

# Dementia and Manual Therapy

## - Ref 31DB

with Dawn Brooker

6<sup>th</sup> May 2020

### TRANSCRIPT

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**Steven Bruce**

This evening we're turning not for the first time to mental health. I'm joined by Professor Dawn Brooker, who qualified quite some time ago as a clinical psychologist, but is now the director of the Association for Dementia Studies at the University of Worcester. This is a faculty which she set up herself, having spent a lot of time working at the sort of triangular interface between people experiencing dementia, their carers and academia and researchers. She's actually got her PhD in the improvement of quality of care for elderly people suffering from dementia. So, I don't think there's very many people who could be better qualified to help us understand how dementia might impact us in our own practices and what we can do to improve the care we offer patients. Dawn, good evening.

**Dawn Brooker**

Good evening, Steven.

**Steven Bruce**

You know, I work through that quite a lot. And I got it right so many times and I stumbled over the title of your PhD, which really annoys me, I hate it.

**Dawn Brooker**

Don't worry, I do as well, I do as well.

**Steven Bruce**

But like you I have a piece of paper in front of me so that I can have some sort of stimulus to stimulate the old memory but yeah, so tell us about the, first of all the association. Why is it not a research establishment or?

**Dawn Brooker**

Okay, so we are a research centre, our focus is very much on researching into person centered dementia care. So, we're interested in how we can understand the experience of dementia and how we can help support people through the various stages of dementia, and within health and social care. So, as you can see on the picture, that's my team, there's about 20 of us at any one time. We're multiprofessional, multidisciplinary, I'm a clinical psychologist, but I also have on the team, nurses, medics, occupational therapists, few social workers as well as people who had a more straightforward career in gerontological research.

**Steven Bruce**

What's the balance for you? I mean, how much are you right at the coreface dealing with someone who is experiencing some form of dementia, as opposed to herding your team of cats here in their various directions?

**Dawn Brooker**

I do, I lead a lot of research directly. So, I'm doing stuff at the moment as varied as, we've just finished a big project looking at how you support people with advanced dementia in care homes using an intervention called Namaste Care. I'm also doing a lot around community interventions, how we can help people at the early stages of dementia, to adjust well to living with dementia within their communities. So yeah, and anything in between those two things. I do a lot of frontline research.

### **Steven Bruce**

Well as you and I already discussed, I mean, I guess the main focus of what we want this evening, given that most of our audience is made up of chiropractors, osteopaths, and some physiotherapists, is, first of all learning what we're likely to see as primary care practitioners and whether we might actually be the first person to spot the signs of dementia, but also what we can do to help care for those people when they come to visit us and perhaps even care for the people who are caring for them, because I imagine it might be quite a stressful environment for both parties. And perhaps a little bit of the science behind it, although you did warn me that you are not a pathophysiologicalist, you are a psychologist, and therefore your expertise is slanted in a slightly different direction. I know you know your stuff in that respect as well. Where would you like to start? Actually no, I should tell the audience, we decided to do something different this evening, we're doing some polling. And we've never done this before on our live shows. So, if you're watching on Facebook, or you're watching on Vimeo, there are going to be some questions coming up. And Justin, my techie, will be putting up a little box where you can say whether you think the answer is false or true. And you'll have a couple of seconds to do that. And we'll just see what the audience thinks, because I think you've got an opinion that people know more about dementia than they imagine going, Dawn, is that right?

### **Dawn Brooker**

Yeah, a lot of people have personal experience with dementia. I remember when I started in the field a long while ago now and I used to tell people that I worked in dementia care people used to say something like, oh well, shoot me if I ever get that, you know, that's, that would be awful. Or, what is dementia? That's just about being old, isn't it? Whereas now when I say what I do, most people will report personal experience dementia, either a parent or a partner or even themselves. So,, as we will find out in the quiz dementia is more prevalent in...

### **Steven Bruce**

It did strike me based on what you said there, I remember Terry Pratchett, quite famously, had early onset Alzheimer's, I believe didn't he?

### **Dawn Brooker**

He had a posterior cortical atrophy, which is a type of Alzheimer's.

### **Steven Bruce**

But he said that he wanted to go to Dignitas, and he wanted to end it all rather. But he was very, very aware that by the time it got to the stage where he'd want to do that he might be beyond the stage where he could

give informed consent to that treatment, which is a real quandary, I imagine for many people finding themselves faced with that.

**Dawn Brooker**

It is. And also, I think, for many healthcare staff, you know, because we're diagnosing people much earlier. Many people early on in the diagnosis will go through that horror, that terror, what's it going to be like at the end? I want to finish it, and I want to maintain control of my life. And I think, when I think back to when I first worked in dementia with people at much more advanced stages, those conversations never took place. And you get a lot of healthcare staff now who were really thrown by that sort of, almost you've got to go into counselling mode, when somebody starts raising those existential questions and questions it's about later on, so our skill set as healthcare professionals has to change, because we are having to have those conversations now. And they're hard conversations.

**Steven Bruce**

Yeah, I imagine they are. Mind you, the medical profession as a whole is dealing with a lot of hard conversations at the moment, isn't it?

**Dawn Brooker**

Yes, yes, indeed. Crikey. I almost thought I was in a COVID free zone then for a while.

**Steven Bruce**

Sorry.

**Dawn Brooker**

Absolutely we are, you know, at the moment, trying to deliver good end of life care for people living with dementia and for family carers, who may not be able to visit, it's terribly, terribly hard.

**Steven Bruce**

Yeah, I suppose it is important that we start this off by defining what is meant by dementia.

**Dawn Brooker**

Yeah. So, should we give a go on the quiz?

**Steven Bruce**

Right? So, here's question number one then. So, you're asking us whether dementia is an umbrella term for diseases that cause progressive nonreversible damage to the brain and asking us in the same breath, are there over 200 types of dementia, each describing a different way in which the death to the brain cells occurs. So now the audience has got the option to say whether that's true or false. Justin tell us when we've got a meaningful answer.

**Dawn Brooker**

I put this up there because we use a lot of words synonymously with dementia, we use Alzheimer's type dementia, we use Alzheimer's and related dementia, you know, the Alzheimer's society actually looks after everyone with different types of dementia. So, I may be giving away the answer here. But I think to define some of our terms at the beginning is...

**Steven Bruce**

So, what do we got Justin?

**Justin Hedges**

Okay, so on Vimeo, 84% of the viewers are saying true. And 15% are saying false. And on Facebook a 100% are saying true.

**Dawn Brooker**

That is true. Yeah. I mean, it is a, there are many, many different variants of dementia, we tend in this country to use dementia as our umbrella term for all of those different types. But if you go on to something like Alzheimer Research UK, you can watch videos of people with very rare forms of dementia. So that's quite an important thing to be aware of now, is that if you have somebody with a diagnosis, knowing what subtype of dementia they have, will give you some clues on how you can support better.

**Steven Bruce**

So you just said the Alzheimer's Society deals with all types of dementia. So does that mean that Alzheimer's is the most common type of dementia?

**Dawn Brooker**

Well, let's ask the audience.

**Steven Bruce**

We'll grab some prizes, didn't we? We don't actually know. We don't actually know who's saying what we just know how many what percentage of people are saying this, so.

**Dawn Brooker**

I like the battle between Vimeo and Facebook, though, because Facebook won the last one.

