

## 89: Dementia

*The challenges of pain management in people with dementia, different medications and why an iPod could be latest tool in our first aid kit.*

*According to a survey carried out by the Alzheimer's Society, Dementia is the most feared health condition in the UK. Last year alone, 225,000 people developed dementia.*

*In this episode of Airing Pain, Paul talks to Professor Peter Passmore about the challenges of treating chronic conditions in people who develop dementia, including different medications and why we instinctively link age with pain.*

*In 2012 Lloyd Hughes authored a report, Managing Chronic Pain in Patients with Dementia. Now a GP trainee, Lloyd discusses how he incorporates his findings into every day patient care and what we can all do as individuals to prepare for a future that may well include dementia.*

*Andy Lowndes, Deputy Chair of Glasgow based charity Playlist for Life, describes the power of music in helping those living with dementia – whether as a patient, carer or loved one – connect with each other and reconnect with themselves.*

**Paul Evans:** This is Airing Pain, a programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain, and for healthcare professionals. I'm Paul Evans and this edition has been funded by WG Edwards and Cruden charitable foundation.

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**Andy Lowndes:** I've seen many times those tumbleweed moments where we've seen in care homes and hospitals, families coming to visit, and after they've said how are you today darling, nothing comes back. And that becomes a really difficult, painful time for family members who are visitors of that person.

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**Paul:** Now, according to a 2016 survey carried out by the Alzheimer Society, dementia is the most feared health condition in the UK. And in 2016 alone 225,000 people will have

developed dementia. So, what are the implications for someone with a chronic pain condition who *also* has dementia?

Well, Peter Passmore is professor of Ageing and Geriatric Medicine at Queen's University Belfast. He's also consultant in old age for the Belfast Social Care Trust.

**Peter Passmore:** It's hard to avoid pain in all conditions. But in dementia, there are difficulties knowing exactly whether people are in pain or not, more so as the disease progresses. That can influence so many things. We normally focus quite a lot activities of daily living in people with cognitive impairments. Pain can worsen that, but it can also affect their mobility, it can affect their sleep and their mood, and it can cause behavioural problems.

The patients sit in a vast variety of locations. Some people are at home - that might be a milder level of dementia, [for example] just after diagnosis [and] they can communicate maybe as well as you and I. [Other] patients may be in hospital - they say that at least sixty percent of people in the nursing home situation have got dementia, so clearly that's a sector where we're very interested and where maybe not so much attention may have been paid. The more confused, more behaviourally abnormal kind of people end up in a different kind of nursing home - again, I think it's very important to be aware of pain *there*. And increasingly there has been an increase in interest in palliative care; the services for dementia I think have shied away from it before but now they're taking much more of an interest. Certainly in Belfast, the hospice is very active there.

**Paul:** It's hard enough for a person *without* dementia to make themselves understood about their pain, to describe their pain.

**Peter:** Mhm.

**Paul:** But I guess communication is one of the big issues...

**Peter:** I wouldn't say it doesn't happen in early-stage dementia but those people have more of a memory, so I suppose this is something that you might remember from before: if you've had something painful before, then the same thing happens, your systems are functioning and you can say "Oh, that pain, [I] can describe that". I think - yes, as things progress, naturally you'd start to get worried, because people lose their memory for what that painful experience may have been, they can't describe it, and secondly their language facility is

one of the things that go when you get to more advanced stages (certainly with Alzheimer's disease).

So, you're absolutely right, for a variety of reasons. I think you've got to have a high threshold and a high index of suspicion. Personally I always ask people if they're in pain, as a routine question, even if they don't seem to be in pain.

**Paul:** You ask people if they're in pain?

**Peter:** Mhm.

**Paul:** Is it automatically accepted by people that, if you're old, pain is a natural progression? [That] age means pain?

