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

**Transcript**

**HP14 (OPMH)**

INT:  
OK, so the transcription has started now.

Participant  
Umm.

INT:  
So the first question, it's just quite an open question is can you tell me about your involvement in medicine management for older people with dementia or mild cognitive impairment, please?

Participant  
So, as in all the circuitry I'm involved in prescribing medications, so prescribing medications for all the people, whether it's for functional mental illness but from depression, anxiety, sycosis, bipolar, including people with dementia, starting them on as tall Coleman Astris? inhibitors, memantine and if need be anti-psychotic medication.

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

Participant  
I feel very strongly about this.

Uh, and I think this is something I try and incorporate in my practice.

If I a particularly see there's someone on a cocktail of medications and they don't make sense and to try and work with the patient first to see how much we need.

All those medication, is there a need to rationalize?

Umm is there a benefit in continuing medications which they've started many years ago, and especially if they've been medications which give them more anticholinergic effects, are going to affect their cognition?

So I kind of stopped having conversations with people when I see them and if I see them on medications like this, just start having conversations about what are their views and how would they.

How would they consider whether you know if you wanted to come off that medication slowly and the need to stop it? Yeah.

INT:  
Thank you.

And how much are you involved in decisions about deprescribing?

Participant  
Umm, I think as I'm in my letter part of my training, so hire training.

So I'm pretty autonomous in the way I can see patients assess patients, treat and deprescribe.

So I don't always have to check in with my seniors, so I feel quite OK about taking that decision of deprescribing with the patient and working with primary care, working with the GPS.

So I've done that in my laptop? part of my training.

INT:  
OK.

Thank you.

And I'm who?

Who else drives involved with you in decisions about deprescribing, please?

Participant  
So it would mainly be primary care which is the GP, because that's usually where the medications come from.

Working in (name of locality), we also make sure that we if there's a medicines at home team involved and especially if they are involved in setting up the nomad for the patient.

So we'll try to get them on board and say that this is the particular medication we're trying to stop.

So as to make sure that that medication doesn't go in the next. Yeah. So it's mainly the patient, if the patient has the next of kin who's involved and with the patients consent we involved them.

But yeah, usually it's this, uh, these are all the people I would interact with in deprescribing.

INT:  
Thank you.

And what are your thoughts about advantages of deprescribing?

Firstly please.

Participant  
I think it is.

Umm, just if I give an example of medications such as umm, I'm a trip to line which has got so many anticholinergic side effects and the anticholinergic burden it has on people with cognitive impairment and dementia just trying and reducing and easing that burden makes such a big difference.

And I think having that conversation with people about how this can just, you know, have an effect on their cognitive ability.

Stop it from worsening.

Just improve that quality of life and especially with anticholinergics which give other side effects with dry mouth, urinary retention, Constipation, just making that small difference, sometimes patient see improvement in themselves.

INT:  
Thank you and any disadvantages on the other hand?

Participant  
Think does it montages?

I've found in my practices when somebody has been on a medication for many, many years and I don't know whether it is a cycle logical level of dependence on the medication.

But then when we try and reduce and stop it.

They may not experience it withdrawal, but I think it's a know whether that medication was serving some kind of a person having a placebo effect that occasionally my patients have wanted the medication back.

But if they've had that choice at, that's what they want.

They have actually felt better about it, but that's what I've always found.

It's people who I've been on it long term, maybe reluctant to come of it, and if they do come of it, suddenly feel the need to go back on it.

INT:  
OK.

Thank you.

And any challenges as well in terms of the deprescribing?

Participant  
The thing challenges are, one is, I would say the lack of knowledge and proper guidance sometimes in wanting to if I wanted to reduce that certain medication, how do I communicated effectively to my patient in showing what deprescribing would achieve.

Maybe if there were better tools out there that could be communicated to patients, it would make deprescribing a lot easier, more useful.

So I think precisely it's the lack of knowledge and guidance around.

INT:  
OK.

Thank you.

And any thoughts around how those challenges might be resolved?

Participant  
Again, I think coming back from a simple if there were guidelines appropriate guidelines that everyone could follow and everyone's on the same page and so everyone's following the same thing and all GP's are following the same thing, all community teams are following the same thing.

Inpatient teams are following the same thing, so I think if there was appropriate guidelines which are standardized and everyone's on the same page, everyone's following them so that there's consistency in the service we are providing.

