



AECC University College

Clinical
& Rehabilitation
Services

Patient Reflection





Patient Reflection

We are grateful to our MSK patient, who kindly shared their story with us and is happy for us to share it with you. We also share our Clinical Reflection at the end of the piece.

1. Patient Story

"It is the beginning of August 2023 and this is a story I need to get out. Out of my body, my mind and to the outside world. It is a simple story. A progression of everyday events that happened to me and I am sure must have happened to thousands of people who have put their faith and trust in the medical profession.

"The following is about how easy it is to become medicalised; to suffer from the anxiety of receiving diagnoses which could have led to unnecessary operations; to incur years of wasted time and money on scans and X-rays; to go to countless practitioners in an attempt to confirm these potential diagnoses and receive the right help needed, at a cost to the private health care insurers which ultimately reflects in higher annual premiums.

"The consequence of all of the above is that many people cannot afford private care and have to rely on the NHS, increasing the waiting lists for consultations and treatments."

2. Diagnosis

"My symptom first began in March 2017. I had been working out on a reformer in a small group Pilates class and afterwards, when I went out for my normal hour long walk with the dog, I noticed a burning feeling in the upper thigh of my left leg.

"It wasn't too unpleasant so really didn't give it too much thought and carried on as normal. As it happened, I was looking forward to a special holiday with my husband to celebrate our 50th wedding anniversary.

"We had arranged to drive around Europe in our car staying at various destinations, from Bruges, through Germany and Italy and ending up in France. However, as can be imagined, this all involved a huge amount of driving most days, on average 4-5 hours.

"From the start of our trip, the burning feeling in my left leg became worse and it became really painful to walk. It was a real nuisance but I wasn't worried about it, and assumed that I had probably just strained a tendon and it would settle down with a bit of stretching. However, it really didn't, and I was compelled to buy some trekking poles in Germany to help me distribute the weight and take some tentative steps.

"However, by the time I returned home, it was significantly better and I put it out of my mind.

"I resumed my regular activities, walking, playing golf, yoga, swimming, but the burning sensation returned intermittently. It wasn't until the summer of 2020, just when the Covid lockdowns were in full swing, that I decided it was time to find out what was going on with my leg, and I went to my private GP for a consultation.

"He admitted he really didn't know and said he would refer me to a rheumatologist, and I made the appointment. Little did I know that the dye was cast!"

3. Surgery Suggested

"The rheumatologist asked me why I had come and I presented my symptom - the only one I could report. He asked me to lie down and briefly examined the flexibility of my hips and said that the mobility of both wasn't very good.

"He also asked if I got any groin pain on either side, to which I replied no, that it really was only a very specific small area in my left upper thigh, as I had said. He looked somewhat confused and said that this was not a normal symptom of hip arthritis, which he thought I was suffering from, and decided to send me for an X-ray and MRI scan of both hips.

"While I was waiting to hear when I could go down for my scans, he came out of his room and again said that he was pretty sure it was osteoarthritis, that hip replacement was a very common and successful operation; it was now possible to have both done at the same time! I had my scans and went home to await a phone call from him for the result.

"A few days later he called. Yes, he could confirm that both hips had osteoarthritis, the right was worse than the left, which was mild to medium. Although he had kind of prepared me for this result, I was nevertheless gobsmacked.

"I hadn't felt any real problems with my hips and this was a real shock. The whole country was officially locked down. What was I going to do? A few days later I received a phone call, which I initially thought must be a wrong number. But no, it wasn't.

"She asked for me by name and said she was calling from a hip surgeon's practice as they understood I needed hip surgery. What!! And then the penny dropped. The surgeon had been given my details by the rheumatologist and wanted to be the first in line for the work!

"I stammered my way through the brief call and said that, when I was ready to go ahead with surgery, I would call. I felt very upset at how all this had come about."

4. Increasing Anxiety

"I carried on in the difficult time of Covid lockdowns for another year and a half, trying very hard not to think too much about my hip problems. However, having been given the information about my degenerating hips, I became anxious on a daily basis about making them worse in what was a very difficult time, and lost all confidence in my usual exercise regime.

"However, towards the latter part of 2021 I was recommended to a spinal and orthopaedic clinic in Central London, and specifically to a very experienced hip surgeon. I took my scans with me to this consultation, and he did his own very similar examination of my hips.

"Fortunately, I felt somewhat relieved when he said he didn't feel there was any great urgency for an operation, and I should come back if I had any further severity in my hips.

"I carried on for about another 6 months, until the anxiety I was feeling led me to go back to the clinic to see whether it was time to have one hip replaced. I was physically moving less and less, felt stiff and vulnerable more and more, and even my family started urging me to go ahead in the hope that my quality of life would return to what it had been before.

"I again went to see the hip surgeon with my diary, fully intending to put in a date for an operation. Whilst being examined, I experienced a slight niggles in my lower back, which I assumed was being referred by my hips, and I asked him if he could have a look at my lower back while I was on the table.

"Did I have one leg longer than the other, was something out of alignment, which needed clicking back. He checked both legs and my spine, and quite rightly said there would be no point in doing a hip replacement until we found out what was causing the back discomfort, as it could render the replacement unsuccessful. He sent me off for a CT scan!