**Peter:** Y'know, there is an attitude out there among old people, and certainly the studies and the literature bear that out: 'Sure, what do you expect, I'm eighty-five, I've done this, that and the other all my life and it's just wear and tear'. That is a prevalent attitude. And that's allied with attitudes like people not wanting to take medication or 'become addicted' - that *can* be a problem and you will get a lot of the studies that show that older people, those without dementia, are in pain and quite a large percentage of them don't take any medication. Immediately you'd look at medical professionals not detecting and treating that. But part of that is in the patients themselves, as in your question, where they're just not that happy to be on constant pain relief.

**Paul:** 'Aches and pains' [as they say].

**Peter:** Yeah.

**Paul:** What do the research papers say about health professionals or carers at nursing homes - how should they communicate with people with pain?

**Peter:** Our studies certainly show that there's a couple of barriers there, that there is a difficulty with detection, and people are not sure about what they should be doing to try and detect pain. And then, after that, the issue would be a kind of pro forma or some sort of suggested regimen for managing that pain when you've got it. And of course they also have to liaise with the GP. So there are issues around that. Certainly from our studies it looks like the awareness, knowledge, and the training of care staff and care homes [are] very

important [in trying to] get over these hurdles. We know well from the studies, they're several that show what those barriers are.

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**Paul:** That's Peter Passmore, professor of Aging and Geriatric Medicine at Queen's University Belfast.

Lloyd Hughes is a GP trainee working at the Royal Edinburgh Hospital in Geriatric and Stroke Medicine. As a medical student, he worked in nursing homes as a social support officer. He co-authored the report *Managing chronic pain in patients with dementia*.

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**Lloyd Hughes:** I think it's a very interesting area for a whole variety of reasons. You have all these different types of patients: you have patients that have had chronic pain then developed dementia. Then, you also have patients who may have not had problems with dementia who then developed chronic pain. And from my experience, working in the nursing home as a support officer, it seemed to be a very challenging experience for the GP to try and manage these patients.

First of all, most patients, with the exception of those with genetic dementia conditions, are older and have other health problems [like] lung disease [or] kidney disease which means that some of the [range of medication] that you'd think about using in pain is more limited. Secondly, the gold standard of everything they teach you at medical school is about history taking and clinical examination. [But] clearly, in patients with communication or cognitive difficulties, it can be challenging to get an accurate history, and in some forms of dementia it's difficult to get a clinical examination as well.

**Paul:** Let's start with communication. Somebody without dementia might know exactly where they've been in the past, what's happened in the past. [With dementia] you're starting with a blank sheet.

**Lloyd:** Exactly.

I think one of the joys of general practice is the fact that we do have access to long medical histories. I think, one thing when speaking to the GPs is that when you're going to visit a nursing home and you know you're going to visit certain patients, you have a bit more of a

read about the background - that applies to everything, including pain. Trying to get an idea as to why these patients are experiencing pain is more difficult.

Now, that's why caregivers and nursing staff in nursing homes are very important in the assessments of these patients. The communication [issue] in dementia is not an all-encompassing thing; there's different stages of dementia. What doctors and nurses and caregivers have to try and do is to use the communication that the patient has to the best of their abilities to support a diagnosis. [But] I think sometimes doctors are bad at hearing a diagnosis of dementia and assuming that [the patients] are not going to be able to give a history, and it's somewhere kind of in the middle.

**Paul:** Where do you start? How do you know that a person has a chronic pain condition?

**Lloyd:** The easy cases are when the patients have a long-term diagnosis on the system which they may have had for a prolonged period of time and might have developed another disorder. The more challenging ones relate to concerned voiced whether by family members or even the patients themselves about a behavioural change or mobility issues; these are called 'vague presenting complains', which they don't necessarily come to you and say 'I've got pain in my hips' or 'chronic issue with my knee that's been going on for three months'. It's more the fact that the wife may say 'John's not been so good on his feet the past six month, he's not sleeping as well [as before], he's being a bit more repetitive in some of his behaviours'... So, from our perspective it's about trying to think what else can explain this. And sometimes it's a progression of dementia, but often there is something acute that's precipitated this so that can often be pain or discomfort or those kind of things.

