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

**Transcript**

**HP07**

INT:  
like to begin by asking you quite an open question and that is, can you tell me about the care you provide to people with dementia or mild cognitive impairment, please?

HP07  
So I'm I basically provide it's a bit, it's a bit complex. My role changed about a year ago.

Prior to that, I had a specific patient list and I looked after a nursing home and now I'm salaried and I come into contact really more as an acute situation. So I do more acute general practice and less chronic management.

INT:  
OK. Thank you. And how much of your workload is caring for people with dementia or mild cognitive impairment?

HP07  
Oh, good question, I would say. Ooh, I don't really know, probably quite look I I'd say probably about 20% in some form, although they may come with physical.

INT:  
Mm-hmm.

HP07  
Physical issues rather than the actual and cognitive impairment issues doesn't make sense.

INT:  
Yep, Yep. OK, so the come with physical issues rather than cognitive impairment issues.

HP07  
Yeah, that may be the presenting problem.

INT:  
and how many are taking multiple medications from those 20%?

HP07  
Almost all, in fact, all.

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

HP07  
So I assume you're asking about medication for all conditions rather than just related to managing mild cognitive impairment.

INT:  
Yeah.

HP07  
And say for the common cognitive impairment medication, so managing anxiety and that sort of or behavioural industries or things like that, I think we have less involvement for the physical issues.

We're probably the main instigator and prescriber.

INT:  
Umm. The physical issues, yeah.

HP07  
It depends on the level of cognitive impairment too.

INT:  
Mm-hmm.

Yes.

HP07  
So if there's involvement from the OPMH, then we won't make that medication decisions generally, but if they're not under OPMH, then we will make medication decisions

INT:  
Sorry, what was that?

HP07  
Older persons mental health.

INT:  
The acronym the

OK.

So if they're under there, then you wouldn't make the decision to start, right?

But you? But if they're not.

HP07  
Didn't really.

INT:  
Yeah.

HP07  
It's a bit of a generalization because sometimes we would, but generally we wouldn't, unless it's an acute issue.

INT:  
OK. Thank you.

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

HP07  
I think it's a brilliant idea.

INT:  
I could you say a little bit more about why, please?

HP07  
And because I think there's a very big tendency to start medication and the very and people are very apprehensive to withdrawal medication, which offers may not be of any benefit.

INT:  
Thank you.

HP07  
And I think it complicates things.

So and there are might be medications that you they really need to get symptomatic and help.

And there are some that probably are not gonna make much difference to them, and it's just the balance between qualitative life and the need to take multiple medications and side of things actually.

INT:  
OK.

It's that balance there as well.

HP07  
Yeah, but only gets hard is to stop medicines than to start medicines.

INT:  
OK. From and why?

Why is that?

HP07  
The state of doing harm.

INT:  
Umm.

HP07  
And even if it might not be anything to do with what you do, and they would tend to be in, I'm assuming I'm sort of slightly assuming everyone's relatively elderly. So no one knows what's ahead anyway, and you could stop something that ultimately causes.

INT:  
Umm.

INT:  
OK.

Thank you. And any other challenges around deprescribing?

HP07  
And. What?

Not really.

INT:  
OK.

HP07  
I faced family.

INT:  
Mm-hmm.

HP07  
May maybe may not want medications stopped other.

INT:  
And how do you kind of manage that situation?

HP07  
What a family.

INT:  
Yeah.

HP07  
Don't want medication stopped you normally. If you have a discussion about the rationale and the risks benefit profile, then. And I think it it's, it's a, it's a shared decision.

INT:  
Umm.

HP07  
You wouldn't.

You wouldn't unless it was a, a, a harmful drug.

INT:  
Mm-hmm.

HP07  
And from that you wouldn't go against family wishes to stop the medication.

And unless there was a very good reason to do so, and because you need, you need to have that shared decision with the patient, the family and what you believe is the right thing to do and you just discuss it and come to a shared decision really.