**Steven Bruce**

Yeah. Well, on the basis of one poll, we can say that Facebook users are more knowledgeable than those on Vimeo. So, we'll see how that goes. Right then Justin, what do we got for that one?

**Justin Hedges**

Okay, so far, they're actually changing. So, let's give this one a minute more or so.

**Steven Bruce**

Okay. So Dawn, in the previous slide, you said 200 different types of dementia, over 200. I mean, some of those must be incredibly rare.

### **Dawn Brooker**

Incredibly rare. And I think, also when you've got, as we will find out and as most people will know, dementia tends to occur in people who are older, you know, so the brain has all sorts of things that happen to it over the lifespan, many people will have mixed types of dementia. So, you might have a bit of Alzheimer's going on you with a bit of Frontotemporal dementia with a bit of vascular dementia. You know, although, as, when we make diagnoses, we like to be very precise, but it is still a full science and interestingly, nowadays we try, well the memory assessment services try to subtype dementia, so if you get a diagnosis, you should be told what type of diagnosis, what your subtype is. We have quite a few people who we know have had dementia in their lives who have donated their brains following their death to the brain banks. And a lot of them are coming back with different diagnoses on post mortem.

### **Steven Bruce**

Interesting you should say this we had a broadcast at lunchtime when we were talking about physical therapy and pain science and how actually in physical therapy, we really have no idea what it is we're diagnosing when we say this is what's wrong with you. We're taking a best educated guess, but we can't see exactly what it is that's causing the problem. Anyway, Justin, have we got an answer on whether Alzheimer's is the most common type of dementia?

### **Justin Hedges**

Yes, so on Vimeo we have 53% that have said true and 46% that have said false.

### **Steven Bruce**

Right. And, on Facebook?

### **Justin Hedges**

It is not telling me.

### **Steven Bruce**

Facebookers are hiding their light under a bushel, right?

### **Dawn Brooker**

I bet they got it right. Okay. Yeah, it is true. And that's partly why the Alzheimer's society, as we said, is the main charity, and it is terribly confusing for people because they think if I've got vascular dementia, does that mean that the Alzheimer's society won't help me and they will. They will.

### **Steven Bruce**

The ones that you've put down here, vascular mixed dementia, dementia with lewy bodies and frontotemporal, are those the key ones? We've got a graphic here which shows that and basically 62% is Alzheimer's.

**Dawn Brooker**

Yeah. So that's the vast majority of people you see with dementia will have Alzheimer's type dementia. And that tends to be people who are older as well. Although you can get Alzheimer's disease earlier in life, but the vast majority of your 70, 80, 90 year old who's got dementia will probably have Alzheimer's. So that's the main one to be aware of. Vascular dementia, quite a big chunk there. You know, related to heart disease, what's good for your heart is good for your brain. So, if you've got something going on in your circulatory system, in the rest of your body, it's likely that you've been having some damage and that damage has led to cell death. This idea of mixed dementia, so when people have got more than one type of dementia again, I think that's probably bigger than you think.

**Steven Bruce**

Is there a typical mix, are there more common ones?

**Dawn Brooker**

Yeah, more commonly vascular and Alzheimer's. But the great news about, if you've just got pure vascular, you know, if you take care of some of your cardiovascular risk factors, you can pretty much stop it in its tracks if that's all that's going on. So, it's quite an important subtype diagnosis to make, that one. And certainly, there's some evidence to suggest that vascular dementia is decreasing. You know, because we've got better cardiovascular health now going into our older generations, less smoking, etc.

**Steven Bruce**

But we're trying to counter that with our obesity, I believe, aren't we?

**Dawn Brooker**

Yeah, yeah. And there is a huge link between diabetes and Alzheimer's. There's quite a few theories about whether this is actually the tangles and plaques that you see in Alzheimer's, whether that's actually something to do with your nutrition and your diabetes and how you're processing sugar. So, I think there will, there's a lot of research going on, to try and find the cause.

**Steven Bruce**

I've had a question related to exactly that. It came in a few minutes ago from Dawn, who says what's your opinion on the increased risk of Alzheimer's in postmenopausal women via their increased risk of diabetes? And she says in particular when they're on statins?

**Dawn Brooker**

I'm not the experts on that. I'm fairly expert on postmenopausal women having been one. But in terms of the statins stuff, I have to say it's not my area, so I wouldn't like to answer that directly. I think we probably

we did quite an interesting study, though looking at women and dementia. And I think we miss a lot of early dementias in women who may be having cognitive changes which their GP often puts down to the changes that you get around menopause in, not being as quick as you were previously, which, you know, usually comes back again, when you're postmenopausal. You come back to full cognitive function. So, I think we often dismiss those midlife, that might be early signs by seeing that as a problem in menopause. In men we wouldn't be wouldn't be saying that.

**Steven Bruce**

Yeah. So, on there, is there an array of risk factors that are well known for the different types of dementia? Cardiovascular health you've mentioned for vascular dementia?

**Dawn Brooker**

I mean, that's mainly what it comes down to, what is good for your heart is good for the brain. So, if you keep a decent weight, you don't smoke, you're a moderate drinker. There are all sorts of theories that have happened over the years of things that might be causally related to dementia. When was first working 30 odd years ago, you know, it was all about aluminium saucepans?

**Steven Bruce**

Yeah, I remember.

**Dawn Brooker**

There's also theories about, is it about dental hygiene? Is it something to do with the bacteria going, you know, so it's a very lively field. And what I would say is, just recognise that people are desperate to find a cause. And then if they've got dementia in the family desperate to find something that they can do to stop it, and will do all sorts of strange stuff, which may do no good whatsoever. So, I think it's always worth, go to the Alzheimer's Society or Alzheimer's Research UK. Those are your two main websites where, if you put in that sort of question about statins, for example, you will usually draw up what's the best evidence. It is out there, but be wary that there are a lot of myths around what causes dementia.

**Steven Bruce**

Did aluminium saucepans come off clean in the end? They were, yeah, they're all right. Good, glad to hear that. Just a question that occurs to me here, this is a potentially very, very lucrative field for drug manufacturers and others. So, does that mean that there is a lot of money being pumped into research to try to find these answers or is it just far too difficult a challenge to find?

**Dawn Brooker**

It has been a huge area over the last 25 years. But the success of finding a drug treatment has been very elusive. You know, we've had a lot of things that look promising, but then turn out to have side effects like death, you know. They're not, when they get into human testing, you know, a lot of kidney, liver failure.

**Steven Bruce**



On the plus side it cures the dementia, I suppose.

**Dawn Brooker**

Well, that's right, that's probably killed the patient. And also, you know, if you go back to that slide earlier, if you've got over 200 different etiologies going on, and it's very difficult even sometimes to diagnose a bog-standard Alzheimer's type dementia, then you're getting people into clinical trials, it's very difficult. One of the things that we'll perhaps get on to later, though, is that the common thinking now with drug treatments is that most dementias or most of the early damage occurs in your brain in your 40s and 50s. But you don't see the clinical signs of Alzheimer's or a lot of the other dementias until the 70s and 80s. So, by the time you're seeing people presenting clinically, actually the disease process is so well advanced, that you're going to have to have some huge drug in order to reverse it. Right? So, the thinking now is if we can get a good biomarker for people in midlife, it's more likely that you're going to be able to give a medication then or some lifestyle change then that will prevent the dementia later on. Now, at the moment, the only way you can get a biomarker for Alzheimer's type dementia is through a lumbar puncture. So, we're not going to be screening people giving them lumbar punctures that are quite a dangerous procedure anyway, for a disease that there's no cure for. We're not at all into screening at the moment.

