

Airing Pain Programme 120: Osteoporosis

How we prevent, manage and diagnose this 'silent disease'

*This edition of **Airing Pain** has been supported by a grant from The D'Oyly Carte Charitable Trust.*

*Osteoporosis is a largely ignored condition that affects over 3 million people in the UK, with women being more at risk; a condition which, because the symptoms are difficult to notice by patients, is often referred to as the 'silent disease'. In this edition of **Airing Pain**, we learn why prevention, assessment and management are key factors to deal with this condition and develop a correct model of care in the health services.*

First-off, Paul Evans speaks to Dr Emma Clark, Consultant in Rheumatology & Osteoporosis at North Bristol NHS Trust, to find out about the causes and characteristics of osteoporosis. She discusses how osteoporosis can be ignored or misdiagnosed as osteoarthritis, as well as ways in which we can look after our bone health. Dr Clark also talks about how she is currently developing a clinical tool for primary care professionals to help them identify signs of osteoporosis when they meet with their patients.

Paul also speaks to Sarah Leyland, Nurse Consultant at the Royal Osteoporosis Society, about the new focus on prevention, mainly in terms of lifestyle changes and developing a model of care designed to identify people who are at higher risk of osteoporotic fractures. She also describes the range of physical exercises she has developed to reduce the risk of fractures and help with pain after fractures.

Paul Evans: This is **Airing Pain**, the programme brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain and for those who care for us. This edition of **Airing Pain** has been supported by a grant from the d'Oyly Carte Charitable Trust. I'm Paul Evans.

Emma Clark: Less than a third of people with osteoporotic vertebral fractures are being identified. If we can find people who have vertebral fractures, we can give medications to reduce the risk of future fractures. We can reduce the risk of a hip fracture by about half and that is so important because hip fractures for the individual can be a disaster.

Evans: Osteoporosis is a condition where bones lose their strength and become fragile. It's sometimes referred to as the 'silent disease' because, although almost 3 million people in the UK are estimated to have it, few know that they do have it until that is they break a bone, most likely in their wrist, hip or spine. And according to the charity Age UK, there are more than 300,000 fractures every year due to osteoporosis. Emma Clark is Consultant Rheumatologist at Bristol's South Meade Hospital. She's also Reader in Rheumatology at the University of Bristol where she does research into osteoporosis.

Clark: As we get older, like many parts of our body, our bones age and with time they become thinner. Both the outside of the bone but also the struts, which make up the mesh-like structure inside the bone [become thinner]. And this means the bones become more fragile and easier to break. It is this combination of the thinner bones and the increased risk of them breaking that we call osteoporosis. Our bones develop obviously from the time we're born, and they carry on [developing] through adolescence, through growth. Interestingly, even after we stop growing around fifteen or sixteen, our bones continue to strengthen up probably until [our] mid-twenties or late-twenties. At that point, that is what we call peak bone mass.

Evans: Let me go back to the beginning. It's quite pertinent for me because my granddaughter has just broken her hand, or broken her knuckle, and she is seven years old. What they've explained is [that] it's not actually real bone that she's broken, it's what might turn into a bone. So what is the development of a bone from early age?

Clark: So we've got different types of bones but generally our bones are laid down, actually, when we are a foetus. Inside the uterus the pattern of our skeleton is laid down as cartilage, and then it turns into bones as we age. Our bones finish growing, the cartilage finishes turning into bone at the time of adolescence (when we stop growing up in height). They can still thicken up, as I said, until our late-twenties.

It's very interesting that your poor granddaughter has broken her knuckle, because actually childhood fractures are really common. They do not mean that that child is going to get osteoporosis. I think that's really key. Probably 45% of girls and 30% of boys will break a bone before they reach adult height. It's an indicator that they are doing activities; it's more of a marker really of exposure to injuries. In some ways, it might be good because it means that these children are running around and doing activities. They're being physical, which is what we want to encourage.

Evans: Well, that is quite encouraging because two of my grandchildren have just broken bones. One in the leg and one in the knuckle! So at the age of 30, you were saying, bones are fully grown, at their peak?

Clark: Yes, absolutely at their peak. Then they stay like that until we develop the natural age-related bone loss which is actually the same in men and women. But women have this little acceleration during the menopause. Of course, women are generally smaller than men anyway so women's peak bone mass is lower than men's. Then they have this period of accelerated bone loss around the time of the menopause. But both men and women do lose bone as we get older.

Evans: Why is that?

