

NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

Multiple Technology Appraisal (MTA)

Percutaneous Vertebroplasty and percutaneous balloon kyphoplasty for the treatment of osteoporotic vertebral fractures.

My Story .

Patient expert. - Christine Sharp.

Four years ago I suffered a bad fall on my back. The pain was so horrendous that when I arrived at A & E I had to be given gas and air just to be able to get out of the car. I wasn't x-rayed, just sent home with strong pain relief.

During the night I collapsed and had to be admitted to hospital, when they decided to x ray my back. The result was that I was fine and could go home.

I went straight to work as I was a self employed hairdresser, and was concerned about my business.

I decided to see a well recommended physiotherapist, as I was struggling at work due to the severe pain. He treated me for around three weeks and then insisted I go back to my GP for a scan, as he wasn't happy with my lack of progress.

It was only then that I was told I had borderline osteoporosis and three fractures in my spine. I thought to myself, well, being borderline is not too bad.

I continued to carry on and work as well as I could, but with great difficulty.

During this time I saw no fewer than three GPs due to the severe pain. Each time I was given new pain relieving drugs, which had no effect and made me ill.

The last GP I saw gave me morphine patches, and said, "this is the end, we can't give you anything stronger" to which I replied, "does that mean a shotgun next?" to which he replied, in all seriousness, "might be the kindest"

As I walked out of his surgery, he wished me good luck, and I remember thinking, is good luck the only thing on my side?

The morphine made me so ill, that I lost a stone in weight, in a month. I couldn't eat and was being sick every half hour. No drugs helped with the pain at all, just made things worse, having to cope with the awful side effects.

Within a few weeks I sustained three more fractures just going about my daily life.

I can't tell anyone, how bad the pain was. I was screaming out when I tried to get in and out of bed. I could barely stand upright, and felt I had the stance of an animal rather than a human being.

You become an expert on how to do things without hurting your back, as every movement, no matter how slight causes immense pain.

I couldn't lift a kettle, so found a way of using my elbows on the work surface to take the weight.

I have to use my arms to turn over in bed and to get me in and out of bed.
Just taking a bag of sugar off the shelf, is a nightmare.

You sit at a table and wonder why your chair is lower than everyone else's, as your chin is almost touching the table, to realise it's not the chair it's you that's smaller.

It was at this stage, that I had to make the heart rending decision to stop work. A job that I loved. I had struggled for a year with these fractures and terrible pain, and couldn't continue with the nightmare of trying to stand and carry on.

I had built up my business over 50 years and had to just walk away.

It was then I requested to see a consultant rheumatologist, who took x-rays and said I was the worst case she had seen for my age, 66 and was seeing me too late.

In fact, I wasn't borderline osteoporotic, but had severe osteoporosis, with a significant risk of lifetime fractures.

I was immediately given four infusions of Pamidronate, over an eight week period. During this treatment I sustained another major fracture, just walking down a step.

It was then decided that I should have a two year course of Teriparatide, a daily injection. This in itself was a challenge, as I had to inject myself. One of the hardest things I have ever had to do in my life.

It was then suggested I see a pain specialist, with a view to Percutaneous vertebroplasty. My first consultation consisted of a thorough physical examination and discussion. re. my pain levels and drugs I had been prescribed and effects. As I am not good at tolerating the drugs and they didn't help with the pain, it was suggested that I may be suitable for the vertebroplasty procedure.

The next stage of the proceedings was to have detailed x-rays taken of my spine by the specialist in a theatre setting to ascertain the state of my damaged vertebrae in order for the specialist to make the decision, as to whether or not I was a suitable candidate for the procedure.

After the x-rays I was told immediately that he could go ahead and perform the operation, and did I want to go ahead with it.

Shock, horror, I couldn't believe that I was asked this, without any discussion, re. The benefits or risks involved.

I did ask what the benefits would be, to be told, it MAY help with the pain.

I said I would like some time to think about it and consider the implications involved.

And so at my next consultation, I was asked what I thought about the vertebroplasty, my reply, "scary" to which his reply was "you think it's scary" he did also.

The next stage was for me to be referred to a Neuro surgeon in Leeds, who I guess was more experienced in spinal operations.

I had a consultation with a physiotherapist, who booked me in for an MRI scan, for them to see exactly what state my spine was in.

This in itself was an horrendous experience, as you can imagine having to lay on your back on a metal bed, with a curved spine.

It just felt as though I was entering a torture chamber, and for almost an hour.

The result of this scan, was that my vertebrae were too badly damaged for me to be able to have the procedure, however, she went on to say that my spine wasn't too bad!!!!!!

How on earth could she reach that conclusion, when I have multiple fractures, lost 4 inches in height and in constant pain.

She also said I had to be very careful, as there was loose bone which could touch my spinal cord, and had to go to A & E immediately if I had any problems with my legs, bowels or bladder!!!

For whatever reason, I just don't think they wanted to take me on.

To be perfectly honest, I think I was relieved that the decision had been taken out of my hands.

I was never given much hope of a good outcome.

To be told that it MAY, only help with the pain, seemed hardly convincing to me. There was also the possibility that having the procedure could cause further fractures, above and below the insertion sights.

The risks seemed greater than the benefits, but that was maybe, because I was never given any confidence that I would benefit from it.

My overall view is, that the medics I saw were inexperienced and not confident enough in the procedure, so therefore I didn't have confidence in their expertise or lack of it.

I was literally terrified, as once that cement has been inserted into the bone, that is it, it can't be removed

It would have been a great help to know more about the procedure, and to maybe hear of patients who had benefited from it, in order to make a valued judgement.

The impact of osteoporosis and spinal fractures on my life and my husbands has been devastating. In the past three years I have gone from someone who was running my own hair salon, walking 20 to 30 miles every week. Helping with a youth club etc. never still always on the go. I am now 4 inches smaller, lost more than a stone in weight and gone down 2 dress sizes.

A shadow of my former self.

I now struggle just to get through a normal day, due to the pain and exhaustion.

The physical and psychological effects are enormous and take time to adjust to.

Due to the loss of 4 inches in height, affects my digestion, I can't eat large meals as my intestines are scrunched up into less space.

Breathing is also a problem, it is difficult to inhale enough to fully expand my lungs, due to my stomach being pushed up into my diaphragm.

Walking any distance is extremely difficult, as you are constantly struggling to be upright, as your body is wanting to bend over, and you feel as though the ground is pulling you forward, a terrible strain, and very exhausting.

You become paranoid about falling, terrified in crowds in case somebody bumps into you.

When in a car, the seatbelt comes across your neck instead of your chest, and you are constantly looking in your mirror in case the car behind is too close, for fear of a bump.

Then there is the problem of body shape, this is difficult, as clothes don't fit properly, you catch a glimpse of yourself in a shop window, or on a photograph and it makes you cringe at the shape you have become.

This has serious affects on your self esteem, and it would be very easy to descend into a downward spiral of depression and despair.

Life for me will never be the same.

Day to day living with these painful fractures is a living nightmare, but life goes on and for me to be kept busy is my way of coping and getting on with life, in the best way possible.