Airing Pain Programme 91: Not an Old Man's Disease

This programme was funded by a grant from The Schuh Trust.

Gout is the most common form of inflammatory arthritis and affects 1 in 40 people in the UK. So why do we still see it as something that exists only in the pages of Victorian novels? In this episode of Airing Pain we go inside the Houses of Parliament and speak with MPs, clinicians, patients and UK Gout Society members to find out why.

What is gout?
Gout is a type of arthritis caused by a build-up of uric acid crystals in the joints, most frequently the feet. As with many conditions, flare-ups can be brought on by a number of factors including lifestyle, stress and diet. Some people, however, have a genetic predisposition. Paul Webber and Alan Hughes both suffer with gout, describing the pain as being repeatedly being kicked in the shin and worse than a red-hot poker.

What's the treatment?
Treatments for reducing pain during attacks include icing the joint and taking medications, however there are also long term treatments. There are lifestyle changes we can make, such as consuming less yeast-rich food and drink, staying active and drinking plenty of water. Despite being relatively inexpensive to treat, gout comes at a great cost to the economy and society, as the Chief Executive of ARMA, Sue Brown, highlights.

Consultant Rheumatologist Dr Jonathon Rees identifies a lack of awareness in primary care, with cases often going undiagnosed. Paul also talks to Michael Snaith about his early gout and gender research at the UK's first gender reassignment, and Lord Ramsbotham sums up perfectly why gout really is no laughing matter.

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 health care professionals. I'm Paul Evans, and this edition of Airing Pain has been supported by a grant from the Schuh Trust.

In March 2017, the UK Gout Society joined forces with parliamentarians, doctors and other charities to help raise awareness of gout: the most common form of inflammatory arthritis which affects one in forty people in the UK.

The event was held in the House of Commons, and was hosted by Jim Shannon MP for Strangford, Northern Ireland and DUP spokesman for Health; to launch the Shout about Gout campaign. Gout or rather those who suffer gout have been the butt of jokes, cartoons and caricatures for years, so the launch of Shout about Gout came into the headline, 'Gout: No Laughing Matter'.

Jim Shannon: So today's event is to get rid of some of those cartoons; some of those caricatures we had in the past. Here is one where King Henry VIII is lying in a chair, about seven stone bigger than he should be with bunions on his feet the size of turnips, with the stilton and the port sitting close by. While that is the perception of some people have, it's time we put the facts on the table. It's time we told people what it is really about.

We also want to raise awareness because it is time that we did so, in relation to parliament and the members. And how government and the NHS can best address the issues, making the resources available, raising awareness that this is important. It's quite an honour to be a sponsor, there is nothing quite, I believe, as salubrious as the House of Commons to come and have an event, but at this stage I am going to ask someone with much more knowledge than me, Professor George Nuki, to come along and tell us some of the facts of the matter and I want to hear this as well.

Professor Georg Nuki: Thank you very much Jim, particularly for hosting this event. I would like to thank everyone on behalf of the UK Gout society for coming today. Gout really isn't a laughing matter, it's not a laughing matter for the patient, but it's also not a laughing matter, at the moment, for the government either.

So what is gout? Well, gout is a relatively simple condition really. It's a crystal deposition disease, caused by crystals of uric acid forming in the tissues. And they form in the tissues when the levels of uric acid in the blood are too high. It is caused by a combination of genetic determinants, but also by life style issues. The epidemic that we have at the moment of obesity, which is associated with type 2 diabetes, but also with hypertension, with chronic renal disease as well. All these conditions are associated.

We have discovered in the very recent past really, by modern imaging methods, that actually at the time one gets one's first attack of acute crystal inflammation, one of the most painful experiences that one can have really, that it is already an established chronic disease. At that point there are crystals in the tissues which are causing low grade inflammation which may be associated with cardiovascular disease, diabetes, renal disease as well.