Clark: Our bones are not actually a rigid static machine that just stays there. You may not wish to know this, but every second, of every minute, of every day we have these cells living on our bones that keep them healthy. We have this really big cell called an osteoclast that wanders over the surface of the bone and takes out little bites. We don't know necessarily why. But we wonder if it does it because it's found a fatigued area, that's a bit warm perhaps or has got a microcrack in it. We don't really know. Then behind it, along come these other cells called osteoblasts that fill it in again with new bone. Our skeleton is continuously bubbling along!

We have got these cells maintaining our bone health and we think that with age the osteoblasts – that build bone – just get a bit old; they don't do what they used to do. The osteoclasts – that take the bites out – continue, but the osteoblasts are no longer quite so efficient; they don't fill it in quite so well. The net effect of this is that our bones generally become a bit thinner.

Evans: Well, the next questions is 'does osteoporosis mean pain?'

Clark: I think that's a really, really important question because, on its own, osteoporosis is painless. You don't know that you have osteoporosis, because it has no symptoms. It becomes painful only when you break a bone.

Evans: Which bones are right in the front line of risk?

Clark: We know there are a cluster of broken bones that are more likely in people with

osteoporosis. These are the wrist, the forearm (you might have heard it called the Colles fracture), the upper arm (the humerus, the top of it, near the shoulder), the hip and a bone in the back (the vertebral body). They break in different ways: the hip, forearm and upper arm snap. You can think of it like a twig being broken. Whereas, the bone in the back does not snap in half. Instead, that is like if you imagine a piece of coral on the beach and you stand on it, it can crush down a little bit. That's a process that starts gradually. They change shape – going from a rectangular shape to more of a triangular shape because the front of the bone squashes down and that is a broken bone.

Evans: Do you mean that they're sort of crumbling?

Clark: No, I don't think the bones are crumbling away because that suggests, in my mind, fragmentation or bits of them falling off. My impression from speaking to patients in clinic is that people have used the term crumbling bones to also mean osteoarthritis, which is a completely separate disease to osteoporosis. Osteoarthritis is the wear and tear arthritis where our joints become worn with age. That is completely separate to osteoporosis, which is purely about risk of fracture.

Evans: How does one fracture a bone in the vertebrae?

Clark: Well, actually, we don't really know. We don't have the full answers. We have got stories from patients. A typical story might just be something simple like reaching up into a cupboard or reaching up outside to hang some washing on the line. And a sudden sort of twinge in the back. Patients describe being outside walking and stepping off a high kerb. It's just the jarring nature again of a pain in the back. But not every patient knows when they have broken a bone in their back because, in some people, it's not necessarily that painful.

Another typical story actually is moving those great big black bins that the lorries pickup. A typical thing is that a patient describes pulling it up the drive and then trying to twist and pull it into the little cupboard where it's meant to go. And that twisting [and] pulling of a quite heavy thing causes sudden pain in the back, which I think lots of patients think, 'I've pulled a muscle! I was way silly, I shouldn't have done that, I pulled a muscle'. I think it may be that osteoporotic fractures cannot necessarily be that painful when they start.

Some patients definitely describe a very sudden onset and severe pain when a vertebral fracture occurs. One of my patients was on holiday in New York. She'd never been to the States before. She stepped off a kerb and the sudden onset of pain in her back was so bad

she thought she'd been shot. She thought it was more likely that she had been shot in New York then had broken a bone in her back when she thought about it. Sudden, absolute agony, the sudden onset pain, but I think is pretty unusual. The vast majority of people do not go to their GP or go to hospital with a vertebral fracture because it probably is not that painful and/or they expect back pain. I think it's something within our culture that we expect as we get older [that] we're going to get back pain. When we do something silly like pull a bin, or try and lift up a plant pot using a very bad posture, and we develop sudden onset pain in our back that's not too bad, we think, 'Oh, well, that's my fault - I have pulled a muscle'. We just wait for it to get better, which it probably does, that acute pain, over about six weeks.

Evans: Is that okay? If I were putting out my bins and I twisted and I felt something in my back. Through 62 years of experience, I would think, 'Ah, I've pulled a muscle, it'll be okay'. Should we be going to the doctor then?

Clark: If we think about adults in general, the vast majority of situations like that will be a pulled muscle. But, perhaps in somebody who's quite old and I don't know what that means. I don't want to put an age on it because we all age differently. But perhaps someone who's frail; perhaps someone who's got risk factors for osteoporosis (perhaps those who are on steroids for other diseases such as asthma, rheumatoid arthritis, bowel disorders and people who are heavy smokers), people who are frail. When people become quite thin, less mobile, have quite a few other illnesses, take many, many medications, that whole package. You know, it's quite difficult to describe frailty, but we all recognise someone who is frail. Perhaps people who are frail who do that and develop sudden onset back pain or someone who's on steroids, they should consider going to their GP or somebody within their practice, it may be another allied health professional such as a nurse or physiotherapist, just to be assessed to make sure they haven't had a vertebral fracture.

