

## **Ifor - My 13 year story with recurring Liposarcoma (soft tissue sarcoma)**

My journey with sarcoma started in the summer of 2004 when one morning I noticed a lump on my left thigh, this was the day after I had done a fast run (well it was fast for me, it would not have counted as a stroll in the park for Mo). My thoughts at the time and not knowing much about anatomy was that I had done something during my run. In the following days the lump did not decrease in size so I made an appointment to see my GP. The GP seemed mystified by what he was looking at and although he did not say my assumption was wrong it was clear he was not convinced.

My GP made a request for me to have an ultra sound scan at my local hospital. I duly went along for the scan, the professional carrying it out appeared to see something but was unable to identify what he saw. This began to ring alarm bells for my wife, Linda but I was still assuming it was something straight forward. As this examination did not confirm the problem an MRI scan was suggested.

A second visit to the hospital was arranged for the MRI scan. On arriving we found the department very busy this we soon found out was due to the MRI scanners being used for some emergency scans. After a lengthy wait it was my turn to have my scan. This being my first MRI scan I did not realise that they were taking longer than normal. Linda waiting near the reception desk later told me she thought there were problems as she heard staff talking and debating what to do. On completion of this scan I left to await further information.

The next I heard was a request to visit my GP, who told me that the specialists at the hospital could not identify what I had and that they had sent my scans to an expert in London. I cannot remember if my GP told me what I had but he did say the lump, or growth had been identified and I should await an appointment for a consultation at the hospital. When I had notification of my appointment it was at RJ & AH. Living in Wrexham I had heard of RJAH, (locally known as Gobowen), but knowing the hospital as an orthopaedic hospital I was bemused why I was being sent to RJAH. On speaking to my GP practice they could not say why I was being asked to attend an appointment at RJAH but suggested I just go with it.

Attending the arranged appointment this was our first meeting with Mr Cool and Caroline. Mr Cool told us exactly what I had and did mention the "C" word, and explained that I had a soft tissue growth called a sarcoma. It did not sound too bad it was operable and the growth could be removed. If it was malignant it could return but it would be in the same place.

Mr Cool carried out a biopsy which showed my sarcoma was an Atypical Lipomas tumour and suggested it was benign. A date was arranged for my operation, this being the 9<sup>th</sup> October 2004.

This being the first operation I had had, prior to this I had not been in hospital for any procedure, I was very uncertain as to what to expect. I checked in the evening before and was operated on the following afternoon after the usual day of no food and being told that I was very relaxed about my operation by the porters, this must have been a good outward appearance. This went well, all I remember is being in the pre opp room the next thing I remember is something tapping the sole of my feet. This was the annoying socks you have on your feet following a leg operation which push what appears to be a small ball onto your foot to encourage circulation.

I was then returned to the ward where I spent a few days before being discharged. About ten days after my operation I arranged to go to my local medical centre where a nurse removed my stiches. On my first visit back to RJAH I was told that the tests on my tumour showed that it was benign. I was also told the size of the tumour that had been removed, I cannot remember the exact size but it

was centimetres by centimetres, which was a bit mind boggling but does support the golf ball campaign. After two weeks I returned to work. I was still under RJAH returning every three months for a check up and chest X-rays. As everything was fine I was discharged and carried on with my life.

All went well until early summer of 2011 when again I noticed a lump in my thigh, this being in the same place as last time as it was under the scar left from my previous operation. As I had been discharged some years previously from RJAH I arranged an appointment with my GP.

I was informed it was a Lipomatus Tumour, a small tumour close to the surface of my leg and that it was a simple operation to flip it out and that they could do it at the surgery for me. This rang alarm bells for me and I requested to be seen by the team at RJAH. This was agreed and an appointment was made.

I was seen at RJAH by Mr Williams and following an MRI it was confirmed I did have a Lipomatus tumour, which as my GP had suggested could just be flipped out but due to my history it was thought that a more invasive operation would be a better solution to also remove some of the surrounding tissue. This operation was still minor and I would be admitted for the day returning home the same day after the operation.

I duly arrived at seven on the 26<sup>th</sup> August 2011 and admitted to Erual ward. I was second on the list for my operation but when it became clear that my fellow patient had had a drink of coke before leaving home that morning I was moved up to first to be operated on. Again this went well and I was back on the ward by mid-morning and discharged later in the afternoon.

This time I was told no one else was to touch the dressing on my wound and if I had problems I should return to RJAH. I had no problems and returned two weeks later and to have the dressing removed and checked over. I returned to work and returned to RJAH periodically for a check up.

