

## **Airing Pain Programme 8: Work and benefits**

***Is work good for us? We discuss working with chronic pain and the benefits system.***

*In the wake of the government's introduction of the Employment and Support Allowance (ESA) which will see all people already on incapacity benefits reassessed for their ability to work by 2014, **Airing Pain** discusses benefit reforms as well as how work affects those living in pain and how they can stay in, or get back into, work.*

*Chris Main, Professor of Clinical Psychology at Keele University, and Elaine Heaver of the Bath Centre for Pain Research take us through the evidence showing the health benefits from being in work and explain how GPs now give 'fit notes' as well as sick notes. Paul Watson gives some advice on how to stay in work and talk to your employer and Dr Shilpa Patel talks about the barriers faced by unemployed people with chronic pain.*

**Paul Evans:** Hello, and welcome to **Airing Pain**. This programme is brought to you by Pain Concern and supported by an educational grant from Napp Pharmaceuticals. I'm Paul Evans.

**Shilpa Patel:** People I've spoken to in my role as a psychologist within the NHS (National Health Service) and seeing chronic pain patients regularly, do want to go back to work and they would love to work if they could find something that would suit them and they'd be able to manage with the pain condition.

**Evans:** Our aim on **Airing Pain** is to be guided by you on the topics we cover and through our panel of experts we try and get answers to the questions you raise on our message board, mail, electronic or otherwise. So today we're focusing on work issues for those of us with chronic pain. It's a huge and contentious area, especially in the context of the Work Capability Assessment and Employment and Support Allowance – the ESA, which replaced a range of incapacity benefits for all new claimants back in October 2008. From October 2010 until 2014 those still receiving the older style incapacity benefits will be reassessed in their ability to work and if, in the view of the Department of Work Conventions, they're found capable, they'll be moved to what they describe as 'other benefits more appropriate to their circumstances'.

Now the fear is that people who are found to be capable of work will be moved to Job Seekers Allowance, which for some people could mean a reduction of around £25 a week in their benefit.

At the outset of this programme I'd like to pass on a request for your help from the Long Term Conditions Alliance, Scotland. They're collecting data on how the welfare reforms affect people. They'd like people who've already been affected, and those who are concerned about how they might be affected in the future, to tell them about their experiences. So, if that applies to you or someone you know, then we at Pain Concern will be glad to pass on your experiences. I'll tell you how to get in touch with us at the end of the programme, so please have a pen or pencil and paper handy to take down the details.

But first the question has to be asked: is work good for us? And to answer it is Chris Maine, who's Professor of Clinical Psychology at Keele University.

**Chris Maine:** There's been some important government reviews that have come out in the last year or two which really have looked at all the evidence there is for the effect of working and of not working on people. People that are off work develop more illness and they actually die more quickly, so we know, particularly in studies of older people, that after they've retired, getting engaged in something – participating – is really very important to counteract the effects of changes that have come about with retirement and sometimes social isolation. And, of course, if people have got pain and they're on their own, they're more likely to get a bit depressed with things, so it's really important to manage the pain rather than it managing you.

And one of the things we're interested in doing at Keele University is looking at how physiotherapists and other healthcare professionals are dealing with concerns about work that are raised by the patients. And very often the professionals don't feel all that well-equipped to deal with work issues. But things are changing – the new 'fit notes' instead of 'sick notes' that have come in, I think, over a period of time, are giving an important message: that work is in fact good for people.

**Evans:** Chris Maine of Keele University.

Elaine Heaver of the Bath Centre for Pain Research is conducting studies into these issues and specifically focusing on the rhetoric we've just heard that work is good for us. Now explain the difference between a 'sick note' and a 'fit note'.

**Elaine Heaver:** The main rationale behind the fit note is that one doesn't have to be 100% fit in order to work and that actually an earlier return to work than has been traditional can be

quite beneficial for people. Also that there are very active things employers can do, such as putting in place phased return to work, or workplace adaptations like a different chair or a different desk or special mousemats, those kinds of things, or bigger changes that might need to happen.

