or caregiver to their input. It depending on the sort of exact situation. Umm, which I think help but tries to bring them in and tries to give them a chance to have a voice. If you know the caregiver may sort of in there in their own mind, to be really helpful and bring all the information along. But might lose sight of the patient in it. And what they want to do, their wishes might get lost in that. So I do try my best to get the patients voice if I can in.

INT:   
Thank you.

INT:   
And who do you think is best place to be involved in deprescribing discussions in primary care for people living with dementia or mild cognitive impairment?

HP05:  
I mean, I think everyone is. I don't know if anyone of us is best. You know, I think if you are diabetes nurse and you got a patient with dementia, he's got diabetes there best placed you know I think if the GP's there with the patient seeing them for an acute problem, they're also well placed. I think obviously pharmacists are well placed because these are the kind of people we target and kind of deal with and we often do polypharmacy reviews. As you know, I think the most pharmacists work in primary care is part of their practice, but I wouldn't like to almost give it a label and say this particular person is the best because I think we all have different experiences and it probably depends on the patient in front of you and what you what your scope of practice is, what you work within. Umm. So yeah, I wouldn't in a in a way I wouldn't like to talk pin that down.

INT:   
Sure, I. And on the other hand is, is. Are there any professional groups who should not be involved?   
You may feel the same way or.

HP05:  
Yeah. Again, I think you know there's no reason why physios or other people working primary care who may be a little bit detached away from medicines, why within their own sort of field and their own scope be able to pick up on certain problematic medicines. And yes, the physios not gonna be able to, you know, it's not appropriate for a physio necessarily to be looking at, you know, the anticholinergic burden probably in most cases there probably are some who maybe do. But you know, if they can look at their pain meds and have a think about whether this is appropriate given the situation they see themselves in or you know, all sorts of things like that. So I don't in a way, I don't think. I don't think there is. I think we all need to know a bit more and be more confident, at least in reflecting on it and thinking it's a problem, even if the even if that person that clinician can't deal with the problem, just identifying it and highlighting it to someone who can is important. So yeah, I think we almost universally can, you know, I think even receptionist when they appreciate someone's in their over 80 and it's on 15 medicines can raise a query with a pharmacist or GP, whoever to say, you know, is this right? Right. Does this need looking into?

INT:   
Thank you.

INT:   
And in terms of leading those discussions who have told you think is best place to lead the discussion?

HP05:  
Difficult to saying. Umm, again, I suppose GP's you know, our stretched all over the country and don't have masses of time. Time. So I find it really helpful when the GP's broached the subject with the patient or carer and then tell them you know the go and see the pharmacist cause they've got time, they can sit down with you and go through this. So I mean from that sense in that we the way in which the structure of our profession in primary care is built, it's built on being adaptable for these kind of situations and allowing us to have a bit more time and the best of … got is double booking and appointment. So they've got 20 minutes from rather than 10. You know, it's still isn't really masses of time for them, so. You know, maybe in that sense, the way in which we've been structured, not necessarily because of up, not necessarily because our profession is best placed, but because of the way we generally work in primary care, we might be best placed, whereas nurses have the same difficulties as GP's and that they, you know, they have quite strict sort of schedules for different things they do, they have their diabetes review and they've got 20 minutes and it might be difficult to consider deprescribing and that appointment, umm, so from that aspect, it might be pharmacists or with support from pharmacy technicians and things. But the initial sort of identification and the initial steps can be done by anyone, I think.

INT:   
And when is it appropriate or not appropriate to involve patients?

HP05:   
Umm, so I think it's broadly Speaking of appropriate for the vast majority of instances to involve a patient. I mean, there's very few hand for you know, times where it's been deemed appropriate to not involve the patient. Umm, it might be. I'm trying to think of like examples we have. You know, maybe, you know, significant mental health issues aside from the dementia that meant they were very it was a bit patient. I'm thinking I was very fearful of being poisoned and you know, and changes of medicines can be really scary for them. New tablet appearing in the you know, the cop in the morning. So sometimes this, I guess, where we go down the COVID administrations route where it might not always be appropriate to involve the patient because it's in their best interest to take a medicine or stop a medicine. But I mean, I can't see a reason other than, you know, significant mental health problems where we're doing it in their best interest where we shouldn't. I mean, there's been a very few occasions where someone with dementia has been diagnosed with, say, terminal cancer, and it's been sort of decided by the family member that it's in their best interest, kind of almost not to inform them because it's gonna cause them unnecessary distress and not change. You know, they're not gonna have treatment or, you know, nothing's gonna change as a result of the diagnosis. And it's just going to cause distress. And so, you know, they might be given medicines as a sort of symptom relief or something, and that might be appropriate to not tell them. But I think there's always a way of. And wording giving medicines, that doesn't stop them patient understanding. So I think it's very, very few indications when it's not appropriate to involve the patient.