**Paul:** We are just talking about nursing homes at the moment.

**Lloyd:** Mhm.

**Paul:** Firstly, going into a nursing home, it's a change of environment anyway so people will act differently. When nobody knows how this person will act in the new environment, how would you go about assessing it?

**Lloyd:** That's probably the most challenging point: the point of admission. Because patients are moving from home into a new environment, what generally will happen in this patient group is the nursing staff will do an admission and that will be an advanced care plan which will involve a whole state of getting a background on the patient on what they've done before. Then the GP will come in and review the patient.

Often it's very difficult, on meeting the patient for the first time, to say 'We've got a problem here' or suggest [that there might be] pain, but the key issue is to document what the GP, caregivers, and care nurses have experienced, and what is normal or what the patient's baseline is. That is really important.

In most GP records for patients in nursing homes, there is a summary - an e-KIS (Key Information Summary) summary, which basically explains what the patient's current level of health is when they're well. Then, it's about comparing that over time. It may be that in three or four weeks things change, or it may indeed be that that *is* the new baseline, but it's just about having an appropriate and accurate assessment at the initial presentation and using that at your comparison point to see what happens over time.

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**Paul:** Lloyd Hughes.

**Paul:** If people with dementia are on medication for pain, or anything else for that matter, some of those medications can have side effects such as causing confusion, drowsiness or any number of things, in fact. So how do doctors establish whether *those* side effects are because of the medication or the dementia? Professor Peter Passmore:

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**Peter:** That's a very good question at a practical level. You see this in practice all the time: You have somebody in pain, and you may be trying to estimate what is the nature of that pain. Is there a neuropathic component to it? How severe is it? I think for pain a lot of the time it is a best guess - well, it's an *informed* guess in our case - when we go in with medication: which medication do you pick, and at what level? How do we manage the pain without causing the patient any untoward side effects?

In this population with dementia you're already in a situation where the brain is compromised, so what happens is: the more pain you have, the more delirium you get. So that's problem with the pain itself and that affect will the level of confusion that the patient and also the carer will feel as well. The difficulty you have is if you try to go with the likes of amitriptyline, which is very commonly used, certainly in primary care; if there's a neuropathic component pregabalin is commonly used; and then if the pain is more severe you have to reach for the opioids.

The issue with all three of these is— amitriptyline alone can cause more confusion as an tricyclic antidepressant with its anticholinergic effects. Opioids also have anticholinergic effects, so if you have to use those together there's a combined effect, on top of the medication people may already be taking, as you said. Pregabalin can also be associated, even in lower doses, in vulnerable old people with more confusion. So, you can see how it's a two-edged sword: the pain causes more delirium, and then the medication may cause a little bit of delirium and increase confusion there as well.

So it is a balancing act: I think you do look at the person in front of you and you try to make an estimate of their biological age, what weight they are roughly [and so on] - those will all influence the drug handling things.

The kidney function for opioids and for the likes of pregabalin is pretty important, because those drugs are predominantly excreted through the kidneys so if the kidney function is down, as it often is in old people, you will modulate your dose accordingly. It's a balancing act and I think that's why people do need to look at the population they're dealing with and be pretty well informed about the drugs, particularly about renal function and try and get it right.

It's easy if you can observe the patient; in the hospital where I work that's pretty straight forward so if someone seems to become more confused for example if you've prescribed an opioid that can be titrated back. But it's not so easy probably in the community, for people at home or in the nursing home sector. So the GP, if they prescribe and it's appropriate, [might well advise the patient and the carer] that they need to report back if there are any untoward problems and the situation can be then treated.

**Paul:** Professor Peter Passmore. Lloyd Hughes again:

**Lloyd:** One of the benefits of being in a nursing home in some regards is 24-hour care. If you're a GP seeing somebody at home you make an assessment based upon a clinical examination of maybe 10-15 minutes (maybe longer in a home visit). When you're in a nursing home you've got different staffing rotations, you're seeing patients overnight and in the day and you can get a more comprehensive assessment of what the patient's behaviour is over time - the same as caregivers when they're at home.