"I returned to him to find out the results a couple of weeks later. I was greeted at the door with a smile, he saying he had some good pictures to show me. This naturally sounded hopeful. I was informed, however, that my spine showed I had Spinal Stenosis in my L5/S1 vertebrae with a degree of degenerative arthritis and also that the facet joint on the left side had some arthritis, which might cause certain symptoms.

"However, he didn't make too much of what the scans showed, but suggested I have a chat with his colleague, who was a spinal specialist and he would explain it all in more detail. I therefore made a further appointment with the spinal specialist hoping for a bit more clarification."

5. Spinal Specialist

"He seemed a personal chap when I eventually met him and proceeded to put my X-rays up on the screen. However, before any explanation and after a personal zoom call with his wife, he finally got around to explaining my problem, and he immediately asked if I'd like injections in my back.

"I was confused and said I had merely come so he could explain the condition to me, as suggested by the hip specialist. He finally said, very briefly, that I just needed some suitable exercises from a physiotherapist. I had expected that he would refer me to the physio department at the clinic, but he simply asked if I knew one, which I said I did, and that was that.

"From that date onwards and for the next almost two years, I have visited various therapists in the hope of finding out a little more information about my condition and how to help my body rehabilitate."

6. MSK Treatment

"I had a lot of trust in the first physiotherapist I went to as I had been treated by her and her colleagues over many years for minor ailments. She read out to me the referral letter sent to her by the spinal specialist, which stated the problem, and that no manipulation would be necessary, only exercises.

"She said she disagreed with this and proceeded to manipulate my back two or three times in the half hour visits, asking me to get off the table and bend forwards and backwards to assess the progress.

"She carried on treating me like this for another 4 sessions, which always seemed to inflame my lower back, resulting in my inability to comfortably do the basic stretching she suggested I do.

"I realised this wasn't working for me and didn't go back. I won't bother to elaborate on most of the other therapists - five other physiotherapists, two osteopaths, a chiropractor, a second rheumatologist for another opinion, a psychotherapist as I started feeling very anxious and depressed, and two private GP's, who both recommended the new drug, Arcoxia, for my arthritis!

"To be fair to all these therapists, they were trying to treat the condition that I had been diagnosed with, and that I had told them was the problem."

7. Impact of this Experience

"Since 2020 when I first presented my leg symptom to the first GP, my medical journey has left me confused, frustrated and fairly lacking in hope for any solution, I must confess. What had started as a single symptom in my left leg, had radiated around my lower body and appeared to be getting more and more complex.

"I have been a psychotherapist for more than 30 years, specialising in stress reduction, and have the tools available to help with anxiety and stress, but I was overwhelmed a lot of the time. I felt I was becoming a different person emotionally and even a semi-invalid on the days I preferred to stay at home in my discomfort."

8. Integrated Rehabilitation Centre

"However, I was recently recommended to a highly experienced physiotherapist who is the director of a rehabilitation clinic in a university, and again in desperation, I decided to have yet another consultation. I was astonished that within the first few minutes of listening to my story, he was looking at me in amazement after hearing the diagnoses that I had received.

"He simply stated that I had not got facet joint syndrome, I may have got a narrowing of my L5/S1 vertebrae, and also some arthritis as is inevitable for anyone over 50 years of age.

"However, this is NOT what was causing me such discomfort at times. He said what I have got is tendinitis, which creates the muscle problems I have been experiencing, particularly in the last few months with all the stretching exercises I had been told to do.

"I did not need major stretching exercises to strengthen my core which could exacerbate the problem; I should simply resume what I was doing before the diagnoses, such as walking, playing golf regularly, and even swimming using the breast stroke, building up slowly of course!

"In fact, anything else that I wanted to do, as I could not damage myself in any way, as the problems that I had been diagnosed with were not causing the discomfort I had originally felt in my upper thigh. I looked at him in astonishment and am now trying to assimilate the statements he has made which could transform my way of thinking and my general anxiety.

"In summary he said that he always teaches his students to work with the symptoms, not the pictures, since it is only the symptoms that can help diagnose the problems. On a wider level, he has had so many patients over the many years he has practised, who have not been diagnosed according to their symptoms, but according to X-rays and other scans.

"This seems to represent a frightening and disturbing pattern of patients having unnecessary procedures and operations. There is an important financial aspect to this as well, which has cost our private insurance company for most of these outpatient consultations and visits to therapists, some of whom we have paid personally.

"But we have experience a major increase in our premiums year after year, the cost of which would deter many people from private health care. This in turn puts more pressure on the NHS which is witnessing a record level of waiting lists for consultations and treatments of any kind.

"How can a story like this be avoided? I feel the onus should lie with our first port of call - in most situations, the general practitioner. Are they too quick to send people off for consultations with specialists when the symptoms do not appear to need urgent treatment, without first recourse to non-invasive treatment such as physiotherapy, massage, acupuncture to see if the body responds to this? As we can see, an X-ray may only tell one part of the story."

9. Reflection by our Clinical Team

The patient story informs, directs and reasons the diagnosis and care plan. Its so easy to fall into assumptions about a diagnosis and trying to make it "fit". Being critical of reasoning is key.

"What are you now not doing that you used to?" and "Why did you stop?" these were key as the patient was told they had a problem, and was informed to alter her lifestyle and yet had been successful in managing this before seeing the clinicians.

Clinicians were referred to for rehab for a specific reason, yet never asked or questioned the diagnosis due likely to a hierarchical belief that the proposed diagnosis must be correct and that it was permanent. Things may be incorrect, and of course can change.