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

**Transcript**

**HP12**

INT:  
Transcription facility started now. Can you tell me about the care you provide to people with dementia or mild cognitive impairment, please?

Participant:  
Yep, so I am twofold, really.

So first of all, for the patient themselves, I can carry out a home visit.

I carry out an assessment and that consists of how do they get their medications?

Do they know why they're taking them?

Are they safe in their home?

Practical things like shopping, you know who does the cooking?

Cleaning.

Do they need any help with that?

So we go through all that.

And I also look to see if they're due any reviews if they're under the older person's mental health team, or if they need any support or any social groups.

And then the other side of it is actually a support the carers and I have quite a lot of patients, families on my caseload and that could be that I get them help through an organization such as Andover mind.

So that they get a a person specifically to support them ongoing.

It could be make sure they've got the right benefits and any entitlements and also sort of some support for them in terms of emotional support and and and social stuff and.

And if a person is a veteran? and I make sure if they're happy that they can get access to an Admiralty nurse via Royal British Legion.

INT:  
OK.

Participant  
So it's quite involved and it's a big part of my caseload actually.

INT:  
Hi, thank you.

And umm yeah, that that kind of brings me on to that next question which is how much of your workload if you had to put a rough percentage upon it?

Participant  
I would say at the moment, obviously it's a changing animal, but I would say probably around 50%.

INT:  
50%, OK.

Participant  
Umm.

INT:  
Thank you.

And how many of those people are taking multiple medications?

INT:  
Would you say?

Participant  
I'm just about most of them and that's not always just just for the dementia, for the mental health, it's other health conditions as well, mainly due to their age.

INT:  
OK, great.

Thank you.

Umm, so the workload is usually 50% of the total is for people with dementia or mild cognitive impairment, is that right?

Participant  
Itch, yes.

INT:  
But then there's majority of your patients, including those rather reasons are are taking multiple medications.

Yeah.

Participant  
Yes.

INT:  
OK.

And what involvement do you have in there?

Medication management, please.

Participant  
I I make it clear that I'm not medical at all.

So all I do as regards to the medications is make sure they, you know, I ask how they get their medications, how they order them, do they get them to delivered?

Would they like them delivered if that facility is available?

Anything I can do to smooth it out and to take away some of the stress?

It may be that I go back to our prescriptions team within our PCN and ask for them to look at, perhaps, though, you know, a nomad for that person or, you know, whatever is appropriate and and also if they run out some medication and they haven't sort of been able to or don't know how to reorder them, particularly my patients and don't have anyone to care for them.

I ensured that that gets sorted and that's normally through our pharmacy or prescription team within the PCN I task them.

INT:  
Thank you.

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

Participant:  
What's my views?

INT:  
Yeah. Sorry.

Participant:  
Sorry, Cindy, it just slightly cut out the beginning, sorry.

INT:  
Yeah.

Yes.

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

Participant  
I think it's.

I think it's important for them to be taking the correct medication and some important that, you know, people are keeping their eye on it and that they're actually taking their medication because that's always can be a challenge.

But I have to say that where I work, our PCN is as a fantastic sort of prescription and pharmacy team that really do carry out the reviews, particularly the pharmacy team, and try and ensure as best they can that the people are on, you know, the the right to medications and get things sorted quickly.

INT:  
OK.

Thank you.

And any advantages or disadvantages in terms of deep prescribing of inappropriate medication for people with dementia or mild cognitive impairments and maybe advantages first please.

Participant  
So.

So the advantages of it I would say is that they perhaps have less medications to take.

INT:  
Mm-hmm.

Participant  
Is how I how I'm seeing that which is gonna be better for them and specific to their needs, because obviously things can change.

So I would say that's quite important.

Could you just repeat the question?

INT:  
Yeah, sure.

Participant  
Yeah.

INT:  
Sorry, so it's around your views of deprescribing inappropriate medication for people who who are living with dementia or Mark cognitive impairment.

And the specific questions was any advantages or disadvantages?

Participant  
Thank you.

INT:  
So we just discussing the advantages of deprescribing for those patients, yeah.