INT:  
OK.

Thank you. And any advantages to deprescribing that you can think of?

HP07  
Uh, yes, I should think so, in that I think there's a horrible percentage of admissions to hospital that are result of side effects of medication.

I can't remember what it is, but admissions to hospital a very large percentage in the elderly population are related to side effects from medications.

INT:  
Many challenge, sorry.

Any advantages specifically for people with dementia or mild cognitive impairment in terms of the deprescribing?

HP07  
Well, well, yeah, because it's just one more thing.

If they've only got to take, I'm imagining, although I don't know if there's any evidence, I'm imagining they have to take three tablets.

INT:  
Mm-hmm.

HP07  
That's easier to manage than if they've got to take six, so they're more likely to have compliance with the ones that are likely to be beneficial to them.

INT:  
Umm.

HP07  
If there are less of them, but also imagine the side effects can be more problematic in a population with mild dementia or with dementia.

INT:  
Mm-hmm. OK.

OK. Thank you.  
And just going back to the challenges again, we're going deprescribing.

HP07  
No.

INT:  
Do you have any thoughts of how they might be resolved?

HP07  
And evidence that it's beneficial. So there was a I don't know what it's called off the top.

INT:  
Umm.

HP07  
I think it's called stop with a double P or it might be with a double T don't remember exactly what it's called, but when we got the information about ‘*anticodon energetics’* and the combined effect of prescribing them, we definitely were more aware that we shouldn't prescribe these classes of drugs.

HP07  
That would cumulatively cause a problem, and we're much more aware of that now. Yeah.

So I'm.

INT:  
That evidence in the stop, stop, start, yeah.

HP07  
I mean, I wouldn't be doing this if I wasn't.  
I'm a big fan of research, so if you can prove that deprescribing is beneficial then you'll get people to deprescribe provided you can disseminate that information. Umm.

INT:  
Umm, OK, so that evidence in the research and dissemination as well there as well, OK, and what types of medications would you feel most comfortable deprescribing for people living with dementia or mild cognitive impairment and why please?  
Mm-hmm.

HP07  
What if there is a particular class and I'm trying to think?  
I don't think there's one in particular that I would feel any more comfortable and less there was evidence to back it up. So for example, I'd be quite happy if you were given different parameters for blood pressure for an elderly population or a dementia population. And they said we can tolerate a different parameters then I would stop the medication and stick within those parameters.

INT:  
Mm-hmm.

HP07  
Likewise, if we were told and this little evidence for use of SSRI's and in the dementia population, then we would, then we would do prescribe. It's actually I.I think there's a particular class that I would be more confident in deprescribing than others.

INT:  
Umm OK ah.

HP07  
So really, I'd be slight.

Yeah.

Commencing the cardiac drugs.

INT:  
OK. Could you say a little bit more about why please?

HP07  
While that obviously if someone has a cardiac history, they automatically get full medications now and that.

And the reason that they get them is that it's a proven better life expectancy.

So not generally for symptomatic relief. It's more to do with life expectancy and the theories.

INT:  
Umm.

HP07  
You stop something and then they have a heart attack, which may be nothing to do with you stopping it, but it's just that that is more of a final episode. If you set it to, I mean, whereas if you stop a, say for example an antidepressant apart from if there's an acute risk of, you know, suicide, which is actually incredibly rare, you're actually probably not likely to do significant harm except for they may become lower and mood. So it won't necessarily be such a final event.

INT:  
Umm OK, thank you.  
And then the other thoughts around medications, which you'd either feel more comfortable or reluctant to deprescribe your people living with dementia, or mild cognitive impairment?

HP07  
And is made the drugs that I have less knowledge of, and I'll be but I that, but the specifics of what those would be, I don't know because I'm trying to think what class of drugs we commonly prescribed and I faced the, the this sort of sedatives.  
If they're started by the end, a OPMH team, then I'd be I'd be more apprehensive, but the chances are that they would be under a OPMH and therefore I wouldn't deprescribe without collaboration with them.