INT:   
And in terms of informal caregivers such as family members, are there any occasions when it is or is not appropriate to involve them?

HP05:  
If the patient doesn't consent. Which I guess is tricky when you're dealing with dementia, and it's difficult to assess capacity and I guess having the background from the notes from their GP about their capacities helpful, but capacity is capacity assessment is kind of a single instance, isn't it? And if you saw them the following week, it doesn't necessarily mean they don't have capacity. If someone says no thanks, I don't want you to speak to them. I'll generally abide by that. You know, if it's a really concerning situation where we're stopping and medicine and their family member is the one who deals with a particular medicine, then it it's a difficult situation, isn't it?  
And I might speak to a GP about the best option. For what to do and how to communicate things safely and how to make sure the patient is safe. But yeah, I think. Yeah, I guess if you also want to ask about this concerns around safeguarding, you might want to make sure the career or family member isn't there. Umm, so you so you can ask the relevant questions if there's concerns there? Umm, but I can't think of any other reason why it wouldn't be appropriate for them to be there.

INT:   
And in terms of what would is this engagement with health and social care colleagues to support shared decision making?

HP05:  
You just repeat that, I think you broke up slightly.

INT:   
Yeah, sure, sure.

INT:   
What would assist engagement with health and social care colleagues to support shared decision making?

HP05:  
I mean having access to them and being able to speak to them, what easily would be helpful, you know, more often than not you might get an email address or a phone number that goes to voicemail or you know. So I think that's the main barrier really for me is speaking to them when you need to speak to them, be for them being able to come to an appointment, being able to organise an appointment where they can come with the patient, if that's what's needed. The logistics around that, they're busy people, I'm sure. Umm, I don't know what would assist in that. Maybe probably some form of technology to enable you to for us to all share, you know, availability or I don't know, umm. And I like, you know, we have issues and this is the team where we work in terms of involving the. Hey, what is it? I'm trying to say like in ascending access to people with dementia and the assumption is their family member or their carer opens it on their behalf, but we can't seem to send a text. How does that work? Do we send a text to their carers? Ohh, you know, you're kind of breaching the, you know, you're not sending something direct to the patient that way and kind of just the legal nitty gritty and making sure you're doing things appropriately can cause barriers to having an easy way of trying to middle your way through that, you know clear documentation around you we can speak to without necessarily getting the patients consent each time would be helpful to know. Otherwise you have, you know, multiple healthcare professionals trying to speak to a patient to get consent, to speak to another social care colleague about their medicines or about whatever. And it just creates lots of delay and complications. Can't think of anything else. So if you're asking what's making what would make it easier, aren't you? Some of engaging them. I mean, I feel like we work in different departments, don't we? We it feels like a separate organic what it is a separate organization can be as I preorganization communication is always atrocious between even different departments in the NHS. So between care as working in a care home or you know, care as working for a private agency or via the Council or whatever is just, you know, every stage you need to add a layer of communication against more and more complicated. So ways in which we can communicate more easily? Umm, about a patient more, you know, MDT sort of forums where you can get different healthcare professionals involved with a patient together and the relevant people from health and social care. So I guess we can understand them and their concerns with the patient and they can also understand our concerns in terms of you know, medicines and making shared decisions about stopping them or starting them or whatever or other interventions. Umm. Yeah. And that's the main things. So building a relationship with them, they're often sort of a name on a piece of paper, and there's no sort of. You know, face to a name or knowing that much about them.

INT:   
What would assist engagement or involvement of patients living with dementia, more cognitive impairment and all their informal caregivers in the deprescribing process?

HP05:

So I think giving them information that they can take away, it's helpful and helps engage them. You when you sit and talk to someone about their medicines, they probably absorb a fraction of what you're saying. So when we're making shared decisions about starting or stopping medicines in that group of patients, I really try and send them away with a leaflet, a link to a video, whatever it is that will help them understand the risks or benefits I might just write a few notes down in terms of the risks and benefits of the medicines. If there isn't something available, it might be that we wrote. I write down some notes or send them a letter with some notes about things.  
We've discussed them to think about and then we meet again. So they've had, you know, they can take it away.