And the idea is also to focus on capacity, not incapacity. And it is based around some very good evidence that work is good for a lot of us a lot of the time and most of the people I interviewed didn't disagree with that, but some of the issues around the fit note that came up in our study were to do with how that is practical, particularly in a small workplace, for example, and people feeling a little bit pushed sometimes to go back to work before they were ready. And the GP now on the sick note, he or she just used to say, 'You are fit'; 'You aren't fit.' And now people may have seen these, they can either say, 'You may be fit for some work now, taking into account the following advice' or 'You're not fit', so the language has changed quite substantially as well.

**Evans:** Elaine Heaver.

Now whether it's a fit note or a sick note seems irrelevant when you are indeed in work but at the same time facing the stress of losing a job because of your condition. And that's exactly the worry that one of our listeners has contacted us about: 'I've been diagnosed with fibromyalgia and I'm worried that I'm going to lose my job. How can I stay in work?' Well we've contacted leading pain expert and physiotherapist Professor Paul Watson of Leicester General Hospital on your behalf...

**Paul Watson:** Now this is something a lot of people face. And the first thing that anybody needs to do is actually discuss it with their employer. Often people will struggle to remain at work – they feel that, particularly in the economic climate we have at the moment, 'The last thing I want to do is mention to my employer that I'm having a hard time because I'll be the first one to lose my job.' I can understand how people feel like that, but it's always going to be very difficult to make any workplace adaptations unless you talk to your employer first. It's also helpful to talk to somebody who understands about keeping people in work, work retention and return to work, so you need either a physiotherapist who has experience in advising people on returning to work or an occupational therapist and then, once you have people to advise you, to approach your employer.

**Evans:** So, having opened the topic on how work benefits us, the positives, if you like, what are the negatives? Chris Maine...

**Maine:** Pain can affect work in a number of ways: it can affect things that they actually do; it can affect their tolerance for sitting and maintaining postures of various sorts and, of course, if they're not sleeping too well, they may get really tired and this may affect their concentration. Some patients, of course, will be on medicine and some medicine does have side effects, which can affect their performance or concentration and so forth.

Pain can be a barrier to people working entirely and of course on some of our rehabilitation programmes we focus particularly on the obstacles to getting back to work. Some of these are practical things, like people needing help, for example, with advice about certain types of chair or certain ways of doing their work perhaps. But a lot of it is to do with the patients themselves, the employees, and the fact that they've lost confidence in how to cope at work. And of course sometimes we have unsympathetic working situations with managers or colleagues that are causing difficulties and this can be an additional stress.

**Evans:** It doesn't take much to adapt. It's not even the workplace in many things, it's adapting people's minds to allow people to work, isn't it?

**Heaver:** Absolutely, I really agree. It's about a sort of mindset of the person, the people around them, their family, their friends, their doctor and particularly, obviously, their employees and their employers. And, again, I interviewed quite a few teachers and they tended to have good support from colleagues, because teaching is such a, sort of, vocation and such a full on kind of job that they felt people were willing to perhaps cover one lesson for them here or there, do something like that, another lady talked about a school who'd taken her off cover duty so she wasn't having to move from place to place around the school building.

**Evans:** Of course in a school you can relieve teachers of playground duties, lunch duties, you can't relieve them of a class of thirty shouting children.

**Heaver:** No, and one of the very simple examples I can give you where the mind-set had not been shifted in a way that was helpful to her is this particular participant had to go to the hospital every six weeks for a day and she knew that and the school knew that and they knew that they took her on, but every time she had to go to this hospital appointment she was made to fill in all of these forms and go and ask the cover supervisor and she felt she was being humbled, in a way that was not helpful to her by doing that, and as they *knew* the whole year in advance which day she would need to be off, that could have been organised in one fell swoop at the beginning of the year, and she just wouldn't have felt that she had this stigma attached.