The extraordinary thing is we have known about it and how to treat it pretty effectively for at least fifty years, and there are now new treatments as well that make it possible to treat people with more difficult cases of gout. But despite us being able to potentially cure it for all this length of time, it's increased in frequency and the prevalence of it now is one in forty people in the population; more common than rheumatoid arthritis which people think of as the archetypal inflammatory disease. And it causes a great deal of physical disability but also loss of earnings, it has enormous economic consequences.

For the National Health Service it has tremendous implications because whereas admissions to hospitals now, with rheumatoid arthritis, have gradually fallen with modern treatment, with gout, not only has the frequency of the disease increased,

but the number of people being seen in Accident and Emergency, being admitted to hospital with gout is constantly increasing.

There is no reason for this and we should really concentrate on treating the disease to a target level, that by getting the uric acid in the blood down below the level at which crystals will form and at a level in the tissues when the crystals will dissolve again you can actually, potentially, completely cure this disease. But we know at the moment that less than half the patients are being treated in primary care and actually receiving uric acid lowering treatment. And in less than ten percent of the patients are the uric acid levels in the blood actually being monitored at all.

Now there has been a very recent study funded by the Arthritis Research UK led by Professor Michael Doherty in Nottingham where they have done a randomised controlled trial looking at some five hundred patients with gout and comparing patients who are seen and followed up by nurses with patients receiving routine standard care as it is at the moment. And showing that with those patients with nurse-led treatment have actually managed to achieve the target that one is looking for in better than ninety per cent of the patients, compared with less than fifty percent in the people being given routine care at the moment. And that has been associated with better patient reported outcomes; so less pain and so forth. There is going to be a health economic analysis as well, which I am sure will highlight the differences. So gout isn't really a laughing matter for any of us; thank you.

Paul Webber: My name is Paul Webber, I am here in the Houses of Parliament, Dining Room A, with the UK Gout Society as I am a gout sufferer.

Alan Hughes: My name is Alan Hughes and I am here for the same reason.

Paul Evans: You both have gout, what does that mean to you?

Paul Webber: It means when I get an attack, a lot of pain and not necessarily being able to do all the things I would like to do when I don't have gout.

Paul Evans: What does the pain feel like?

Paul Webber: If you have ever played football and not worn shin pads and had someone repeatedly kick you in the shin and you are unable to move; that's what the pain feels like.

Alan Hughes: I will go along with that, but my way of describing it is 'take a red hot poker out of the fire and stick it in the affected joint and probably you will have some pain relief'.

Paul Evans: Now you are both defying all the rumours about what gout is, you are both fairly young people, you are not the old doddery people in the cartoons.

Alan Hughes: No, gout has been laughed at over the years, you know. It's a rich man's disease, too much rich living, too much red wine, too much port you know.

And I find that not to be the case and I have proven it over the fifteen, twenty years that I have had it. I was told early on that tomatoes is a bit of a trigger for gout, so I have stayed off tomatoes over the years and I have proved that, tomatoes if I eat tomatoes which is in almost everything we eat, then it can trigger an attack.

Paul Evans: Do tomatoes do the same thing for you?

Paul Webber: No, I was quite interested and surprised to hear that but I have not necessarily thought that my gout was associated with food. For me I believe that my gout is firstly hereditary, my grandfather had it, and also I think it is a little bit stress related. So if I am running around at work, trying to balance work with children that sort of thing, quite often I will have an attack and I will look back at the week I have had and I will think that I was a little bit crazy in terms of the commitments that I have made with just running a family and trying to do my job.

Dr. Tim Tait: My name is Doctor Jim Tait, I am a Consultant Rheumatologist working in Sheffield. Gout is an inflammatory condition in its acute sense but it also has a chronic phase. So it's the acute attacks that people notice mostly which is caused by a crystal forming within the joint, that the body then reacts to. An acute attack is incredibly painful: it normally starts in the foot but can affect any joint in the body, usually lasts about ten days to two weeks and then settles down of its own accord or with treatment.