HP05:  
They can remind themselves of what we've talked about and they maybe have time with their family member or their career to discuss it before making the change. I think it's particularly when you're seeing someone on the 1st instance, you might get them on a good day, but you might also get them on a bad day when actually talking about these things isn't appropriate or is where we difficult for them. So giving them time and giving them, you know, something to go back on, to remind themselves about what was discussed is sort of helpful. And in the same way, we sort of have leaflets for people with learning difficulties about medicines. We're kind of meet the same thing for dementia, which I have we have. I've some bits from different various different places, but I don't have all the medicines we could possibly have that might talk about risks and benefits from their point of view. You know, there's lots of leaflets about statins and the benefits it would give you, but there's not a very much about kind of as you get older, these are some of the risks that go up with age and these are the limited benefits it might give you, you know, make a judgment on what the right thing to do is for you. I'm there's nothing. There's often things that aren't quite like that out there. You know will help, I guess from to help them understanding what their medicines are for.

HP05:  
I know some pharmacies are good and is your statin is As for collateral and those kind of things and just having simple ways of making sure they're aware of what medicines are taking and why they're taking it. So that you know they need to know about these things before they we can go down the road and share the decision making. First step often is education, isn't it? Before they can make a decision. Umm.

INT:   
And in terms of anything around what would facilitate good communication with patients living with dementia, mild cognitive impairment and all their formal caregivers in deprescribing.

HP05:  
I am giving them time talking to them face to face. You know, having the opportunity to talk to them face to face, it's very difficult to talk to people with dementia over the phone and, you know, things can sort of flit all over the place. So trying to be in a calm environment, having sort of dementia friendly environment somewhere where they know ideally might be a home visit and having the opportunity to do a home visit. So they're in their own environment rather than dragging them into a clinical setting which they don't recognize. Umm, giving them time? I'm having kind of whatever they do to manage their medicines in front of them, whether it's their, whether it is their medicines or whatever they do to help them prompt to, to understand what you know, remind themselves what they are and what they're for.  
  
INT:   
And what language should be used in communicating information about medications of people with dementia or mild cognitive impairment and their informal caregivers?

HP05:  
Yes, I think this goes across the board that you don't want to give him too much information too quickly, which is why things need to be done over several visits. You don't. You probably don't want to go through kind of every medicine. You what you want to do is go in and prepared to know the ones. Maybe you want to target, so you want to use simple language? I'm probably still open and closed. Kind of questions to probe and it also to assess their understanding, you need to ask the questions in order to assess their understanding and kind of their capacity for making some decisions about it. Umm, but you also don't want to sort of demand them with too much. You don't want to ask too much of them and tie them out or make them potentially risk them.  
Sort of getting agitated or confused as a result of asking lots of questions, which is why often in their own environment are calming environment is a good place to start. It might be that you want to ask them certain questions and then ask their permission to ask their carers other questions when maybe you see them getting agitated or distressed, or you know that they're not focusing on what you're talking about, or that might be a time to just end things and bring it back to another day. In terms of language. A simple language, jargon, not to avoid. Use medical terms. Use the simple terms. Or the terms they use themselves. You know, if they describe I've got blood pressure and you say it the same way. You didn't say hypertension or high blood pressure? Umm. Yeah, I don't think of anything else.

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

HP05:  
And it can be more difficult. Umm, it comes sometimes be difficult to judge the response. You may not get a consistent or a clear response, which is why you need to revisit it over several instances, particularly if it's a difficult decision like stopping anticoagulation. It might be that you to do that over several discussions in order to try and get a consistent outcome of consistent response before making the judgment. I mean, the people with mild cognitive impairment, it may not be too challenging. They may acknowledge they have some problems with memory and it's quite easy to then sort of almost use that as a sounding board for raising some of your concerns about medicines and seeing what their thoughts are about some of the risks associated with medicines, particularly things which may be making their cognition worse. It can be a useful tool to make them appreciate some other concerns with the medicines because they have, they still have insight as to their into their dementia. They appreciate that things aren't as they used to be. Umm, so it can be helpful and it can be very challenging to try and understand their priorities, what their wishes would be back when they had capacity or when they're when they're cognition was to appoint that they could make judgment calls as sometimes it's difficult to understand whether you're getting the carers view about what the carer wants or the carers view about what they think the patient wants. It's not always the same as it.  
  
INT:   
And anything, anything there or not, those kind of comments you've made that would help facilitate involvement in shared decision making or for patients?