**Steven Bruce**

And I wonder how many patients would actually want to know the answer to that question, since there's no cure.

**Dawn Brooker**

Yeah, that's right. You know, so yeah. When we're, we're not in the business of screening for dementia at this point. But if we have a simple blood test, and I think that those are in development, then that might be different, so, and that will come. So, I think the hope is that we find something, we find an easy biomarker, where we can screen and give people the choice then, say, well, it looks from your profile, that you've got a 67% chance of developing Alzheimer's in your 70s or 80s. Do you want to go on this trial? You know, I think that's the direction that we're going into with pharmacology rather than thinking that we're going to find a cure for those people who've currently got dementia.

**Steven Bruce**

I got a few questions for you, which I really ought to try and get through because they're pouring in as I might have anticipated. Diana's asked a very sensible question here, I think, she says if one type of dementia is assumed, is it worth investigating for mixed dementia? Her father has normal pressure hydrocephalus. But we suspect also Alzheimer's, the GP won't refer to a memory clinic.

**Dawn Brooker**

Yeah, I, again, I think it's always as with any condition, trying to get a diagnosis from somebody who really knows what they're talking about, and the memory clinics by and large do because that's their day-to-day job. They will be aware of the many different types of dementia whereas a GP will only, you know, they'll

see a dozen people a year, maybe with a new dementia. So, I would push for, if you're not happy with the diagnosis, I would reach for it.

**Steven Bruce**

Okay. Very hard, isn't it though if the GP says no, we're not going to do that, and they're not going to do it against the interests of the patient, but they think it's not worth doing. But perhaps if they don't understand the problem as well as they should. Any ideas how much training GPs get in dementia, they must do some of it in their qualification period?

**Dawn Brooker**

Yeah. more now than they used to. I think there's been a lot of, there's been a lot of education courses that have been focused at GPs, particularly, again, going back to the diagnosis issue. And we'll have a slide. Maybe we ever get to it later on about the percentage of people who get a diagnosis of dementia. And that has really increased in recent years because of the memory assessment service that now is pretty widespread across the UK. So, if you go to your GP with an issue around cognitive changes, memory loss, you should be able to get an easy referral in to a memory assessment service anywhere in the country. What we know is, time ticks on. And most people who worry about their memory or that they might have early dementia, worry for about two or three years before they go and seek help. And usually, they go and seek help because their partner then becomes more worried about them, badgers them into going to get it checked out. So, if you then go to your GP and your GP says, there's nothing wrong with you, look at you, you play golf, you're doing all right, aren't you, go, you know, just normal ageing, then if that person goes away, they don't come back quickly. So, I think huge education programme to change GPs behaviour, for the average GP, there's huge pressure on them to change their behaviour and their knowledge around all sorts of different disorders and I think it, really it's the whole primary care team that if they become much more dementia aware, you know, that then helps to move us in the direction of people getting help quickly.

**Steven Bruce**

Just an administrative point here, Dawn, I've been asked to ask you if there's something beeping in your room, whether your spaniel is playing his computer games at your feet there or?

**Dawn Brooker**

Nothing beeping in my room at the time.

**Steven Bruce**

I can't hear it either. But somebody's asked me to find out if there's some beeping going on. You talked about cardiovascular problems earlier on being a risk factor for vascular dementia, Pippa Slack has asked what sorts of cardiovascular damage you're talking about stroke, cardiac arrest, cholesterol levels?

**Dawn Brooker**

Oh, complicated. So, really, if we look at, I suppose all of those things, obviously in the extreme, but if with, I suppose I was meaning more in giving just general advice on when people ask me about what can I do to

decrease my chances of getting dementia, I would say that the same things that you would do to decrease your chances of getting heart disease or having a stroke, you know, regular exercise, keeping within normal ways, not smoking, drinking too much or all of those things.

**Steven Bruce**

What's the period of transition, you talked about memory loss of being a significant issue earlier on, is that going to be so marked that a partner would notice it instantly? Or is it so gradual that you have to think back a year and say, hang on, this is a very, this is a significant change for only 12 months.

**Dawn Brooker**

It's a very, with most dementias, particularly, with most dementias, some vascular dementia, if you get a stroke, and then perhaps a series of transient ischemic attacks, you might see some quite rapid deterioration. But with most of the other dementias, it's terribly slow and insidious and you don't notice it on a day-to-day basis. And it's often people who haven't seen the person for a while, maybe adult children that live away, who pick up the changes between visits, rather than if you're with your partner day in day out. Yeah. So, it is very slow.

**Steven Bruce**

In terms of the therapies that are offered, I've been asked and they haven't given their name but they've asked, if there's no cure, what's the point of the drugs that people are being given? And they mention in particular, Donepezil?

**Dawn Brooker**

Yeah so, Donepezil, I didn't get onto that one, that's been our most successful drug, aricept was its trade name. And what that does is to, in Alzheimer's disease it's all about your neurotransmitters and your acetylcholine and those sorts of things. So, what an episode does is that it maximises the acetylcholine in the brain so it stops the inhibition of it, it stops the uptake of it so rapidly when synapses are fired. But if you get to a point where that's so depleted, the Donepezil will no longer work. So, it only works at relatively earlier to moderate stages, when you still got enough of that particular neurotransmitter to help.

**Steven Bruce**

Over the long term, does it extend the lifespan of the patient or?

**Dawn Brooker**

That's a moot point? It seems to some people, there's lots of anecdotal evidence and people who've been on it long term who will say it does, you know, but we also know the hugely strong placebo effect we have with medication, particularly in an area like dementia. So, the medications are, we have a complex relationship with our medications.

**Steven Bruce**

The quality of life is definitely improved in those early years you say.

**Dawn Brooker**

It can help people certainly feel brighter in their thinking and be, you know, feel more on top of things.

**Steven Bruce**

Have you any opinion or thoughts on Lion's Mane mycotherapy research?

**Dawn Brooker**

No. Don't know what it is.

**Steven Bruce**

Okay, well, apologies to whoever asked that question.

**Dawn Brooker**

Sorry, wrong expert here. Dementia care is my thing.

**Steven Bruce**

Fiona's asked about DNA testing. Does that give a future percentage chance of getting Alzheimer's?

**Dawn Brooker**

I'd be very wary of it.

**Steven Bruce**

Are there people out there claiming that it does?

**Dawn Brooker**

Yeah. Yeah, there'll be people out there claiming all sorts of things around DNA testing. Again, keep an eye on Alzheimer's Society websites, Alzheimer's Research UK. They'll give you the best guidance.

**Steven Bruce**

There seem to be quite a few people with interest in particular types of drug or other research, Alexandra's asked about HRT, and if you know about an HRT drug called Climaston. Apparently, it increases by three times the risk of memory loss in women.

**Dawn Brooker**

Okay you take a drug for one thing and it upsets something else.

**Steven Bruce**

I guess the telling points is if it's HRT you would expect people to come off it after five or so years, at least to try leaving it. And if the problem is reversed, then it's not dementia. I guess. I'm looking at you quizzically in case I'm talking complete and utter bollocks here, which wouldn't be the first time. Yvonne asked about

diagnosis. What is the gold standard diagnostic method for Alzheimer's or vascular dementia? Is it a CT scan looking for vascular occlusion to give a vascular diagnosis?

