

PRACTICE

A PATIENT'S JOURNEY

Spinal injury

This patient describes his seemingly interminable wait for surgery for prolapsed intervertebral discs coupled with a complete absence of useful information and worries about income support

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The BMJ welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

My experience of back pain began ironically at a moment of great joy for me and my wife in June 2003—just before the birth of our second child. A few days before my wife went into labour, I sneezed, and so began a sequence of events that still affect me today. I never had a weak back before this, but I sneezed, fell to the floor, and it took three months for me to get straight again. The pain was horrendous. I saw my general practitioner immediately and was referred to a surgeon at the local NHS hospital. I waited about 12 months for this appointment. I have a little dog, and if I'd have left her in pain for so long I'd have been prosecuted for cruelty by the RSPCA. I had some physiotherapy treatment and had to take amitriptyline, co-codamol, and diclofenac, and that is unpleasant. When my back went into spasm I had to have diazepam as well. Sometimes I used an ice pack belted on to numb my back totally, to enable me to do things I had to do.

My GP kept signing sick notes for time off work, and I visited a chiropractor. As far as I know, my GP did not press the hospital, perhaps because he thought it would make no difference. Finally he gave me the telephone number of a back surgeon who works both privately and within the NHS, whom I saw privately. At his suggestion, because of NHS waiting lists of between nine and 12 months, I paid £650 to have scans done privately. The surgeon said I had a prolapsed disc at L45 and that I had been born with narrow nerve channels which were making things worse. He referred me back to his NHS clinic and said that I needed a bilateral decompression and a discectomy to release the pressure and open the nerve channels. He then had an injury, and I was transferred to another NHS surgeon.

I was put on a waiting list, but was not seen at the hospital between my private consultation and the operation. I met the anaesthetist, who asked if I had any questions. I asked if I could meet the surgeon who would be operating on me, but did so for the first time only on the day of the actual operation.

A wait too long

I'd never not worked in my life before this happened. I didn't know anything about signing on or incapacity benefit. I didn't know what to do. Each month, because I was on an urgent waiting list I thought I was going to have my operation, but then I didn't, so I started feeling depressed. When you put the television on, the politicians say, "Everybody is operated on in three months." People kept asking me, "Haven't you had your operation yet?" and I felt silly. Several times I was telephoned the evening before my operation, when I had prepared myself to go in, to be told it had been cancelled.

You're left so long by the hospital system; there's never anybody to speak to, and I never met anybody who'd had a success from the operation. It felt as though there was no support or information on success rates. When you go to see your surgeon you're in with him for five or 10 minutes. He explains about the operation, but you go home and mull it over, and it would be easier if there were people to speak to and perhaps to reassure you that what you're having done isn't such a big thing because they do it all the time and it works for people. They never gave me any statistics on success rates, and it was very frustrating having to wait. The surgeon's secretary worked only part time so it was difficult to get information.

When I had been waiting for over 12 months, my GP advised me to contact the Patient Advice and Liaison Service (PALS), who were excellent. I don't know what I would have done without them—I think I would still be waiting now for my first operation. Then I got a letter from the hospital asking what I wanted as an outcome of my complaint. I replied, explaining

that I just wanted my operation. I said, "All I'm asking for is my surgery." Straight away I got a letter asking me to come in for my pre-op assessment and saying that my operation would happen in the next week. The operation was carried out in a private hospital but funded by the NHS because their waiting list target had not been met. It was as though I got a fast response because I'd put in this complaint about not being seen within the waiting list target. After the operation, they gave me exercises to get mobile again and they saw me every three months.

After the first operation, I sneezed again and damaged two more discs. I had another scan and was told I needed a spinal fusion, and after that failed, a 360° spinal fusion, with lots of different procedures in between.

After the second operation, I had metal work and loose screws moving, pressing on nerves to my legs. I had difficulty walking and functioning. Loose screws such as these can cause permanent damage. I had difficulty putting my feet down, so I worried about permanent damage. I was told that, while the fault was aggravating my nerves, it was very rare for it to cause permanent damage but they could not rule it out. Because of the long wait, my GP wanted to send me out of the area, but we were told, "There's only Mr A at the local hospital because all spinal surgeons work differently." I wanted him anyway because he is said to be the best spinal surgeon, and he is very nice.

Impact on me and my family's income

After my first operation, I was sent for an incapacity benefit medical examination. I'd had my operation, but things were starting to go wrong. I told the assessor that I had had an operation five weeks previously, and I was doing my physiotherapy but something was going wrong. He asked to see my scar, and I showed him. He said, "I can see you've had an operation; this won't take a moment." So I imagined everything was fine.

Five days later I received a letter telling me my benefit was stopped because there was nothing wrong with me. It said: "This patient has not got a problem bending, twisting or lifting."