Participant  
I think some of the disadvantages is that people believe on certain medications or they convince themselves or the families convince themselves that that's the magic answer.

So if the if they prescribed item is taken away, that can cause either real problems or or perceived problems and worries for the family.

I have had carers that have done some research themselves.

I call it doctor Google and found out medications that they think their loved ones should be on and don't understand why the GP or whoever can't give that, and sometimes it quite persistent on that.

So medication could be quite an inflammatory subject.

INT:  
OK.

Participant  
Actually with my patients.

INT:  
OK.

Thank you.

And in terms of those challenges, any thoughts around how they may be resolved?

What might work?

Participant  
I think.

It is difficult one because obviously it's the social prescriber.

I'm I tend to be there and I'm I'm doing the home visit so so I'm there.

And so I'm a pair of eyes to see about the medications, but I have to be very mindful that I don't have the clinical knowledge to make any decisions about the medication.

So I think it's a good idea perhaps to be the pair advisor, actually.

INT:  
Mm-hmm.

Participant  
See what medications they are taking or see if I can, you know, find that out and they're taking in them and then report that back.

So I think they're there might be a, you know, a role there.

But otherwise, I think social prescribing shouldn't necessarily be used for that, because otherwise it starts turning into a different animal of what it's supposed to be.

INT:  
Right. OK.

Thank you.

Participant  
It's a it's a fine balance, is what I'm saying.

Yeah, yeah.

INT:  
And yes, fine balance.

INT:  
Thank you.

INT:  
And what types of medication and and it may not be appropriate to your to yourself particularly, but would would you feel most comfortable deprescribing for people living with dementia or mild cognitive impairment?

Participant  
It wouldn't.

It wouldn't know it, wouldn't it wouldn't apply to me because I I wouldn't have that.

No, I wouldn't.

INT:  
Not sure if that question is not no, it's not quite relevant and no no.

Participant  
Well, I wouldn't have the authority and I wouldn't have the knowledge.

INT:  
To yeah fit for Scribe directly.

Participant  
No.

INT:  
Yeah, sure.

INT:  
And in it it what what are the main things that you think would need to be in place for successful deprescribing for someone dementia or mild cognitive impairment and that might be from your perspective as a social prescriber.

So what?

Participant  
Yeah.

INT:  
What things might might help with that process?

Participant  
I think being in touch with with the patient on a fairly regular basis, I know there are time constraints.

I I do recognize that and some other challenges and and making it accessible for the patient as well.

So for example, a lot.

INT:  
No

Participant  
Uh, OK, it's a nightmare today.

INT:  
Hopefully you know that's just.

Participant  
Yeah, I don't know.

What?

What's going on today with my Internet?

It's terrible.

It's normally good.

INT:  
Yeah.

No, that that's fine.

That's that's good cause it's it's just it's gone back to the original transcription and continued.

That was absolutely fine, so don't worry if that happens again.

Participant  
OK, OK.

INT:  
We'll just umm, come back in or something.

Participant  
Yeah.

INT:  
Thank you.

So shall I?

Shall I go back to that question?

Participant  
I'm so sorry.

INT:  
Which is so it's fresh.

Participant  
Yes, I was in my flow.

INT:  
So it was about your thoughts of the main things that need to be in place for successful deprescribing for someone with dementia or mild cognitive impairment as a as a social prescriber, yeah.

Participant  
So making having regular reviews, I know there's time constraints on that, but also speaking with the with the person themselves, I think it's no good sending a a sort of an online questionnaire or a text.

You know, I think it needs to be accessible and also ensuring that there's permissions on their medical records for the patient with dementia, for us to talk to a family member so that we're able to effectively communicate if that's what's needed, to make sure that the person you know gets access to the right sort of medication.

INT:  
OK.

Thank you.

And I'm so the next question is about you describing your experiences of having deprescribing discussions.

So I'm thinking you may not have had those discussions in in your role, but have you had it might be perhaps you could describe the kind of discussions you may have around deprescribing?

Participant  
Yes.

INT:  
I know you're alluded to earlier in terms of the the carers perspective of that, so maybe those kinds of discussions which come up that might be helpful.

Thank you.