**Dawn Brooker**

Again, I think, in a memory assessment service, you'll get a good multidisciplinary team assessment. And so it will often depend on the stage that somebody presents at as to what different tests you might do. Sometimes that would be a scan. Other times it might not be a scan. And as I was saying earlier, even when you've gone through that, when we have evidence, you know, when people have gone through that good diagnostic workup, at post mortem, it turns out to be something else. So, again, and but the other thing I would say is, I think our diagnostics are getting better all the time with dementia. And I think they are getting better at earlier stages. But diagnosing a dementia at an earlier stage is more complex than diagnosing it at a later stage. You know, so we really need to have those specialist diagnosticians to help us through this.

**Steven Bruce**

Right. What actually goes on at a memory clinic?

**Dawn Brooker**

Well, it depends on how the memory clinic is set up. Usually, the principles are that you should have quick referral in. So, you shouldn't have to go through the psychiatric service in order to get into the memory clinic because, it's interesting when you were introducing me, you introduced me, you introduced this as a mental health topic. You know, and there is a lot of stigma around dementia. And there's a lot of stigma around dementia because the very word in English, you know, has connotations of madness of being demented. And a lot of, you know, a lot of our people who are experts in dementia, trained through psychiatric services. So I think having a route in something that isn't a psychiatric service, it's a memory assessment service is an important way of saying, this happens a lot, go and get it checked out. It's like going to a, I can't think of another clinic, but you know, it's going for, I think making sure that we're not putting up too many barriers into memory clinics. The GP would usually do things like eliminate all, they do a blood test, so they'd eliminate thyroid and all the sorts of things that might be masquerading. So, by the time you go to a memory clinic, you've had all your blood work done. And then it's really a question of either going for scans, taking the good history, often taking a history as well with the person's nearest and dearest because there may be issues there. In good memory assessment services, the recommendation would be that before the person goes through that assessment, they have a bit of pre diagnostic counselling. So, if we find out this is Alzheimer's, do you want to know, how do you want to know? Who do you want to tell? And then the same person that does that pre diagnostics should also do the post diagnostic disclosure of the news. So that should be your gold standard process, really.

**Steven Bruce**

And you mentioned scans. We're talking MRIs, brain scans?

**Dawn Brooker**

Yeah.

**Steven Bruce**

Okay. Yvonne's asked about, well, again, that's about gold standard. I beg your pardon. Peter says he's had MS for 40 years and does that make him more at risk for developing dementia?

**Dawn Brooker**

Peter, I don't know would be the answer to that.

**Steven Bruce**

Okay.

**Dawn Brooker**

I would recommend the MS society would be...

**Steven Bruce**

That I'm sure he's very familiar with.

**Dawn Brooker**

Yeah. I mean, it's not an area that I know particularly well. I can't think, but I've seen lots of patients who had MS and then go on to develop dementia. But honestly, I wouldn't want to say because it's not my area.

**Steven Bruce**

Josephine's asked about vitamin D, what are your views on vitamin D combined with B 12 to lower homocysteine levels along with omega three, apparently, and this is why I'm keen on asking this question for her, she went to a talk that suggested that Alzheimer's could be prevented in inverted commas with this combination of supplements.

**Dawn Brooker**

Yeah, there's quite a lot of research looking at really quite complicated nutritional therapy with exercise therapy, and it was a three-pronged physical approach, quite a complicated regime. The evidence looks fairly strong. But I remember reading the paper and thinking it was such a complicated regime, I'm not sure that your regular person would actually manage to do it. But again, it's a very active area of research, you know, if we can find a way of slowing down or preventing dementia, then obviously we'll all want to do that. But again, I would urge caution, you know, check out the validity of research, because there are a lot of claims made by people who have not done cluster randomised controlled trials in this area. You know, they've done a bit of pre post.

**Steven Bruce**

Okay, Helen's asked about lifestyle changes to slow the progression of vascular dementia. Any thoughts on that? What do you advise people?

**Dawn Brooker**

Yeah, I mean, I think, again, the obvious ones of losing a bit of weight, getting more exercise, stopping smoking if the person is still smoking, doing all of those sensible lifestyle changes that we know will help.

**Steven Bruce**

Yeah. They're pretty much as you alluded to earlier on, they're pretty much the same, the changes we ask everyone to make for every form of dysfunction, aren't they, whether it's a physical dysfunction, systemic or otherwise. And I wonder how many people are willing to make those changes? Do you find people very receptive?

**Dawn Brooker**

I think there's a whole spectrum, isn't there? You know, there are people who will make a lot of changes when they're first diagnosed. People live with dementia. Or people can live with dementia a very long time, and there's that, I think emotionally, there is like any life changing diagnosis, there are different stages that people go through, in that immediate post diagnostic phase, people's emotions are all over the place, it takes a while to take it in. Sometimes people react with denial. And so, they will make no changes whatsoever. And will say the doctors have got it all wrong, there's nothing wrong with me and will continue with a particular lifestyle that we know isn't particularly good for them. Some people will make a lot of changes very quickly. And then within three months, they're reverting back to their normal type of behaviour. So, I think the next challenge for us in this country is, we are getting better at early diagnosis. What we're not getting better at is that what we do with people in that post diagnostic phase, that's the next big challenge. The NHS secondary services, particularly if you look at psychiatric services, will only next see the person with dementia when they're presenting with significant problems. And that might be a sort of eight- or 10-year period before that happens. So how we help people to make good adjustments in that recognising that not all of the adjustment will happen in the immediate post diagnostic phase, we're talking a period of a couple of years. Some people can make lifestyle changes that are going to stick. They might be deciding to move house during that time or closer to the rest of the family. They have to learn psychologically to like themselves again with their dementia, to recognise that they have this diagnosis but they're still them. And if it's your partner that's got dementia, you have your own adjustments to make as a partner, you know your own fears and anxieties and learning to love your partner again, you know, so there's stuff that each party needs to do separately and stuff that they need to do together.

**Steven Bruce**

I guess the question that occurs to me here is that if I were a heavy drinking, heavy smoking couch potato, and this is not a question for a poll, we're not asking for people's opinion on this. If I if I were that character, and I got a diagnosis that I was suffering from one or more forms of dementia, I'd be saying, well, if I change my lifestyle, is it going to make any difference to the length of my active life? And if it's not, I'd be asking why the hell should I change? I should have done it 20 years ago, I didn't have a diagnosis then.