INT:  
Mm-hmm.

Thank you.

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

Participant  
In practice, I've found taking people off medication such as the tricyclic antidepressants like amitriptyline, so I'll give an example of this particular one because this is one I feel most comfortable.

With uh one is, I understand the medication.

So it is, uh, synthetic medication in the 1st place, but in primary care it gets prescribed for all sorts of other things.

Start from sleep to pain and people have been on it for years and years without somebody having given a second thought to it.

Seeing is there a need to review this at some point and so when they come to our service, I think that's the time I feel comfortable enough and confident enough to have that discussion.

The patient about coming of medications, which I've got good knowledge about.

INT:  
Thank you.

And what medications and the other hand would you be reluctant to deprescribe and why?

Participant  
I think medications such as opioids.

Medications for their urinary incontinence, again because it's not my area of expertise.

I don't know enough and I don't know enough alternatives to suggest, so that's where I'm more reluctant to advise.

INT:  
OK.

Thank you.

And anything that would help encourage you to support reducing those medications that that you've been reluctant to anything that might help.

Participant  
Yeah.

Again, if there was a proper guidance to follow, there were guidelines on this, how you can try and reduce this particular opioid medication.

These are the alternatives, so if there was a set a set of guidelines to follow that I know I'm doing it safely, then I would feel safer to do it.

INT:  
Thank you.

OK.

And sips for just bear with me.

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

Participant  
I think most importantly is the.

Uh.

Ability to know.

First of all, the list of medications people are on and I think we're quite good at on our referrals and I think they've got ‘system one’ in (name of area) so it's uh, which allows us to have an idea, an excess, what medications people are on.

So that's one good thing.

Umm.

And secondly, I think it would be, can you repeat that question again, sorry.

INT:  
Yes, of course.

Yeah.

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

Participant  
And I think during assessment is time to have that discussion to address the medication and if there were handy guides uh on deprescribing on stopping certain type of medications in dementia or what type of medications make cognition worse.

I think if they were handy guides which clinicians could discuss with their patients, I think it would umm sit better with patients rather than doctor making this changes alone, patients are able to see that this is actually a recommended thing.

There's guidance around it and I know I would feel safe for knowing that these are the alternatives.

INT:  
Umm.

Participant  
If there was a handy guide patient handy guide.

INT:  
OK.

Thank you.

And how much are you involved in?

Or do you support decision making around?

Does it deprescribing that takes place in primary care?

So how much are you involved in?

Or do you support decision making around deprescribing that takes place in primary care?

Participant  
Yeah, I would definitely all support that.

I think we work very closely with our primary care teams with our GP.

So I think we're quite good in a communication letters to our GPs where most recently I can think about how we talked about think reducing somebody who was on? amitriptyline and stopping it.

I just communicated it with the patient first, but communicated this with primary care just via ohh my clinic letter.

I'm actually this got Communicator.

I think that my the GP received the communication and they acted on it.

They called the patients, had the discussion and they worked on reducing and stopping them at amitriptyline.

INT:  
OK.

Thank you.

And what are the barriers or facilitators of your of being involved in those deprescribing decision making in primary care?

Anything that you've noticed, what helps or on the other hand hinders that process?

Participant  
I think sometimes when there is lack of an alternative medication, if you've stopped something and then the patient wants something in addition, sometimes again lack of knowledge.

What is the other alternative?

How how do we solve this?

There are certain medications I would be able to know an alternative and recommend, but I may not know it all, so I think it's lack of knowledge.

INT:  
OK.

And and on the other hand, what are the facilitators?

Participant  
I think it's the openness and engagement which I've received from the GP's who have taken on board if we've suggested a medication change in terms of deprescribing, we've had positive response to it.

...  
  
We've not met it with reluctance.

We've actually had GPS come back to us and say this is what you proposed.

And yes, we've taken them off this medication and if they wanted to discuss an alternative in the future, we happy to discuss that.

So I think it's the fact that cheapies are also in collaboration.

Participant  
Umm.

And working together and I think in system one allows us to know what's happening in GP land.

So that's a big advantage I find working in Portsmouth, so if I've had a discussion about deprescribing, I can see on the other hand, when the GP has consulted the patient, they've actually had that conversation.

So System one allows that.

INT:  
OK.

And it is that not the case in in other localities, our system.

