

Erm... I've got a back problem at the moment. And this has been going on for almost a year. Erm, about (pause) 11 months ago I suddenly started having a sharp onset pain which radiated from the buttock down to the back of my leg. And if somebody at that point in time had actually said to me it was back problems, I wouldn't have believed them. Because it didn't... I've never had back problems before. Erm, my background is nursing so I've always known how to take care of my back. I've known how to move people, how to... Erm, be able to transfer patients safely. And I've never had any back problems. But my husband has and I've seen what it's like when someone is living in extreme pain. And I've also known what it's like, erm, to see someone depressed as a result of that. And also the frustration that person feels when they don't know what's wrong with them. But the experience I've had over the last 10 months, I've certainly compounded that. And it's given me much greater insight into the full impact and frustration of trying to feel as if you're being managed effectively. (Pause) Erm, we moved doctors about 2 years ago because we moved house. And I've never... I don't go to the doctors. If I had been to my doctor (pause) the same number of times this year as I've been to the doctors I'm now with, I think alarm bells would have been going off. Because I was one of those patients that were seen for female health checks and usually with the children when they were small and the occasional chest infection that people get. You know? When you're working in the Health Service and you're picking up every virus or bacteria that you pick up when you're working out in the community. But certainly I was not a regular doctors visitor. I believe it's best to just manage it yourself. And if things are serious eventually you'll be led... You need to go. So, and that's the attitude I took. I had this pain down the back of my leg. Everybody had an opinion on what it was – tendonitis, it was an inflammation... And I tended to agree. That's what I thought it was. That I somehow had this inflamed tendon. But after a month I thought, "Right, I need to go and see the GP." So I made an appointment, saw this male doctor and he said that he didn't know what was going on in my back. Well, he didn't mention back then – he said it could be my back. But he thought that it would be best that I would be referred to a physio. So this would have been, possibly, mid-March and in the meantime he gave me some medication. Which was, erm, dihydrocodeine. Which is quite a strong medication. And because I work and because I need to function I was quite reluctant to take that medication and I'm sure they would see that as non-concordance or non-compliance. But the reason being I'm the person who supports the household. I work. And I need to be able to come to work and be intellectually alert. And I also knew that if this pain that I was having – that was not the right medication if this was a nerve pain. So... (Pause) Erm, I managed it myself with paracetamol and ibuprofen. I could cope with it. The only time I got it was when I had been sitting for periods and then suddenly I would get, like, a cramp down the back of my leg. And once I was walking I was able to walk for miles – which we like to do. I was going to the gym 4 or 5 times a week and doing 20 minutes on the treadmill and 20 minutes on the bike. Erm, swimming was a bit problematic. But that was where my physical capability was at that point in time. So I then, erm, saw the physio and the physio said that if it was a purist... A purist would say it was a back problem. But he wasn't convinced. So for between – I would say probably late March, April until the end of June – we didn't have a diagnosis. And when I was going back to the GP I was told that they couldn't do anything until they'd had a diagnosis. So the physio referred... Suggested I went to see, er, someone privately for a second opinion. Which I did. And this guy actually said he thought I'd had a pro-lapsed disc in February. So he gave me back exercises, which I did regularly across the summer – could actually feel some improvement. Which was great. We went on holiday. At least I felt as if I was a little more agile. Less pain-free. I continued to take paracetamol and Ibuprofen. And then in October I had bent down one morning to pick up the \_\_\_ from the bottom of the bed and had, like, this electric shock across the middle of my back. And since then the pain has been excruciating.