**Evans:** Elaine Heaver and before her, Chris Maine. Doctor Shilpa Patel is a research fellow at the University of Warwick and she's also a health psychologist with Milton Keynes NHS Foundation Trust. Now, the subjects of her research into the relationship between those with chronic pain and work were all unemployed people.

**Patel:** Some people are very understanding and are very aware of chronic pain, some employers and some organisations; others, I think more it's about the lack of understanding and the knowledge about how chronic pain affects somebody and how things like pacing activities are important during the day. So if you've got somebody, for example, doing an office type job, it's important for them to, if they've got a back pain condition for example, regularly take a break, maybe walk around, have a stretch, it's important to do those things but, you know, you're there to work and sometimes that can go out the window.

I know there's much more being done to try and increase awareness within workplaces about disabilities and things like that, so it'll be interesting to see where we will be in, sort of, ten years time, as to see what employers are like then, but at the moment it very much depends on who your employer is and how understanding they are.

**Watson:** If there's a workplace that's causing people symptoms, then a responsible employer should actually do something about that by assessing the workplace. Because sometimes the modifications can be quite simple, that could be done. It may well be that you have to discuss changing working hours and once again, you know, that obviously has to involve the employer, the human relations department, etc. It may also be helpful getting a union rep in to advise you as well, if only to be a friend to facilitate discussions.

There is also a scheme called Access to Work in some places, where you can get help from your local Job Centre, if any specialist equipment is required, so if you need a chair – a more comfortable chair or a more adaptable chair – or if you need a change to your work environment which needs specialist equipment, then you can go and discuss that with the Access to Work people. You can access them through the job centre or through the DWP website to find out more about it.

But the very important thing is for you all to talk and discuss a way forward, for the employer, one of the healthcare practitioners and the person trying to remain in work themselves to get together and discuss a management plan, and I think the sooner you do that, the better. Because what often happens is people struggle, they then start taking little bits of time off work, the employer starts getting annoyed, they start getting into disciplinary issues when really it's a healthcare issue, so the sooner you discuss it, the better for everybody concerned.

**Evans:** Paul Watson. Now it seems to me that there's a strong danger that the new rules we're talking about put small to medium employers, SMEs, at a distinct disadvantage in comparison with larger companies. Elaine Heaver again...

**Heaver:** The government has to be fair and when I say 'the government' I mean both Labour and the coalition. They have put in place mechanisms for smaller employers to be able to access occupational health lines, for example, and there's something called the Challenge Fund whereby an employer who needs, say, a new chair, a better chair for an employee can get 90 per cent of the cost back. But one of the things we found in our study is a lot of employers simply were not aware of these means of support, so were obviously not using them. But it did seem to be, as a broad rule of thumb, that the bigger the company, the better the chances were of finding a more suitable role for the employee, whereas smaller companies really struggled with that.

**Evans:** One thing some people have told me is that employers might want someone who's registered disabled on their books for other reasons – for box-ticking, if you like – but somebody who is sick really is a bit of a burden.

**Heaver:** Mmm, interesting point. The sort of distinctions between the use of language about being sick and disabled and whether or not it's useful in a politically correct sense to have a disabled person in your company, whereas if your employee is sick then the employer might shy away... And certainly, from that point of view... I went to a conference about a year ago that was designed for employers who wanted to improve the work health and wellbeing of their employees' lives and there were a couple of sessions that were quite shocking where, for example, in one particular session, a lawyer stood up and said, 'If somebody starts to become sick, just get rid of them, just pay them off, it will be, you know, better for you in the long-term, financially and in terms of bother.'

But actually one very big company round here had been incredibly supportive of employees, especially employees who have some experience because they recognised it's not just a sick person, it is an actual human being that they're dealing with. And from a business point of view they recognise that person carries a lot of experience, so there have been cases both ways, where just because somebody is sick it's not the end of the road and that is one of the positive things I want to stress.