Participant  
That's not the case in other localities where I've worked in .... and there were and I've not had the benefit of seeing what's happening in primary care.

It's not always communicated back to us.

INT:  
OK.

Participant  
Yes.

INT:  
So accessing that that system and seeing that communication, yeah, OK.

And how do you?

Sorry one follow up question was any other thoughts about what may assist engagement with primary care colleagues to support shared decision making?

Participant  
I think just be communicating better.

Uh.

Maybe if we had some joint training sessions on uh deprescribing, maybe again, I come back to the fact that I think we do need guidelines in place on deprescribing so that it's not different to what GP's are doing.

It's not different to what's archivists are doing.

One common set of guidelines so that all of us are following, and so that that's why that will enable the consistency and ease of doing it.

INT:  
Thank you.

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

Participant  
Much easier in people with mild cognitive impairment.

Uh.

Where they still have that ability to make decisions, a people with dementia.

Again, it depends how much they have progressed in their dementia, and are they able to partake in decision making.

Most people with mild to moderate level of dementia still have that ability to make that decision and are able to take part in those discussions.

Umm for people with dementia who have progressed considerably in terms of their cognitive decline, they may not always be able to make those decisions.

And that's when we have to rely on their next of kin.

Umm.

Or someone who's a quarterly legally appointed a power of attorney for health and welfare to discuss.

Have a discussion with them.

Yeah.

INT:  
Thank you.

And any other barriers to UM, involvement in shared decision making for those patients you mentioned.

Participant  
Umm, I think it would be people who have a progress quite far in the dementia, you know, moderate disappeared level of dementia are not able to make this decision from themselves and then they do not have anyone.

But to make those decisions?

Umm, so it's uh, it's as if the doctor is making it for them.

So those are the ones we often struggle with because we're just doing it in their best interest, but there's nobody else to advocate or have that discussion for.

INT:  
OK.

Thank you.

And on the other hand, what would facilitate their involvement in shared decision making for those patients?

Participant  
I think during our clinic assessments we invite patients to talk about medications.

So I think that's open discussion, open and honest conversations about medication.

Earlier on, trying to make sure that if they are not able to make that decision, would they want a family member with them, who else needs to be involved in medication change decision making?

Umm, involving uh, do you want us to speak to your GP?

Participant  
So I think having those early on conversations with patients to say if you're struggling to make this decision, who else can be liaise with?

Is it your family or is it your GP?

INT:  
Thank you.

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

Participant  
Again it to, but my clientele that the demographic of population I see in all the people are the language needs to be really simple.

Uh jogging free.

If possible, uh, so that patients understand it, uh, so we still talking about what the implications are of medications and deprescribing the side effects, the benefits, but it needs to be in more simplified language.

So the handy guides if I'm talking about need to ensure that it is communicated and very clear.

Simple steps.

Yes, that would help.

INT:  
It's simple steps.

Thank you.

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

Participant  
Yeah, I feel quite comfortable.

Participant  
Uh, so for many of my patients, it is sometimes making the decision because they are unable to and the caregivers are able to make this decisions with the doctors, with the healthcare team.

So, it's been very comfortable decision making process.

INT:

And again, what would help facilitate their involvement, that's the informal caregivers of patients with dementia, mild cognitive impairment.

What would have facilitate their involvement in shared decision making?

Any thoughts or reflections?

Participant  
I think it all boils down to better communication. So right from our very first assessments, when we do, even if you've seen the patient on our own taking the patients consent and saying ohh is there somebody I can talk to about your care about your medication, about your diagnosis, having those conversations early on and liaising with caregivers earlier on rather than making that hasty decision at the last minute.

So I think engaging with them earlier on, better communication.

Umm, but patients consent.

INT:  
Thank you.

And, umm, on on the other hand.

Any thoughts of around the barriers in facilitating those shared decision making with informal caregivers?

Participant  
I think it says, uh, there are there's I think there's a small portion of our population where the but they are very much on their own and do not have the comfort of having are the caregivers around them.

And I think that is a barrier because then we are leasing just the healthcare team is just liaising with the GP and there's nobody else involved for that patient.

INT:  
Thank you.

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

Participant  
Again, better communication aids.

Handy guides.

Tools.

But you if something was in writing rather than, I think it might population a lot of our things are online sometimes and they struggle to get on to these systems online or navigate their way online.