**Dawn Brooker**

Yeah. Yeah. I think one of the issues about, in that adaptation phase, that post diagnostic adaptation phase, is that nobody can tell you what your prognosis is, we know generally that those lifestyle changes will help some people some of the time, but we don't have that sort of precision medicine at the moment. You make these changes, you know, this will happen. And a lot of what we're doing psychologically, is trying to help people at that post diagnostic phase to cope with that uncertainty. To say, I can't tell you what life's gonna be like in six months or three years' time. In actual fact, you know, nobody can tell anybody what life is gonna be like in six months or three years' time. We all know that our lives can change over six months. And all of our fine plans go up in the air. And I suppose if I think about one of the things that I've learned from people with dementia, it is the importance of being in the here and now and enjoying the here and now and not putting things off. You know. So, I think that psychological well-being is as important as giving everybody a healthy diet sheet. We've been looking a lot at what encourages people to go along to groups, early, post diagnostic groups, people with dementia. We're doing some research on a Dutch community model called meeting centres. And the meeting centres bring together in very local communities 15 couples on a regular basis and it's like a club so, you know, it's very relaxed and warm and friendly. Do a lot of peer support a lot of social activities, but it's also a vehicle for doing your healthy lifestyle stuff and getting people a bit more engaged in their community. And, of course, what people like about that is just talking to other people. You know, it's the social side of things. And I think we often overlook, one of the biggest disabilities that people face in dementia is isolation and loneliness. And so, it's how we get people together, and it's been very interesting in this time of COVID, that all of our meeting centres have had close because people can't no longer meet together in groups. But in those communities where we have meeting centers, what you have is such a strong community connection between those 15 couples, that actually they're all doing Zoom meetings together. There's they're all reading and contributing to the same newsletter they're having online choir practice. So, I think we have to recognise that our numbers of people living with dementia are so huge and will get bigger. And it's how we capitalise on that. It's how we get dementia to be part of our normal conversation in our health care practices and in our communities. So, it's no longer shameful. It's no longer a stigma.

### **Steven Bruce**

I felt I was a bit ticked off earlier on because I raised the spectre of COVID. But you just raised it. So, can I ask, is there an association between death from COVID-19 and dementia? Is it one of the core comorbidities which increases the risk?

### **Dawn Brooker**

I don't know whether it increases the risk. But you know, what we do know is certainly in the care homes at the moment. I mean, age is an obvious one. And if you look at the numbers of people that most carehomes will have 60 to 70% of their residents will have dementia of one form or another.

### **Steven Bruce**

The statistics will be distorted anyway, won't they? Yeah.

### **Dawn Brooker**



I certainly wish. But we're also seeing increased deaths from non COVID deaths as well. And I think there will also need to be some work to look at what's caused those deaths because one of the things that I suspect is happening is that we've been working a lot with care homes to try to decrease the dependence on sedating drugs in dementia, because we know antipsychotics and other sedatives increase the risk of stroke, of falls, of injury. And often people with dementia just get left on them without them being reviewed. And I suspect if you're trying to keep a person isolated in their room who doesn't understand that they need to stay in their room because of their dementia, the temptation to put them on some statin drugs is very high. So, I think that the death rate in dementia through COVID will be quite complicated when we start to unpick it.

### **Steven Bruce**

Pip's asked another question, this time about the relationship between sleep and dementia, particularly with reference to eight hours being needed to allow the CSF to permeate the brain and wash away tau proteins, etc.

### **Dawn Brooker**

I'm sure sleep is terribly important. Again, it's an area of research. It's quite active. I don't have chapter and verse on it at the moment. But it is, again, it's part of that sort of being healthy and as you say, making sure your brain is in tip top condition. And often, if we look at the sort of neuro chemistry around what makes us forgetful, lack of sleep, feeling anxious, those sorts of things, the higher your cortisol levels, you get less able to recall and remember, so all of these things are related, you know, this is your brain and it's a very sensitive organ.

### **Steven Bruce**

Yeah, there's been a lot of chatter about this next one over the last few years, I think, and Harvey's asked about it. Is there any genuine research or meaningful research which suggests that sudoku and crosswords and things like that can help to preserve brain function?

### **Dawn Brooker**

Yeah, again, it's an area that has, as you say, a lot of interest in it and a lot of people will try and flog your things that's going to increase your brain capacity. I think, you know, one of the things we know is that the more synapses that you can develop in the brain, the more robust your brain is. And the way in which you develop synapses is by learning new skills and doing more complicated things. So, we know, for example, that people who are bilingual, have a lower incidence of dementia, because their brains are more complicated. So, we also know that, you know, ballroom dancing seems to be quite good for your brain as well because it involves a lot of different movements and spatial awareness as well as rhythm. So, I think the idea that, but the idea that you can just do one thing and that that then helps the rest of your brain, it doesn't really hold up, theoretically. So, having a varied lifestyle, having social interactions, talking with other people, doing something that's a bit spatial, learning a new skill, doing your crossword, you know, all of those things together, will help to keep your brain active and in as good health as you can. But if you've got a genetic loading, that means you're going to get a dementia, you're going to get a dementia, you know, so I

think that's the other thing to say, you know, I think there are lots of things that we can advise and things that won't do us any harm. But we should also be very aware that some people will get dementia no matter what lifestyle changes they make, you know, and be mindful of that.

**Steven Bruce**

I've got a few questions coming up, which I want to get on to for our little poll. This next slide of mine is just an illustration of a video which is available from the Alzheimer's Research UK organisation, which apparently is very good video.

**Dawn Brooker**

Yeah, it's a cartoony one. But it's a very sort of straightforward one and it will take you through those five basic types of dementia, talks about what's going on in the brain and what you can expect.

**Steven Bruce**

It's pretty simple. There is probably something which we might want to refer our patients to look at all their or people who are worried about their family members, rather than necessarily being scientifically informative for healthcare practitioners themselves.

**Dawn Brooker**

Yeah, it's an easy way in and they do a lot of very good material.

**Steven Bruce**

Sorry, I brought this up a little bit ahead of time. But I thought it'd be fun to get on to another question.

**Dawn Brooker**

Yes. So how many people in the UK are living with dementia, I've put a figure of 860,000 up there.

**Steven Bruce**

860,000. I'm trying to work out what that is as a percentage, out of sixty million someone got to do it for me. So, is it true or is it false? We'll leave it up. I mean, does it really matter, how many there are? Because I suppose it increases the incidence of people coming through our doors, doesn't it?

**Dawn Brooker**

I think it matters hugely. Yeah. I think it changes the narrative around dementia. You know, when I first started as a psychologist, dementia was a relatively rare condition. We called a psychiatrist if we had somebody with dementia in a care home. Now our care homes are full of people with dementia. And I think that's what changed, is why we hear about dementia a lot more, why it's much higher at the policy agenda.

**Steven Bruce**

So, 860,000. What do you reckon? Professor Brooker? Is that true or false?

**Dawn Brooker**

I think it's true.

**Steven Bruce**

Justin, did we get any answers from the other two sources?

**Justin Hedges**

Yes, so Vimeo, we have 70% of the viewers think true, and 30% think false, and Facebook, hopefully will let me know. I'll get back to you with Facebook.

**Steven Bruce**

But interesting, you said here by 2050, we can expect it to be 1.7 million, is that because the population is growing? Or because we're getting just a growing incidence or for other reasons?

**Dawn Brooker**

It's because our older population are growing, you know, we are living longer and that's great. But the incidence of dementia, as we will find out probably on our next question...

**Steven Bruce**

I put this infographic up, it'll be available in the downloads, but I mean, it just shows that you know, it's going to grow considerably by 2050. So, you said there's some really big numbers being thrown around with this.

**Dawn Brooker**

Well, and I think globally, you know, we tend to sedate, a lot of our big growth in dementia has been within Europe and the United States and North America are really, you know, but globally, we're expecting the numbers of people living with dementia to double every 20 years. So, 81 million people on the planet with dementia by 2040. And by 2040 71% of people with dementia on the planet will live in low- and middle-income countries. So, you know, we're thinking about Central Africa, Asia, South Asia.