That's really important because often, from my own experience of visiting patients at home or in nursing homes, they might actually be fine when you go and assess them, but there is

a concerned voice from the nursing staff saying 'Actually, he's not sleeping at night, he's not comfortable in his bed, he keeping trying to go over in his chair, you can't lie him flat' - those kind of things. So you get a bit more information about how the patient's managing across the 24-hour period. I think that's one of the things I've learned a lot about, actually.

**Paul:** I'm making a sort of assumption - a false assumption - that dementia means old age and care in a nursing home.

**Lloyd:** Even twenty years ago the diagnosis of dementia was— that was the diagnosis. Whereas now, there are lots of different types of dementia, and the different types often can affect different age groups. So there is a much better understanding of vascular dementia or multi-infarct dementia and actually that is not uncommon [as I saw when I was in Dundee] in patients even in their early sixties.

You're quite right that because these patients are often physically more healthy when they develop these cognitive problems, there *are* more challenges because you can manage these patients at home, they may have fewer other medical issues, which means that you can try different medications differently.

Actually, there is some new research now that suggests that patients with vascular dementia may experience more pain than those with Alzheimer's dementia or dementia with lewy bodies because of the type of damage that happens to the brain. Different dementia syndromes manifest different types of pathological changes. There's a lot more research now looking at vascular dementia as a dementia which causes more chronic pain or can cause pain-type symptoms or affect patients' experience of pain if they do have other things going on like knee pain or osteoarthritis.

**Paul:** So what are the challenges for the people who are cared for at home, rather than in a nursing environment?

**Lloyd:** There's often a lot of caregiver stress, there's often a difficult dynamic between family members. Also, you have patients who manage [well] with mild to moderate dementia in their own homes and you're thinking about issues of safety, how they are managing at home, can they provide support with CPN-type followup, have they got behavioural issues, are you able to get district nurses to keep a closer eye on them... So a lot of it is a balance of paternalistic medicine where what we want to do is keep everyone safe and well, but at the same time promoting independence. So I think the question of [how to balance the two] is a big challenge.



**Peter:** The evidence probably shows that the better you know the patient with dementia, the better you're able to say whether they're likely to be in pain. Against that, you have some studies showing that actually caregivers are *not* too good at reading pain. That's a fairly critical thing, because if the patient can't quite indicate for themselves, if the carer isn't spotting the signal...

The implication is that [caregivers] know [the patients] very very well, so suppose they're seeing all day every day, they can quite often say to the nurse or another medical practitioner 'They always do that when they're in pain so I think they're in pain'. But I think the implication is when people aren't involved in that constant level, there could be difficulties in recognising what is a feature of pain from a behavioural perspective. So I think we *assume* that carers always know but I'm just not sure that the evidence bears that out.

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**Paul:** Peter Passmore, Professor of Aging and Geriatric Medicine at Queen's University Belfast.

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**Paul:** So, from what we've heard I think it's fair to say that an overriding issue for people managing chronic pain with dementia is one of communication. I'm going to move from what the health professionals can do to open those channels of communication, to what we - the loved one, spouses, family members, those in early stages of dementia *and* those of us who may or may not develop dementia in the future - can do to keep those channels over for as long as possible.

Andy Lowndes is the deputy chair for the charity Playlist for Life.

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**Andy:** Playlist for Life is really a simple tool which is based around identifying the unique playlist of a person's life in music and helping a person living with dementia and their family to access that playlist. What we found was that by giving a person access again to the soundtrack of their life it's enabling them to reconnect to themselves through the memories and the emotional connections and all of the stories around that music.

**Paul:** But the question must be asked: If you are losing your memory, why aren't you losing your music?

**Andy:** This is the killer question, y'know? What we found was that many reminiscing triggers are used nowadays. In a previous life I was involved in stuff like football memories and I've used visual imagery, photographs, and so on. That seems to stay for a long time but eventually even recognising yourself in an image can disappear. But the one thing that seems to remain is our ability to respond to music. We don't know exactly why that is, but certainly evidence from even some of the work that we've done shows that connection to a piece of familiar music enables an emotional reaction to happen, which means that memories can be retrieved when even other forms of triggers seem to be lost.