Participant  
So I think if there was something in paper.

Participant  
On a card on a guide out which we could give to people.

Participant  
And then they've got it with them.

INT:  
No, I.

Participant  
That helps because I think that is the biggest disadvantage we have because a lot of things, there's lots of stuff online and it's not really jargon free.

Participant  
It's not very simplified.

INT:  
Wouldn't.

Participant  
It's got quite complicated language on it, so I think there is a need to simplify things and to have things on paper and that can aid communication, because then it's there's a leaflet, there's a guide you could keep to the patient or the caregiver. Umm.

Participant  
And then everybody's singing from the same hymn sheet, she'd.

INT:  
Thank you.

And UM, in terms of a HEALTHCARE colleagues, any thoughts of tools or resources which would be helpful to facilitate shared decision making for those patients?

Participant  
Again, this I would say the same thing.

It's about having those common handy guides.

Participant  
Uh, we've got guides for people who are on anti psychotic medication, for example.

What is it that you know?

What checks need to be done?

What bloods need to be done, they've got flow charts on there.

Umm.

And they're not just online.

We've got them on paper in print.

Uh so, but my nursing staff go out and see patients and they start them on antipsychotic.

They know that they can show the patient, their caregivers.

This is the set of Bloods that need to be done.

This is what we'll need to be looking out for.

It's very clear it's.

Uh, it's very stepwise and I think that is a sort of thing which we are lacking when it comes to deprescribing.

We do not have access to any of these tools.

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

Participant:  
I think again it's spending time with patients spending time with their caregivers, talking them through the guide.

I'm hoping them understand what is the change which we are suggesting. What we are proposing, what are the benefits of it?

What are the downsides of it making it very clear using that very simple language? Yeah.

INT:  
Thank you.

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

Participant  
I didn't would be. Uh one thing what we do in our services, if we have proposed a medication change, it's important.

Participant:  
It's our responsibility to follow up what's happened with that change and not just discharged their care GP sometimes or if even if we have discharged AG's, it's a very important that we communicate that the GP follows up or reveals the change.

What's happened?

Most of my patients, if I proposed a change, will remain on my caseload, at least for the short term, so that I can follow up.

I can have another visit or I can have another review where we can see what what's changed.

What's happened? Umm, so I think that's that need of follow up or review, if not by the service who's done it or at least have we communicated to primary care that this actually needs to be followed up.

INT:  
Umm OK, thank you.

And how often should patients medication be reviewed?

Participant  
Umm, so I think that will very much depend on what medication it is.

So uh, I wouldn't be able to answer that on the ohh, you know, on top of my head.

Uh, so patients who come to us for initial assessment are obviously would see them if I've done a medication change, I usually follow them up in four to six weeks time or sometimes earlier.

But again, as I said, it would depend on what medication it is.

But if there was a handy guide, it would inform all of us how to follow up.

Went to follow up and then then GP's have a guide and as well to know when to follow up this person.

INT:  
Key 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, please.

Participant  
Yes, I think there's definitely a big uh training gap that we all know that we've got medications with anticholinergic side effects, anticholinergic burden, but I don't think any of us are properly trained or have had that adequate amount of training.

It's very much self study or reading up the modestly or reading up some papers online and trying to figure out your way.

So that I don't think we've had any formal training in place to say how, how do I go about doing this with I think in Community teams, you can always go back to your supervisor if you're working with and say, well, I want to work with this patient and come off.

amitriptyline and your supervisor will guide you how to do it, but I don't think there's that consistent level of training everywhere.

INT:  
Thank you.

Participant  
Does the real gap?

INT:  
OK.

And how could these needs be best met?

These training or educational needs.

Participant  
So this all would need to be part of our training, I think if it was part of our curriculum or isn't, it's not part of the curriculum, but I think whatever teams we work in, but it's community inpatient or lists or whether there was a training module or training delivered, uh, particular specifically what deprescribing.

I don't think I've ever come across any training module on deprescribing as so far.

INT:  
Thank you. Finally the last question is, is there anything else you want to tell me, or you wish to add to what you have already said please?

Participant  
Ohh no I don't.

I think I've hopped on and on about the handy guides and need for guidelines.

And then the last bit yeah, need for additional training, yeah.

INT:  
OK.

Well, we've come to the end of the interview now.

I'm just going to stop the transcription.

Just bear with me a second.