Linda - Metallosis NHS

Linda’s story (for updates see below)

21st June 2011

I was almost 55 at the time of I had my right hip resurfaced in 2005 and had it done locally in Plymouth, Devon. Because I had private medical insurance through my employment, I was referred to a surgeon at the local private hospital who suggested that resurfacing would probably be a better option than THR for me as I was still relatively young. Although he made it clear that the procedure was relatively untried at that point in time, he also said he’d done over 24 of the procedures and was very pleased with the results. I’ve never been the sort of person to question or doubt an expert; if he said it would be a good idea, then I was happy with that; I just wanted rid of the arthritic pain and get back to a normal existence. It was not until I found the hipsrus and surfacehippy Yahoo groups while convalescing postoperatively that I discovered this was a very technically demanding procedure and it was advisable to have it done by a surgeon who had performed many more than the 25 or so mine had experience of.

But I remained optimistic that I’d be OK. I had a few issues with the hip feeling as if it was moving out of place and then back again sometimes in the first few weeks of recovery, but then things improved and from 2006 to 2008 the hip felt pretty good - I could walk normally and could lead with that leg going upstairs with no problem. There was the occasional squeak but that was all and a lot of the time I almost forgot I had a ‘false’ hip at all.

In the summer of 2008 it suddenly started squeaking much more and then, in the autumn, I got pain in the groin such that I found it painful to lift the leg when standing (for instance to lift the leg a few inches to step into a shoe). Having discovered how important surgeon experience was, and still able to see someone of my choosing because I had private insurance, I decided to see a top consultant rather than return to a local one. I was also just becoming aware of the metallosis issues that were emerging.

The consultant concerned said my cup angle was not ideal given the state of knowledge in 2008 but that it could have been an X-ray of a hip he himself had done in 2005 - the implication being that my surgeon had not done anything wrong, but rather that knowledge had improved between 2005 and 2008. From what I’ve read more recently, the opinions on ideal angles may have been revised yet again since 2008. The following investigations/procedures were done - ultrasound, aspiration of fluid from the joint and a right psoas tendon steroid injection. The doctor who performed the ultrasound said there was more fluid around the joint than there should be at 3 years, and there was some echogenic material in there (I never managed to get an explanation of what that meant) but I was also told that nothing unexpected had been found. I cannot now remember the colour of the aspirated fluid but I do remember asking about it as it looked alarming to me (not that I knew what it should look like!) and was told that, if metal was present, the fluid would look like it contained coffee grounds, which mine didn’t. The pain gradually subsided over a period of a few weeks.

However, the hip has never felt the same again since that episode as it did in the 'good' period between 2006 and 2008. I’ve experienced more frequent squeaking, as well as a grinding sensation quite regularly. If I
lie on my back and let my right foot flop outwards, there is a definite clicking sensation in the hip if I then move the foot to be pointing to the ceiling again (though that movement is not painful as such). The hip has very definitely felt weak since then - I'm unable to lead with my right leg going upstairs unless holding onto a rail and I've been constantly aware of the presence of something 'alien' in my hip, even when it's not exactly painful, in a way which just wasn't the case during that 2006-2008 period.

I had another distinctly painful episode in the summer of 2010 – again in the groin area and around the outside of the hip, also on the outside of the knee. I was limping again and the hip was very sore and uncomfortable in bed, such that I had to sleep on my back. This episode lasted about a month. Things gradually improved again over the course of a few weeks and I was back to being relatively pain-free, though there was that distinct squeaking quite frequently, and also the definite grinding sensation when walking upstairs and during certain other movements. I would also regularly experience a strange pain down the front of my thigh; more like something coming from a nerve rather than purely physical. It would sometimes make me gasp and I would have to stop walking or standing and take the weight off it for a few minutes. But ROM was fine and I could do a walk of 2 or 3 miles on the flat without too much trouble.

In the autumn of 2010 I received a letter which was being sent out re the problems being found with some MOM resurfacings. I decided to see my GP and ask for everything to be checked out even though I was going through a relatively good period. He was a bit reluctant to refer me, saying that any problems were seen in the first five years so there probably wasn't anything wrong. But he did do a referral and I saw a different consultant from the one who did my operation, but at the same private hospital (this time on the NHS as I no longer had private medical insurance). He was also reassuring, but decided to do a blood test, CT scan and MRI scan. He told me that the metal ions in the blood were elevated but that was to be expected, that the MRI scan didn't show anything and that the CT scan might indicate some loosening of the cup so he wanted to see me again in six months; time to keep an eye on it. That follow-up visit took place on June 6th 2011 and a couple of X-rays were done before the consultation to check for any evidence of cup loosening.