**Steven Bruce**

On current prognosis, we're all going to be low-income countries.

**Dawn Brooker**

Probably. I usually put this slide up when I'm talking to students by saying if you get good at dementia, you can travel the world because there's a lot of it about. I've done a lot of work in the years with Japan, who are our super ages on the planet who live a very long time. I mean, I think the population of Japan is about 157 million, and they've already got 6 million citizens with dementia. So it's a real health concern globally.

**Steven Bruce**

But this next question of yours is an interesting one, does actually the rate of or the risk of getting dementia increase as you get older? And you've asked the question, once you get over 60, does your risk of developing dementia double every five years? So, for the audience, is that true or false? Does the rate increase or does it get less? Because one way around would be an encouraging thought for someone who's just been given the diagnosis, but the other way would be quite disappointing I'd have thought, as you know, it's not the diagnosis, is as you get older, yeah.

**Dawn Brooker**

It's when you get your diagnosis, you know, is it rarer to get in at 60 than it is a 90? And what's the rate.

**Steven Bruce**

Justin put us out of our misery? Is it more likely?

**Justin Hedges**

Okay, so, on Vimeo we have 66% think it's true, and 35% think it's false. And on Facebook 73% think it's true and 27% think it's false.

**Steven Bruce**

Well, and now we hear the truth. It is true.

**Dawn Brooker**

It is true. So, you got the percentages there. So, you can see, and that goes back to that earlier infographic. That's why we're seeing the increase, it's primarily, we are living longer and Alzheimer's disease particularly, we see that doubling.

**Steven Bruce**

So of course, of course, we're getting people asking about what's this going to mean for us in practice, which is of course what we want to get from this, first of all, what are we going to see in practice which might alert us to the possibility? What effects might we see in family members as a result of dementia, which again, we might be asked to deal with?

**Dawn Brooker**

Well, go on to the next slide, can you, which breaks it down. I'll put this slide up. I'm in sunny Worcestershire or not so sunny at the moment, but I think doing this sort of age breakdown for, these were just drawn off of the Worcester County Council website, estimated age breakdown of citizens living with dementia. And, you know, we look at our, you do get people being diagnosed with dementia or you do get an instance of dementia at those younger age groups and if you get dementia under the age of 60, we know that you're half as likely to get a diagnosis if you're over the age of 60, because people just don't expect you to have dementia. And you'll still be in work and you'll have adult children. So, although that number is relatively low, it's a huge impact on people's lives when it's this early, and so just be, one of the things that is

always important to be aware of on an individual patient level, is just because somebody is not elderly does not mean they have not got dementia, you know. So that's one thing.

**Steven Bruce**

Actually, maybe I misunderstood that last question, is the greater likelihood of getting a diagnosis of dementia due to people just looking into it more clearly, if you are old, if you're 85, they'll assume it's the first thing that's wrong with you, whereas you're 60 they won't?

**Dawn Brooker**

Yeah. I think that there's certainly some truth in that. The figures are based on what we expect to see in a population by age breakdown and other socioeconomic factors. So that's what the projections are based on the incidence, whereas the diagnosis is often quite lower than the actual incidence, but yeah, you're absolutely right. If you go, it's our stereotyping, isn't it? But if you look in Worcestershire at thereal big increases, of course, they're occurring in your over 80s. And look what's happening to you if you're 85 plus. So, it's worth if you're doing some thinking and future strategy planning about what is going to go on in your catchment area, drill down some of these figures because you will have a changing age population there. And you know those cohorts of populations as well. You know, a 70-year-old now is not the same as a 70-year-old was 30 years ago, you know, our life expectancies, our expectancies of our health care, our social care change, we're just getting the baby boomers coming up, who will be a right stropky lot, so that that could make for some interesting time in older people services.

**Steven Bruce**

But I guess then, we are not expecting, as osteopaths, chiropractors, physios, we're not expecting to be the person who first recognises this but there's a chance that we might be the person who sparks the diagnostic process. So, is this true that the first symptom of dementia is memory loss? This is one for the audience. Because, as you said earlier on, I mean, you go to a doctor, a GP, they're generally screening very broadly for dementia. I imagine this is the sort of thing which might alert them.

**Dawn Brooker**

Yeah, it's what a lot of people think.

**Steven Bruce**

Any news there Justin?

**Justin Hedges**

Results are still coming in. Just give it another minute.

**Dawn Brooker**

Well, I'll talk a bit about you know, because we use the term memory assessment services, we often talk about dementia as, you know, interchangeably with memory loss. But it can be an early symptom. I don't want to spoil the result.

### **Justin Hedges**

Okay. So, on Vimeo, we have 64% that say true and 36% that say false and Facebook is saying 71% say it's true and 29% say false.

### **Steven Bruce**

Keeping that one under your hat until the results were in and and most people, myself included, would probably have assumed that memory loss would be the first symptom per se.

### **Dawn Brooker**

Yeah. Okay. It was a bit of a trick question. I have to say this is a bit of a psychologist question because, poor learning of new information is a common symptom, which is slightly different from memory. So, you're, particularly, if we say in Alzheimer's disease, for example, as the most usual dementia that we'll see, that poor learning of new information is a pretty cardinal thing to be looking out for. So, if the information is in the brain already, so if you know how to ride a bike, ride a bike or grow tomatoes or recite a poem or the songs of The Beatles, you know, it's all in there, that's not going to go. But if somebody gives you an exercise, a rehab exercise to do, your chances of remembering that are going to be pretty poor.

### **Steven Bruce**

Remembering how to do it or remembering to do it at all?

### **Dawn Brooker**

Both. So, there is that sort of remembering to do something on a regular basis without prompts is going to be very difficult and remembering those, you know, the complexity of how to do something, remembering when your next appointment is. So, I think it's important to develop a bit of a sophistication around understanding that the symptoms aren't just that people can't remember anything anymore. But if we go on to the next slide, which is a bit of a schematic of the brain, many people in the audience, this will be a familiar sort of diagrammatic picture of the difference. The different areas of the brain, different modes and we know, by and large if you get a damage within your temporal lobes, you'll have problems with new learning speech and understanding. We know that if frontal lobes is about reasoning behaviour, stopping, starting, executive type functions, planning things, parietal lobes, the whole knowing where you are spatially in relationship to other things, and your occipital lobes are very much about your visual processing. So, given that dementia, the dementias impact on different parts of the brain at different times. You know, if you can start to conceptualise this as a neurological disorder as opposed to a psychiatric disorder, and you start to understand the neuropsychological symptoms, then that gives you a way in to assist your patients. So, I just wonder whether it might be worth flipping to the next slide. So, you know, these are some of your sort of cognitive symptom awareness. And again, I think some of these terms, this terminology will be familiar. So, we've already taught about the learning and the remembering of recent things So, you know if you're if you're seeing a patient and they're asking you the same question over and over or not, not being able to remember something that you told them at the beginning of the interview or consultation, by the end of it, you know, that's a bit of an alarm system to me that somebody is not processing. Dysphasias,

communication, difficulty understanding and using language, typical Alzheimer's type early languages were the nouns all drop out, so you get a lot of thingamajigs and the whatsits and, you know, the whatchamacallit. I will now have, I would say 100% of people on Facebook now diagnosing themselves as having dementia because that happens to all of us to a certain extent, particularly if we're tired or, she says, becoming a bit dysphasic herself. So that sort of being able to process language. And therefore, if you are trying to help somebody understand, being very mindful of how well you communicate, not giving lots of confusing instructions?

