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

**Transcript**

**HP03**

INT:   
So the interview day is the 11th of July. So I just like to start by asking you, can you tell me about the care you provide to people with dementia or mild cognitive impairment, please?

HP03:  
I'm personally that I'm usually the first person that the family or the person comes to tell about the memory issues or confusion, or possibly the clinician that notices some that comes via another. So a nurse might have mentioned something when they've seen the patient. So I'm first point of contact and making an initial assessment of the patient. Organizing blood tests and to exclude physical issues, examining the patient as appropriate, and then making a referral to the community LED mental persons team.

INT:   
Thank you.

INT:   
And how much of your workload is this please?

HP03  
I'm it's a minor part, but I do have a reasonably elderly population, so I'm sorry I don't know if I know any figures about how many cases we speak there, but it it's a relevant part of our workload in terms of ongoing review of them.

INT:   
Mm-hmm.

HP03  
That is something we do have a specialist…..team, nurses who sort of managed that for us so that that becomes more of a chronic disease management nursing role. But obviously we also get involved when things are much more serious and deteriorating.

HP03  
Various reasons, medication reviews or when things can reach crisis point, etcetera, etcetera, so.

INT:   
And that that brings me along to how many of those patients are taking multiple medications.

HP03  
Pretty much all of them.

INT:   
All of them, OK.

HP03  
Yeah, I use or something that the GP at the moment is doing, but we are looking as a PCN to hire specialist pharmacists who help will help us with the multiple medication interaction, sort of pathways etcetera.

INT:   
Thank you.

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

HP03  
At the moment the GP's are doing all the medication reviews so when they come up the meds come up for review. We check the, you know, medicines have been checked appropriately with blood tests that there's been no deterioration in renal function and the review of whether the meds are effective and falls to the whichever chronic disease it is.

INT:   
OK.

HP03  
So some of those will be reviewed by the GP, most if they're cardiovascular, diabetes, image that they will be reviewed by the specialist team, probably within our nurse. OK.

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

HP03  
I think that you have to take every area of their health under advisement, and yes, it's a good idea and reducing anticholinergic load is obviously very important. But you know you don't want to destabilize other conditions. So it depends which area we're talking about, but it's always our plan to try and get people off meds if we can. But with the proviso that we don't want to, for instance, destabilize heart failure or hypertension control or diabetes or something.

INT:   
And any advantages in terms of deprescribing inappropriate medication among people living with dementia or mild cognitive impairment?

HP03  
Ohh loads. I mean, I mentioned anticholinergic load, they're often very dizzy and very umm wobbly because they're elderly, they have interactions, it reduces their renal function which can contribute to their ill health generally they the interaction between the meds you can get such things as falling magnesium level, which worsens confusion and drowsiness and fatigue. And it can be confounding the cognitive impairment. There's this huge advantages to getting people off meds. If you can just within the proviso of not making things worse.

INT:   
OK.

INT:   
And on the other hand, any disadvantages?

HP03  
Well, as I say, destabilizing other conditions.

INT:   
OK.

HP03  
And patients with dementia obviously usually have nomad packs and carers, but in the impaired cognition stage, when things are quite mild, there's often an issue with compliance as well, and changing things confuses people. So that's a disadvantage, but it's also an advantage to changing to, reducing them because you are getting poor compliance anyway, so you don't quite know what they're taking half the time anyway you.

INT:   
Thank you. And in terms of those, those disadvantages or challenges, do you have any thoughts about how they could be resolved?

HP03  
Having a specialist pharmacist we think is 1.

HP03  
Big way of really supporting patients a lot more than GP's have the capacity time wise to do and spending much more time with them explaining checking into actions. And you know, watching patients on multiple meds, a lot close more closely. Obviously you said the nomad packs or involvements at the carers or …to aid compliance. Umm … the family is a useful tool to try to dig you know deprescribe. Often they're very keen for patients to be deprescribed as well.

INT:   
Umm OK, thank you.

HP03  
So yeah, I think using our pharmacy colleagues is probably the biggest one that, that this within the surgery, not the chemists.

INT:   
And what types of medication would you feel most comfortable deprescribing for people living with dementia or mild cognitive impairment and why?

HP03  
Opioids and antipsychotics, because they really aren't appropriate anyway. Yes, I'm uh, people get stuck on stuff for donkeys years. Umm, say and I think they found the situation and they can and really contributes. It falls and also confusion in themselves. The other one that I'm very keen to get people down and off is and they get stuck on for years is PPI? and obviously there's an issue with renal and complications with those. Umm, yeah, so I opioids and antipsychotics and anti-psychiatric drugs ideally.