On the back of that there is a chronic phase: people who get acute attacks may get one or two a year, may get many, many more. But the damage comes from the repeated acute attacks and the accumulation of the crystals in the joints and other tissues and it's that that the treatment is aimed at lowering.

Paul Evans: So let me just talk about that. You say crystals form within the joints, uric acid. What is uric acid? And what has that got to do with gout?

Dr. Tim Tait: Well uric acid is the product that is in the blood stream and it is produced by a breakdown of tissues or energy production within the body and by ingestion of its precursor, which are purines. After a certain amount [of uric acid] is in the blood you can't dissolve it and it spills over to the tissues where it forms a crystal called monosodium urate, and it is the crystal form that causes the acute attacks.

Paul Evans: What treatment is there?

Dr. Tim Tait: Well, there is treatment for the acute attack, which is painkillers, anti-inflammatory, steroids, colchicine drugs like that, drugs to reduce inflammation and get rid of the acute attack. There is then longer term treatment to try and lower the level of uric acid in the blood stream and in doing so – if you lower it below the blood threshold – then the crystals in the tissue will start to dissolve back into the blood stream and eventually dissipate. And it's this longer term treatment that is aimed at treating the gout itself.

Stuart Reed: My name is Stuart Reed the Patient Trustee of the UK Gout Society which means that I have gout, or I had gout, or I may get gout again in the future. The week before I had gout I had lots to eat and perhaps brought it on – steak, liver and bacon, lamb, curries, jellied eels, lashings of red wine, I like a drink – and three days later I had a ferocious attack of gout that laid me up in bed for a week. I was on crutches for a week after that and then I had a limp for a month. So I said; no more, I have changed my life style. I don't drink, I eat lots of fresh vegetables and fruit. I don't eat meat that might raise my uric acid levels and that's what I hope to continue.

Paul Evans: So it's the management of gout, the self-management of gout, that maybe patients have their own responsibility to look after themselves perhaps.

Stuart Reed: I think you are right there, yes. I would agree with that.

Dr Jonathan Rees: My name is Jonathan Rees and I am a Consultant Rheumatologist. I am based at Addenbrooke's at Cambridge. So Rheumatologists are the consultants who treat gout and have the biggest interest for them, although of course it is often managed more frequently in general practice as well.

Gout is a huge problem and burden but it is relatively simple to treat and you can make an incredible difference to people's lives very, very easily with simple treatments. Unfortunately it has not got the profile it deserves. If only there was a little bit more resource or a little bit more education of our colleagues in primary care we could really manage this condition much more effectively, make a huge difference to many people's lives. That would be a fantastic thing to do.

Paul Evans: So how do you bridge that gap?

Dr Jonathan Rees: Gout is under diagnosed. When it *is* diagnosed it is under treated. So I think the most important thing is working together, perhaps to produce new guidelines and to work with our colleagues in primary care to maybe just to help them to stop and think: 'Is this gout?' If it *is* gout: 'What is the best way we can manage this? And how can we really help our people and not just improve their gout but really put them into complete remission?'

It is probably the most painful thing a guy can get and it is very easily treatable and very easy to improve those pain levels. And there is nothing more satisfying in medicine than taking someone out of pain.

Dr Adrian Dunbar: I am Adrian Dunbar, I am very recently retired, but I used to work in primary care as a muscular-skeletal specialist, [a] chronic pain specialist.

Paul Evans: Now you were a GP, so you were working in primary care, you would have been the first port of call for somebody for who it is told needs help. So what do you do for them?

Dr Adrian Dunbar: Well, you make the diagnosis and that's not very difficult and you give them acute treatment, which is fairly straightforward. The important thing is that you need to see them again.

Paul Evans: Acute treatment means that you just attack the pain as it is happening now.

Dr Adrian Dunbar: Yes, and you need to see the guy again within a few weeks, to check the symptoms have settled down, but also to start investigations and long term treatment if your diagnosis is confirmed.