INT:  
Umm.

HP07  
Umm so I don't see that being an issue and I'm trying to think what else?

HP07  
No, I don't.  
There's a particular class.

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

HP07  
And the ability to follow up proactively. Time, which we don't have very much of and.  
I don't think there are that many barriers. I think it would be seen as quite a positive move.

INT:  
Yeah.  
So sorry.

INT:  
What are the main things that you think need to be in place for successful deprescribing for someone education?

HP07  
And education and education and proactive support.

INT:  
Proactive support.

HP07  
But practice follow up.

INT:  
For up to phone.

HP07  
Sorry, I wasn't very specific proactive.

INT:  
Umm.

HP07  
So rather than expecting the patients to come back to you when they run into a problem, the ability to follow them up and book them in with a designated appointment to follow up.

INT:  
Designated appointment.

INT:  
OK.

INT:  
And thank you.   
And please describe your experience of having deep prescribing discussions with people living with dementia or mild cognitive impairment or their informal caregivers.

HP07  
I would say on the whole it's been always fairly positive, and I would say everyone's keen pushy, much not to take too many medications and unnecessary medications. Very occasionally, if they are, sometimes if you have dementia, they almost like.

INT:  
Umm.

HP07  
They like the fixed routine of what they're doing, and therefore they wouldn't. That I'd say that's the exception that they wouldn't want to change things. So actually even changing it so they like their fixed creatine. And I think if they're already on the medication and they're that type of person, they would struggle with trying to change it.

INT:  
Umm, change to the routine to yeah, OK. And anything else that you've observed that in terms of what works well about having those deprescribing discussions with people living with dementia or more cognitive impairment, all their informal caregivers?

HP07  
And just discussing why you're doing it.  
The reasons why you bring it up giving them options so not saying we are gonna do this, but just saying I wonder if so, being not vague but just giving them choices. Shared decision making.

INT:  
Umm.

HP07  
Basically, with either the patient or the family or both for well cause -  
Is it? I mean obviously if you've got a medication that's doing harm, then you'll stopping it and they don't necessarily have a choice about that. I mean, that's a, but I'd say that's the exception. That's very rare. Generally speaking, you've got a medication you think is of little benefit or no benefit, and the combination of all their medicines is becoming very complex and therefore you're balancing the risk with a possibly no benefit or minimal benefit.

..  
INT:  
Hey.

HP07  
And so if you just have that discussion, I would say that generally speaking, most people want to be on less medication, OK.

INT:  
And anything else that works well.

HP07  
I don't know if it works well, but I wonder whether a pharmacist who has a bit more time may be able to do the discussion better than we can.

INT:  
I'm on the other hand.  
Any challenges you mentioned there about the fixed routine for someone with dementia and struggles to around that?  
But anything else?

HP07  
And so I would say the problems, the challenges, are more lying within are my world so time.

INT:  
Time.

HP07  
That's it. The easier option is to carry on with what's there than create more work taking stuff away and then potentially having to reintroduce it or having a deterioration in XYZ.

HP07  
Say the challenge is time for my perspective or it's more with us than with patients.

INT:  
OK.  
Thank you.   
Who do you think is best place to be involved in deprescribing discussions in primary care for people living with dementia?

INT:  
Mild cognitive impairment.

Umm.

HP07  
I would say our pharmacist team that not everyone has a pharmacy team.

INT:  
And could you say a little bit more about why, please?

HP07  
Again, it's time.

INT:  
OK.

Any, any.

HP07  
It's exactly the time.

HP07  
I don't think they're knowledge is necessarily. I mean, I think they're drug knowledge is properly a bit better than ours, but I don't think it's actually much.

HP07  
I think we've got the knowledge. I just don't think we've got the time, unfortunately.