Meanwhile I continued to have the squeaking pretty regularly, the grinding (particularly when going upstairs) and the strange pain down the front of the thigh from time to time, but I was functioning reasonably well most of the time even though the hip continued to feel not quite right.

A couple of weeks before the appointment on June 6th I started again with significant pain and tenderness in the whole hip area and I've been unable to lie on my side in bed. If I try to turn over in bed it feels like something is grinding and moving in the hip and I'm only free of pain when I lie on my back. I've been noticeably limping again.

At the June 6th appointment my consultant told me the X-rays did show quite a steep cup angle but he had other patients with an equally steep
angle who were happy. He also said there was no evidence of cup loosening. I discussed with him my concerns but, while he couldn't give me any particular reason for my symptoms, he didn't seem to think that I needed to be concerned about metallosis and that I needed to think about whether my symptoms were bad enough to warrant a revision or whether I was better off living with them. He told me a resurfacing revision was difficult and, when I asked, said he had done five. I didn't ask, but it may be that none of those were for metallosis, and therefore it's quite possible he had no experience at all of revising a hip with damaged surrounding tissues.

I discussed the possibility of seeking opinions from other surgeons, which he was quite happy with, and he arranged for me to have a CD-ROM of the X-rays, CT and MRI scans to take along to any further consultations I arranged.

From my internet research I was aware of Vicky and her website so, that afternoon, I decided to write to her telling my story as I've done here, and ask if she thought my symptoms could be caused by something less potentially damaging than metallosis. She immediately wrote back with an offer to consult with some top surgeons but needed my X-rays and blood results. Because I'd never seen the actual blood results I had to get those sent to me. I sent Vicky the X-rays and a copy of the blood results when they arrived and waited for the response. By Sunday June 12th Vicky had forwarded responses from six surgeons, all of whom said the metal ions in the blood were sky high, the cup angle was too steep, my symptoms indicated metallosis and I needed a revision as soon as possible to prevent further damage.

As I've read that resurfacing revisions for metallosis can be tricky, given the damage to soft tissue and bone which can be found when they operate, I am keen to have this operation done soon, but by someone who has done more than five resurfacing revisions, and by someone who has experience with dealing specifically with the metallosis damage.

I am currently battling to have this done on the NHS at a hospital where I feel they have the necessary expertise, but a rather unsympathetic and unknowledgeable GP (you have to have a GP referral whether getting NHS or private treatment) is making the task difficult. I have appealed directly to the local health trust that I should be referred somewhere with specific expertise of this issue, and I'm waiting to hear what they have to say. If I haven't made headway soon with the NHS we will have to pay for private revision; my husband and I don't want to risk further problems due to surgeon inexperience.

I'll update as the story progresses. To be continued...

One of the consultants Vicky spoke to calculated out Linda's numbers to parts per billion or PPB which is what the surgeons all go by. Most say that anything above 10 is considered high. Linda's numbers currently are as of September 21, 2010

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27th June 2011 update

Last Thursday I received a confirmation from the Patient Advice and Liaison Service lady dealing with my case that I had a right to an NHS referral for a second opinion to a hospital department of my choice which appeared on the 'choose and book' system. After that, if the diagnosis was that a revision was necessary, I would have the right to have that revision done at the same place.

After considering all the pros and cons I decided I'd like to be dealt with by the team in Stockton-on-Tees, on the basis that they now have the most experience in dealing with patients with this particular issue of metallosis.

I've seen a different GP this morning who was actually interested and concerned, and will be doing a referral today to Tony Nargol at Stockton Nuffield.

Kind regards.

Linda

25th August 2011 update:

I had my consultation with Tony Nargol on Tuesday 23rd. We were very impressed by him and the whole team at the Tees Nuffield hospital. We were not booked to see the physiotherapist but nevertheless got to spend a fair bit of time with him. He was very enthusiastic about Mr Nargol's expertise and it was apparent that they work as a really close-knit team, which also inspired confidence.

