

My Story

By Claire Huson

Smashing Chondrosarcoma

When I was first told that I had a Chondrosarcoma, the first thing I wanted to do was to find out as much information as I possibly could (hello Google!). Once the science geek in me had read all there was on the technical side of things (the Sarcoma UK website is fantastic for that), I wanted to find out how other people had coped, what they had experienced, essentially I wanted to know what was around the corner for me and to feel like I wasn't the only one that was going through this - that others had gone before and were OK! I know that sounds a bit melodramatic, but hey, I had just been told I had cancer!!

What I quickly found out that there were no personal stories out there, so this is mine, and I hope it helps anyone out there who finds it.

So, who am I? I'm Claire, in my 40's and before all 'this' happened towards the end of 2015 I was fairly active - well, I jogged 4/5 times a week and went to the gym. Don't get me wrong, I was no health nut, I also liked to eat (a lot) and loved the odd glass of wine (I am human after all).

In hindsight, I'd had a few twinges of discomfort in my left knee for a few weeks, but I'd put it down to me being very flat footed, so much so, that I went on a Friday at the beginning of August to have my running gait analysed then I bought a fancy (which means expensive!) new pair of trainers. So, armed with these new wonder machines, I woke up early on a Sunday morning, warmed up properly (I think this was the first time I had ever done that) and went for a run - I had a new route to try, I was going to work on my pace, actually feeling excited about running, then 100 yards in I had such agonising pain in my left leg and knee that I had to stop and hobble home feeling very sorry for myself.

I didn't think too much of it to be honest the rest of that day, got myself through the Monday even though driving was really painful but the Tuesday the pain was even worse - so off I went to the doctors. She had a good look at it, got me to move about and told me essentially it was soft tissue damage and to just rest it, but if it were no better in a couple of weeks, to give her a call and she'd refer me. So that's what I did, and the majority of the pain went away, I was though left with a nagging pain at the back of my thigh that wasn't getting any better. So a phone call to the doctors and she referred me to an orthopaedic consultant at my local hospital. Luckily as I had BUPA cover, this appointment came through quickly, by now though it is the beginning of September.

The consultant agreed with the doctor that it was probably just soft tissue damage and that I should rest it, but as a precaution I should have an MRI scan. When I came to book the scan the only days available were Fridays or Saturdays, so I booked one the following Friday. I get there, lie on the machine and nothing happens, it's broken! So I have to book another appointment. However, September was super busy for me, My sister got married at the end of the month, so there were hen parties to go to, cakes to be made, the wedding itself and of course I needed a holiday to recover from it all! Essentially, I didn't have the MRI until the beginning of October.

I had the scan on the Friday and the following Monday I had a phone call to ask if I could see the consultant the next day. Now at this point, when I tell anyone the story (if they've not fallen to sleep by this point!) I always get asked 'weren't you scared that they wanted to see you so quickly?' and no, I wasn't - I genuinely thought that the consultant had seen how long I'd waited for the scan and thought he'd put me out of my misery as quickly as possible! So, off I go to see him fully expecting him to tell me that I'm being a drama queen and that I should run on grass in future and not pavements!! The next 10-15 minutes are a bit of a blur to be honest, he told me that the scan had shown a tumour at the bottom of my left femur and that as he couldn't help me any further he had referred me to the team at the RJAH hospital in Oswestry, specifically a Mr Cool (I definitely remembered that name!). His secretary came in with directions and a map on how to get there and that they could see me today, so off I went. Most of that journey was spent not thinking about the tumour, but 'Oswestry?!? Why am I going to Oswestry?!?', I'd never heard of the RJAH at that point so it just seemed very random! Looking back now, and talking to other patients, I know I am extremely lucky to have been referred to the RJAH so early on in my process and for that I am extremely grateful.

Once I got to the hospital, I felt like a was a rabbit in headlights, having to go to the tumour unit, then x-rays and then finally seeing Mr Cool and the lovely Jane. They both calmed me down, went through what was happening and what was going to happen next - I left the hospital feeling really OK about all this, yes I may have a tumour, but I was definitely at the right place with the right people to get it fixed! I had a call later that week to say I needed a biopsy the week after and as part of the pre-op I think I had every type of scan there is, which if you're a bit of a geek like me, was amazing - everyone at the hospital is so patient and understanding, even my weird 'how does it work' questions were well humoured!