And more debilitating. I went back to see my private physio who said he thought that I'd probably just aggravating the nerve. To continue doing the exercises. And at that time I actually felt quite isolated and quite alone. I felt absolutely lost in a system that I should have known how to find my way around. So, erm, I bumped into the physio that I'd been seeing at the gym and explained the situation and he suggested that I made an appointment. And usually making an appointment can be a 4 week period before you actually get an appointment. So that was another 4 weeks, taking us up to November. By the time I saw him, erm, (pause) he asked me what I was doing in terms of exercise. He still thought that possibly it was a disc. It was just sticking with the exercises. And, erm, my husband at this point was quite concerned because, obviously, I was... My mood was becoming low. I was feeling very frustrated. I felt this had been going on for 6 months with no progress. And I'd also had another injury, which was being managed by the orthopaedic surgeon. So he suggested that I went, erm, a rehabilitation centre that the Fire Service run. Thinking that that might, erm, enable me to at least become more physically active and perhaps cope with this situation better. So I went to see my GP, erm, before Christmas. And she said she didn't really want to sign the form until I'd had a back x-ray – which I was surprised at because they tend not to do back x-rays for, erm, back problems. Er, it's generally frowned on. And certainly a friend of mine – who's a Nurse Practitioner – she was quite surprised as well. But anyway, I went before Christmas, had the back x-ray. She gave me some tramadol. She said to relieve the pain. And I have looked in the \_\_\_ and I know that yes, it can help nerve pain. Because I've now (pause) adjusted to the fact that this is what I'm having. It's sciatic nerve pain. Erm, (pause) the tramadol made no difference, whatsoever. So I had an appointment to see her just after Christmas and I went back to see her. And I said I'd come for the results of my x-ray. And I already knew what the results were because she'd filled in the form to go to the rehabilitation centre. And this was my medical history. A hernia at the age of 4, varicose vein surgery and minor degeneration of the spine. And that was my medical history. And (pause) she said that I had minor degeneration of the spine and that, erm, (pause) the way that it was best managed... It was arthritis, so I needed pain killers and I needed exercise. And I was quite distressed. I felt quite low. I (pause) felt (pause) that I wasn't being listened to. I said to her that I felt that it might be seen as minor degeneration – which I think anyone of my age who was x-rayed would see. Because of the very nature of the job. And she said, well, that was the way it had to be managed. And I said, "Well I think I need to be referred. I feel I need to be referred and see someone else." And she said that no-one would look at me, not at my age. And not with that condition. So I said, well I knew that some of my friends had been to a back management service and, er, she said, "Well that would be in this pain service that was provided in the hospital." But there was an 8 month waiting list. So I felt quite despairing at the thought of managing this for another 8 months. Er, without... And she said the G... They would expect that the GPs would start to manage the pain within, erm, the primary care. So she gave me more medication. I had to continue taking the tramadol. And then she gave me some \_\_\_, which is a \_\_\_. Erm, and then she said... I asked whether it would be safe for me to take them since I had, once had a \_\_\_. And she said, well, if I had a problem with that, she could give me a \_\_\_ which would protect the stomach. And I explained that I'd had a real reaction to \_\_\_ when I'd had the ulcer and had real, you know, bad gastric (pause) complaint. Which had inhibited my quality of life completely. So she said, "Well, we would probably do without that at the moment." And I said to her, well, I knew quite a lot about pain. And my understanding was that for sciatic pain it was best managed by, erm, \_\_\_, \_\_\_, something like that. And I know when my husband has a problem with nerve pain and I asked about \_\_\_, I was told that he had to be seen by a consultant. Now I felt strong enough to be his advocate and say to her, "Well, how long will it take to see a consultant because he was obviously worse than I was." And she said two months – and I said, "We're not prepared to wait two months. I

think you need to have a conversation with the consultant.” And she rang me and said, “We’ve got a script for \_\_\_ for him.” But that was interesting that I felt that I couldn’t actually do that for me. I felt that although I’d challenged her, she said, “Well I think the first step is \_\_\_.” Which makes you concerned that this is about finances. And I also know that when my friends and my husband were taking \_\_\_, you know, they lost the morning. And when you’re working, how can you lose a morning? How can you perform? And I said to her, “If I was still a District Nurse, I would have been on the sick now for a month. I would have been on the sick for, actually, 12 months. I wouldn’t have been at work since last March. You know, people would be looking at me now and thinking, “Well, what exactly is her diagnosis? What exactly are they going to do to manage this lady?”” And when I came out of the surgery I cried, all the way home. Erm, I felt so despondent. This was on the Friday. The Friday before New Year. New Year’s Eve we