Paul Evans: You mentioned earlier that it is a perfect condition for general practice. What do you mean by that?

Dr Adrian Dunbar: First of all it is not difficult, it's not very high tech: it doesn't require much apart from blood tests and regular treatment. It's a relatively safe, cheap drug in the first instance that doesn't cause very many adverse effects: few people are allergic, not very many, so there is no reason why GPs can't control the vast majority of patients with gout.

Paul Evans: It seems to me that even if you threw a lot of money at it, it doesn't need that money.

Dr Adrian Dunbar: It does not need a lot of money, it needs awareness. In primary care there was this thing called Quality of Outcomes Framework, which essentially told GPs what they needed to be doing and to get the disease taken seriously it should have gone in the QUOF, like high blood pressure, high cholesterol, yes it is just the same kind of problem. Hyperuricemia should be treated just the same as hypercholesterolaemia, it needs to be reduced.

Sue Brown: I am Sue Brown and I am Chief Executive of Arthritis & Musculoskeletal Alliance, ARMA. I am here today because part of the role of ARMA is to make sure that we support all of our members in the work that they are doing, so it's brilliant that Gout UK Society has this reception here to raise awareness of something that I think people know very little about.

Personally I was surprised when I started work at ARMA and found out just how common gout is. My background is; I have got twenty years' experience in health and social care policy, but particular experience of working in alliances so one of the things I am really passionate about is the way groups work together and speak with one voice, they have so much more power than if each of us tries to do it by ourselves and that really what ARMA is about.

Paul Evans: Who are you speaking to? And what are you telling them?

Sue Brown: Well, who we are speaking to is everyone who has an impact on the services and support to people who have muscular-skeletal conditions. And what we

are telling them is muscular-skeletal conditions are really common, really important, often misunderstood and possibly given less priority than they should be.

Paul Evans: I will bring out my little cynicism mode for just a moment and if I said why alliances – chronic pain alliances, whoever – need events like this [it's] because there is one thing that really gets things done: the cost of the condition to the Exchequer.

Sue Brown: Well certainly muscular-skeletal conditions cost an enormous amount to the Exchequer. That's partly the cost to the NHS for treatment, but it's also the cost of people without treatment that could be in work but are not in work because they are not getting the treatment they need, and that obviously costs the Exchequer a lot in terms of lost tax revenue.

Paul Evans: But it's not just lost tax revenue, it's people who are in work, working below par, if you like, to companies. They are not filling their jobs, there is a societal cost to all these conditions.

Sue Brown: Absolutely, there is a societal cost in terms of people who could contribute more to their companies and to the economy. There is also a societal cost in terms of people who maybe could be caring for grandchildren but are not able to. All the different ways in which we contribute to society and to our communities are impaired if you have an untreated and unaddressed muscular-skeletal condition.

Dr Michael Snaith: My name is Michael Snaith I am a retried Rheumatologist. I was a Research Fellow and did a study on gout in the Kennedy Institute in 1969. Secondary gout is very much associated with lifestyle, so primary gout really has nothing very much to do with lifestyle, it has more to do with genetics. You can get gout and be a slim, non-alcoholic drinker, non-venison eater and still get gout. And you would say ''why the hell have I got gout because I am not a drinker or an eater.''

But secondary gout *is* more likely to occur in people who over eat, over drink and are overweight, which is why particularly nowadays [when] you have an ageing generation, you should be addressing the issue of lifestyle-induced gout. Very, very important to treat patients with gout with tablets but it is equally important if they are overweight and have risk factors such as dietary excess, alcohol excess, and weight excess [that] they should be encouraged along those lines, as well as taking the tablets. It should be part of the government's approach to obesity you know, corn syrup for goodness sake, corn syrup which is in American drinks, or was, induces high urate levels. These things occur; we know about them; it's a societal approach as much as anything.