In September the next year 2012 I found another lump in the same place as my other two. As I was still visiting RJAH, I phoned up and asked for an appointment as I had found another lump. This time I was seen by Ms Cribb, and Jane, Mr Williams having retired in the last year.

Following the usual checks and MRI scan it was clear that I had another tumour in my leg. A biopsy was arranged, this time a more formal procedure using ultra sound to show where the sample was to be taken from. This showed that I had a de-differentiated liposcroma a grade II liposarcoma. Again it was shown to be benign. I was informed that as the tumour had rapped itself around my quad muscle and femoral nerve, some or all of my muscle may have to be removed with the tumour which would result in some loss of mobility. At this consultation a date for the operation was arranged. It was also suggested that a follow up course of radiotherapy may be appropriate, this to be discussed in more detail following the operation.

Before my operation I attended the pre operation clinic where following the usual tests and filling in of forms I was taken through the proposed procedure and asked to sign the now usual disclaimer, (sign of the change in times since 2004).

On the afternoon of 19<sup>th</sup> December 2012 I arrived at Ludlow ward to find that I had my own private room although on the small size a worthwhile improvement since my 2004 visit. Early on the morning of the 20<sup>th</sup> I was asked to put on a gown and the usual black arrows etc. were drawn on my left leg. I was then left until three without food and drink, then taken up to theatre.

This time it being a more serious operation I was told they were going to give me a spinal anaesthetic which they could give me when I was awake or when I was under the general anaesthetic. It was clear the preferred method was when I was awake so I agreed to this. This was carried out and although not that bad was the worst part of the operation process, again as the last thing I remember is trying to talk to the two nurses and then waking up after the operation. I was returned to my room where I had a sleepless night watching night time TV and chatting with the nurse every time she came to check on me.

The next morning as I was feeling fine and had not used the pain control I was disconnected from some of the attached tubes etc. This time I had a drain tube to drain my wound into an attached bag which was to accompany me where ever I went during my stay in hospital. The contents of this bag being measured and then emptied every morning.

I was up quite soon using a walking frame and then crutches for support as my leg was weak following the operation and the removal of part of my quad muscle. I was also given a calliper to attach to my lower leg to give me extra support but this did not work as I could not attach it to my leg without it falling down. My leg not being a standard leg shape!

At one of the visits from Ms Cribb she was accompanied by Mr Cool who after approving of my musical tastes gave me a demonstration of how I could walk now that I had lost some of my femoral nerve.

This was by keeping my leg straight and kicking out to the side to move it forward. It seemed that he was exaggerating the movement but I was not very impressed as I appeared to be able to sufficiently move my leg to walk, all be it using crutches.

The following Monday the amount of discharge from my wound had reduced sufficiently and a replacement calliper had arrived so I was allowed to go home with strict instructions not to let anyone touch my dressing and to return if I had any problems.

At home I had a restful week reading and watching the occasional DVD and thinking that my daughter did have something when she spent all day reading (if left to her own devices). Later I realised this was due to the after effects of the operation and in a couple of weeks, when I had fully recovered I was back to normal and not reading novels.

During this week I was also walking around to strengthen my leg I got to the stage of discarding the new calliper, again it did not work very well and kept slipping down. By the time I returned to clinic the following week for the first check up and have my dressing and stiches removed I was walking unaided. By the comments I was getting it appears this was unexpected and the physio at the time who was prepared to help me walk had an easy session. At this time my leg was weak and did give way at times. After time my remaining quad muscle and the other muscles in my leg did get stronger and I was able to walk longer distances and do most things which did not require a quick step, although it was never as strong as it was before the operation.

At the first consultation after the operation, I was told that part of the tumour was a different colour to the rest and that it was thought that this section could be malignant. On return of the results from the labs this was confirmed, this meant that the previous discussion as to whether I should have radiotherapy was now a strong recommendation. I was given the choice of going to Glan Clwyd as I live in Wales or Christies. As RJAH are partnered with Christies and distance to both centres is similar I elected to go to Christies.

In January 2013 I attended a day clinic at Christies, a contrast from the calmness of RJAH. At this clinic they explained the treatment I was to receive and what I should expect. I saw a number of different people, doctor, physio and others. The six week daily sessions for radiotherapy was duly arranged. At the first session one of the team went through what was going to happen before taking me to the one of the many radiotherapy rooms at Christies and explaining as part of my first session how the radiotherapy treatment was given from the equipment in the room.