HP05:  
Umm, I think I mean some of the tools that we already have available like ohm, you know, some people may not be able to speak well or may find it difficult to form the response that they want to give. So having like pictorial responses can sometimes help you know :) and sad face or whatever. And yes and no. Sometimes can be helpful that can help sort of facilitate not just shared decision making, but understanding the patient’s wishes or concerns, or about thoughts about something. I think any way of being able to understand what they feel or what they used to want, they know what their, what their priorities were in life before the dementia. f you're unable to gather that information and obviously information sharing among agencies among would be really helpful. Umm. And again, our best better by the tech in terms of giving the patient information to take them or what take away with them to understand and digest in their own time would be helpful. I mean, there's all sorts of trials and things out there using iPads for assessing people's health and whatever, and all these different things and think people with dementia sort of been left by the wayside with some of these things. Maybe tech isn't the priority of their thoughts, is it? But sometimes it can be really helpful. Umm, I can't think of anything else.

INT:   
And how do you feel about engaging informal caregivers of patients with dementia or mild cognitive impairment, shared destitute? Sorry, the shared decision making this part of the deprescribing process.

HP05:  
How do I think about engaging them?

INT:   
Yeah, formal caregivers.

HP05:  
I try, and I try and engage the patients. I try and give them time to talk like we'll talk to do and shared decision making, giving you know asking an open question asking how they are asking what's going on giving them time to talk and by them having the time to sort of offload it can often help identify the main problems identify their main concerns so that you can focus on their concerns and make sure you address them. Some of which may or may not be linked to the things you're wanting to address, but at least opens the door to then trusting you and appreciating your input. And so it might be that the first or second consultation of dealing with things which actually aren't what you wanted to talk about initially, but it opens the door to the conversation and to them knowing you, umm, so I guess that's how I kind of go about it. Umm given the time to express their concerns?  
  
INT:   
What tools and resources are needed to facilitate shared decision making relation to deprescribing for patients living with dementia or mild cognitive impairment, so the tools and resources?

HP05:  
Though I think we need evidence about what the right decisions are to make, and I think we're getting increasing amounts of that, I guess I like data. So I like to know like numbers needed to treat over a certain age. Or, you know, there are lots and lots of bits of research popping up all over the place in the last couple of years about risks of certain things in people with cognitive impairment. Because I sort of an underrepresented group in research, aren't they? So I think we need more understanding about the risks with using medicines in those groups of patients. Umm, you know, there are some useful things out there. GP evidence that puts numbers needed to treat and things like that together. So some easily accessible resources that we can go to have an idea about that fine balance of risk and harm for these people with data relevant to them, not just like crappy clinical trial data that's not relevant to our 85 year olds with dementia. You know real life data that that links with similarities with them. Anyway, umm, they also said about, you know, literature that is targeted at people with dementia or cognitive impairment. That helps educate them about certain conditions or certain medicines which is lacking. Umm. What other resources? I mean, I think we have access to a lot of resources, things like you know what you can crush and all that kind of stuff in terms of when people need liquids. While the tools I mean nice to do some shared decision making tools, don't they in terms of they do once per sleeping tablets and for all sorts of things, certainly. But they're long winded and I can't see a pet, you know, some patients with the more significant dementia engaging with something like that. But some things like that are helpful for people with dementia, because it's summarizes risks and benefits and lets them write stuff down and bring it back another day. So you can catch them at a time. That's good. And they can have time to think about it and write stuff down. So even if on the day you see them next, if they can bring that with you, bring that with them, then you might capture what they were thinking at the time. They were a bit more lucid.

INT:   
Thank you.

HP05:  
Think of anything else. No, thank you.

INT:   
And how best would patience with living with dementia or mild cognitive impairment B followed up as part of the deprescribing process.

HP05:  
Umm that by the same person you know by someone who knows them someone. They've met someone they trust in the same environment, ideally, whether that's at home or the same building, the same room, whatever it is can be helpful. So it helps sort of prompt them remembering, you know, they see you again. Ohh yes, I remember we talked about that, and we thought about stopping that and so that's I think that's it. Essential. In terms of ongoing care, you know, these are the people that have the same GP. Umm, you know the same sort of group call group of people who manage them, who know them well to make these decisions.

INT:   
And, umm, in terms of support for patients living with dementia and their caregivers, any thoughts around what would work well there that support them during the deprescribing process.

HP05:  
I mean having the opportunity to kind of ask questions after the event, you know, sometimes feel there's a problem in healthcare generally that you they walk away and there's no easy access back to ask questions. That kind of thing, you know, having an easy accessible point of contact with queries about these things? Umm. What else? Yeah, I'm not sure.

INT:   
And just return you to the question about following up patients as part of the deprescribing process.

INT:   
How often should the patients medication be reviewed?