No.

INT:  
It's the time and are there any professional groups who you think should not be involved?

HP07  
And. Well, only days that are not haven't got the necessary knowledge about what they're stopping and why they're stopping it.

INT:  
OK, seven, one more around the knowledge, yeah.

HP07  
Yeah, it's more to do with the knowledge rather than anything else, OK.

INT:  
Than the professional group.

Yeah.  
OK. And who is best placed to lead the discussion around deprescribing?

HP07  
And I still think the pharmacist is fine and you could it depends.

You could have a nurse specialist.

There's some nurse specialist who would be brilliant and so, but it would depend on the medication that you're so. For example, if you got a nurse specialist in diabetes, they're the people who would need to deprescribe diabetic medication. You wouldn't wanna GP doing that, that's all and say it's just the specialist in that field, if that makes sense.

INT:  
Mm-hmm. Do you and are there any occasion when it is or is not appropriate to involve patients?

And this is patients with dementia mark cognitive impairment.

HP07  
I think you should always try involve the. Can I just go back to that specialist one?

INT:  
Yes.

HP07  
I just said I don't mean I don't mean specialists in secondary care.

I don't. So I don't think, I don't think they need to be involved at all, and unless there's a specific question or a concern about stopping a medication.

So when I say specialist, I just wanted to clarify and then a nurse specialist within primary care.

INT:  
Umm yeah.

No, that's fine, yeah.

HP07  
Sorry and I thought I thought if you reread that it might sound wrong. And what did you just ask? Sorry.

INT:  
Yeah, sure.  
Yeah.

INT:  
Are there any situations when it is or isn't appropriate to involve patients and that's patients with dementia? Mild cognitive impairment in those deprescribing discussions in primary care.

HP07  
And I don't generally, but if I if they were on a medication that was doing harm and I felt it was unsafe to prescribe to them. But they're dementia wasn't allowing them the capacity to process that information. Then we would obviously have to make a decision that they potentially would not totally understanding that decision. But then that's when they've lost capacity. If about that decision, so therefore it's more you, you can involve them, but ultimately if they can't make a decision with capacity about it then, then you've got to make the decision in their best interest with their family. So and that does happen occasionally. I can't really think of a situation where it has, but I'm sure it will have done.

INT:  
Yeah. So then generally involve them, but they don't have the capacity. Then you make that decision with their family as that. Is that correct?

HP07  
Yes.

INT:  
And again, when are there any situations when it is or isn't appropriate to involve informal caregivers?

INT:  
And I mean, family members buy that in those deprescribing discussions for those patients.

HP07  
I think it patients aren't. I don't have capacity or all capacity for that decision.

Then I think you should involve the family or the carers.

INT:  
Mm-hmm.

HP07  
But otherwise, ultimately, like with anything in medicine, if a patient has capacity, they should make their decisions themselves that you can. Obviously, we quite often will say, do you want us? Would you like? Would it be OK to discuss it with your family? Would you like us to discuss it with your family or but ultimately, if they have capacity and they say no, they're less. There's a very good reason you're not gonna go. You can't, you know, legally you can't.

INT:  
OK.

And thank you. And what do you see as the role of informal caregivers of family members in those deprescribing discussions?

HP07  
And well, I think they are definitely involved in all aspects of medical care if they want to be, which sometimes they do and sometimes they don't. And you have to remember that the patient is the patient and the family may have differing views to the patient or to yourself. And that happens. I, in my opinion very, very rarely. And again, you then have a discussion and if, if you're really in a position where you're being asked to do something, you don't think it's the most appropriate or in the patient's best interest, then you would involve someone else.

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

HP07  
And do you mean carries when they're in a home? Is that what you mean?

OK, what means like there, sorry.

INT:  
Yeah, sorry. So I think it's just more generally engaging with other health and social care colleagues to support shared decision making. It could be in in the home or it could be within secondary care but and anything you think about engaging with other colleagues across health and social care.