INT:   
OK. And but would encourage you to support reducing or stopping a medication.

HP03  
Umm sorry.

INT:   
Sorry, what would encourage you to support reducing or stopping a medication?

HP03  
I don't think having targets or any kind of payments is really gonna cut it. I suppose payments would because that would help fund the pharmacist. Umm to possibly would, we have obviously at like the antibiotic antibacterial, it's, So … you something like that? Where it's sort of name and shame thing.   
What patients are? But it's not so clear cut case, obviously, where the patients are feasible for them to be off them. So the big fan of targets and, you know, stick with and prescribing habits. But I think education around the topic is important.

INT:   
OK. Thank you. And what medications would you be reluctant to deprescribe and why?

HP03  
Umm, diabetic meds and she hypertensive meds.

HP03  
Why?   
Because they all preventative, they largely don't have so much in the way of interactions and secondary effects. And therefore they're more likely to be doing more good than harm. Umm. But I just thought of something just now. All the other one I'm very keen to Deprescribe is actually statins cause they're a bit pointless in the very elderly and they just rife with side effects. So I think things that control disease and improve quality of life would be things that I wouldn't want to deprescribe.  
But I think that covers a huge area really.

INT:   
Thank you.

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?

HP03  
I'm plenty of support and time. Umm, uh, I think education of patient and family is another one. But yes, time to explain and. Resources to make sure they have the appropriate meds monitored and monitor the effect of stopping things.

INT:   
Thank you. Describe your experience of having deprescribing discussions with people living with dementia or mild cognitive impairment, or their informal caregivers.

HP03  
Mostly they're very keen.

HP03  
Umm. And there were occasional people... feel frightened to come off meds often. That's the patient rather than the family, but it can equally well be the family are worried, particularly if you're trying to deprescribe an antidepressant. They're worried the effect that might have on granny’s mood. And how that might impact on how they're managed and cared for. And I think it's mainly people are very keen to not being quite so many pills.

INT:   
OK. Thank you.

INT:   
And what works well about those discussions?

HP03  
Having a dialogue and discussing how umm you know with the patient and their family, how that might look and what to do if things are not going well and putting in appropriate follow up plan.

INT:   
And on the other hand, but what challenges have you encountered?

HP03  
Some people are completely rigid in that they don't wanna change anything, and at certain stages at it, it's almost easier. When people are completely demented and somebody else's making decisions for them and putting the pills in front of them in the this the earliest stages, patients don't easily grasp things. So discussions have to be more careful in order to, you know, ensure that they've got the capacity to understand and agree. So yeah, the in the simplest ages when people are still got capacity, it's a much trickier conversation and also monitoring things when people are self-reporting and they haven't got a caregiver in with them much of the time if any then they may not be so reliable a witness about what the impact of stopping things is.

INT:   
Thank you.

INT:   
And when and how should such discussions take place?

HP03  
I think it it's a good thing to do as part of the annual dementia would be, which are dementia nurses do get involved with, but it if we're going to institute an annual or biannual twice annually rather and not biannual twice annually, medication review by a proper trained pharmacist, then that would be an appropriate time to have that conversation. Obviously, if you are starting any new meds or changing any meds for something else, it's always a good opportunistic time to have a conversation as well.

INT:   
And what should happen in these discussions?

HP03  
Umm have a look at interactions, see if anything is easily changeable. And mention that to the family and patient and or patient and seek their views. Look at compliance as an issue and whether patients are actually taking them. I'm regularly whether they're having any issues swallowing them, whether they have experiencing any side effects themselves, not just what we potentially might be seeing as an interaction. o your dialogue basically.

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?

HP03  
Either the dementia champion nurse or … sees them. Or the that's the bomb test within the practice.

INT:   
And are there any professional groups who should or should not be involved?

HP03  
I don't think it's a conversation for the there's sort of less trained nurses such as HCA's, or even to a certain extent, a junior practice nurse.

INT:   
OK.

INT:   
And who is best placed to lead the discussion?

HP03  
Probably the dementia nurse.

INT:   
If you could just tell me a little bit about why.

HP03  
Because they have by definition and just had a very lengthy conversation with the family and the patient, they have half an hour slots and so they will have gleaned or can glean a lot of information about the impact I of medication on patients life, who's giving it, how it's being taken, the compliance of it, any symptoms that patient has just described which. Might be construable as related to medication, plus they are quite senior nurses, so they're understanding of the medications is probably adequate.

HP03  
And I would say a pharmacist or a doctor would understand that element better.   
But I think you are somebody who takes the lead on it.

HP03  
And I think that somebody who's had all the conversations.

INT:   
Conversations, OK. And when is it appropriate to involve patients?