Because having a vertebral fracture means you are at one of the highest risks of having another fracture, including a hip fracture, and hip fractures are completely devastating. If we can find people who have vertebral fractures, we can give medications to reduce the risk of future fractures. We can reduce the risk of a hip fracture by about half, all the evidence suggests. That is so important because hip fractures, for the individual, can be a disaster. I think 20% of people are not alive twelve months after their hip fracture, a third of people cannot go back to their living arrangements that they had before. They need additional help; they need to change living upstairs to downstairs; they need to go into nursing homes or more sheltered accommodation. And they are very expensive – they cost the NHS lots of money. We've got a very good medication that we can use to reduce that risk but, at the

moment, less than a third of people with osteoporotic vertebral fractures are being identified through a variety of reasons, I have to say, but one of which I think is [that] we don't really understand the typical story of somebody with an osteoporotic vertebral fracture. That's why I'm focusing my research at the moment.

Evans: Well, what don't we understand and what is your research?

Clark: One of the problems is that back pain is very, very common and people find it very, very uninteresting. By people, I mean family members, I mean doctors..., I mean...

Evans: 'It's just another ache and pain.'

Clark: Absolutely, absolutely. When someone says, in a clinical situation, 'I have back pain'. The most common reaction to that is, 'Oh, and just note it down' rather than saying, 'Well, tell me about that. Where is it? What is it like? How does it start? What makes it worse? What makes it better?'

My research is really trying to find out is there a difference in back pain between someone with a vertebral fracture, and someone without. I think it's clear that there is a difference. For example, people with back pain and osteoporotic vertebral fractures describe a chronic background pain that they describe as grinding, gnawing, a sort of a dull ache. It's not necessarily in the centre of the back, it's often a bit more around the sides. That is probably because when you have one or more broken bones in the back, the shape of your back has changed, the height of your back is shorter, you've shrunk a bit. All of the tissues, the muscles, the ligaments, the ribs are now in less space; your trunk has shrunk and changed. That gives sensations around the waist area that might be described as grinding or a dull ache.

We also find that there is a difference in the pain that happens with daily activities and movements. So patients with vertebral fractures describe pain in their back or trunk region building with activity and reaching a real crescendo or peak at which point they have to stop, and often lie down or recline backwards – so lean back and extend the spine to relieve the pain. The typical movements that contribute to this are standing up and leaning forward slightly and unfortunately that is sort of the position of work for humans. When we're washing up, for example, or preparing food, or doing a jigsaw, or working on the keyboard, we're leaning forward slightly, putting the weight of our upper torso and head on the front of our spine. For people with vertebral fractures, I think that is what is contributing to this crescendo

or peak in pain.

The time to reaching this peak varies. It seems to be much shorter in people who are older, possibly because they have less muscular mass around their spine. Pain in people with vertebral fractures tends to improve enormously on lying down, so people with vertebral fractures often get quite a good night's sleep. These descriptions are different to people who have back pain due to osteoarthritis, where often lying down is one of the worst times. Patients with osteoarthritis also tend to describe pain shooting down the legs or pain worse with cold and damp weather. Those two things don't seem to occur in people with pain due to vertebral fractures.

Evans: That's Consultant Rheumatologist Emma Clark. Sarah Leyland is a Nurse Consultant now working for the Royal Osteoporosis Society, a charity that provides information and support for people living with osteoporosis. It has many resources, including a specialist nurse team-lead helpline.

Sarah Leyland: Our aims are to make sure that people get the help that they need, certainly in terms of care. Making sure people are diagnosed appropriately and get access to the appropriate medications and treatment in order to prevent fractures. We've got a new focus more recently on prevention, making sure that people who are younger, who are not yet affected by the condition are making lifestyle changes to keep their bones strong and get the best bones they can to put them in the best position before they lose bone in later life.

We're also very interested in a model of care within the Health Service that's picking up those people who are at the highest risk of further fractures. We're supporting a model of care called Fracture Liaison Services where, when someone breaks a bone, they get a proper assessment to check out could this be related to osteoporosis. People [then] get assessed, they get treated and they get followed up in specialist teams. It's making sure people are fed into that system.