Participant  
Yeah.

Participant  
Yeah.

Participant  
So yeah.

So yeah, so the so the carers obviously asking about medication or researched about medication or indeed the person themselves, you know with the dementia, I get a lot of patience saying that the medication isn't working or they don't feel particularly well.

So we have a conversation around that, again me making it clear that I'm not clinical, but going back to that GP in tasking them to to have a an initial conversation with that person.

It's quite challenging to to to get hold of.

There's quite a wait to get hold of someone from older persons, mental health and a lot of the people with dementia are sort of diagnosed and then kind of discharged, if you like.

So there's kind of a bit of a wilderness after diagnosis, which I think there is a there is a gap in provision there of which we try and plug some of it social prescribers.

But there's a bigger piece of work that needs doing, I feel.

Right.

Yes.

INT:  
OK, so after that initial diagnosis from the OPMH team then then you say there's a this kind of gap where you're coming into to support, yeah.

Participant  
Yes, yes, yes.

Yeah, and sometimes it tends to be when when the person's crisis in case they don't know what support is out there.

It's not like they're giving a nice little handbook with his all the services that you can access, which is a little shame, actually.

INT:  
Umm.

Participant  
And then the carers kind of stumble along and it all gets a bit fraught.

And then I tend to get involved.

INT:  
Right.

OK, so you'll be there.

That that.

Yeah, there's initial discussions after the diagnosis and umm, in terms of those discussions around deep prescribing.

So the general discussions.

What do you think may help those those kind of discussions from from your perspective what what would be helpful for you?

Participant  
I think I'm a training for the social prescribers to be more equipped to have those discussions and, you know, feel more comfortable having them.

I think that's really important.

Perhaps being able to take that back to some kind of clinical supervision so I can speak about it further and that tends to be through, I mean, I can always go back to a GP, but I won't always get an instant response and sometimes a response is needed.

So it can be a little clunky, but I understand obviously the limitations of, you know, everyone's time etcetera.

INT:  
OK.

Thank you.

Participant  
No.

INT:  
So that's support training for social prescribers and then they're the linking with the GP's as well.

Participant  
Yeah, yes, yes.

INT:  
Yeah.

INT:  
OK.

Thank you.

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?

Who do you think is best placed to be involved in those discussions?

Participant  
I think, well, we have, we have, you know, teams within our SURGERY).

So I think it needs to be, you know someone that's comfortable having those conversations and knows what that what they're talking about.

So the prescription team and all the pharmacy teams, so either or.

So them having the discussions and then can perhaps help make those decisions.

INT:  
OK.

Thank you.

And are there any professional groups you think?

Who?

Who should or should definitely should not be involved in that, or or not?

Participant  
Umm, not necessarily.

you know I I tend to see it as you know obviously medications as a clinical thing but there is an organization that we use all the time.

Participant  
So (local) Mind and they have support workers, so perhaps some kind of, you know, training or some kind of facility that they can offer because they're supporting a huge number of patients on an ongoing basis with dementia or mild cognitive impairment.

INT:  
Right.

This.

Participant  
So they have the contract to support them, so maybe part of the contract could be built in in the future to to do this work.

INT:  
Yeah.

Thank you.

And would they also be involved in that that gap area that you mentioned after diagnosis?

Participant  
Yes, 100% they are.

They are, so they help with emergency care planning.

So if the carer for the person with dementia, you know something happens to them, what will happen?

Umm, you know ongoing support all the benefits, so anything and everything that helps that person stay well and independent in their own homes and and deal with the carers stress as well.

INT:  
Thank you.

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

Participant  
Umm, notoriously difficult to talk to.

We can do professional online referrals and the occasional emailing if we have an email address or for social worker.

But there does need to be more joint working.

Sometimes we do have MDT meetings every Tuesday, so there's normally a representative, so at least that allows sort of, you know, two way conversations about a specific patient or we can take a sorry specific patient to the MDT meeting.

So that's helpful.

I have carried out joint visits on my request and also social workers request to a patients house.

So that's worked well.

INT:  
OK. OK.

Thank you.

And what would desist engagement or involvement of patients living with dementia or mild cognitive impairment and their informal givers?

