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

**Transcript**

**HP11**

INT:  
So first question is, can you tell me about the care you provide to people with dementia or mild cognitive impairment, please?

Respondent:   
So currently the care that we provide is I work as an outreach part. What my part of my role is called outreach. Two mornings a week I will visit the elderly usually, and the house found quite often they have got dementia. Umm, so that can be there can be. The reason I would go out to visit is it could be a new onset of more confusion.

It could be that it's actually just new confusion and memory loss straight away.  
So part of that would be bloods, just a general kind of talk, referring them to the older person's mental health team. So that's kind of my input as far as dementia is concerned.

INT:  
thank you and how much of your workload is it please?

Respondent:   
When I do my outreach roll, I'd probably say is umm about 50%.

Umm.

INT:  
50% OK.

And how?

How many of those people are taking multiple medications?

Respondent:   
probably about 90% of them, yeah.

INT:  
90%, OK.

Thank you.

And what involvement do you have in their medication management?

Respondent:   
Unless they're having problems with.

Sort of administering their medication. I don't really so I could set up like the nomad trays or those kind of things for them, but do that quite a lot because then they're not confused about what they're taking if they haven't already got that set up. But that's really where my input would stay apart from actually taking medications out of the home. That's the other thing that I probably end up doing. Or when I sent up the nomad trays, actually removing all the other medications.  
But that's about it.

INT:  
Thank you.

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

Respondent:   
I'm all in favour of it, really, because I think quite often they just left on stuff that's no benefit whatsoever. So yeah, get them off as much as they as you possibly can.

INT:  
Thank you. And any advantages or disadvantages that you can think of regarding deprescribing of inappropriate medication with people with dementia?

Respondent:   
 less confusion. Nobody likes taking medications anyway. Uh, you know you're cutting down the additional stress that it's putting on the body by processing all of this stuff.

And it saves money so there isn't. I think I think it's a win, win situation all around really.

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

Respondent:   
Umm, I think it would depend on the age. Umm, but for the majority of people that are in their kind of 80s, maybe 90s, we see a lot of people in their 90s as well. Umm, things like statins. Umm, depending on their mobility, I would say things like, you know, the bone reinforces but depends whether or not there are some sort of mobilising around umm, all the usual things that like blood pressure medication or heart medication or diabetes or anything like that, then that has to stay.   
But there's a lot of other things that just, you know, that just don't need to be there really. So I think it depends on the age of the person.

INT:  
OK. Thank you. And what would encourage you talk to support reducing or stopping a medication?

Respondent:   
I think patient. Not compliance.   
Concordance. Uhm yeah, I think. I think everything's just over prescribed anyway, and there comes a time when that leads to start. So I can't say that there's anything specifically that would make me want, you know, that would that would spur me on to do that.

I'm very in favour of it anyway.

INT:  
And what medications would you be reluctant to deep prescribe and why?

Respondent:   
What anything sort of cardiovascular. So heart medication, blood pressure medication, diabetes.

Umm, you know anything that was if they have an autoimmune problem. Yeah, there's there's a. There is a big group stuff that you wouldn't want to stop.

INT:  
and if you could just say a little bit more about why those medications please.

Respondent:   
Well, their life, if you stop them, their life threatening.

INT:  
OK.

And what would be the reasons for you to not support reducing or stopping a medication?

Respondent:   
It is gonna be beneficial to the patient. So if none of that is is beneficial, then there's no reason to stop or start anything. Umm, so yeah, it's really it's really just about what's in the best interest of the patient.

INT:  
OK. Thank you. 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?

Respondent:   
I I think a good history. So a good understanding of what's going on at home. Are they going out and about? Are they likely, you know, are they prone to falling? Is there osteoporosis that they likely to fracture? UM, so I think a good all round kind of like, you know, from the carers from the family.

So really, for as far as they prescribed me as concerned, I think it has to be knowledge of what's happening, a good knowledge of actually what's happening.

INT:  
Good knowledge. Thank you. And umm, please describe your experience of having deprescribing discussions with people living with dementia or their informal caregivers.

Respondent:   
Umm. So majority of times people are quite happy to not have extra medication. I would say umm, there are sometimes those people or family members. I would say that it gets twitchy when things are stopped because they feel that they're, umm, sort of. Yeah, there there's a very good reason why they would prescribe those things in the 1st place. So why are you stopping them?   
So some people do get a little bit twitchy. I'd say it's probably more family members than the actual person themselves. Most people can't wait to stop taking hundreds of medications.

INT:  
OK. Thank you. And what works well about those discussions?