HP07  
And so I don't and I don't quite understand that question.

INT:  
Sure.

HP07  
If I'm really honest because I don't think we have engagement, so therefore I'm not sure how you would engage.

INT:  
OK.

HP07  
And obviously if you want to stop a cardiac medicine and they're under a cardiologist, you can ask the cardiologist for advice. If you're not sure what to do and we would do that with that if that's what you mean, we would do that without thinking.

INT:  
Umm.

HP07  
And if they lived in a nursing home, we would talk to the high home. If they didn't have next of kin, or they may liaise with the next of kin or the family or carers. If we're thinking about doing it, they may be the intermediary and yes, then we would definitely involve them in those if that's what you mean that we would involve them in the discussion.

INT:  
Yeah. Thank you. And what would insist engagement or involvement of patients living with dementia? Mild cognitive impairment and nor their informal caregivers in the deprescribing process.

HP07  
Sorry, say that again.

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

HP07  
Time again.

Time.

HP07  
Yeah, I think that's probably the primary barrier.

But also, if they're not living at home often, getting hold of family is quite hard.

INT:  
Umm.

HP07  
So if they live in a nursing home or a residential home, we can often spend a lot of time trying to get hold of carers. Uh with family?

INT:  
Thank you. And what would facilitate good communication with patients living with dementia?

mild cognitive impairment and then formal caregivers in deprescribing process.

HP07  
The communication from us or from.

INT:  
Yeah.

HP07  
Sorry again, I'm not so if there was any, if there was written information, patients really quite liked written information, not necessarily on paper, but the ability to. So if you could summarize the evidence, if there is evidence saying the evidence supports not giving too many medications to people as they get older, and therefore we are always looking for medication to, that may not be offering any benefit. And this is the reason if you give them that information as a general thing, then it provokes a discussion. I would imagine a leaflet like that would be quite useful.

INT:  
So that written information prevents discussion. OK.

HP07  
Thanks.

INT:  
And is that for the patients or and the formal caregivers both.

HP07  
Thank and it's great.

INT:  
Yeah.

INT:  
What language should be used in communicating information about medications with people with dementia or mild cognitive impairment? And their informal caregivers.

HP07  
And the language that they would understand.

INT:  
Umm.

HP07  
So quite some relatively simple language, but I mean they would could always ask for more detail if they wanted it, but the basic outline is probably better simple of.

INT:  
So simple language, but that opportunity again to be able to follow up again.

HP07  
Yeah.

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

HP07  
Sorry, say that again.

Again, sorry.

INT:  
Yeah.

HP07  
But I'm really.

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

HP07  
Yeah, I'm quite happy. Didn't to discuss.

INT:  
And any thoughts around what would help facilitate those patients involvement in shared decision making? Anything that works well that you've observed or thoughts around that?

HP07  
No, just giving them tie them time.

HP07  
So you might need more than you might need to raise it as a. What do you think about this?

Let them go away and think about it and then bring them back again to make a decision.

INT:  
OK. So that that that time and giving them time.

HP07  
Giving them more time? Not necessarily saying it is time for us, but also giving them time to process what you're saying to them.

INT:  
And any anything else that you think may help or you've observed as work well.

HP07  
And no, not really. I mean I not that I can think of.

INT:  
OK. And on the other hand, what are there in barriers to their involvement in shared decision making? What's not work so well?

HP07

capacity and their ability to process the information that you're giving them.

And I said, as I said, the routine if they've got a routine and things are just sort of as they are, they sometimes don't like change if you. So to me they would rather carry on with what they're doing and medicines can be quite complicated with the chemists, so they may. It may be in fact what to do with that.

INT:  
Mm-hmm. OK. And 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?

HP07  
I've no problem at all. I think that's something we do quite regularly about lots of things.

INT:  
And again, anything that helps facilitate their involvement in shared decision making that you've observed.