We're very interested in preventing fractures but we also have always had a role to play in terms of support, so people either wanting information, local support groups, peer support or coming through to our specialist helpline and getting access quite rapidly. We also support health professionals, so we run conferences, training programmes [to] try giving them the tools they need to help them do their job.

Evans: What do people who contact your helpline worry about most?

Leyland: They're worried obviously about the impact of osteoporosis on their future life – on both their day-to-day living and quality of life, but also that it might shorten their life. They've heard about people dying as a result of osteoporosis, so people ring us they're fearful. They may have had a diagnosis, someone's told them they've got osteoporosis and they want to know what the future will hold. They also often ring us if they're worried about the drug treatments [or] the medicines – they don't want to take them unless they really need to. They've heard about health risks associated with the medications. We talk a lot about that. Then at the other end of the continuum, we talk to people who've had fractures, particularly vertebral spinal fractures, who are living day-to-day with pain and symptoms and are struggling often and not getting the care and the help that they need.

Evans: If somebody were phoning you, and this might happen with lots of conditions, people really want that help at primary level, at GP level and they feel they're not, perhaps not being taken seriously, perhaps not being listened to. How would you advise somebody to go back to a healthcare professional, a GP, and say, 'Listen, please will you look at this? Please, I'm worried about this'?

Leyland: I think that's where being informed makes people feel a bit more confident. That's where the charity can be helpful because if people know a little bit more about the condition and what the options are, then they're more ready.

We also encourage people to be, and this is the same as for any condition, to be prepared for their appointment because there's so little time. Go in with your questions ready and sticking to those, perhaps writing things down, maybe taking someone with you if you don't feel very confident. We can't advise you what to do, but we can take you a bit further down the pathway. Help them to understand who might need a referral to a specialist because everybody doesn't need to go to the hospital, but some people may benefit from that. Particularly younger people because the treatments and the care pathway is not so clear in a younger person.

Evans: Sarah Leyland of the Royal Osteoporosis Society. Now, earlier in this edition of *Airing Pain*, rheumatologist Emma Clark talked about her research into developing a method whereby it would be easier for health professionals in primary care (GPs that is) to identify a vertebral fracture as opposed to osteoarthritis.

Clark: The whole point of this research is to produce a very simple clinical tool. So, basically

a checklist and it is absolutely aimed at GP practices – the first point of contact, whether that is a GP, a nurse or a physiotherapist. The goal is that in the next few years we will have this simple checklist. When an older person goes to their GP practice with back pain the healthcare professional produces this simple checklist and ask, 'Have you previously broken a bone? Is your back pain worse when you lean forward? Is it better at night?'

I don't know exactly what it's going to include, because we're currently doing the research. Ideally, this is going to be an app so it's just done very quickly on the computer and the answer will come up 'this person needs an X-Ray' or 'this person does not need an X-Ray'. It will recommend an X-Ray if the checklist has suggested this person may well have a broken bone in their back due to osteoporosis, so a vertebral fracture.

Evans: You mentioned earlier that [whilst osteoporosis] may not be reversed, perhaps the progress [could be] stalled or halted.

Clark: There are two pathways of management, of help, that should be given to people with an osteoporotic vertebral fracture. The first are interventions to improve their pain, their quality of life, their fatigue and posture. The second is, as you say, to reduce the risk of further fractures. So those large cells I talked about, those osteoclasts – that walk along the surface the bone and take a little bite out – we have a medication available that inhibits them.

Evans: What can we do earlier in life to manage our later life osteoporosis?

Clark: I think it'd be really helpful at this point to remind everybody that actually our peak bone mass is quite strongly determined by our genes, our genetics. Probably 80% of our peak bone mass is determined by the way we're made. Osteoporosis is not our fault in the majority of situations but there are some things we can do to really optimise our peak bone mass, such as do not smoke, do not drink excess alcohol. It is alcohol excess that's also associated with poor nutrition that is probably bad.

In terms of nutrition, daily protein intake and calcium intake is really important. As a growing person, we should have over one pint of milk per day or equivalent. As an adult, we should have one pint of milk per day or equivalent. Obviously, there are other fields that you can get calcium from that it's not just dairy products. There are lots of really useful resources online, such as the Royal Osteoporosis Society, where people can go and identify if they're getting enough calcium in their diet.