**Evans:** Elaine Heaver. You're listening to *Airing Pain*, presented this week by me, Paul Evans, and brought to you by Pain Concern, the UK Charity providing information and support for people who live with pain. Now, as I've said, one of our aims on *Airing Pain* is to find answers to questions you've raised with us, so please do take advantage of this

opportunity to connect with our experts via our message board, email and not forgetting pen and paper.

But before we continue please bear in mind that whilst we believe the information and opinions on **Airing Pain** are accurate, based on the best judgements 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 and your circumstances and therefore the appropriate action to take on your behalf.

Today we're focusing on work issues raised by you on our message board. Now the previous listener was asking how he or she could stay in work. Another listener with neuropathic pain says: 'I've been out of work for two years. How can I get back to work?' Professor Paul Watson.

**Watson:** This is a related topic but also different in that it's much more complex. If people still have contact with their employer, I think it's important to actually discuss with their employer that they would like to come back to some form of work. I think that, once again, talking with the physiotherapist and occupational therapist, to discuss the type of work which may be possible... But you're only really going to *know* what type of work is possible by actually trying it out. And therefore if you have contact with your employer, getting in touch and saying, you know, 'I'd like to come back, are there any openings?' and discuss the number of hours that you think that you might be able to do, say just for a couple of hours a day and then see how you go, so that would be one way.

However, unfortunately, most people who have been out of work for two years usually haven't got a job to go back to – their job has gone or they've been made redundant or they've had to retire on ill health grounds. So the vast majority of people who've been out of work for two years usually haven't got a job to go back to.

**Evans:** Paul Watson. A further stressor and challenge for someone with persistent pain is in trying to convince people of the full impact the illness has on their lives. For example, filling out an application for Disability Living Allowance or Employment Support Allowance can be a major cause for concern. Elaine Heaver again.

**Heaver:** The kinds of questions that are asked in a new work capability assessment, was a particular problem for people, because our participants with chronic pain felt these kinds of questions on these kinds of forms do not capture the experience of the illness itself. A very simple example, a lot of the chronic pain patients talked about its fluctuating nature and some of the questions, as I'm sure people will be aware, say things like, 'can you lift a heavy

bag of shopping? can you turn on a tap? can you do this? can you do that? how far can you walk?’

And people said to me, ‘Yes, I can do those things, but then I might be flat on my back for three days.’ And there isn’t space within that form to express what these activities’ impact might be on the rest of their lives. So that was a really big issue and one that we have thought about raising with the DWP and we have had some communication with them on that. They say that their advisors are trained to take into account worst case scenarios, but it’s often very difficult by the nature of written communication, as opposed to an oral interview with somebody... the form can become very problematic in that way because it’s almost too objective to capture what’s happening for people in their everyday lives.

**Evans:** That’s right, it’s easy for me to say to you, ‘I can do something today, and... I could do it last week, but I can’t guarantee that I can do it tomorrow.’

**Heaver:** Yeah, absolutely, I mean that word ‘guarantee’ is key, I think, in terms of... I started looking at chronic pain patients at work – people felt very strongly, ‘Well who is going to employ me?’ – employability was a big issue that wasn’t picked up by the government, people felt.

**Evans:** And that fits my own experience in the private sector too. The outcome of a process that took nearly a year from when I’d become too ill to work was that the occupational health doctor contracted by my employer concluded that my, ‘functional capability must now be deemed to be permanently impaired’ and that I was ‘permanently incapable of carrying out my role’.

So, if I were to apply for a new job suiting my experiences and capabilities, I may well be able to impress my prospective employers at the interview whilst at the same time showing no visible signs of being chronically ill. So how, in all honesty, could I accept a job where I or the employer wouldn’t know from day to day whether I’d be fit enough to turn up the following day?

**Watson:** There are, increasingly, a number of employers who are quite willing to take people on on a trial basis. The Department of Work and Pensions in Job Centres had tried to set up, with a number of employers, who would just take people on a short job experience. Now I know sometimes people feel that, ‘Well, I’m working for nothing.’ I know we all have mixed views about that, but I think the only way people are going to know how much they can do is actually by engaging in some type of workplace activity.