I had to go to a tribunal. My benefit was stopped for 11 weeks. When I got to the tribunal they couldn't believe I was there. There was a spinal specialist, a judicial officer in charge of the process, and an official from the Department of Work and Pensions. The spinal specialist asked what was wrong with my

back, and I told him I had just had a bilateral decompression and that I was waiting to have a three level fusion. When he heard this he looked down and whispered to the other man then told me to relax—case dismissed. The whole process took a matter of minutes.

After the second operation, JobCentre Plus contacted me to go for a "back to work" interview. I telephoned them and explained that I couldn't go as I was in plaster waiting to have a titanium rod inserted in my spine. I also explained that I was in plaster to my knees. They said they could stop my benefit and asked if I would be better next week. I said, "You get me my operation, and I'll be straight back at work." I was going mad. So she spoke to a manager and said they would contact me again in six months. This is what worries you when you're getting better. I received incapacity benefit of about £96 a week. I have to pay for all my prescriptions, and they're more than £20 a month. I only found out recently that you can pay so much a month. I have had to wait over a year for each of my three operations, and PALS helped me each time. To get my final operation, I had to make an official complaint against the hospital.

What next?

I must now let the bone grafts take. I am now on work related ESA (employment support allowance) and am involved in Patient and Public Involvement in research at Keele University to see if I can help others by getting involved in research. Nobody should have to wait so long for an operation when they are in so much pain. Nor should it be necessary to have to use PALS just to get follow-up appointments. I also think there should be more information and support available.

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- 1 Cohen SP, Argoff CE, Carragee EJ. Management of low back pain. *BMJ* 2008;337:a2718.
- 2 Gibson JN, Waddell G. Surgery for degenerative lumbar spondylosis: updated Cochrane review. *Spine* 2005;30:2312-20.

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A doctor's perspective

I first met Martin Davies in May 2012 after his transfer from another surgery. His reason for attending was that he had started experiencing pain in his arms and problems with his neck. He was extremely apologetic for wasting my time as he had no expectation of help, but wished to know if there was something that could be done for his symptoms, and if there was any help available in support of his disability benefit claim. His gait was abnormal, with his neck projected forward.

His medical history showed that he had had three back operations that had not been entirely successful. Miraculously, he was not depressed merely frustrated. His own determination to keep walking and keep going had not served him well with the staff of the job centre, who seemed to have downplayed the seriousness of his medical condition. The only useful role I could undertake was to refer him yet again to the spinal surgeon and support his claim for disability benefit and attempt to coordinate his care. (His cervical pain is now under investigation, magnetic resonance imaging has shown minor disc bulges at C5, C6, and C7. He has had computed tomography guided root block with no success.)

I see several cases of lower back pain a week. Guidelines from the National Institute for Health and Care Excellence (NICE) advise conservative management for the first six weeks unless patients present with red flag features. After assessment patients are issued with a back care leaflet, offered analgesia, and advised to return if the problem is not resolved within six weeks. Most cases resolve on their own, leaving a small group of patients who may develop persistent back pain and may need to be referred for specialist advice. The possibility of having an operation that can solve all their difficulties is often raised by patients. A prediction of the results of such operations are at best inconclusive. (In their review of the management of back pain, Cohen et al report that only 15-40% of such patients can expect a highly functional outcome,¹ while Gibson and Waddell report the difficulty of managing the patients' expectations.²)

There is clearly an important shared role for the GP and the surgeon in this area. Unfortunately, doctors are often poorly prepared for this role, leaving the important question of success rate to the premise of "Trust me, I'm a doctor." In general, the medical profession is not adept at enabling patients to make an informed choice about risk assessment and probability of outcome. Risk and probability should be presented in a manner that a patient can understand. Patients cannot always make a properly informed choice, as the emphasis is on informed consent.

The Integrated Care and Treatment Services (ICATS) for back pain are invaluable in reassuring patients and managing the investigation-cum diagnostic phase. However, the problem still remains of how to manage them long term when all that can be offered is tablets, exercise, and the occasional reassurance session with their usual doctor, which is generally unsatisfactory for both parties.

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See me in my plaster cast www.youtube.com/watch?v=QxTstAAISCg

With my sister filming, we made a short video which we put on YouTube showing what it's like to be in a plaster cast. I had no pain when I was in it. It was to see if the operation was going to be a success because it replicates what they do with the metalwork in your spine.

Useful resources

SIA: Spinal Injuries Association (www.spinal.co.uk)

The leading UK charity for people with spinal cord injury. It is a user-led organisation; its elected trustees are all spinal cord injured and are voted for by the spinal cord injured membership. It aims to offer support and assistance from the time of injury and for the rest of a paralysed person's life; provide services to increase an individual's quality of life; support the families of newly injured people; increase knowledge and awareness of the causes and consequences of spinal cord injury; and campaign for the best medical and social care for spinal cord injured people.

Disability rights organisations and Citizens Advice (www.citizensadvice.org.uk)

These can help with advice about welfare rights and this may include help with tribunals.

NHS complaints system

This is currently under review (see <https://www.gov.uk/government/news/review-of-nhs-complaints-system--5>)