The biopsy itself was fine - I went into the hospital as a day patient, waited around a bit to go down to theatre, woke up after the general anaesthetic, back to the ward and then went home. There wasn't any pain from the biopsy itself at all; I was just left with a tiny hole at the side of my leg close to my knee, which healed up within a couple of days. I then had a 10 day wait for the results. So, on October 30th I met again with Mr Cool and Jane and they went through my available options and the associated pros and cons of each of these, including showing me that if I went for the option of having the tumour removed, what the implant would look like - which prompted me to ask the most important question I could think of at the time 'Will I set of the airport security scanners?!'. I made up my mind there and then that I was going to have the little blighter of a tumour taken out - to me it was an easy decision, I didn't want anything like that in my body, despite knowing the risks associated with the surgery. I did though go away and talk to my family about it, especially knowing that if I went through with the surgery I'd become reliant on them to look after me for a while.

Once I'd let Jane know my decision, there was a little whirlwind of having to get more x-rays for measurement purposes and to also sit down with Mr Cool again for him to go through in more detail the operation and to make sure I fully understood the risks associated with it. As the tumour was still localised I had the option of when to have the surgery, either ASAP or I could have waited until after Christmas- but I wanted the operation done as quickly as possible, I don't think I'd have enjoyed Christmas knowing I had the surgery coming up - I just wanted it over with.

So, that's how I ended up at the beginning of December being admitted to the RJAH for my surgery. I had the end of my femur and knee removed and replaced with some metal (this is what I tell people as I feel people's eyes glaze over if I say the phrase distal femoral replacement with an EPR!), I normally then follow this with telling them I'm bionic!

The operation itself was straightforward. Mine took about 3.5 hours and I woke up in the high dependency unit. I had a bit of pain in my leg, but they soon increased my medication and it was gone! Something to point out to anyone - you will need to use a bedpan. I think I knew this before and had chosen to not think about it. Yes, it's a horrible process (especially for woman - I can't pass comment what it's like for a man!) but the nurses have seen everything and they are so lovely and respectful; it's not too bad, honest!

The next few days are a bit of a nice, medicated blur! I had the odd twinge in my leg but no real pain at all - mainly because I still had a nerve block in my leg. The nerve block was removed on either day 2 or 3 and that was uncomfortable - but the nurses were on standby if I needed any more drugs!

By day 3 I could swing my leg out of bed and sit on a commode - heaven, no more bedpans!! Honestly, you will come to really love the little wins!

Also on day 3, my physio (the excellent Geraint!) came by to see me and got my leg brace changed to some sort of weird cage contraption! He also gave me some exercises to start doing.

Day 5, Geraint got me to stand up and shuffle a few steps which was really weird using a walking frame. There was no pain at all, but I was very conscious of the feeling of my knee 'locking' i.e. when my leg is straight, there's a very strong feeling of it almost snapping straight - the only way I can describe it is to think of a hinge, it bends great, but when you straighten it the two 'arms' butt against each other and lock it - it's a really weird thing to try to describe to someone. Now that I was up, it meant I could go to the bathroom on my own! It's starting to sound a little bit like I'm obsessed with toilets!! But those little acts of independence and 'normality' felt like such huge achievements to me - so no matter what you're little acts of normality are, rejoice them!

Over the next few days I started walking a bit more, progressing from a walking frame to crutches. Once I was comfortable doing that, I had to learn to scale Everest, well walk up and down a few steps. Again, the amazingly reassuring Geraint showed me how to do it and then made sure I was confident in going up and down them. Once I'd achieved that it meant I could go home! So after 8 days at the hospital, it meant I could go home to my Mums with a list of exercises to do. As far as pain goes, I didn't feel any. I took ibuprofen and paracetamol when the hospital had told me to and that kept the pain away. The hospital gave me a two week supply to take home with me and once that was completed I didn't need to take any more. It's also worth pointing out that for 2 weeks post op, I needed to have a daily injection of Clexane, which the nurses will do for me initially, however, if once I left the hospital I had to do this for myself, but again, the nurses will showed me how to do it. Once you've done the first injection, the rest are easy!

At 2 weeks post op, I went to have the wound examined and re-dressed. It was also at this point that I had my brace changed to something more flexible that would keep my knee cap in place (my knee cap has been a bit troublesome with it not wanting to be where it

should be - over time and with exercise, this has pretty much resolved itself). This was the first time I'd properly seen my leg since the operation, my scar is about 35cm long and at that point looked quite horrible! Although everyone there reassured me it was looking perfectly normal, whatever that may mean. I also spoke to Geraint about my exercises and trying to walk on crutches now that I could bend my leg slightly, and then it was home again - and Christmas!