Now, there's also things people can do at home, because if you think that you are going to have to do a job for, sort of, two or three hours a day, perhaps people can set up activities that might mimic that in the home. I know this might sound a little bit off the wall, but if you are required to, say, sit at a computer, you could start building up your sitting tolerance. So it would be that you would sit and perhaps do some work sitting down at desk or at a table, so you can go to an employer quite confidently and say, 'Well, I can sit as long as I can get up five minutes every half an hour, I can sit at a computer for two hours, three hours', or something like that.

If you are looking for a more physical job, perhaps you could look at doing some simple tasks around the garden or in the house so you can assess what your physical capacity is, and you can say, 'Well I know I can pick up and lift things up to a certain weight so many times a day. I can, you know, bend and lift. I can pick these things up.' So you get an idea of the sort of physical capacity that you have. And that sort of thing, in addition to advice from a physiotherapist or an occupational therapist can give you a little bit more idea and confidence in what you physically can do before you start applying for jobs.

**Evans:** Did you find any of your participants taking blame themselves for not being able to work?

**Heaver:** That's a really interesting question, the sort of blame that people put on themselves. The biggest issue that came up with that was worrying about what other people think of you, because they can't always see what's going on for you and what's wrong and therefore internalising some of that stigma, that certainly was a big issue and people had to work very hard. That came up not just with employers but a lot with neighbours. People were saying, you know, 'I worry, because my neighbours know I'm off sick for six months or whatever period of time and they see me walking around town and they don't know that a) I'm supposed to do some walking every day and b) again, it has a big impact on me and how I am the day after.'

And I remember particularly one fairly young participant being very angry because they felt that yes, she was working but at the expense of absolutely everything else in her life; she had no physical or mental energy left at all in the evenings or at the weekends, but she felt that society, by which she appeared to mean both people very close to her and very broadly – society, the media, papers, etc. – would judge her so harshly if she stopped working and tried to create a better balance for herself, it wasn't something she was yet prepared to do.

**Evans:** That's right, it's a powerful thing, isn't it, where our employers or neighbours or whatever, they see you working 100 per cent, but they don't actually see or realise that 100 per cent is 100 per cent and there is nothing left at the end of the day.

**Heaver:** Yeah, yeah, and just little things again, you know, two... more than two people actually, really specifically talked about commuting in London on the tube and how problematic that is. And the story with this was that they would get the disabled seat because they really needed it and then would be asked to move in quite nasty ways, not even, sometimes, because somebody else wanted it, just because another passenger saw them sitting there, saw they *looked* physically fine, perhaps they didn't have a stick, perhaps they just looked OK on that day, but that was a really big problem again in terms of how society was viewing people and how people were having to internalise that.

**Evans:** Elaine Heaver's research is moving into a second phase. And this is where you can help.

**Heaver:** One of the findings from the first study was just how important it is to get employers to be really thinking about how to help people return to work or retain current workers, but if anybody out there is interested in participating in the next phase of the study, which is really focusing on employers and employees and how we can make the system better in that way, please contact me. And if anybody is an employer who's listening to this, or if anybody has an employer that they think would be interested, we would love to interview them.

**Evans:** And if you can help Elaine Heaver then please contact us at Pain Concern and we'll pass on the details. I'll give you contact information at the end of the programme.

You're listening to ***Airing Pain*** with me, Paul Evans, and we're discussing issues around employment for those of us with chronic pain. So what are the barriers we set ourselves in getting back into the workplace? And if the Department of Work and Pensions is so anxious to get us there, what are they doing to help? Paul Watson, followed by Shilpa Patel...

**Watson:** The Department of Work and Pensions have been trying to set up schemes to help people back into work, so there are a number of training schemes available. Now I know people can be quite cynical about training schemes, because it's just a way of keeping unemployed people entertained rather than actually being helpful, but there are a lot of new programmes being set up. The first thing is, that if people are unable to go back to the work that they had before, because it's too strenuous or whatever, is to identify the skills that they actually have got which an employer would like.