had friends coming round and I just felt very depressed. And I made a brave face of it. And... But I’ve never felt stress like I felt. I felt... I’m normally someone who copes – I can multitask, manage... The drugs that I was taking were making me feel sick. I couldn’t concentrate. I was dizzy. I felt shaken inside. I had a rash. (Pause) One morning I just lay in bed until 1:00 and my husband said to me, “Have you had a nice lie in?” I said, “I lie in bed because I don’t have any pain. And if I get up, I’m in pain. So why get up?” And then I was coming back to work and I had to perform on the first day – quite poorly, I must admit. And, erm, it was to everyone’s amusement. So I made the decision after about a week to stop the drugs and feel that perhaps I just manage the pain and feel as if at least I can perform. I’ve seen the physio, and at this point I got angry and actually said that I wanted to be referred. That I felt, you know, I had been a very fit woman until 10 months ago. And that I was now being, erm, pigeonholed into someone with arthritis. And I didn’t feel that there was any physical symptoms that I had arthritis. (Pause) And that I needed to have a referral. But without the letter from the GP, how could I see anybody? You know, this is the gatekeeper. And the GP who’d referred me originally, to get the diagnosis, you know, (pause) he wasn’t involved anymore. The physio wasn’t discussing things with him to my knowledge. He was now in a position where he was having to persuade this other GP to refer me. And she’d already decided I was probably come menopausal woman with, erm, (pause) with back pain. That was minor. And, you know, as empathetic as she’d tried to be, I had still been pigeonholed. And, er, I was insisting that I... Even if I paid privately. (Pause) And I’m someone who works in the NHS. Who is familiar with the NHS. Who has navigated the NHS. Who’s been an advocate for so many people in the NHS and yet I’m sitting here feeling like this. In absolute despair. And wondering what is the end going to be for me? And it leaves me with little hope for people of my generation who are now the ones who are going to be expecting something of the NHS. And it seems as if, because of finances, and because of different, erm, attitudes, you’re just left to get on with it yourself. (Pause) I That’s great. R Is that alright? I Fantastic, yeah. R Mmm. I I didn’t realise it was such a serious situation you were in, you know? R Mm-hm. Yeah, yeah. I (Pause) And, erm... (Pause) You obviously think that doctor had just pigeonholed you? R Mm-hm. I Yeah. (Pause) And she could put... Is she the person who refers you then? Or she’s actually blocking a referral or...? R (Pause) When I had... When I asked the doctor if I could have a referral I said that I felt that I really needed to be referred to a neurosurgeon. And she said that nobody would look at me because of the minor diagnosis. And I said to her, “Well, this might seem like a minor diagnosis for you, but in terms of quality of life...” (Pause) And because she doesn’t know me personally, I explained to her the sort of physical activities, erm, (pause) you know, the personality that I was. And how people are commenting that that’s changed. That I’m quieter. That, erm... (Pause) I think my husband’s quite worried, because my moods are quite low. But that didn’t seem to really persuade her. She felt that her clinical judgement was that I didn’t really need to be seen. And because of the minor

condition it was not something that should be seen. Only because of the arthritis that she now decided I had, would I need to be seen – and possibly for surgeon... By an orthopaedic surgeon when the arthritis had got so bad, erm, that perhaps they needed to do some surgery. But my feeling was, well, how do you deal...? How do you come to terms with where you are physically, if you don't know what your diagnosis is? If you've never been properly investigated. (Pause) I had a fall, hurt my shoulder, erm, \_\_\_ with the physio, was eventually referred to a consultant. The consultant was very concerned at the injury. He sent me for an MRI scan, and I'm waiting to go back to see him. And he's telling me that I may need surgery. Now, at least you know what you're dealing with. At least I know that I can make choices and I've got options. But now I can't see any option because I don't know what those options are. And I feel, until I've had the relevant investigation – which I think is an MRI scan – then, only then, can they say, "Well, this is what you've got." My husband, he left the Fire Service because of a back injury at work. He'd had back problems with discs over a period of years, on and off. He eventually, after a fight, with several GPs, went to see a consultant, had an MRI scan, and was eventually told a diagnosis. So he understands what the diagnosis is. And he understands that there's nothing that they can do. And he understands that he will have periodic, chronic pain. And when that's there, he manages it. It's very difficult for him, but he knows that that is what his life is going to be. I think, perhaps, I would just like to know what my life might be and perhaps I'm being unrealistic in my expectations. But I actually don't think I am. And in fact, if you look at the back standards, it actually specifies that there should be appropriate investigations. That there should be red flags. The last time I saw my GP, I said to him... The physio – I said, "I'm now getting nerve pain (pause) into the calf. I'm getting tingling when I'm standing up, like pins and needles into the calf." But I'm just told it's now moved to a chronic stage.