

How easy is it to take responsibility for your own health and to work in partnership with your health professionals when facing joint replacement surgery?

I am extremely fortunate to have experienced a productive partnership with my GP, rheumatologist and rheumatology specialist nurse over the past 3 years. However, my recent movement through NHS systems concerned with orthopaedic surgery has not been quite so satisfactory.

Consultation with an orthopaedic surgeon (within 12 weeks from consultant rheumatologist's referral letter)

After over 5 years of out-patient investigations (rheumatology/neurology) because of pain in my right knee which was affecting my mobility, I was told that I needed total knee replacement surgery and that I would be referred to my regional NHS Elective Orthopaedic Centre (a centre of excellence, as it only deals with hip and knee replacement surgery).

At the orthopaedic consultation I tried to ask questions and to discuss the impact of orthopaedic surgery on my form of inflammatory arthritis. My diagnosis is undifferentiated spondyloarthropathy and, in my case, it shares some of each of the characteristics of AS, rheumatoid arthritis and psoriatic arthritis. The consultant did not want to see my list of daily medication (including anti TNF) or my very brief medical history. He said he was *"only interested in my knee"* and that all my questions would be answered when I attended the pre-assessment appointment at the Orthopaedic Centre.

The NHS produce an information leaflet called "Questions to ask"

which details the best way for a patient to prepare for medical appointments and how patients should feel they are a partner in decisions about their treatment and care. It suggests patients take a list of medication/information to appointments: I have been doing this for many years, long before this leaflet was printed. This practice is usually necessary, as full medical notes never seem to be available at a consultation following a new referral. Some health professionals are very happy to read my prepared patient information because it saves time, but others are not.

Unfortunately, patients have to be quite tenacious to be involved in this so called partnership and this is not that easy when you are struggling daily with chronic pain.

Pre-assessment clinic appointment at the Elective Orthopaedic Centre

Prior to the appointment, I was sent a very impressive patient information pack, containing a lot of helpful information. The production costs involved in this information pack must have been extremely high. During the time that my operation date was cancelled or rescheduled 5 times, I was sent a second information pack and 2 further information CDs. This appeared to be a complete waste of NHS resources.

My pre-assessment appointment with an advanced practitioner was not very satisfactory. One of my queries was about anaesthesia. The options were spinal anaesthetic (lumbar

puncture or spinal tap), epidural anaesthetic or general. A recent MRI scan had confirmed continuing problems in my spine, which were relevant to anaesthetic choices. I was told that the anaesthetist would decide on the day of my surgery and I would get a chance to ask my questions then.

Various tests were carried out to establish that I was fit for surgery. During that time I had to get on and off an examination couch and change position, supervised by the senior nurse. Occasionally, she attempted to pull me around to whatever position she wanted me to be in rather than allowing me to move slowly, in my own way. She did eventually understand, after I had politely reminded her of my inflammatory arthritis and what it meant to my mobility.

I tried to discuss queries about my medication; in particular when to stop anti TNF injections before surgery and when to start them again after surgery.

I was told, *"You will be able to discuss all this with the anaesthetist/surgeon on the day of your operation."*

A month after that appointment I was called back to the centre (which is some distance away) for further blood tests. As my surgery date had been cancelled or rescheduled 5 times, the original blood tests were apparently no longer valid. I continued to ask questions about when I needed to stop the anti TNF and my other medication but all this chopping and changing of surgery dates caused real problems with the anti TNF because

you are supposed to stop 2 weeks before surgery. The changes also caused problems because I live alone and had to make arrangements for my aftercare and these involved other people.

The day before surgery

A member of the pre-theatre team telephoned and was extremely helpful and encouraging. He answered all my queries and I felt very reassured by his calm, supportive telephone manner.

The day of surgery

After 2 hours waiting in reception, my daughter and I were asked to make our way up to the pre-surgery area. Suddenly, every procedure was being rushed through. They were all very caring and professional people but it was obvious that I was going to be moved into the operating theatre at break neck speed, which would leave almost no time to talk to the anaesthetist or surgeon. I became even more anxious when my anaesthetist announced that I would be having a spinal anaesthetic. I tried to explain why a general anaesthetic was preferable and fortunately my daughter took over and I was finally offered what I wanted. There was no discussion about how my pain would be managed after the operation as stated in the information pack.

There was no time for me to speak to my surgeon about my other concerns. I was well aware that replacement joint surgery is quite brutal (out of necessity) but as I have limited movement, particularly in the hips, pelvic girdle and lower back through inflammatory arthritis, I was extremely concerned about how my body would react to the surgery. Throughout this hospital experience the orthopaedic teams appeared to be very focused on the operation and seemed to have little interest in or knowledge of inflammatory arthritis and how it might affect a patient before, during and after orthopaedic surgery.

Post Anaesthetic Care Unit (PACU)

The surgery was very successful and I spent a short time in PACU.

Care on the recovery ward

I was optimistic that I would be able to return home after 3 days. The hospital stay is normally 3 to 5 days. But my recovery did not quite go to plan and I had to remain on the ward for 7 days. The ward management was excellent, particularly the cleanliness.

I saw my consultant briefly each morning, which was very reassuring, and began working with physiotherapists on the third day. Once intravenous medication stopped, I became much more aware that my body was very stiff as I had by now been immobile for 3 days. I was also experiencing severe pain in my lower back, sacroiliac joints, hips and neck in addition to the expected pain in my new knee. This meant that throughout my stay on the ward, I felt very sleep-deprived and I had to constantly justify why I continued to need painkillers and liquid morphine because as time went on I was told, *"you should be experiencing less pain now"* (i.e. in my right knee only!) The nights were extremely difficult to manage. The patient information pack refers to *"Patient Controlled Analgesia"* but this kind of pain management was neither discussed nor available. I really did not feel that any of the ward nursing staff (all levels) had an understanding of inflammatory arthritis.

