Early Community Intervention for Memory Loss

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Introduction

My name is Jessica Moss and as Head Occupational Therapist for Older Adult Mental Health, I'm governed by best practice for occupational therapy for older people with mental health needs and dementia in Aneurin Bevan to make sure we're delivering evidence-based and quality practice. And we have to be in line with things to do with good dementia care.

Identifying a service need

We have Welsh Government guidelines and we have a dementia action plan in Wales, which people have engaged with that process to say that people living with dementia and their carers would like to have more access to allied health professionals like occupational therapists much sooner in their journey. We did an audit in 2020 which identified that our occupational therapists working in the community in older adult mental health were tending to see people, much later in the journey by the time people got referred. We weren't reaching people around the time and early within their journey of being diagnosed. And one of the issues with that is that people might be starting to miss the opportunity for developing strategies to live well and put strategies in place that compensate for having cognitive and memory changes. So on the back of that audit, I explored what was best practice, internationally in the UK, and we identified some best practice which was a programme of getting in very early, where you actually were able to demonstrate to people and try out different strategies that compensate for memory changes that impact on day-to-day living.

Development of the service

We were able to secure some funding so we could try out a pilot to develop service around early intervention. And we trained our Occupational Therapists that were delivering that pilot in an evidence-based programme called Home-Based Memory Rehab, which was developed by an OT from Ireland, Mary McGraw. And this intervention has been delivered in Scotland for quite a number of years, Ireland, and another service in Wales, Cwm Taf, have been delivering a very successful similar early intervention service.

It demonstrates that getting in early is like future-proofing and longer-term benefits of, there's an element of education, there's an element of, if I cope and manage this now, those strategies and impact on everyone, myself, and everyone around me is positive rather than waiting for things to go wrong. So, we had two occupational therapists who did the pilot, one in Newport and one in Blaenau Gwent, Matt and Lisa, and we very quickly got a fantastic number of referrals. People were absolutely biting our hands off at that point where they were coming into memory service, getting a diagnosis of either dementia or mild cognitive impairment. And most people that have agreed to have the service have seen the whole programme through. The programme consists of a really person-centered initial assessment, which has been more like a getting to know you, what really matters to you, what's your lifestyle, what does that matter, how do you want that to be focused on strengths. And then after that, they have a number of sessions where each session is a theme, so the first session is how to remember things that you need to do. And we actually give people an orientation clock, a whiteboard, a calendar, if that's what they wish, and we show people how to use those three things in conjunction. So, when you get your appointments, you know, say you've got doctors' appointments, you will put those appointments onto the calendar weekly, you'll update your whiteboard, you'll tick things off, and the clock will help you orientate it. It's Tuesday the 21st of November, I'll check, I can correlate that with what the whiteboard is saying, what's on today. So, the strategies on their own can work, but together they can really complement.

People are different, their home environments are different, their lifestyles are different, so we don't just stick to the same strategy. So, we had a gentleman that was still working, had a very busy working life, so he

wasn't in the house all day, so we used apps instead of, or using, you know, digital technology rather than that to help remind him of his appointments. So, it's not prescriptive, it's just that we cover certain themes. So, some other example, the other themes we cover is remembering things that people have told us, remembering names, remembering things we need to take out when we go out, when we leave the house, how to, you know, look after the, how to secure the house when you leave the house. So, the kind of very practical, it gives you a toolbox, but very much geared to each person and their lifestyle, and you know, there's no set way of doing it. So, the person's very much in the driving seat, but we offer them choices. And then each session you check back on how the session before went. So, to see if that was successful, if anything needs tweaking. And that's why people like, they like that sort of coaching, sort of approach to trying something out, checking in before moving on to the next lot of strategies.

Impact of the service

What we found on average is that people have embedded seven self-management strategies at the end of the programme, which was not expected. We would have been delighted if people had two or three that made a difference, but we found on average it was seven self-management strategies. And we also used another occupational therapy standardised assessment and outcome measure, which demonstrate people improved in 8 to 10 of 12 areas to do with occupational participation and daily living. So, we don't measure whether people's memories have gotten worse. We're measuring whether people's ability to do things for themselves and their participation in doing things day to day has improved. And we've consistently found, you know, far more than we expected that those areas have improved.

We've also then captured feedback. So patient experience feedback, family, and carer feedback. And 100% people say it's been of benefit. Over 90% of people have said they know how to be more independent and carers now know much more how to support someone to be more independent, which is a fabulous outcome because we were very shocked actually, even though people may be awaiting a diagnosis or just referred for a diagnosis. People had lost a lot of things that family had very lovingly taken over. So, things like managing appointments, answering the phone, going to the shops, and remembering things you need to get. So, it was more surprising how much people were losing in terms of their independence. So, to know then at the end that that's the level of difference we're making in terms of independence, but both the person and their family feeling much more independent or confident in how to manage that is again was a real surprise. There would be this number of people that would give that feedback.