HP05:  
And that depends on the patient. I think at the very least, annually, ideally more often you know the people with lots of medicines. It should be at least probably 6 monthly if you're 10 or more, 6 monthly. I would say, you know, if people who are quite unwell, people, medically, it should probably more often than that, it might be monthly for some people in care homes. And so I think it's difficult for me to say one size fits all. I think it's judged on a case by case basis.

INT:   
And what are the potential facilitators to integrating shared decision making in relation to deprescribing medication for patients with dementia or mild cognitive impairment into your everyday practice?

INT:   
So what are the things that would help?

HP05:  
So I think the main challenges are time. You might think you're dealing with a quick query from a patient and it's not. Umm, So what would help facilitate it? Umm. Having sort of more flexible options about how you manage these patients and where they're seen. Umm. What would help facilitator sometimes having you know a meeting, an MDT can help facilitate it. You could you've got all the people there. Who know the patient who might know different aspects about the patients? You know, we had so frailty MDT once a week, and you might have community matron who goes and sees the patient at home. Who then says I'm going to go to the house and there are harder and it's full of stuff. And you don't get that from seeing the, you know, you don't get that look at their medical history or anything like that. So and that might add to your concerns about the risk of falling over and things like that. So having a the wider group of people who care for the patient, including maybe social care, umm, would really help understand the risks and be able to inform, you know, the best decisions and support shared decision making because you can appreciate the risks and benefits better by knowing the bigger picture. You know from everyone.

INT:   
OK.

INT:   
And then then you two other thoughts around potential facilitators or barriers to integrating shared decision making for those patients into your everyday practice?

HP05:  
Umm, I guess access and information from that wider team. Umm, you know, the wider MDT here were involved with the patient. Umm, it might be lack of notes, lack of information. That's a barrier you might, you know, we put often get people from who lived in Spain for 20 years and then get dementia and come home. And you've lost lights of 20 years of records that you don't really know what's happened and why it happened. In the barriers, I suppose, isn't I? I mean, some of the barriers are other clinicians. You know, they want to aggressively treat one aspect of their medical care that may not be a, in my opinion, appropriate. And you've got the challenges associated with conflicting sort of specialists for their area who you know view things differently to your own. So conflicting sort of ideas.

HP05:  
And I guess the patients understanding and ideas about their medicines and decisions to make about them can be tricky. You can get a whole group of elderly patients sometimes who don't. You've grown up in a world where sort of a doctor's a paternalistic kind of person. And they make the decisions and they just follow them. And so having shared decision making is a bit of an odd experience for them. When you say this, this option does this option? What do you want to do? And they say, oh, I don't know, you just need to tell me what to do. So that's sort of, you know, they've already shut down the option of shared decision making. Umm when I try and turn it around a little bit and try and help them to make a decision.

INT:   
And can you identify any training or educational needs for you or your colleagues to enable you to safely stop unnecessary medications for someone living with dementia or mild cognitive impairment?

HP05:  
Yeah.

HP05:  
I mean, I think it's we all need like your updates about new information about the concern, the risks and benefits of these medicines. As always, new data coming out and keeping abreast of them is quite difficult when you're dealing with kind of deprescribing stuff. You have to look at the whole medicines list of you know holistically. And so you have to be quite a generalist. I think personally is pharmacist. We often come into primary care as OI deal with diabetes and I deal with hypertension and I deal with asthma, but actually you definitely the ability to think brought more broadly and that's quite tricky and we're not trained to deal with this stuff. It's so we all need more training. Nurses, doctors, pharmacists, whoever we need. Regular kind of updates about medicines and the risks of harm. We need, you know, sharing of information. We need kind of our population data understanding where we fit in the grand scheme of things. Umm, you know, getting secondary care data is I'm trying to work on something now and it's just so difficult to join the dots and understand cause and effect with some medicines and understand the risks with some of them and the harm vice versa. What we start in primary care and the influence on secondary care, but also back again, yeah, trying to get that information and share that information and appreciate the sort of chain of consequences that happen after starting a particular medicine. It can be really difficult to understand and it's super complicated. And it's difficult to prove benefit from what you do. Sometimes it's difficult to quantify the benefit you bring when you stop things or start things or whatever, because more often than not, I think this pharmacists where you know we're always being asked to prove our benefit. Umm, I'm trying to do. That's difficult when you work within sort of the deprescribing realm. Yeah, I think I've gone off on the tangent though.

INT:   
No, not at all at all.

INT:   
And is there anything else you want to tell me or anything you wish to add to what we've already said and you reflections?

HP05:  
I feel like I've talked about quite a lot.

INT:   
Well, thank you very, very much. Come to the end of the interview now, so I'll just put the recording off.

INT:   
Just bear with me a second.