Working for an understanding employer I arranged for the sessions to be in the afternoon which allowed me to be in the office in the morning or work from home and leave after lunch to travel to Manchester. I always left in plenty of time to allow for any hold ups on the M56, fortunately in the six weeks of travelling I did not have a hold up (this was not the case on my return journey which was at times at rush hour). This allowed me plenty of time to find a parking place at Christies, (no mean feat, as this was just before the multi-storey car park opened and one of the visitor parks had been closed) and take my time to get to the treatment area.

The treatment did make me feel a bit tired over time but not to such an extent that I could not carry on with work and everyday life. Possibly the treatment being on my leg and away from my upper body did not have as great an effect on me as it appeared to do on patients having treatment to parts of their upper bodies as they appeared to be suffering more than me.

On the whole the course of radiotherapy went well except for a couple of occasions when there was a problem with the equipment and we had to change rooms and then fit in with other patients. Also possibly due to my liberal use of E45 moisturiser before starting the radiotherapy and during the course of the treatment, I only suffered a slight colouring of my skin not unlike the reaction to a mild sun burn.

On completion of my treatment at Christies I selected to be discharged from Christies and to have all my follow up appointments at RJAH. Life returned to normality, although the weakness in my leg did mean I walked with a slight limp and I was not able to do longer walks, any running and making getting up steps etc a bit more difficult. I also suffered some swelling to my knee and some nerve pain in my thigh following activity.

A large change did happen at the end of 2013 as I retired from work and became a pensioner. For the next six months I arranged and supervised work to extend our house along with other home improvements, extending our home now the family had left home seemed to make perfect sense to us. Towards the end of the work on our home I started setting up my own company, this enabled me to carry out consultancy work mainly for my old employer through a couple of consultancy companies.

Prior to a routine six monthly check up in October 2016, I did notice a lump next to my scar, as I was due a visit to RJAH and thinking the lump may be scar tissue I waited until my appointment to mention my findings. At my appointment I saw Caroline and as soon as I told her about my suspect lump, she confirmed this would mean an MRI scan. Following Caroline's examination she confirmed I had a lump where I suggested and that she had also felt a second lump in the back of my leg.

Following my check up appointment on the 24<sup>th</sup> October an urgent MRI scan was arranged following which I was asked to attend for an ultrasound guided biopsy on the 4<sup>th</sup> November. On Thursday 10<sup>th</sup> November I received a phone call as we were on our way to Bristol to visit our daughter and young granddaughter. I was asked if I could attend an appointment on the following Monday 14<sup>th</sup> November with Mr Cool.

On our return from an enjoyable weekend in Bristol we attended the appointment with Mr Cool and Caroline. In summary Mr Cool had to tell me that my liposarcoma had reoccurred and that his recommendation was to amputate my leg at the hip but before this was arranged they needed to check that I did not have metastatic spread to my lungs which if I did would mean that the amputation would not be appropriate.

Fortunately Linda was also with me as shortly into the discussion I was not fully taking everything in, it is the only time at this type of consultation I had gone hot and sweaty then cold and shivering within a few minutes. A CT scan scan of my lungs had been arranged for the next day.

The following morning while preparing for the CT scan I had a phone call to cancel the appointment as the CT scanner had broken and they would let me know when they could offer me another appointment. I made my concerns as to the urgency of the scan known and also spoke to Jane to let them know the position. Fortunately I had a phone call mid afternoon from the CT scan section saying that the scanner had been repaired and could I attend for my scan that afternoon. As it only takes us 30 minutes or so to get to RJAH we jumped in the car and made our way to Gobowen.

It was late on Wednesday afternoon when Caroline phoned me to let me know the CT scan showed that my chest was clear and she asked if I had thought any more about the amputation of my leg. Up to this point I had been in shock and not been able to discuss my situation with anybody. Fortunately Linda although she had similar feelings was able to carry on and act on my behalf. Caroline's phone call lifted our state of wellbeing and made the amputation seem an acceptable procedure. Caroline also asked if we would like to have a further discussion with her and Mr Cool the following day.

So on Thursday we were back to RJAH to meet with Mr Cool and Caroline. Mr Cool explained further the possible three alternatives I had. Firstly I could decide not to do anything but my future would be unclear. There was a possibility that he could do surgery to remove the sarcoma but this would also require replacing my blood vessels which would probably lead to infection and in my mind it was very likely that my sarcoma would reoccur. The third and recommended option was to have the amputation. To help us see the extent of the sarcoma Mr Cool showed us the MRI scan from which it was clear that the recommended procedure was the better solution. Hence I agreed to have my leg amputated as it seemed the only option which gave me a chance of a future.