People absolutely love the strategies for remembering things they have to do. But they know the people might struggle a bit more with things like remembering things people have said or remembering names. And those things can have a huge impact on confidence and can stop you going out and taking part in things. So, a really good example is a lady who had cared for both her father then and mother and had been isolated then as well over Covid and hadn't left the house in five years. She had only the very early changes of mild cognitive impairment, but a lot of her confidence was being impacted by the fact she couldn't remember when things were on. And, you know, organising her appointments and things out in the community was getting very difficult, remembering things that people told her, remembering people's names. And although we didn't do intervention to help her get back to doing things, when we followed up three months on, she's actually started volunteering, which was a dramatic change.

So, we almost provide the sort of toolbox sort of right for that person and their lifestyle that then allow that person themselves to go on and think, OK, I've got these tools. I'm going to live the life I want to, which is one of the things we're really reinforcing that, you know, although, you know, some of the conditions we're working with may not necessarily have a treatment to eradicate. That it's about rehab is about living as well as you possibly maximising your health and wellbeing because outcomes are far better in terms of, you know, your health and wellbeing, the impact on your family, your carers and just living life, life until your last breath, life is there for living. You know, and sort of changing the story really that I think we all sort of hear about anything to do with dementia, cognitive changes, which is very depressing how we actually put that across.

And that's not to say, obviously, that's not a difficult thing to come to terms to and people can't, you know, sort of have time and space to kind of deal with the difficulties and think about that.

But it's very much about, we might not be able to change the condition that you've got, but we absolutely can help look at how you feel as good as you can about living with that and doing stuff for yourself. And there's a huge loss of identity when people take stuff off you, even if they do that with all the best will in the world. Then carers have that responsibility forevermore. So, if we leave that too long, there's not a lot we can do about it. But if we get in this early, we're able to put those strategies in. And even if things change over time, so where a carer might say have to help a bit more with the whiteboard, that person will know that strategy that's become part of day-to-day life.

It's not it's not something new and odd at a later stage that someone's going to think, well, I don't like this. They've been the person that's agreed to it. And I wanted that, which is one of the unusual things about this approach, it's not being done to the person in their best interests it's very much on their terms. And I do often wonder, is that why we get such incredible outcomes and feedback as it's people are expecting to live with dementia, everyone to come in and do everything where this is like, no, you're going to be in the driving seat. There's no way you can fail in it.

So, we reassure people, you know, you can't get anything wrong. It's all about what works for you, which in our worst situations, things will happen at some point in our lives to be given that support with expertise, but also to allow you to be making the decisions is what any of us would want, really, in that situation. We've been astonished because it just has this ripple effect on everyone involved because those first strategies, we try are not random but strategies to remember what things are because they tend to work the best. And then people are bought in. They're like, okay, this has really worked. Tell me what's next. But it's also the fact that we're coaching someone as an occupational therapist are the ideal profession. You know, that's their skill base. A unique skill base is to look at how you adapt despite your health or social care needs. It's pure occupational therapy in terms of it doesn't matter what your health care need is. We're going to find how we adapt in a way that works for your unique set of circumstances and the way the condition impacts on you. And we'll go with what works, and that is a skill, an art, and an expertise in making that work for someone. It's not just, oh, we'll try this and it always works.

There is theirs, you know, there's expertise and how you make that feel quite important. It's very unique to the skills of an occupational therapist. And I think, you know, that it's reinforced with the dementia action plan for Wales is set out, which is, you know, we know this condition has a huge impact on society, huge impact on our health services. It's the leading cause of death and a lot of the causes of the death are to do with deconditioning people dropping out of life, which has a massive global effect on health and care needs. So, this is changing that story at the beginning, but with the right, just right skills in just the right way.
We've found that we are getting around 25% of new people being referred into our memory services but are getting 25% of those actually referred to this service, which is just a quarter. Which again, it's not going to be for everybody. Sometimes people, by the time they're actually seen in memory service, it may have been a long journey and they might be further along and this may not be the right fit for them or their circumstances. But we are pleased that we're getting at this early stage, at least 25% of new people referred and practically 100% of referred people see the programme through. We've had a couple of people where they don't like their first sessions. So that's good to have a way of knowing at session one that it's not working, it's not for them but I can count those on one hand, so it has exceeded our expectations, and our real wish is to continue the pilot as it is in such great demand. But we need to get in timely and the risk is that we'll have long waiting lists because everybody wants it.

Further developments

We're doing some quality improvement work to make it more efficient looking at combining some of the sessions, not going in quite as many weeks. While people are waiting, we are looking at some initial

information with some telephone guidance so they may be able to start using a couple of those sessions before. Then they may not need as many sessions once they're in the program and we can just keep freeing up as much capacity to get to as many people that want the service.

Ultimately, it's created a huge interest across Wales, across occupational therapy, in dementia services, primary care, and that it really fits with some of the frameworks for work like the AHP framework for Wales, the dementia AHP framework for Wales, getting people in early that Allied Health professionals have the right set of skills to offer rehabilitation and interventions that are non-medical model, but are adaptive and enabling. And then improve the health conditions of people of Wales, hoping this is the kind of thing that keep people active and independent.