Paul Evans: So the lifestyle issues, many of them are well known – diet, keep your weight down, exercise, get your blood pressure down, this sort of thing – but are there things particularly associated with gout?

Dr. Michael Snaith: Well, drinking beer is more important than drinking port by a long way in terms of the population and weight. There are a few drug induced

causes, but the most important issue regards to body weight and an intake of a combination of protein, offal particularly, meat proteins and alcohol associated with weight. On top of that, there is still the existing relatively small proportion of patients who have primary gout. They need treating with medication and that medication needs to be kept up, because if you don't treat the uric acid level and get it down you will deposit crystals in lots of tissues – not just the joints, other tissues as well – so management of gout is multi-factorial. You really have to address the issue of the uric acid level and the body in which the uric acid level is elevated.

Paul Evans: Now, when you did your research, your MD back in 1969, what were you focussing on?

Dr Michael Snaith: Well focussing actually on a few interesting things like post-operative gout. There is an incidence – still is, there was *then* even more – incidence of people who develop gout having recovered from surgery. The reason for that is they get ketosis. Ketosis is when you start consuming fat because you are not getting enough calories in, you become acidotic and that retains urate at the kidney level.

The second very interesting one is who gets gout, men or women? The answer is men: why, what happens when a man becomes a man from being a boy? The answer is his uric acid goes up. Now at puberty a man's uric acid rises, it's not until the menopause that a female's uric acid rises, so throughout their pre-menopausal life a woman has a lower level of uric acid than a man.

So ask yourself the question: how would you do a study to demonstrate the difference between men and women in terms of their uric acid metabolism? You choose men who are about to take female hormones. So we took advantage of one of the first – if not *the* first gender reassignment clinic in the United Kingdom – and studied men who were about to start oestrogen in order to [become] transgender and that was in 1969. That was fascinating and we showed quite clearly that if a man takes Stilboestrol, which is what was given those days, his urate drops.

Lord Ramsbotham: I am Lord Ramsbotham and I am a cross bench member of the House of Lords, I was a former soldier and then became Inspector of prisons for a time.

Paul Evans: And you have gout.

Lord Ramsbotham: I have gout, I got gout in 1982 and my father had gout before me and he told me he was leaving it to me and his grandfather had said exactly the same thing to him. Luckily my sons haven't got it.

Paul Evans: When did it first appear?

Lord Ramsbotham: I was forty-eight, it appeared when I was visiting a Headquarters in Ireland. I slipped on the stairs and kicked my toe on the bannisters

and thought I had broken my toe, and went to the doctor and he just roared with laughter and said ‘that’s gout’.

Paul Evans: And really that sums up why we are here today, that gout is no laughing matter.

Lord Ramsbotham: It’s no laughing matter, you know, I mean, I think the sooner it gets known to be the most common form of arthritis and is treated as such, I’m afraid the image of the red faced old colonel drinking port with his foot wrapped in red velvet… it’s got itself a bad name. And I think it ought to be regarded as something to do with arthritis and it requires a disciplined approach to it.

Paul Evans: And recognised beyond the world of comedy.

Lord Ramsbotham: Absolutely, it’s no laughing matter.

Lynsey Conway: Thanks again, Lords, Ladies and gentlemen for coming today. My name is Lynsey Conway, I run the Secretariat of the UK Gout Society. I just want to say a few words about our small but perfectly formed charity. We were established in 2002, the charity was established by George Nuki and Dr. Michael Snaith who I am delighted to see here today. You won’t be surprised to hear given the growing prevalence of gout, that last year we had over a quarter of million visitors to our website and three hundred thousand patient information sheets were downloaded, but yet gout is still misunderstood and under treated.

So what we would like you to do today and I think some of you already are, is to help us shout about gout: share your experiences about gout, demystify gout and the stigma that is attached to it; that it is an old men’s disease [for those] that swill port and eat copious amounts of venison, which it is not, given the age and range of the people who are here today and suffer. And to follow us on Twitter by shouting about gout, by using the hash tag ‘shout about gout’. So thank you very much again, thank you Jim particularly for hosting this for us, thank you very much indeed.