HP07  
Just to get in tight time on both sides, if you sort of mean same thing, let them think about what you're suggesting and then let them discuss it together probably at home with the patient as well .

INT:  
I said that that process time again and discuss with the patient and on the other hand, what do they kind of barriers to their involvement in shared decision making.

HP07  
Their barriers. You mean the carers?

INT:  
No, sorry. The barriers so it could be barriers generally to involving them in the shared decision making.

HP07  
Yep, I think it's just conflicting. Opinion. I think that's a difficult situation where the family wants to do something different than the patient, and that phone calls stress and anxiety for both.

INT:  
And how could those kind of uh areas be resolved or helped?

HP07  
We're just discussion. I don't think there's and presenting evidence and then hopefully making a shared decision.

INT:  
OK, that discussion and evidence and what tools the resources are needed to facilitate shared decision making in relation to deprescribing for patients living with dementia or mild cognitive impairment.

HP07  
And maybe highlighting a tool that highlights medications that may not be of any benefit and would be useful.

INT:  
And any other tools or resources.

HP07  
No, maybe website that tells you about, you know you can click on your medicines and look at the evidence or your in prescribing in dementia or mark or with different payment. So I don't know maybe that but I don't know how much would engage in access that.

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

HP07  
And I don't know how much they would be supported because it will depend on what service provision was in place

INT:  
Yeah, just how? Any thoughts around how best that might work though?

HP07  
At well, that's why I said I think you need formal follow up that that's why I said earlier.

HP07  
So you need to have them with a designated appointment to follow up after you've taken the medicine. And I would do it gradually and slowly. So you don't take lots in ?, you know, you don't stop lots. You just stop one and see how you get on and then stop another if there's more than one you want to stop. So I would do a slow process.

INT:  
Slow process of follow up OK and who should be following up patient?

HP07  
I didn't get matters.   
It can either be the GP or a pharmacist or a nurse specialist.

INT:  
OK.

HP07  
It's a person with the knowledge of those medications.

INT:  
That's it's going around the knowledge.

HP07  
Yeah.

INT:  
OK. And any thoughts around how often patients medication should be reviewed?

HP07  
No, not really, because it will totally depend on the medication.

INT:  
OK.

HP07  
Of.

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

HP07  
Knowledge is knowledge and time.

INT:  
Knowledge and time? OK. And on the other hand, what are the potential barriers to integrating shared decision making?

HP07  
But the answer is probably the same.

INT:  
It's type.

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

HP07  
So if there was evidence of summary sheet of the evidence of the benefits of deprescribing versus continuing, but if that ever, I don't know if that evidence even exists.

INT:  
So summary sheet, deprescribe

INT:  
Thank you. And any other thoughts around any training or educational needs that could support you? Or your colleagues.

HP07  
No, not really. I mean, just any education and any evidence would be useful.

INT:  
And then anything specifically for those patients with dementia or mild cognitive impairment?

HP07  
No, not really that I can think of.

INT:  
OK. And is.

INT:  
Is there anything else you want to tell me or anything you wish to add to what you've already said today?

HP07  
And no, not really.

INT:  
Umm.

HP07  
I've been involved in trying to in deprescribing previously for a trial and it was quite we were very positive about it and so we have had some knowledge about deprescribing, and it wasn't plain sailing.

HP07  
So, but I still think it's a good idea.

INT:  
Umm OK. Thank you. And you do you want to say anything more about what? Any thoughts around that you think might help?

HP07  
Umm, no, not really. Well, it just the trial was brilliantly run. So it was a bit problematic from that point of view, but I didn't think that was everyone's fault. But I thought the medicine and the idea behind the medicine was good. How the study was running with a bit complex.

INT:  
And anything else you want to add that you haven't already had an opportunity to do so today?

HP07  
No.

INT:  
OK, well, I've come to the end of the interview now, so just turn the transcript off.

Thank you.