**Steven Bruce**

We've been asked already about how we make a practice dementia friendly and it kind of leads on to my question here is that, I'm guessing that for a lot of this, it's really important that perhaps we speak to family members, because some of these changes, for somebody might not be changes. Somebody might always have been a little bit dysphasic. And it's a significant thing, and they won't notice that themselves. But I guess also, the problem is that it's very slowly insidious, so nobody's going to notice it suddenly happening.

**Dawn Brooker**

Yeah, yeah. And, you know, as I put up at the top there, both the site and the degree of damage will determine your symptom pattern, if you've just got a little bit of a communication problem so, communication is like a bit like a game of tennis, you're realising that you're having to bat the ball back to somebody to help them out to to get to their next word. That can happen quite a lot in earlier dementia, whereas in more advanced dementia, somebody may not have the ability to understand sentences of more than three words, you know, so the degree of dysphasia will change.

**Steven Bruce**

So I suppose that answers one of my questions, which is are those symptoms there, those signs ranked in order of likelihood or anything, but it does depend on the area of the brain that's been affected.

**Dawn Brooker**

That's right. But you know, if you're, as dementias progress, more and more of the cortex is impacted, so what might start off as a problem learning new information, or having the occasional dysphasic episode may well then go into dyspraxias, into visual processing problems and technical function problems. So as the dementia progresses, you expect to see more different types of symptoms.

**Steven Bruce**

Somebody quite sensibly asked here, whether we're likely to see any physical signs, you know, physical weakness, perhaps, or might that just be secondary to something like a lack of body awareness, which means that people stopped doing exercise that they might have done before.

**Dawn Brooker**

Yeah, yeah, I mean, I think the whole-body stuff is really interesting. I would love to do some research with chiropractors and osteopaths around this, you know, certainly if you think about body awareness, dyspraxias

in practice. So, one of the things that I will often teach care workers is, you know, you're trying to get somebody with dementia to stand up, you know they can walk. So, you stand in front of them and you say, give me your hands, lean on the push yourself off from the chair, right? Push yourself up and the person's bottom goes further and further back in the chair, because the more they're given the instruction to push themselves up, the more they are, their wires are all crossed, and they're doing something else. And then the care workers sort of thinks well, I'll come back in a minute then because he's obviously not wanting to get up, care worker walks away and the person gets up of their own volition. Now, that's a fairly typical dyspraxic type symptom that you see in the setting of dementia. If the care worker gets the person into flow, rather than giving them instructions about what to do with their body. So if she says something like, Harry, have you seen our new goldfish that we've got over here? You know, then Harry automatically gets up because he's not thinking about where he's going to put his leg or his bottom. He's just moving. I think that's, if you're giving patients instructions on how to move bits of their body, then they may well find that quite difficult. Whereas if you can do something to music or get people moving more naturally without thinking about it, the body is actually very good at doing things in flow still. And I think the other thing that I'm increasingly aware of in our works around, we do quite a lot of work around dance and movement therapy in dementia. People have huge body memories. You know, if you put some music on, even for somebody that is, has quite advanced dementia, and it's a waltz, and you waltz with them, they know the waltz, they might not be able to tell you that they know how to waltz, or they won't be able to show you what the steps are. But the body remembers. And I think that there are probably all sorts of emotional memories that we hold in our bodies, that I would guess you and your practitioners would come across a lot, you know, it's sort of some movements or some parts of the body bring back particular memories. And if we could go on to the Alzheimer's slide, that one I think might help just round this little bit off.

### **Steven Bruce**

So basically, the stuff you learned early on will be the last to leave you?

### **Dawn Brooker**

Absolutely. Yeah. What often we're doing with people who have very advanced dementia is going back to some very basic bodily movements. That rocking, stroking, stroking face, stroking arms, hooking. You know, it's that sense of those very fundamental things that we have as human beings in our development are still there, well within your dementia. It's the stuff in the later years and since the dementia sets in, that they're much more fragile, you know, we spend a lot of time rehearsing our early and middle years' experience. And you know, a lot of what we do then, in reminiscence, or using music is often focused on people's times 15 to 25. Those are your big social memories. That's when you know every song that was in the pop charts you knew at that time, you decided which football team you supported or what sport you supported, what car you were going to drive, you know, those memories are usually really well held. And so, if you want to strike up a conversation with somebody to help take their mind off whatever, if you're trying to do a, something with them that's a bit painful or difficult. Get them talking about that era, because that will help them to feel more confident, because you're tapping into those memories.

### **Steven Bruce**



Can I drag you forward quite a few slides because, again, they say that time whizzes by but this is something which will be of particular interest to all the people watching here. And it's an interesting question for the audience. People living with dementia lack the mental capacity to make decisions about their health treatments. In other words, we can't get informed consent from patients who are experiencing dementia. Now, is that true or false? We'll leave people to answer the poll. Justin, just be aware I've gone on to slide 39 here.

**Dawn Brooker**

Yes, yes.

**Steven Bruce**

This is a really topical quiz. It's always a topical question with us because we're constantly being, having it drummed into us that we must ensure that we get, sometimes people say informed consent, some people say valid consent, and there's a legal debate over which is the important one which we can go into here. But obviously, consent is a very important thing, important presumably in your line of work. But also, in ours where there is a very small but some possibility that we could do physical damage. And when also we just can't treat people against their will. So, Justin, what are the answers on this one?

**Justin Hedges**

Okay, so they're still coming in but generally speaking, Vimeo are saying 47% are saying true and 52% are saying false. And on Facebook they're saying, 40% are saying true and 60% saying false.

**Steven Bruce**

Okay, so just over half in both cases saying that it was false that people with dementia can give consent, which is good, because you're going to explain that now, aren't you, Dawn?

**Dawn Brooker**

I am, yeah. Again, so if we go on to the next slide, as you say, it is a complicated, it's a complicated picture. And I think the issue is that mental capacity and dementia, so a diagnosis of dementia is a reason to question whether somebody might have capacity issues. So, if you know that somebody's got a diagnosis, you need to be taking capacity to consent seriously, because it's one of the reasons that we do that. And people's rights are protected under the Mental Capacity Act, which very clearly says that decision making capacity is both situation and time specific. So, somebody may have the capacity to consent to, I don't know, give me an example of something you would consent to.

**Steven Bruce**

Articulation of a joint, I mean, it doesn't really matter does it?

**Dawn Brooker**

Articulation of a joint, okay. But they might not be able to consent to having bowel surgery, you know, so I think it will...

**Steven Bruce**

Why? Why is that different? I know the potential negative outcomes could be different, but actually it doesn't surely impact on your ability to say yes or no to a treatment.

**Dawn Brooker**

Okay. So, in order to, so on the slide that you've got up at the moment, in order to decide whether the person can make a decision, it has to be about a particular decision. So, we might be thinking, articulation of the joints and bowel surgery. So, they have to, to be able to say that somebody has capacity, you have to be able to tick the box on these four things. So, the person has to be able to understand the information that is relevant to the decision they want to make. So, the decision around articulating the joint or having information about consequences about surgery, the complexity is quite different. So, if you've got a more complicated thing, they might not be able to understand, you know, the percentage survival rates and the side effects and all of those sorts of things. So that may mean that they could make a decision about a simple thing, but not a complex thing.