Caregivers.

Sorry, in the deprescribing process.

Participant  
Perhaps having some kind of sort of, you know, patient forum might be an idea where they've, you know there there's peer support and you know conversations around that or perhaps someone that's trained or people trained within the PCN that are able to access those groups, like dementia hubs, memory cafes, they've sort of things to have open conversations and let people know about certain things.

So, you know, perhaps going out into the community can into the community rather than relying on the patient to come into us.

INT:  
Thank you.

Participant  
Yes.

INT:  
So patient patient forums and someone frowned.

Participant  
Patient forums.

Yep, and that can take many forms.

It doesn't have to be obviously face to face those that want to do online etcetera, so make it accessible for all.

INT:  
Umm, so having a flexible approach to that?

Yeah.

Participant  
Yep, yes.

INT:  
Thank you.

Participant  
I'm.

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

Participant  
Well, just as I've said, so, some people prefer different different methods of communication.

Participant  
Always ask my patients or their carers how they want me to communicate, so whether that's text, call, email, face to face visits, meeting them somewhere, you know that's a little neutral or more convenient for them.

And we also offer patient dropping.

So anyone can drop in to us and we also have Andover mind at one of the drop inns and I'll let the patients and their carers know that they can access us twice a week through patient droppings.

INT:  
Thank you.

Participant  
Uh-huh.

INT:  
And so this this next question again might not be quite relevant, but it it may provoke some thoughts around this, I'm going to ask it is is in terms of how do you feel about engaging patients with dementia or mild cognitive impairment in shared decision making as part of the deprescribing process.

Participant  
Mm-hmm.

INT:  
So it might be your thoughts around that involvement of patients in that deprescribing discussion.

Participant  
So I think it's really important to involve the the patient because they it it's it's a patient LED service.

You know, they should be in and and have informed make informed decisions about their own care.

And that's a big part of my role.

So as long as they have, you know, a capacity and if they prefer to have someone with them to to, to kind of take notes, you know, whether that be a, you know, a care provider or a carer within the family, but absolutely essential that they're involved because it's about them.

INT:  
Yeah, sure.

And the same question, but now for informal caregivers of patients with mild cognitive impairment and shared decision decision making as part of deprescribing process.

Participant  
Yeah.

INT:  
What are your thoughts about engaging in formal caregivers?

Participant  
I I think that's important if the patient is happy for that, it goes back into again.

Obviously, you know respect consent data sharing, confidentiality, all those things.

So as long as they're adhered to and the patient is happy, then I don't see a problem with that at all.

Participant  
But once again it goes, you know, it's an individual circumstance and patient decision if they have capacity to make that decision.

INT:  
I thank you and any things that help involve patients in shared decision making.

Any thoughts what would facilitate their involvement in that?

Participant  
And again open, you know, open communication, collaborative working with other organizations that might be engaging with them.

Just giving them an opportunity to to have conversations with with, you know, with, with multiple people really I think is really important rather than just relying on their GP practice.

You know, they can have conversations, you know, with other organizations.

So for example, the Admiralty nurse and Royal British Legion, you know, be able to have these conversations and she will be able to deal with medications as well, which we can't.

INT:  
OK.

Thank you.

And what do you think are the barriers to their involvement patients involvement in shared decision making?

Participant  
It down to communication again.

Sometimes time constraints.

Umm them fully understanding things sometimes and obviously them some of them you know may forget or not fully understand so they may have capacity in some ways but in some ways less.

So I'm unable to absorb and retain information, so there are some of the barriers.

INT:  
OK.

I thank you and the same question around enablers and and barriers for informal caregivers.

What do you think may be the enablers or things that might help their involvement in those discussions?

Participant  
I think being accessible to them so that you know how to contact, you know, people that can help them, like the social prescribers, I think it's really important and again all the organizations out there in the you know, the voluntary sector public sector that can also support caregivers, you know, need to be able to have those those conversations.

So it's just widening the net a little bit.

So it's not just on social prescribers and GPS to have those conversations.

INT:  
OK.

Thank you.

And on the other hand, what are the barriers to their involvement?