I had an X-ray and an ultrasound scan. Mr Nargol said he could see some evidence of bone damage on the X-ray, and the ultrasound showed a large accumulation of fluid containing 'floaters' (bits of tissue which have broken loose) around the joint. He said that, in their experience so far, those who have high metal ions without extreme pain or other symptoms
are the ones in which they tend to find the most damage, but he was also positive about getting me back in good shape eventually - recovery might just take a little longer this time than after the BHR. I was also warned that, if they think there's a high risk of dislocation, I need to be prepared for the necessity of wearing a brace for a while.

He will put in a ceramic/poly THR - he told me the advantage of the poly over ceramic for the cup is that there's less likelihood of dislocation and I suppose as I told him I'm not athletic or sporty, then wear issues are less of a concern. When the poly cup liner wears out (should get at least 10 years from it) it can be replaced without changing any of the other components.

Surgery is scheduled for October 14th.

Best wishes.

Linda Wright

30th October 2011 update

I had my surgery on October 14th 2011 at Nuffield Tees Hospital. The revision was performed by Mr Tony Nargol.

Mr Nargol found a lot of bone damage - a hole in the pelvis almost fist-sized he said, but thankfully no muscle damage. He also found metal debris down the inside of the femur - the first time he'd seen this in all the revisions he's done. Extensive bone grafting was needed. He installed a Zimmer ceramic on poly THR. I signed a release form for the extracted BHR to be given to David Langton's research project on failed MOM devices. Because of the bone grafting I was to be 30-50% weight-bearing on the operated leg for 8 weeks.

For me, the immediate after-effects of the surgery were minor; I felt fine, had a light supper and didn't need the morphine pump provided. The nursing staff were rather less pleased with my state as my blood pressure was extremely low and resisting all attempts to raise it! They finished up phoning Mr Nargol at 4am and were told to give me 2 units of blood, which I had between about 5am and 9am.

After lunch on Saturday 15th the physiotherapist arrived to get me out of bed on a walking frame, but when I was vertical with my legs out the side of the bed I came over dizzy and light-headed and knew I couldn't manage. She hastily got me back into bed but I came out in a cold sweat and promptly brought up my lunch! Further attempts in the afternoon to get me out of bed and walking with the help of the frame worked fine. I needed assistance to lift the operated leg in and out of bed, but I could walk quite well once up on the frame.

On Sunday 16th, the physiotherapist got me off the walking frame and onto crutches. The first few steps felt scary and unstable after the security of the frame, but I was soon up and going at a reasonable pace; the biggest problem was trying to gauge whether I was getting the 30-50% weight-bearing right, and fears that I might be putting too much weight on the operated leg. I was taken up and down some practise stairs.
By Monday 17th I was feeling much more confident on the crutches and had a few more short walks down the hospital corridor and up and down the practise stairs. An X-ray of the joint was taken.

On Tuesday 18th I was discharged at about 11am. We drove from Stockton to Bromsgrove (about 3.5 hours) with 3 stops for me to stretch. We had a disabled room in a hotel in Bromsgrove for the night and then continued to home on Wednesday 19th (another 3 hours), again with frequent stops.

Mr Nargol made 3 visits to check on my progress in the days between surgery and discharge, and spent a long time answering my questions on one visit. All the staff at the hospital were attentive, pleasant and friendly without exception and, as far as it's possible to say such a thing about major surgery, the whole experience was very positive.

Three times a day I have been doing the standing and bed exercises I was given and each day have felt stronger and more mobile. On Friday 14th (exactly 2 weeks post-op) I had a physio appointment and was told I'm doing really well for someone at the 2 week point, and just to continue with the same exercises, increasing the number of times per day and/or the number of repetitions. The hip is feeling great considering I'm only 16 days post-op now. We removed the dressing this morning and the incision is well-healed. I'm actually feeling frustrated that I can't put weight on the leg as it really feels good and as if it could take it, but I obviously don't want to jeopardise the healing process.

The only real pain I'm having at the moment is in my shoulders, from all the weight I'm putting through them on the crutches, and my heels - lying on my back in bed leads to really sore heels.

I have my next physio appointment on 16th November and my follow-up with Mr Nargol on 25th November - exactly 6 weeks post-op.

Linda