Paul Evans: For more details and advice on managing gout and the #shoutaboutgout campaign, go to the UK Gout Society website, which is ukgoutsociety.org. And as always whilst we in Pain Concern believe that information and opinions on Airing Pain are accurate and sound, based on the best judgement that is available, you should always consult your health professional on any matter relating to your health and wellbeing. He or she is the only person who knows you, your circumstances and therefore the appropriate action to take on your behalf.

And don’t forget that you can download all editions of Airing Pain, both audio and transcripts from Pain Concern’s website which is painconcern.org.uk. I’ll leave you and the House of Commons with the words of Paul Webber and Alan Hughes.

Alan Hughes: It’s interesting today coming and talking to different people and Paul, who said that he seems to think it is stress related as well. I am a full time policeman; I deal with road death mainly, so my job is very, very stressful, so it could have

something to do with it, maybe not, I don't know. But it is great to come to something like this where everyone can share their views. And the feelings and the trips they have been on, to see if there is any common ground.

Paul Webber: And I am definitely going to try to cut out tomatoes to see if that has an effect.

Alan Evans: So you have established tomatoes have an effect on you, how do you manage it? You are in a full time job, a stressful job as you say, you are a police officer.

Alan Hughes: Yes, that is full time, and there is family life as well, it's just trying to get the balance right, it's self-medicating on the drugs I have been given and being very, very choosy on the foods I eat.

Paul Evans: Do they know at work that you have this condition?

Alan Hughes: Yes, yes, and I get mocked for it daily. Mocked for it because it is an old man's disease.

Paul Evans: Absolutely, which is why we are here today to try and dispel that myth. You both started this in your mid-twenties

Paul Webber: One of the things I find particularly embarrassing is that when I am at work I feel that twinkle in my toes, I feel them tingling and I know that I have got a couple of hours before the pain really, really starts to kick in. I work in Canary Wharf: I catch the tube, I catch the train and then I have to walk. If I am in a situation when my toe is swelling up [amd] I've got my shoes on, everything in my brain is telling me to take my shoes off. I know full well I can't take my shoes off – if I take my shoes off I won't be able to get them back on. I might not have a pair of trainers there, I might not have a pair of flip flops there. And even if I have, try working in Canary Wharf and walking home with a suit and a pair of flip flops. You are going to be laughed at, those are the things that affect me most about having gout. It's the embarrassment, it's having a gout attack at work, it's not being able to run around after my son.

Paul Evans: If you were speaking to somebody in their mid-twenties – you started having gout in your mid-twenties – to somebody today starting that journey, what would you say to them?

Alan Hughes: Speak to your GP, tell them everything and gather as much information out of them as you can. You know I think GPs aren't aware of exactly the pain, they are happy to give out the pain relief, the anti-inflammatories, so it's a simple quick fix for them. No, if you are suffering from it, look at the symptoms online, you can do that, no problem with the technology these days but then speak with your local doctor and highlight the problem.

Contributors:

- Ben Davies, clinical specialist physiotherapist in pain management at Sirona CIC
- Linda McGlynn, Patient and NHS Engagement Manager Diabetes Scotland

More information

For more support and information on living with diabetes, as well as advice on how to look after your feet, visit:

- NHS Choices http://www.nhs.uk/Livewell/foothealth/Pages/Diabetesandfeet.aspx
- Diabetes UK 'Putting Feet First' https://www.diabetes.org.uk/putting-feet-first#camp

Contact:

Pain Concern

Unit 1-3, 62-66 Newcraighall Road

Edinburgh

EH15 3HS

Tel: 0131 669 5951 / Email: info@painconcern.org.uk

Helpline: 0300 123 0789

Open from 10am-4pm on weekdays.

Email: help@painconcern.org.uk

Facebook / Twitter / Website