

## **Sarah's story**

From birth I was born with a small right kidney, in early childhood I developed asthma, in my late teens I was also diagnosed with irritable bowel syndrome, more recently, four years ago, age 28 I was finally diagnosed with chronic functional weakness. My kidney, asthma and IBS problems although they cause me from time to time various degrees of discomfort they are not as debilitating as my chronic functional weakness has become.

On 24 September 2003 I awoke with severe pain in my bladder, my husband took me straight to the Hospital A&E department. They tested my urine which showed my body was fighting an infection, I was given a seven day course of antibiotics and sent home. Three days later I was still in severe pain this had now made its way to my right kidney. My General Practitioner contacted my renal consultant and I was given a longer course of antibiotics. Couple of months then went by and there was no improvement. I seen my renal consultant who thought the pain was more muscular than being my kidney.

Six months on nothing had changed with my pain, I was still off my work, couldn't dress, shower, go to the shops as I couldn't walk five steps without being in severe pain. I was then referred through my General Practitioner to physiotherapy, this took another few months for the appointment. My first visit there I came out with two elbow crutches they were a huge help to me. The pain was the same when walking but I had something I could lean into which helped. After a few visits my physiotherapist then referred me to see an orthopaedic consultant at my local Hospital. The consultant did a full exam and then sent me for a MRI scan, which came back normal. I started to see an Occupational Health Doctor through my work.

Spring 2004 I was still at physiotherapy and receiving acupuncture, this dulled the pain for me for about thirty minutes. I was given acupuncture about four times every couple of weeks then it stopped working. Also I was now using a wheelchair outside and my crutches inside. Whilst all this was going on I was sent for tests to check to see which kidney was working. The test showed that my right kidney had stopped working altogether. I was then sent to see a surgeon at another hospital to talk about the possibility of removing my right kidney. After speaking to different doctors and physiotherapy about having the surgery we decided not to go ahead.

Late autumn 2004 my physiotherapist felt no longer able to continue seeing me as there was no improvement, I was however referred to the hydro therapy at St John's Hospital, this was given to me for about eight weeks but again I showed no improvement so this was stopped.

In autumn 2005 I saw a different renal consultant who had worked on neurological cases and wondered if that was what was going on with me, I was then referred to Neurology. An appointment arrived for early 2006.

Upon seeing my neurological consultant and explaining my symptoms, I was told that I had a condition called Chronic Functional Weakness, suddenly the

pieces of my jigsaw began to fit and this became a very emotional time. I was given some new medication to try and another appointment in six months.

Over the next six months I was sleeping better, my pain was more manageable and I tried to do some extra walking. When I returned to see my neurological consultant I managed to walk in on my two elbow crutches. The next six months were pretty much the same continued to try and improve as I knew I wasn't going to hurt myself. There were small set backs along the way but then I improved a little again.

2007 Autumn I had a major set back one day I woke up and every joint in my body was screaming in pain, it felt like someone was rubbing them together with sand. I waited for two weeks before seeing my GP as at this point I knew I could get different symptoms for a couple of days or weeks but I couldn't take it anymore. My GP gave me some strong pain killers which made me very sleepy. This went on for about a month and a half, then started to get easier.

April 2008 had a chest infection which knocked my back again, then I took an asthma attack and ended up in my local hospital for one week. By this point I felt I was back at square one with my pain. Then in June 2008 I felt extremely ill and was back in hospital with bleeding from my back passage. The doctors there decided to do a laparoscopy to see what was going on, ended up taking my appendix out and after a couple of days I had no more bleeding. September 2008 I was made medically retired. The rest of the year I was hoping nothing else was going to happen.

1 January 2009 back in hospital with pain in my gallbladder, the doctors thought this was due to my medication which I had been on for many years. My gallbladder was not removed.

Spring 2009 still feel like I am back at square one, I am having extra pain in my lower back, put back on strong pain killers and a muscle relaxant. No real improvement being made. October 2009 my GP refers me to domiciliary physiotherapy for an urgent appointment. The physiotherapist was out to see me in four days, exercises were given and my crutches were replaced with a Zimmer. Two months on I have now been given a walker with a seat for use indoors, still need my wheelchair for outside.

December 2009 physiotherapy made a referral to Occupational Therapists as my house needs to be made more disabled friendly.

I would like to summarise by saying in the past six years I have visited a number of doctors who don't understand this condition, I have learnt now to hold my tongue and to let it wash over me, I hasten to add this would not be possible for me had I not been introduced to my neurologist, who was able to put this all into perspective for me. Now as we all look forward to starting a new year we all wonder what lies ahead. No one can really foresee the future we just hope we have the strength to confront it.