The other health benefits will hopefully have a knock-on effect on outcomes from this as well, like the psychological impact. If I were to say, what's one of the huge impacts? It's the condition that people in society fear the most, even more than cancer. And when we spoke to people at the beginning, before they have the intervention, people are feeling very low in terms of their hope about the future. But at the end of the programme, we revisit that question, and almost 100% of people are feeling hopeful, most people strongly agree or agree. I think we've had one or two people thinking about longer term, for a condition that you don't actually provide any medical treatment or any concept that this is a cure in any way.

We were really astounded at how much better people felt. And that's something then that carers and family report is how much more of a spring in the step a person has had, people wanting to do things, people just more motivated to come and help do dinner. Some of the things that we may put down to cognitive changes in terms of motivation and wanting to do but may actually be more down to how they're feeling about the future and feeling about their identity in themselves. So, this gives people a sense of their identity and their control and autonomy, which has a psychological benefit. And it seems like it improves relationships between the family then, because they're not butting heads as much over who's doing what and you're not motivated and you're doing everything for me. families have fed back that it's made it easier. Someone else is coming in and the person may have responded better to somebody coming in rather than family saying, oh, mum, you need to do this. So that helps. It's not therapy for the family, but it seems to have that really positive impact as a result.

It's carers education by role modeling and coaching but doing it practically rather than sitting someone down and saying, you need to do this, that, and the other as a carer they learn something as a result of seeing what's happening and learning that it's okay to step back and allow that person to do stuff for themselves. And it may have positive benefits for them. So very interestingly, for our colleagues, and medical colleagues in memory services, it took a bit of getting used to. It's a very different model of delivering occupational therapy to what colleagues were used to. Previously they used to put in referrals where there was a concern that things were starting to go wrong at home, whether that was somebody starting to leave the cooker on or when they went out, they got lost or weren't managing their shopping. So, things that were starting to become a bit of a crisis point and people were further along in their journey. And our medical and nurse colleagues were perhaps not so used to thinking about occupational therapy as that earlier rehab that we would like to work with people as well, where we could embed strategy.

This new concept of pre-habilitation very early rather than waiting for something terrible to happen, getting in there, knowing how cognitive impairment and dementia will affect how you manage day-to-day living, however things go, it will impact. Let's give you the tools as early as possible. But what started to happen was the colleagues started to hear the whole story and at the end of the programme, the occupational therapist write a discharge and summary letter to the person they worked with that also gets sent to the memory service team and the GP actually describing what somebody did and now could do was the best way.

We did lots of engagement and presentations, but it was actually the proof of the pudding when we gave the feedback of how many strategies people were using at the end of the programme, the other impacts, the feedback that patients and carers had given. Also, then patients were coming back to memory service at different points and for a follow-up clinic and they were telling the doctors and nurses that this was the best thing, it's been fantastic. We've had Alzheimer's Society staff get in touch to say, I went out to see someone today and they were just absolutely raving about this service. And what we've noticed is in one particular borough where people are referred compared to other boroughs maybe a bit later on in their journey by the time they've spoken to the GP, by the time that gets referred to the memory service, they may be a bit more progressed.

Lessons Learned and next steps

In the time we've been delivering home-based memory rehab, the referrals to memory service have gotten better in terms of much sooner because we send the letters to the GP. So, we are wondering if there's a correlation that GPs are seeing I refer someone, they get this intervention so there's a really good reason to refer as soon as possible and I'm trying to engage at the moment in a piece of work with GPs to get any feedback of have they noticed that this service exists? What has been the sort of impact for GPs in terms of this service existing within their borough? And I think that'll be important as well. And we'll get some more formal feedback from colleagues as well.

Now it's been really well-embedded for nearly two years in April, May next year to get that full perspective of how our colleagues have found it. Where does this service sit well? Could it sit in different places? Or could it sit in GPs? And there are other services delivering early intervention. So, in North Wales, I think they're looking at delivering it at more in a primary care GP setting. The beauty of this particular programme is it's been right in the heart of the memory service. The benefit of that is there's conversations between the memory service staff about somebody that's been seen in memory service, how they presented so there's that understanding of cognitive changes, which has really developed those understandings and those communications.

What's also happened is some of the people that have been seen by the Occupational Therapist, may have noticed some unusual presentation as they've been doing the work. So, they've been spending a lot of time seeing people living their lives and they may have noticed some more unusual sort of symptoms. And the Occupational Therapists have been able to go back to their medical and psychology colleagues and say, I'm seeing a bit of an unusual presentation. Some people may not be seen for another 9 to 12 months between assessments, it's watchful waiting for my cognitive impairment, for example, where the Occupational Therapists can notice some more nuanced impacts on function, which has meant people have gotten a sooner and a more accurate diagnosis. And that is a big drive in dementia care because it makes a difference in terms of what you access, the kind of help that you have, the kind of interventions, what happens, the sooner that happens, but the more accurate that is, the better for all involved. So that wasn't a focus of this, the problem is being able to make a difference in terms of the intervention, but that has been an additional huge benefit is that it's adding to the whole diagnosis sort of process to be more timely and more accurate.