A date for the operation was agreed for Tuesday 13<sup>th</sup> December, this date being suggested as we had a holiday booked the previous week to the Christmas markets in Germany. It was thought that having the holiday would be good for both of us and the extra time before a possible operation date would not be a problem.

The decision to have the operation was not as concerning as it could have been as I had been attending the sarcoma support group meetings where I had been with others who had had to go through similar procedures. Caroline had suggested on the Monday that I contacted Ian to chat about having an amputation, however I did not feel able to do this until after making the decision to have the operation. I did contact Ian following my decision, Ian was very supportive and was a great help in preparing me for the operation.

Before we went on holiday I had my first visit to my local Posture and Mobility Service (ALAC) at Wrexham to meet the Nurse, Sue and the Doctor, Dr Keetarut. I first briefly saw the wheelchair person who ordered me a wheelchair and disappeared as soon as Dr Keetarut arrived. At this consultation Dr Keetarut asked me to recount my medical history. Dr Keetarut then went on to explain about the artificial limb I would be offered, although his example prosthesis he showed us

was an old model and not like the one I now have. Following this we chatted with Sue and Jenny the physiotherapist as to what we should expect following the operation.

We returned from our holiday which included a day in London on the Saturday with our other daughter who lives there and I was admitted to Oswald ward on Monday afternoon and given room ten, the room with the views, it turned out that this was only for the first night. I was expecting to be in for about two weeks which meant I would be in for Christmas, however on meeting the registrar he suggested it would be more like three weeks.

The operation followed first thing on the following day and went well, I remember going into pre operation room and seeing Mr Cool, Miss Cribb and others and then sitting up on the bed to allow the Anaesthetist to give me a spinal anaesthetic, the next I knew I was waking up in the recovery unit.

I was feeling fine although I did have a number of tubes coming out of my body and was connected to various equipment to constantly monitor me. When dinner time came I was asked if I would like the lasagne I had ordered. The answer was of course, I was warned by the nurse that she did not want to see it again, she did not. As normal for me the night after anaesthetics I was unable to sleep and spent the time listening to music, chatting to the night nurse, and being bullied, well persuaded to keep drinking water. This seemed to have the right result as in the morning I was moved back to Oswald ward, (it had been suggested I could be in the recovery unit for the following day).

My progress on Oswald ward went well except for a couple of incidents when I was violently ill, this was put down to a reaction to the codeine I was been given. During this time I was given physio by Geraint, which seemed to go well. I was surprised how long I could stand on my single leg, as I had been trying this before the operation and not getting on very well.

Everything was looking good for me to be discharged before Christmas, Geraint had signed me off as being safe to let out, i.e. I could get up off the floor when I fell over after forgetting I only had one leg, fortunately up to now this has not happened. Geraint had also kept Linda busy by arranging for her to go to a distribution point to pick up equipment I would require on my discharge.

It was agreed that I would be discharged on the Friday before Christmas if I continued to make good progress. Unfortunately I developed a chest infection, I understand not uncommon after major surgery which meant I had to have intravenous antibiotics and I had to stay in for a few more days and over Christmas.

During this extended stay my wound started to discharge fluid at two locations which required the dressing to be changed daily. On the 29<sup>th</sup> December Miss Cribb and Jane came to see me. Following a discussion they removed my stiches and I was discharged in time to celebrate New Year at home.

During the following weeks my wound carried on discharging but to a lesser extent which meant several visits to RJAH for treatment and new dressing. As Linda was happy to change my dressing this cut down on the visits or the need for a district nurse to attend me.

On my first consultation with Mr Cool following my operation it was suggested that radiotherapy may be a suitable precaution if I felt like having a further course of treatment. A consultation at Christies was arranged at which I was told that further radiotherapy treatment could not be given as that area of my body had previously received the maximum amount of radiation. This saved me having to make the decision whether to have the treatment.

The year since my amputation has been spent adapting to many new challenges, even what was a straight forward task now needs reassessing and adapting to. There have been frustrations and disappointments the main one being a recurring skin infection I have had in the second half of the year, which is thought by some to be connected to the wearing of my prosthesis. At the time of writing I am well, the chest x-rays at the regular follow up appointments at RJAH and a MRI scan in October have all been clear.

Finally, I would like to acknowledge the amazing support I have had from all the team at RJAH and the Limb Centre at Wrexham but most of all for Linda who has shared this journey with me and has always been my rock with her support, positive attitude and encouragement.

Ifor Jones