Now if you've never been on crutches, be warned you are a bit cumbersome, especially to start with - you can't carry anything, so somebody will have to bring you drinks and food (well that was my excuse to be waited on anyway). Don't be too proud at this stage to ask for help - it took 2 of us with military style planning for me to have a shower! So Christmas came and went, the good thing was I couldn't cook and I definitely couldn't stand long enough to do the washing up!

At 4 weeks post op, I had another trip to the hospital for everything to be looked at and to see how well I was doing with my exercises. It's at this point I'm going to nag you a little and say DO YOUR EXERCISES!!! Your leg will only do as well as the amount of time you put into it. Yes they hurt, no they don't seem to make any difference (initially) but keep doing them! The day I could lift my leg a centimetre off the bed was amazing - for me that was 5 weeks post op, I even took a picture of my leg raised to prove I could do it! In fact I took pictures of my leg every few days so I could see how well the scar was healing! I'm somebody that likes to measure their recovery, so for me being able to see properly how much the scar had healed rather than leaving it to 'hmm...I think it looks better' was a lot better. At this hospital trip, I also booked in when I was going to go back into hospital for my physio, which would start at week 7.

So for weeks 4-7, I was still at my Mums, still on crutches slowly becoming addicted to daytime TV! It was also during this time that I starting to become a bit paranoid, mainly due to having so much time on my hands! Things like - how huge is my knee now (it turns out it is potentially a bit bigger than pre-op, but at that stage, my 'fat knee' was still really swollen), how heavy is my leg now (it feels heavy to start with due to the muscles in your thigh not working very well - it will become easier) and will I ever be able to sleep on my side again?!?!? Like I said, I had way too much time on my hands!

So at week 7 I found myself back at the RJAH for my physio, which I loved! We initially had a consultation where essentially the physio's (Geraint and a student) worked out how well my leg was doing at that point and then it was off to the pool! The hydrotherapy pool at the RJAH is fantastic. The best bit for me was getting into the water and being able to walk again properly - no support just me putting one foot in front of the other and moving! Oh and the pool is lovely and warm! The pool session was followed by the gym after lunch which mainly consisted of building strength in my leg. Plus a new measurement for me to focus on - the leg bend! On day one I managed to bend my leg to 70° - which felt like a huge achievement! The first week went pretty quickly, an hour in the pool each morning and another hour in the gym in the afternoon. Towards the end of the first week it was suggested that a second week would be beneficial if I could do it, which I jumped at. So I went home for the weekend, then back into the hospital for the second week. On the Thursday of that last week - everything seemed to come together all at once, I managed to get a leg bend of 90° (after a lot of bending and stretching beforehand!) and I could walk with a single stick. I left the hospital after those 2 weeks feeling more confident and positive than I had since the surgery.

Then it was time for the hard work - it was up to me and only me when I did my exercises, when I rested my leg and when I pushed myself to not become a lazy so and so! I stopped measuring time since the operation in weeks and changed to months. It felt like there wasn't any progress for weeks and then I'd have a day of suddenly being able to do something I couldn't before, or realise I was walking into the kitchen without my stick!

The leg bends, measured by my local physio went from 90° being achieved easily, to 105° to 120° at my last measurement - it now feels like I can bend my leg as well as my 'normal' one, but I'm still doing my exercises! My walking pace is still slow (my Mom has to slow down for me!) but I can now do more without my stick.

Getting back behind the wheel of a car, which I did after 13 weeks, felt like a huge achievement - I only drove about 1km that first day, but I did it with a huge grin on my face!

After 5 months I returned to work on a phased return to work, and working from home - I work 50 miles away and so I wasn't up to driving that sort of distance then, and that also feels great, I'm slowly getting back to how things were before the op.

I'm now at 6 months post operation, and I'm probably about 90% of the way to being back to how I was before - I still use a stick to get up and down stairs (although getting upstairs is now sometimes manageable without the support), I'm walking stickless around 70% of the time - I still use it when I'm out in public mainly as a signal to others to give me space and I'm driving again. The main 'problem' that I have now is that once my leg is locked, I have to take weight off it for it to be able to bend - but this is getting a bit easier with the exercises, and I'm finding ways around it just in case it stays this way.

The moral of my story? Please do your exercises - there will be many, many days where you can't see the point of them, but I know I wouldn't be doing as well as I am now without them. It's also not a quick recovery, so don't beat yourself up if after a few months you're not up and dancing! Talk to people, the Sarcoma support group has been fantastic for me; I now know I'm not alone. Trust me; if I can do this, you can too.

Claire x