**Paul:** I can see why this is important for a husband and wife or members of family: it opens up communication channels, doesn't it?

**Andy:** Yeah.

**Paul:** On a less personal level, how does this help the clinicians to assess who the person was, who the person is now?

**Andy:** The golden thread that Playlist for Life is for us is that it helps the clinicians, the staff, and the carers to see the very unique person in front of them.

There's a lot of rhetoric in policy now around person-centeredness in care. Go and ask people what that means, and some people will find it quite difficult to explain. But when you can tell a person's unique life stories through music, that helps them to see unique opportunities for different forms of care, different approaches and different communications - different interactions can occur.

You know yourself that if you and I are sitting here talking right now — and you're listening intently, which is great — but if a piece of your favourite playlist were to come on outside in the room out there, you couldn't listen to me anymore, your mind would be taken to listen to that music and to the memories related to it.

That great thing about music being a distraction, this is something that clinicians can use as well. So when someone with dementia, later in their journey, is distressed by their experience, interjecting that familiar music which distracts them from whatever they were doing enables the staff then to engage because they can talk together about that music - it

makes the carer experience that much better for the person with dementia, but also for the staff. And we've had this reported many, many times about almost a *culture change* in the way that staff look after people.

We've had lots of evaluation being done in the hospice movement and in the acute sector and in some care homes, which show us different things are happening: [for example] we've seen a decrease in the number of falls that people are having, which shocked us a bit in the beginning, we couldn't [work out why]. But of course it's simple: If you're looking after somebody who's less stressed, or *distressed* as we call it now - if you're looking after somebody who's less that way, then they're less likely to get agitated and want to get up and around, and therefore they fall less! Likewise, we've seen improvements in people's continence levels - what?! Again: if you've got somebody who's less distressed, they can then recognise when they need to go to the toilet - they're less incontinent. They're not in a panic, they're able to go to the toilet or ask to be taken. [Also,] We've seen improvements in people's nutritional intake, because again they're less distressed so they manage to sit and eat a meal.

We use as part of our training what we call a personalised music assessment tool. It was developed at Nottingham University Hospital trust and the Queen's Medical Centre. They did a study which looked at the impact of personalised music in an acute care setting with people with dementia. What they saw was an improvement in a person's ability to cooperate in their care, improvements in nutrition, less agitation, better communication. And we saw an improvement either in a person's ability to report pain *or* less reporting of pain. We suspect it was because, again, if someone was more relaxed, less distressed, they were able to say 'I need some painkillers'; perhaps they were experiencing less pain because their joints were more comfortable, more relaxed. We use either the Abbey Pain Scale or pain-AD (pain in Alzheimer's Disease) to measure that. So we've seen improvements in things like that.

**Paul:** Now I've been on your website many times. We don't have to tell you to come into our house to be our own musical detective. We can put our own Playlist for Life on the website.

**Andy:** Yeah, yeah. That's a part of what we started, when we started the charity. We didn't want to create an empire of lots of music detectives running around with offices in every town and so on. We wanted to enable people; we wanted to give people the tools to do this themselves. So - absolutely, that tool is on our website. Those trigger questions are on our

website. And what we should all do is not wait until we get dementia in our lives; we should go and do a playlist *now*.

I love music too, obviously I do, this is what one of the reasons why I love doing this.

I have visited many families and many people living with dementia in their own homes and I can remember going to one lady's house in Edinburgh who quite clearly had a playlist of her life in her house: underneath her windows there was a huge rack of LPs, boxes of tapes and cassettes and so on, sitting there. But she couldn't work the machines anymore; she couldn't listen to music that she's listened to all her life - how sad is that?! How sad is it that she couldn't sit in her house, put on a record and close her eyes and be taken on the journey that that music was part of. And that's all that we're trying to do! It has many benefits for clinicians and for families, yes, absolutely. But it's simple, we can all do it.