HP03  
Ohh wait.

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

HP03  
Uhm, when the dementia is incredibly intense, dense and they have a power of attorney, or they're in a care home is less appropriate, but one would always try. But if you've got somebody completely out of it, then that that wouldn't be appropriate.

INT:   
And thinking of the same questions for Informal caregivers, when is it or when is it not appropriate to involve informal caregivers?

HP03  
Umm, that's a bit more tricky if they haven't got, we haven't got the permission as family. The patient to involve them with the proviso that we feel the patient is not a safeguarding risk and therefore need to override that criteria. Basically that makes sense.

INT:   
Yes, yes, I've not got the permission of the patient's.

INT:   
And any other circumstances when it is or isn't appropriate to involve informal caregivers?

HP03  
Umm, if the agency team and they don't regularly go to the same patient, then that isn't appropriate necessarily.

INT:   
And what do you think is the role of informal caregivers in deprescribing the discussions in primary care for people living with dementia?

HP03  
Umm. As a source of information and to reflect the comments of a of the patient and family that you might not be getting in any other way.

HP03  
Umm, patients often tell their informal caregiver things they don't tell us, and they might notice things that perhaps the patient doesn't report. A I think that it has to be by definition informal, unless they've got. You know, if it's a family member who's helping and has power of attorney, then that becomes a very much more serious involvement. But otherwise I think it's that you have in your conversation to get information out of them and to get their opinions and via them. Get the opinions of the patient.

INT:   
Thank you.

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

HP03  
Having enough time I?

HP03  
I do think having somebody who understands medication really well to almost have a group discussion. I mean, in an ideal world, let's, let's say there's you have it almost like a mini MDT with the pharmacist, the dimension nurse, possibly the GP and the family and the patient. But I'm gonna happen in the real world. Umm, not in NHS. Anyway, it would do private sector umm. But the MDT's we do have don't have input from the family and they are. Are they are very much for crisis management? I just don't think that would be feasible. I've gone off in a bit of a tangent. What? But how? What would help you say engagement of everybody?

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

HP03  
I would don't know the answer to that. Now got any time and I I've had the answer to that it probably somebody else would have come up with a plan the.

INT:   
Thank you.

INT:   
And what would assist engagement or involvement of patients with dementia or mild cognitive impairment and all their informal caregivers in the deprescribing process?

HP03  
Umm. Appointments. That's all, umm, fitting around them and visits at home.   
And that's what the dementia nurses.

INT:   
Umm.

HP03  
Umm, which is why I think they're well placed to be heavily involved. Potentially the help of people like age, concern or informal charities like that, especially people haven't got anyone else helping them. Then having that sounded support and involvement at an encouragement from, you know, lunch clubs or other agencies potentially that might.

INT:   
And anything around supporting shared decision making with secondary care health colleagues to.

HP03  
I'm but for the patient making shared decisions with secondary care or primary care making.

INT:   
Umm just assist this with the engagement with colleagues in in secondary care to support shared decision making with patients and their family members.

HP03  
Umm, I don't know because I haven't really done any secondary care and mental health work personally, but I would imagine it's the same sort of thing the time appropriately put aside meetings together with perhaps a the mental health support workers and the consultant and the family.

INT:   
And what would facilitate good communication with patients with dementia or mild cognitive impairment and all their informal caregivers in the deprescribing process?

INT:   
Umm.

HP03  
We use a texting service at QRX, which I think Moto GP's use. Umm it's a worry using it with dementia patients, but when they've got a nominated caregiver he they've authorized us to communicate with. That can be a very useful tool and they can feedback information to the pharmacist that way. Or the GP.

INT:   
It's useful to when they've got a caregiver to-  
HP03  
Yeah, it's not so useful when it's when it's them. Then, if it's just the patient, you have to really talk face to face, I think.

INT:   
OK. And anything else there which can help us to take good communication with patients living with dementia and all their informal caregivers and the deprescribing process.

HP03  
I'm our pharmacist. Within the surgery, do carry their own appointment list as they can forward schedule reviews with them.

INT:   
Mm-hmm.

HP03  
That works.

INT:   
The forward schedule the reviews.

HP03  
Yeah. We have on the prescribing of any medication we have, you know, a stopped date. Where a review is triggered, I'm patients that get invited to make an appointment to review it.

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

HP03  
I whatever is appropriate to facilitate their understanding, it can often be, as I said before, that needs to be a much more careful conversation, more simple conversation. But equally well, the there intellect is you know how high to start with they, they may well, umm, put people off if you talk down to them too much, you have to sort of be careful that you check that they've understood you.

INT:   
OK.