Vitamin D is also really important. Vitamin D is a vitamin that we get through the sun and it is not possible to get enough in a normal diet – we do need to expose our skin to the sun. This can be tricky, because of the other health messages of ‘Don’t burn’, because of the risk of skin cancer. There’s definitely a balance. Plus, also if somebody is poorly and can’t go outside, if somebody’s got dark skin, if somebody covers up for whatever reason, and therefore does not expose their skin to the sun, they should probably take vitamin D supplementation to ensure that they get enough vitamin D.

Part of our problem is also we live in the UK so it rarely gets enough sun and, occasionally, when the sun comes out it can be very fierce, so it’s a bit of an issue for us in the UK. So vitamin D supplementation is recommended to all adults probably over the age of 65/70, but also other people who don’t get enough vitamin D younger than that. Then [there’s] physical activity. Our bones are amazing and if we use them as we’re growing, they will grow stronger. Tennis players, for example, the hand that they hold their racket in, we can show on our scans that the bones are stronger than the hand they don’t hold the racket in. This makes sense: if you use it, it builds up; if you don’t use it, you lose it.

Evans: Rheumatologist Emma Clark. Bearing what she said in mind, Nurse Consultant Sarah Leyland of the Royal Osteoporosis Society has been developing exercise and physical activity resources for people with osteoporosis.

Leyland: The project that I’ve been working on is looking at what is the role of exercise for someone with osteoporosis. By osteoporosis I mean, in the widest sense, people who’ve got reduced bone strength, with or without fractures.

The project focused on [the] three main areas that exercise continued to be important [in]. It was important for maintaining muscle and, therefore, bone strength, or promoting maybe some improvements (though the evidence isn’t very clear). Secondly, exercise [is] really important in terms of improving balance and muscle strength to prevent you falling because if you don’t fall, then some of the fractures that we get with osteoporosis are never going to occur, so not falling is important. We talked about strong, steady and the third area was about straight. How exercise can help you with posture and help you [with] moving and lifting. That may help to reduce further spinal fractures simply by the sort of pressures you’re putting particularly on the front part of the spine. There are ways that exercise might help with the pain you may get *after* fractures. So there are some simple exercises we were providing which might help with the immediate pain problems, but the others that help to

build up the muscles around the spine. The long-term problems that we get with osteoporosis are [that] after you've had a spinal fracture, it's healed but the shape of your spine doesn't go back to what it was. It's often the muscle spasm, the ligament strain, perhaps even the pinching of nerves so it's a more sort of complex problem than long-term pain but exercise can help there as well.

Evans: So you said strong, steady and straight?

Leyland: Yes, so these are just three words that we use to capture the different ways that exercise can help with osteoporosis. It was just trying to get people to, not only think about promoting bone strength, but think about preventing falls. [It's] also to help people who are very fearful because one of the big things is that, particularly if you've had one fracture, you're terrified that if you do anything, if you move, if you lift, you're going to get another fracture. So, the whole project was about positivity and helping people to feel confident, to carry on life normally but with some small adaptations, or feeling that they could take control of it.

Evans: That's Sarah Leyland of the Royal Osteoporosis Society. Before we end this edition of *Airing Pain*, I'll just remind you that whilst we in Pain Concern believe the information and opinions on *Airing Pain* are accurate and sound, based on the best judgments available, you should always consult *your* health professional on any matter relating to your health and well-being. He or she is the only person who knows you, and your circumstances, and therefore the appropriate action to take on your behalf. You can find all the resources to support the management of chronic pain, including details of our helpline, videos, leaflets, all editions of *Airing Pain* and the *Pain Matters* magazine at painconcern.org.uk. For a wealth of information on how to live well with osteoporosis, go to the Royal Osteoporosis Society's website which is theros.org.uk. Here's the society's Sarah Leyland to finish this edition of *Airing Pain*.

Leyland: We've got a new range of exercises, both fact sheets and video clips. So, you can go online and have a look at how to do the exercises. For instance, in the back pain section, you can read about how the exercises may help and you can see some simple diagrams about just two or three simple exercises that you can do straight away. Plus [there's] a short video, for those who have a computer, [to] see how to do it and how to adapt according to where they are. So if they've got multiple fractures and they're frail they can still do something. One of the things we hear is people quite often, even if they've had painful spinal fractures, might see the specialist, the rheumatologist who says, 'I'll give you a referral to the

physio', [but] they don't get the referral for about six weeks [so] they sit at home. One woman told me the rheumatologist said, 'Don't do anything until you see the physio' and she literally sat in the chair, sort of paralysed with anxiety. Whereas we try to give people quick access to information so they can, not only get the care they need, but they can do something now that might help them.

Contributors

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- Royal Osteoporosis Society – theros.org.uk.

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