**Patel:** I spoke to people that worked in the trade industry, people that were managers – there was a range of people that I spoke to – people that did lots of laborious work and to be out of work and then trying to find work related to something that you originally did but can't do that because of your physical pain problem was quite daunting – to then go into another industry and do something else. People often found that very scary to then think, 'I've got to retrain, do something else', especially if you've done something for many years. So yeah, retraining and feeling, 'Maybe I haven't got the skills for something else', they were all barriers to trying to get your foot back into the workplace.

**Watson:** I've worked a lot with people who are trying to get back to work and they are very negative about the skills that they have and I've seen this time and again where people say, 'Well I've worked in a particular job for 20 years, that's all I know and all I've done.' Well, that's not true, because when you talk to people they have got person management skills, they've got numeracy, literacy skills, they might have computer skills and these are things that an employer needs to know about when you're looking for a job.

So you need to spend some time, perhaps with somebody from the job centre, writing down the skills that you have got. And that, sometimes, you need someone to coax those out of you, because people don't readily say, 'Well I'm good at this, I'm good at that.' Often when you've lost your job you have quite a negative view of yourself and you tend to only see yourself in your previous role, so you need to sit down with somebody to identify the skills you have that an employer wants.

You can also identify the skills that you don't have and need to work on, so these might be to do with improving people's numeracy, improving literacy, trying to get some computer skills, etc. Now a lot of people also find that actually having a short session in voluntary work is helpful, because there are a number of things that people who have been out of work for a while have to face and one is that they don't have anybody to give them a reference and, of course, employers always ask for a reference – 'Well what can you do? how good is your timekeeping?' etc. So by doing a short period of voluntary work, that has worked for some people because they have a reference from a respected person that says, 'This person has attended, they were regularly doing x number of hours a week, they were always punctual, pleasant etc.' and that can go quite a long way to an employer, is to have a reference.

**Evans:** Paul Watson.

Now before we end the programme I'd like to make an appeal on behalf of Pain Concern, the UK charity providing information and support for people, like me, who live with chronic pain. They are the driving force behind these fortnightly **Airing Pain** programmes. But the

programmes are not just for the 7.8 million people in the UK who live with chronic pain, it's for our families, friends, carers, supporters and also for the health professionals who wish to hear and share their views and strategies with colleagues and patients. If you're in any of these categories and feel that you or someone you know has benefited from listening to these programmes and would like them to continue, then please consider making a donation to secure **Airing Pain's** future. Just go to our website at [painconcern.org.uk](http://painconcern.org.uk) where you'll find a 'Make Donation' button at the bottom of the page.

And don't forget that you can still download all the previous editions of **Airing Pain** from the same website. If you don't want to or can't donate, well, that's fine, we'd love to hear from you anyway, either to put a question to our panel of experts or just to make a comment about the programme. Either contact us through our website, blog, message board, email, facebook or twitter, or if you prefer good old-fashioned pen and paper then the address to write to is: [...]

And finally, if you're an employer who can help Elaine Heaver at the Bath Centre for Pain Research, or the Long Term Conditions Alliance Scotland, then you can also contact them through us. And we'll make sure they receive everything. Appeal over, and I'll leave you with one final piece of advice from Professor Paul Watson.

**Watson:** If you do find a job, it's very important that you discuss returning to work with benefits advisors. The reason being is there are a number of benefits contingent on returning to work, these keep changing and I'm sure they'll change again, so when you do go back to work, you always discuss with a benefits advisor first. They can tell you of all the sorts of schemes, to do with return to work credits, etc. etc. which are constantly changing, so you'll have a good idea of how much better off you're likely to be and also what happens if you are unable to sustain the job. And it's very important that you talk to benefits advisors beforehand because they can put you in the picture, and once you've got that information you can start to make a much more detailed plan, so please, don't just rush out tomorrow and if you think there's a job going and jump into it, talk to a benefits advisor first, because they can smooth the way and make things a lot easier.

## Contributors

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