INT:   
Thank you.

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

HP03  
Yeah, I think it's obviously appropriate. I and you know it won't doesn't want to be dictatorial in this day and age. You know, everybody needs to be involved. Sometimes you do have to stare people because their understanding of the meds is not the same as ours, but you just put the facts before them and you can influence people. But bottom line is they are the patient and they get to choose.

INT:   
OK. thank you.

INT:   
And what would help facilitate their involvement in the shared decision making.

HP03  
Yes, ensuring the appropriate language and check that patients have understanding of what you've explained.

INT:   
OK.

INT:   
And what are the barriers to their involvement in shared decision making?

HP03  
Umm. The fact that the issues can be quite complex, umm, and to understand the nuance of it is sometimes tricky. Trickly if they've got very many different meds for very many different things. Umm. But I think it's the role of the physician to provide information in a way that can be understood wherever possible. And if you just can't get the information across, then sometimes you do have to make a decision for people.

HP03  
But some. Yeah, obviously one tries to engage patients and family as much as possible.

INT:   
And that moves me onto how do you feel about engaging informal caregivers of patients with dementia or mild cognitive impairment and shared decision making as part of the deprescribing process?

HP03  
Formal as in family or we talking professional careers?

INT:   
Yeah, I think it's more family, but it could involve a professional as well.

HP03  
Families, not any kind of issue. The problem with professional agencies is as a mentioned before, that there's often not one person say a reasonably happy with the patients consent or families consent to talk to a care manager, you know, so say Bluebird care that they usually have some senior person you can talk to who correlates and collates all the information from various people who pop in and bots dealing with just one person on one day is often less helpful. Umm and sometimes you have very, very amazingly good and well informed and experienced care as he can really put the information in a helpful way. But unfortunately, there's for one of those. There's probably 5 here. Who are making snap judgments on one issue and not giving you the appropriate information.

HP03  
So I find professional care agencies less helpful. Care Homes also have their agendas, and I've had bad experience recently with the patient and her husband. We were managing uh compliance with, of medication and sort of finding a pattern of things that worked for her in the community because we could be a little bit flexible, went into a nursing home and all hell let loose because basically they're very, very rigid about when they give things and how they give them.

HP03  
And you know the sometimes that kind of change and that kind of rigidity can be a real problem for   
HP03  
So I'm warbling again.

INT:   
No, no, it's interesting.

HP03  
It's a basically yes.

HP03  
You take on board everything everybody says and I have it utmost respect for, you know, most caregivers and professional bodies, but sometimes they can.

INT:   
And what would help say informal caregivers in terms of family, in terms of their involvement in shared decision making.

INT:   
What would help facilitate their involvement in in shared decision making?

HP03  
Something that conference calling might be useful have thought of doing it.

HP03  
I think it might become a tricky thing, but yeah, obviously inviting them to dementia reviews they're usually come or a representative is sent. So yeah, just involvement really. And notation to get involved.

INT:   
OK, this is what for family members.

INT:   
And what are the barriers to them involvement in shared decision making?

HP03  
They're often working, which is, I think, why having a set appointments very useful, and if they if you picking something up on an opportunistic. And meeting with the patient who's perhaps attended on their own. And then I uh, I'm not sure anybody really picks up the phone to the family member as well. At that point, you know it's a time pressing thing.

INT:   
Time to.

HP03  
Uh, yeah.

INT:   
Thank you. And what tools are resources are needed to facilitate shared decision making in relation to deprescribing for patients living with dementia or mild cognitive impairment?

HP03  
What tools?

INT:   
Yeah, tools and resources.

HP03  
Umm. There's some really good resources on online about medications, which we often send patients and family members about, you know. Interactions and side effects etcetera approach a equivalent sort of literature on deprescribing and how to how to get off certain meds and why it's important.

HP03  
That sort of literature would be useful. Uh, in terms of tools. Uh at the tech service video calling conference calling as I as I said, those things might be useful.

INT:   
Mm-hmm.

INT:   
And key and attempts those medication resources. Do you remember the address for those?

HP03  
Umm, I used the ones on Accurx quite a lot. Umm, so if you basically just type in like you know anticoagulants or antihypertensives or whatever that it will have this at like statins. It will have side effect lists and stuff and so I can use those as a tool to help patients understand the potential issues with a with a medication, I'm not aware of any specific literature and I would be interested if there is on deprescribing I guidelines that is patient friendly.

INT:   
Umm.

HP03  
Umm, they were when I did an opiate. This is not for Dementia only, but I did an opiate withdrawal. Of course, on how to do to get people off opiates. And there were some patient literatures that came along with that that we used. We and we sent out and I think that pharmacists are using similar literature to send patients as well at the moment and as we're having another attempt to get people off opiates.