Participant  
Well, patient not wishing them to be involved, old and and and even though the carers wanna be involved because they are because they caring if that makes sense.

INT:  
Yeah.

Participant  
And I think also we have to be very mindful that the family or the caregivers aren't speaking for that person.

There could be some kind of safeguard issue that that, that that comes up.

You know, we don't know all the family dynamics and so we need to tread very carefully on that because there could be all kinds of, you know, connotations around that.

INT:  
Sure, sure.

Thank you.

And what tools are resources are needed to facilitate shared decision making for deprescribing for patients living with dementia or mild cognitive impairment?

So what tools the resources are needed to help those that shared decision making?

Participant  
I think places where they could do that time to be given to be able to do that, understand how they can do that and understand what it is and understand how to give feedback on whether it went right or whether it went wrong as well.

I think it's really important because how can any any of us learn without feedback?

So I think that's important.

INT:  
Yeah.

Thank you.

And any existing tools or resources which you're aware of that that could be used?

Participant

Umm well, you know we can use online, obviously you know phone calls, emails face to face, speak to us at the drop Inns.

know, but there may be other organisations that already have the resources in place for shared decision making, but it's not something I've looked into.

So I wouldn't know.

I wouldn't be speaking with knowledge.

INT:  
Sure, sure.

And I'm how would patients living with dementia and mild cognitive impairment best be followed up as part of the deprescribing process?

Participant  
I'm having a review that's actually booked in umm it.

I tend to ensure if I book any appointments of my patients with dementia or mild chronic tip, I always try and make sure it's on their calendar, cause a lot of them live by their calendar.

INT:  
Umm.

Participant  
So I make sure that that's on there.

So it's those little practical things as well.

INT:  
And.

Participant  
I also gently remind remind them so.

It depends on what communication method they prefer.

So for example, some say to me or text me on that morning to remind me that I'm seeing or speaking with you at 12:00 o'clock for example.

So I tend to do that if I'm able to umm, so it's it's just the little things that make it sort of, you know, gentle reminders and make it accessible for them and and regular you know if you can, I think that's a really important of regular appointments.

INT:  
Think it's going OK?

How how do you how do you make sure it's in there?

Their calendar, for example.

Umm.

Participant  
I I physically either help them to put it in there or I put it in there, or I would if if a carer excuse me if a carer organisations involved with them.

INT:  
Mm-hmm.

Participant  
I also let them know as well and ask them if they're going out and visit.

Can they make sure you know, however, that person likes to remember or put it on their white board?

Or so I try and ensure as best I can.

INT:  
OK.

Participant  
Obviously you know there's going to be some that fall through the gap, but.

INT:  
Thank you.

INT:  
And I'm can you identify any training?

Participant  
Hey.

INT:  
I know we touched upon a bit earlier or educational needs for you or your colleagues to enable you to safely stop unnecessary medications for someone with dementia or mild cognitive impairment, please.

Participant  
That that would be quite an involved training because obviously that would be involving, you know, medication and prescriptions and I'm not sure that's something that we would touch on as social prescribers.

So it's a bit of a difficult one to answer.

In my particular role.

INT:  
Sure, this is there anything in, in your role that might help you for for your role as part of that?

Participant  
I I well I I have advised my manager that I found it really useful.

INT:  
Umm.

Participant  
So when I was in a previous PCN, I actually did an introduction to medical terminology course and some sort of basic terminology.

And you know, health conditions and all that.

And I've I found that really really useful.

So that may lend itself, I found it useful in terms of actual medications themselves.

I mean, I've done things like I did a Level 2 and mental health where obviously we looked at different types of dementia and the different types of medications for that dementia.

So that may be another suggestion.

INT:  
Umm, thank you.

And is there anything else that you think is important that you wish to say about deprescribing for people with living with dementia or their family caregivers that you haven't been able to say as yet in the interview?

Participant  
Don't think of anything off hand, no.

INT:  
OK.

Thank you.

No, that's that's really helpful.

Participant  
Oh really?

INT:  
Well, we've come to the end of the interview now, so I'll just, yeah.

So I'll just, I'll just stop the transcription for you.