**Steven Bruce**

What sort of questions would a clinical psychologist have in their arsenal to judge that degree of capacity?

**Dawn Brooker**

Well, I think what you would be doing would be talking through, you'd have the conversation that you'd have with anybody about the treatment. And you would be ensuring that they were retaining that information for long enough to make that decision. So, if by the time you've got to the end of it, you're asking, so do you understand what I've just said? Tell me again, what I said about what might happen in theatre, you know, so you're checking back to see whether they've really got that, your five points that you wanted to make, they then have to be able to weigh that information up. So, you know, again, I'm getting the patient to tell me back. So just remind me what you think I just asked you, what was the consequence if we don't do your articulation of the joint, so. And obviously they need to be able to communicate their decision. And that can be in, by nodding the head or whatever, but they need to be able to tell you the yes or no. So, these are the four things that you'd be looking at for each situation that you were trying to get consent for. Now, if the person lacks, if the person doesn't meet those four, we got the next, we got more on another slide.

**Steven Bruce**

Well, the next one's just the dementia guideline.

**Dawn Brooker**

Okay, so going back to the other one, if they haven't got those four. If you can't tick those you can then move on to something that's called a best interest decision. So, then you would be deciding, is this treatment in the best interests of the person to have or not, but you can only go to a best interest decision once you've

demonstrated the person lacks capacity. You can't make a decision in the best interest of somebody who has capacity to make an unwise decision, you know, so that's the, that's the ruling.

**Steven Bruce**

Right? But what if they have a carer next of kin, a family member who comes with them? Is it their job to make that decision, their job to give consent then?

**Dawn Brooker**

Well, it's easier if somebody has got lasting power of attorney for health and wellbeing and again, going back to that post diagnostic advice that we'd be giving. That's one of the things that we try and talk to people very early on in that diagnosis process, to put those things in place, because then it's very straightforward, that you know, they've designated somebody to make those best interest decisions. The best interest decision again, if you go to the Alzheimer's Society website, they've got some great downloads on how you make best interest decisions and who can make them. By and large it's got to be somebody that knows that person well, so often is a next of kin, but you have to weigh up, then, you know, am I sure that this person knows this patient well enough to make a decision in their best interest.

**Steven Bruce**

Lucy's actually asked a question about exactly this, is, she's concerned about how do we support a patient showing signs of dementia if they have no family or other advocate? She says she thinks it's a quite a grey area in for example, terms of contacting a GP, because unless we give them consent, we can't inform other care workers. I guess what you're saying here is that if we judge it's in their best interest and they don't meet those four criteria that you listed there, then we can contact their GP if we feel it's necessary.

**Dawn Brooker**

Yeah, I mean, I think it does often feel like a grey area. Most people with dementia would tell you that, you know, they would rather somebody made a decision in their best interest and didn't talk to somebody because, you know, because they got a problem and we're trying to protect my confidentiality. Often, if you're seeing a patient who you are concerned about in terms of memory, or cognitive changes, it's quite usual that they're going to end up seeing the doctor for something else and often people get assessed for dementia or that conversation about the possibility of it, will start when the patient goes to the doctors for something else, for chest infection, so I think alerting practice partners to a concern is going to be in the person's best interests.

**Steven Bruce**

To change the topic slightly. I've not heard of dementia villages but Josephine sent in a question about them, apparently here people pretend to be postmans and shopkeepers and so on, all on a campus which is safe for the dementia sufferers, but it's happier. Do you have any info on those?

**Dawn Brooker**

Yeah, yeah, that's an idea that started in the Netherlands and it's been going actually for 20 odd years or more now. So, the dementia village Hogewey in the Netherlands really tries to recreate an environment in which the person will feel most at ease. So, it's based on that Alzheimer's arrow timeline I showed earlier, so I don't know what you do for me, create a sort of David Bowie night club somewhere and I'd feel very happy. You know, so that's the idea you recreate that sort of lifestyle the person feels happiest in. I think there is some validity to it. There's never been any decent research done on the dementia villages I have to say. I think it can for some people be highly disorientating and anxiety provoking because, again, you know, dementia is not an all or nothing. It's not a, everybody thinks they're in the past. You know, most people will have insights sometimes that things are different. People don't actually live entirely in the past. They might find comfort from things, from earlier in their life. But if earlier in their life is full of terrible memories and associations, they actually might find that quite upsetting as well. So, I think we are always very wary of solutions that try to treat everybody the same. You know, everybody with dementia is different.

### **Steven Bruce**

Okay. A couple of very quick questions, I hope and then one slightly longer question because we're now really close to running out of time. Catarina asks whether there is a link between dementia and temporal arthritis.

### **Dawn Brooker**

Don't know. I'm disappointing a lot of people here.

### **Steven Bruce**

But we like honesty. And somebody's moved my question around, Olivia asked about a link between nicotine withdrawal and dementia, anything you know about it?

### **Dawn Brooker**

Not really my area.

### **Steven Bruce**

I'll keep going until you get one right. It says about patient advice. It's anonymous. The practitioner says they have an older lady patient who they're noticing has memory lapses. She's very repetitive during a treatment session, and it's been worsening over a few months. Her family's not known to the practitioner, but she's close to her daughter, not sure how to proceed, hasn't seen her for a while, but it's reminding the practitioner of this patient, would it be breaching patient confidentiality to raise concerns with the family? Not sure how the practitioner would approach them either. They probably brush it off, would what they describe there make you think dementia?

### **Dawn Brooker**

Or it could be any number of things. You know, I mean, there may be a sort of physical problem that's causing that sort of heart failure or thyroid or, there are other things that might need to be ruled out before you'd go to the dementia diagnosis, with particularly if you're looking at somebody that's very elderly, they're

lapses into acute confusional states of delirium type states can happen more rapidly. I think too, you know, with any of those conversations, you have a tentative conversation. So, how's your mom coping at home? You know, it's sort of, you explore it, rather than saying, I think your mum's got dementia.

**Steven Bruce**

But that's difficult to do if they haven't actually come into the treatment room, isn't it because you can't actually phone a family member and ask about their health, medical health of someone else. Maybe it's one of those occasions when it's worth a friendly phone call to the patient just to find out how they're doing and say, well, I remember that you were doing some things. I noticed these things in your last appointment. I just wondered how you're getting on at the moment and just make an assessment then by phone and say, well, would you like me to talk to somebody who can make a further diagnosis perhaps?

**Dawn Brooker**

Yeah. It's a process, these conversations, aren't they, you know, you can have the conversation at a time when you've got the time to do it, when you can be relaxed, often it's over a period of time rather than thinking that you're going to be able to do this sort of thing quickly.

**Steven Bruce**

That's taken us to bang on nine o'clock, according to my time that is in front of me. That's really, really helpful. Thank you very much. I know there's a lot of questions you couldn't answer there. But that's fine. There's bound to be things that are outside your scope of practice. But you have answered an awful lot of other questions. And we will make the slide pack available to people and any other resources that you care to share, we will put them on the website and make sure that people know how best to deal with patients who may be suffering dementia.

**Dawn Brooker**

Yeah. Okay. Thank you.

**Steven Bruce**

That's it for this evening.