HP03  
So, but that's not just dementia patients only.

INT:   
OK.

HP03  
No, I don't remember the actual web address.

INT:   
That's know that that that's fine.

INT:   
And how best would patients living with dementia or mild cognitive impairment and their formal caregivers beef supported during the deprescribing process?

HP03  
Basically scheduled reviews and with the same person each time, whoever that might be, dementia nurse or pharmacist or doctor.

INT:   
Anything else?

HP03  
Umm be supported?

HP03  
Be informed.

HP03  
What do if things if there are issues so informed at the beginning, what might happen and what to look for?

HP03  
And umm, so they're prepared for any minor issues if they're stopping something?

HP03  
Umm.

HP03  
And what to do about it if that should happen?

INT:   
OK.

INT:   
Thank you.

INT:   
And how best would patients living with dementia or mild cognitive impairment be followed up as part of the deprescribing process?

HP03  
How best by scheduling something ahead and so they know they've got a set time?

INT:   
And how often should patients medication be reviewed?

HP03  
I think at least six months

HP03  
Or if you're prescribing something new.

INT:   
OK.

INT:   
And is that for, for patients with dementia?

HP03  
As for everyone, actually?

INT:   
Happy

HP03  
But who's but repeat prescriptions?

INT:   
OK.

HP03  
But it dementia.

INT:   
OK and.

HP03  
Or anybody with or not auntie antidepressants or opiates particularly.

INT:   
Thank you.

INT:   
And who should be following up patients?

HP03  
Umm.

HP03  
What do you mean after any deprescribing?

HP03  
I that said before I think it's the pharmacist, primarily he will be taking the lead on this one.

INT:   
The follow up. OK.  
INT:   
And what are the potential facilitators to integrating shared decision making in relation to deprescribing medication for patients with dementia into your everyday practice?

HP03  
I don't know what you just said.

INT:   
Sorry, sorry.

INT:   
Sorry it's a bit of a longer question.

INT:   
So what are the potential facilitators to integrating shared decision making the deprescribing for those patients into your everyday practice?

HP03  
We give me half hour appointments that would work. Uh, yeah, it's time. Basically, umm, protected clinics. Not gonna happen. But you asked for the answer.

INT:   
And anything else that you think would help?

HP03  
Into my everyday workload.

INT:   
Yeah, yeah.

HP03  
Not that I can think of.

HP03  
Time, time, time and more time.

INT:   
Right.

INT:   
And then any resources?

HP03  
Money equals time.

INT:   
Umm.

INT:   
OK.

HP03  
This doesn't cause you can't hire any more doctors, cause there ain ‘t none.

INT:   
OK, I'm on the other hand. What are the potential barriers we may have covered some of those to integrating shared decision making in relation to deprescribing medication for patients with dementia into your everyday practice.

HP03  
It's the opposite, isn't there? The fact I've never got enough time. Too many patients. You've not got the family there half the time you're trying to deal with their acute problem. Umm, it's not in a scheduled time slot. Specifically, to do the deeper scribing is being fitted in round everything else.  
So yeah, it's. You're not having protected time, and they're gonna confuse the hell out of people because you're doing it on the back of something else that they actually came about.

INT:   
Can, you and 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.

HP03  
Umm, I think medication sort of very simplistic information about, but routine medication interactions would be useful, you know. Yes you could, but you can spend, you know, five years studying it and still not really. Every interaction of, especially when you get to form four or more drugs, you most of us know, you know, a interacts with B for the common ones, but it's about the multiples, and if there was some kind of resource that would flash up the likely implications of them being on the combination some kind of program I when you prescribe a new drug it flashes up with these other potential side effects or anything but if he miss or system one or whatever had the appropriate software that could look at the drugs they're on look at their renal function look at their haemoglobin look at their past history and flash you up. Umm, some kind of template? Very simple template saying.   
Look at this. Look at that in the same way the Croft box does. Or like I don't know if you're aware, some of the cancer flash up things where the, the software and the background is identified that they've had bloating and abdominal pain and haemoglobins state and it flashes up and says, Oh yes, they might have bowel cancer. Well, you know, most of us would have spotted that, but because it's embedded, it flashes up at you. And the same for this and that if you're in the middle of a consultation about something else and it suddenly flashes up. Ohh, you know, they were on five drugs and they're anticholinergic load is horrendous, and you know it might be useful. A bit of software to support us.

INT:   
And is there anything else you want to tell me or anything you wish you to add to what you've already said that you think it's important that that we should know?

INT:   
No. OK.