Respondent:   
I think knowledge really and explaining why they were started on these medications in the 1st place and why they're not actually now appropriate.

INT:  
OK. Thank you.

And what challenges have you encountered? I think you mentioned there about family members getting a bit twitchy.

Respondent:   
Yeah, I'd say, yeah, I'd as people think they're either missing out and things don't they.

So, umm yeah, I'd say it's though it. I think I've already. Yeah. covered that.

INT:  
OK.

And any thoughts around what would help facilitate those conversations with family members?

Respondent:   
Oh, No, I don't think there is anything specifically that would help facilitate them.

I think they just have to be had, don't they? And again, it's your knowledge and experience. Ultimately, it's there, you know, whoever's next of kin. It could be their choice.   
So they make that decision ultimately.

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

Respondent:   
When there's when you've identified a need. So when you've identified a need, they don't need to be on that medication. So when you identify a a need for them not to be on that medication . However, that is so it could be a telephone. It could be a face to face appointment. It could be a home visit it could be. It could be flexible. It's in whatever form it needs to to be.

INT:  
OK. And what should happen in those discussions?

Respondent:   
Umm. Look at really just outlining all the things that I've just said previously. So the whys and the yeah, the wise and wherefores as to why you're stopping them.

INT:  
OK. 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?

Respondent:   
Everybody. So the patient, the family and the practitioner. Umm yeah, all of those people.

INT:  
OK. And are there any professional groups who should or shouldn't be involved?

Respondent:   
Oh. But I don't particularly think the cleaning lady should be involved or so. Yeah, I mean I think that's that's individual, isn't it really, I don't think that would have to be done on an individual basis.

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

Respondent:   
….advanced their dementia is umm, you know if they still have a relatively good capacity and and and are able to make those decisions then that's always good to involve them.   
But if they're dementia is quite advanced, then clearly not. It'd have to be done in best interest.

INT:  
OK.

Thank you. And when is it appropriate or not appropriate to involve informal caregivers such as family?

Respondent:   
Well, I think if there's a conflict of interest, definitely not. And that does happen.   
And equally, if there has been issues within within the family, ie they've been under some kind of safeguarding from neglect due to family care, or if the family member themself has got dementia, then clearly that's not that's, you know, not really helpful either.

INT:  
OK. Thank you. And what would assist with health and social care colleagues to support shared decision making?

Respondent:   
Oh knowledge probably.

I don't really know. I can't really answer that one because that's that's their remit. Not really mine.

INT:  
OK. Thank you.

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

Respondent:   
I don't know what would assist them. I suppose it's how it's explained. I don't.   
You know, I don't have an answer for that one, sorry.

INT:  
Thank you. And what would facilitate good communication with patients living with dementia and all their informal caregivers in the deprescribing process? Any things that might help?

Respondent:   
Yeah. So there's obviously you know you can use visual aids. But it's, yeah, we don't tend to use that very much. Really. Um, so we tend to just talk about the whys and the wherefores and why she don't things and why you shouldn't take things we don't tend to use the visualized but you can use things like that.

INT:  
OK. And if you could tell me a little.

Respondent:   
There's the information leaflets for the drugs and so there are those other eight.

INT:  
Tell me a little bit more about why you prefer not to use the visual aids.

Respondent:   
We I don't have access to them.

INT:  
Umm.

OK.

Do you think they could be useful?

Respondent:   
Oh probably not in my role, no. The sort of things that I'm deprescribing aren't, um, people aren't.

I've never really been asked to use them, and people tend to understand quite but easily.

INT:  
Thank you.

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

Respondent:   
Ah well, whatever language they speak, I would hope. Is that what you're referring to?

INT:  
Yeah, could could be broadly in terms of language they speak. And then just in terms of terminology. Yeah, I think the terminology and the how it's word, it has to be, you know, for some people less wordy, for other people, it can be so it has to be appropriate to who you're pitching it to.

INT:  
OK, appropriate to the- to the person.

Respondent:   
Yeah.

INT:

How do you feel about engaging patients with dementia and shared decision making as part of the deprescribing process?

Respondent:   
How do I feel about it?

INT:  
How how do you feel about, yeah, engaging patients?

Respondent:   
Yeah, absolutely. Well, yeah, they should be. It's their care.

INT:  
And any thoughts around what helps facilitate patients with dementia living with dementia?

Their involvement in shared decision making, anything that works well.

Respondent:   
Umm, nothing special, nothing specifically that I haven't already covered. So I would say knowledge and usually the the chance to get off some of their medication is usually what will clinch it for most people.

INT:  
And are there any barriers to patient living with dementia, involvement and shared decision making?