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**Paul:** And I've done it. So could you! The Playlist for Life website is [playlistforlife.org.uk](http://playlistforlife.org.uk). There you'll find all the information and tools to make your own playlist for life.

And now, another trusted source of information is the Alzheimer Society, and they can be found at [alzheimers.org.uk](http://alzheimers.org.uk).

I mentioned at the beginning of this edition of Airing Pain that according to their research, dementia is the most feared health condition in the UK. So does this explain why over half of people in their survey actually put off seeking a diagnosis for up to a year or even more? Well, I've just had my sixtieth birthday. I don't have dementia, but I do have a chronic pain condition. I've made my playlist for life - but what else could I do now, to make sure that my pain issues are managed if I do go on to have dementia?

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**Lloyd:** That is a very important question. I think for a whole host of physical and mental health concerns about developing dementia, I would advise advanced care planning. This term is often bandied around, but all it means is providing a health professional with a good background about what you experience, the challenges that you have, and how that changes over time.

So in the example of pain, you may wish to explain to your care provider about what type of pain you experience, how frequently you get that, what activities bring that on, and how that affects you (that may be with sleep, or in terms of the activities you can perform, those kinds of things). That information is really important, because if you do develop cognitive deficits as you get older, that allows health professionals to get aspect of the history and assess you at that place in time but it gives them an excellent source of reference to say 'Actually, *this* is what this patient has experienced over the last forty years so it's reasonably unlikely that that would have changed a huge amount, so let's use that as a guide' and 'How can we use that to try and improve our management?'

I think that's particularly important as patients get older, because if you've had chronic pain and you're sixty years old, you may be on medications which may well be inappropriate when you're 85. That's not necessarily that they're inappropriate because of the type of pain, but because the kidney function may decline, your liver may not work as well, and therefore the medications that work at 60 may not work and may actually cause a lot of side-effects at 85. Often the same medication *is* appropriate, but it just required dose adjustments.

So this resource — explaining what you're experiencing how you're experiencing it and what types of activities bring on these things — is very important. And that refers to chronic pain but other medical things as well, so I think [you should plan] ahead and [be] open with your care provider. Also, if you are involving other agencies, [such as] if you go into a dementia assessment centre, these are all things that are really important to voice to them, because there's often a brilliant letter written by Psychiatry or Geriatric units which provide that information from your GPs who may see you over the next ten or fifteen years.

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**Paul:** Lloyd Hughes, co-author of *Managing Chronic Pain in Patients with Dementia*.

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**Paul:** I'll just remind you that whilst we at Pain Concern believe the information and opinions on Airing Pain are accurate and sound based on the best judgements available, you should always consult *your* health professional on any matter related to *your* health and wellbeing. He or she is the only person who knows you and your circumstances and therefore the appropriate action to take on your behalf.

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So, to finish this edition of *Airing Pain*, what advice would Lloyd Hughes give to someone whose family member or loved one is starting out on his or her dementia journey?

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**Lloyd:** Try and do what you can. From my experience in working with hundreds of caregivers, I think people sometimes are really hard on themselves, they're overly concerned about what people will think about their decision. I think what people need to do is think about what they can do physically to support their loved one. That may be practical things, may be taking them to clinical appointments, may be arranging support at home, and so on. But also what they can manage themselves. I think managing your own health, both mental and physical, is really important, because if you do that you'll actually be able to support your loved one more effectively.

The other thing I'd say is don't suffer in silence. Dementia is this devastating diagnosis, it's a journey which is often quite long, challenging emotionally and physically. There are going to be periods of time in the vast majority of caregivers' lives where they're very worried, they're particularly down or anxious about things, worried about the future... And I'd say to those people, speak to people! That doesn't necessarily mean 'speak to your GP' - I'd love seeing patients talk about these things - but just being open with friends and family about your concerns, how you're managing. Because talking about these things is really important, and there's actually now a lot more support out there than there was twenty years ago: there's charitable organisations, there's befriender groups, there's dementia day centres... There's a lot more out there. And I think talking about these things may allow you to find solutions that may help you *and* help your loved one.

## Contributors

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