The only health professionals who appeared to treat me holistically and with understanding, were the physiotherapists. They alone seemed to be aware that my new knee joint cannot be viewed in isolation and also acknowledged that I had worked very hard *"to become an active member of the centre's team, before, during and after my surgery"* as far as preparation for surgery, exercise and weight-loss was concerned. Consequently, our

"partnership" worked very well indeed and I returned home feeling quite confident in what I needed to do to obtain the best outcome from this surgery. This was despite the fact that I also had to deal with the acute flare up of inflammatory arthritis.

Discharge from the centre

I was very grateful that I left the hospital ward with all the advice, medication and practical equipment from the nursing staff, physiotherapists and OT team, that I needed for safe recovery at home. The flexion and extension movements of my new knee were already good, which was encouraging.

However, I was interested to note that amongst my discharge documentation there was no mention of inflammatory arthritis in the section which records past medical history. I could not understand why inflammation problems in joints other than the operation site would not be taken into consideration during a hospital stay.

Post-operative physiotherapy and aftercare

As I lived some distance from the Elective Orthopaedic Centre, my aftercare was going to be the responsibility of the local health professionals. Before my surgery, I was told that it would be difficult to obtain local physiotherapy support.

At home the flare up pain was increasing: as I became more mobile I was offered a home visit from a community physiotherapist. She came 10 days later and was very helpful in removing a few of the exercises from the plan, because they were increasing the pain in the flare up areas, and adding in a few new exercises, specifically for the hip and lower spine area, to try to decrease the pain.

During that week, I also had a follow-up phone call from the Orthopaedic Centre. The caller

was puzzled to learn that I was still taking liquid morphine (despite my explanation) on top of my normal medication because her check-list and script was only relevant to the orthopaedic surgery on, and recovery of, my right knee. Existing, non-orthopaedic conditions, which can become exacerbated by surgery, do not appear to be considered when recording the surgery outcome. Of course, the good news was that the scar was healing successfully and the new knee was moving really well. Understandably, this was really the only information required on the form, but of course, it is not a true reflection of my recovery.

A week later I had a second visit from the community physiotherapist and was signed-off because the new knee issues were satisfactory. This physiotherapy support was for my knee alone and could not be transferred to the flare up problem. A new referral was required! I continued with all the exercises to try to ease the pain in the flare up areas for another month. However, although this resulted in improved pain levels, the flare up had still not settled down as much as I had hoped (particularly as I had restarted my anti TNF injections).

Seven weeks after surgery, I saw my GP to ask for help with the management of the situation. She adjusted my medication to help with the sleep deprivation and organised immediate physiotherapy support which miraculously became available a few days later. After 5 sessions with an excellent physiotherapist the flare up began to become less intense and I now have a 12 week recall in place in case progress moves in the wrong direction. I also joined a hydrotherapy class for weekly, half-hour exercise sessions. I have found this type of physiotherapy support particularly helpful in my recovery, but as you have to pay for this, it is something that not everyone will be able to access.

Outpatient follow-up appointment

The review appointment was excellent. There was enough time to discuss all my questions about not only my right knee, but the flare up as well. The consultant was very happy to use my patient information sheet (which summarised revised medication and exercise plans and so on). He said again that recovery would progress gradually over a period of one year and agreed that inflammatory arthritis is likely to be stirred up following joint replacement surgery. This was the first time that this area of my medical history had been discussed properly. I also discovered that the new metal knee joints are not designed to allow the patient to kneel. I can understand that health professionals might not want to indicate what impact replacement joint surgery would have on other medical conditions or to give out more negative medical information. However, I believe that for most people replacement surgery is a last resort. There is a lot of material available if the patient wants to read about how brutal orthopaedic surgery has to be (out of necessity) but I, personally, would have appreciated more information about projected recovery times and mobility problems after surgery. Surely, nobody agrees to replacement surgery unless it is really necessary so as much information as possible should be available to make a considered decision.

Conclusion

My mother (who had rheumatoid arthritis) had numerous joint replacement surgeries over the past 30 years and I was involved in her aftercare. I find it quite depressing that many of the problems she experienced are still an issue now, bearing in mind she was originally being operated on in the pioneering days of replacement surgery. I had hoped that by the time I needed replacement surgery, a best practice regime would have evolved – that is a more effective multi-disciplinary approach.

But we can still try to take responsibility for our own health by being involved in our progress through the NHS systems.

We need to make sure that we, as patients, try to fulfil our side of the partnership by:

- turning up for all appointments and arriving on time to cut out wasted appointments;
- keeping relevant medical information with us at all times as full case notes are not always available at consultations;
- persevering with trying to ask questions during consultations and to change attitudes towards patient involvement in the process;
- acting on advice and instructions from health professionals as it is there to help us;
- exercising before and after surgery and accepting that exercise is an important part of the life-long management of these kinds of inflammatory arthritis.

NASS Member

This is a shortened version of a very full account of knee surgery. If you would like the full text please contact the NASS office (nass@nass.co.uk) or phone. I think it is a balanced account of one person's experience and highlights what went well and what could be improved on. One comment worth making is that the operation had a good outcome in that the knee function is good and improving. This is down not only to the skill of the medical team but the patient's own commitment to pre and post surgery exercise and weight loss. In previous years waiting times have been measured in years but they have improved and in this case the time from the first orthopaedic consultation to the operation was just over 2 months.

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