Respondent:   
Oh. No, I haven't come across any.

INT:  
OK.

And how do you feel about engaging informal caregivers?

Sorry, informal caregivers of patients with dementia and shared decision making as part of the deprescribing process.

Respondent:   
Sorry, can you say the beginning part again?

INT:  
Yes. Sorry.

So how do you feel about engaging informal caregivers? For example, family members of patients with dementia in shared decision making as part of the deprescribing process...,

Respondent:   
Well, yes, absolutely.

It should be. Yeah, that should be encouraged.

INT:  
OK. And any thoughts again around what would help facilitate their involvement in shared decision making?

Respondent:   
It would be the same answer actually as the one that was before, so it would be no different the answer.

INT:  
So the knowledge and.

Respondent:   
Yeah.

INT:  
What tools or resources are needed to facilitate or help shared decision making in relation to deprescribing for patients living with dementia?

Respondent:   
Umm, we don't tend to use any. I have to say we don't really have any tools that we use.

It's really a conversation. And that's pretty much it across the board in general practice.

INT:  
  
And is there anything that guides that conversation?

Respondent:   
With each person is different. I would say probably, you know the GP's or the pharmacist teams, they've all got their own ways, haven't they have of doing things so.

INT:  
OK. And how best would patients living with dementia and their formal caregivers be supported during the deprescribing process?

Respondent:   
Umm well they they be given the support that they asked for. I can't say that most people need support. Umm yeah, I I can't say that they really need a massive amount of support.

INT:  
OK.

INT:  
And just just thinking again about the tools and resources, are there any things that you think might be helpful?

Respondent:

Yeah, I don't know because we don't use them. So I don't know what's available.

INT:  
Yeah.

Respondent:   
I can't really answer that one.

INT:  
So that that's that's fine. How best would patients living with dementia or mild cognitive impairment be followed up as part of the deprescribing process?

Respondent:   
  
So we would, they would be a follow up. So we would generally do, UM, uh bloods normally or three months after stopping certain medications, because just to check that everything was OK.

Or you know, so there would be. I personally wouldn't go out and do a visit. Not just for checking, I might do the blood test, but I wouldn't necessarily go out and just to make sure because it's a time factor really.

INT:  
And who should be following up patients?

Respondent:   
Because really well, actually, I think it's everybody's issue. But it's, umm, usually our pharmacy teams and our pharmacy techs are the ones that would follow up on things like that.

INT:  
OK, so use this everyone's issue, but usually it's a pharmacy teams that would follow up.

Respondent:   
Yeah, yeah.

INT:  
OK. And what are the potential facilitators or things that would work to integrating shared decision making in relation to deprescribing deprescribing medication for patients with dementia into your everyday practice?

So what does the things that will help to integrate that shared decision making into your everyday practice?

Umm.

Respondent:   
Umm communication, I think.

Really just communicating across across the board.

INT:  
OK.

If you could say a little bit more about who across the board and any example.

Mm-hmm.

Respondent:   
Well, GP's, nurses, pharmacy teams, social services, sort of multidisciplinary, really. Carers.

INT:  
OK. Is that in terms of conversations or other forms of communication?

Respondent:   
All of it.

INT:  
Umm.

Respondent:   
Yeah, all of it.

INT:  
What are the potential barriers or things that don't work well to integrating shared decision making in relation to deprescribing medication for patients with dementia into your everyday practice?

Respondent:   
Sorry, that's really long question.

INT:

I'll break it up.

So just thinking on the other side from the last question, what are the things that wouldn't work well to integrating shared decision making in relation to deprescribing medication for patients with dementia into your everyday practice?

So maybe the things that might make it difficult or not work well.

Respondent:   
I'm not communicating and just going ahead and stopping medication.

INT:  
Umm.

Respondent:   
But would definitely be a barrier and some cultural.

Umm, some different cultures? That would be a barrier because, umm, some people, they just, they just view medications differently. So yeah, I think obviously the extent of the dementia umm and family dynamics probably.

INT:  
OK, key. And can you identify any training or educational needs for you or your colleagues to help you safely stop unnecessary medications for someone living with dementia?

Respondent:   
Umm, not specifically, no...: Yeah, it's not something that I do it now. And again, I don't do it all the time, so it wouldn't really warrant. I don't think at this stage, umm and we tend to pass it over to the pharmacy team.

INT:  
OK. And is there anything else you want to tell me?  
Anything you wish to add to what you have already said in the interview today.

Respondent:   
No, I don't think so.

INT:  
Well, we've come to the end of the interview now, so thank you very much for taking part.