

Velcade Three – Marie Morton

This is the story of Marie Morton, one of the Velcade Three...

It was February 1999, coming up to my 50th birthday; we had a nice hotel booked at Newby Bridge in the lakes. We had a lovely weekend apart from a pain in my left leg which was getting worse. I promised Tony (my husband) that I would go to see the doctor when we got home. As promised, I went to the doctor; he thought I had a pulled muscle! He gave me a prescription, told me to rest and to come back in two weeks if there was no improvement. There was no improvement; I went back to the doctors. This went on for long enough, back and forth to the doctors.

It was now March, Easter time, we went to the Dales with friends. My pain was now very bad. I couldn't weight bare and was limping badly. When we got home I went back to the doctors again, still he said it was a muscle problem and gave me anti-inflammatory drugs. I told him that it was so bad it made me cry and woke me up a night. That was when he, reluctantly, sent me for an x-ray 'just to make sure there was nothing untoward going on'. We were into May now, I was unable to work and I had to go to the doctors for the results of the x-ray and to get a sick note. What a shock I had when they told me the results were abnormal and they wanted me to see an orthopaedic consultant. I thought it would be a least six weeks before I got an appointment.

WRONG! I had an appointment within a week!!! I saw a lovely consultant who examined me but couldn't find anything physically wrong with me, but he assured me he would get to the bottom of it. I was given a CT scan with a guided biopsy. It was Friday when I had the tests done. A young doctor told me there was nothing wrong and I would be given an outpatients appointment for the results within six weeks.

WRONG!!! I was in clinic the following Thursday to get the results. I was shaking with fear and nerves! The consultant was very to the point and told me I had a blood disorder called Myeloma! Well!!! I knew I was in trouble because there was an "oma" on the end. He had to refer me to another consultant, a haematologist. I was also told to go to physiotherapy to be measured up for crutches as I had developed HOLES in my pelvis which had made it weak. The consultant didn't want my pelvis to collapse; if it did we

would be in serious trouble. This made me cry. I remember crying for days, blaming my doctor for not listening to me

Maybe a week went by before I saw the haematologist. She was very nice! She explained the treatments to me. They would give me a course of radiotherapy to the pelvic area to shrink the tumour; a very aggressive course of chemotherapy and, if all went well, a stem cell transplant. If I didn't have the treatment I could expect to live for two years. If I had the treatment I could maybe live for five years! Then, perhaps, they might have another treatment for me that could, perhaps, keep me going another five years!!

I have always kept myself fit, swimming three times a week, body pump and aerobics twice a week! It's a good job I was, as the treatment was very aggressive. The radiotherapy and chemo would take about twelve months and three months respectively, after that I would have my stem cell transplant. They failed to tell me that I would be taken to the brink of death then rescued!!! Even now, seven years later, I still suffer chronic fatigue.

Before I could start any treatment I had to have a hick-man line put in. That was an ordeal in itself! Whilst having the procedure I felt an agonising pain. I thought to myself 'don't be soft pull yourself together'! After the procedure I went back to the ward thinking I would have my chemotherapy. NO: the night was long and I had terrible pain in my chest. I remember thinking I hope the pain settles down soon but it didn't. The morning couldn't come quickly enough. Doctor's rounds and I was still in great pain. I was sent for an x-ray. As soon as the radiographer looked at the films he could see what it was. They had put the line into my LUNG and it had to be removed ASAP. Doctors finally came to remove my line, what a relief that was. I asked to be put to sleep when they put it back in. They agreed. I went to theatre and when I came around I had no pain. 'Great' I thought. The next morning the line had come out. So back to theatre again, THIRD time lucky!!!

It was the beginning of August I was finally starting chemo....

I was back home by now. I started with a terrible pain in my right side! My husband took me to the hospital. It was a Sunday morning I will never forget. I was sat doubled up in pain, in a wheel chair for six hours before a doctor saw me. I begged them to let me lie down on a bed. As soon as I was on the bed the bloody doctor came to examine me. He told me I had pleurisy and asked if I wanted to stay in. I decided to go home.

After one step forward and two steps back I finally got on with my treatment. It was now the end of August. We were doing building work at home (having a walk in shower put in as I can't get in and out of a bath) which had taken longer than expected, so I was stopping with my sister in law for a week. The district nurse was calling everyday to help with medication and to clean the hick-man line.

I had to buy a pill box to keep my pills in some sort of order I was taking 15 in the morning and then 12 in the afternoon to counter the affects of the chemo.

I had a cassette which ran for four days. Oh my goodness that did make me feel ill, especially with having to drink a steroid. It was disgusting. I have never tasted anything as bad. I tried to disguise the taste with different drinks but nothing worked. Put it with orange and it would boil up over the top of the glass yuk!!!!!!

I was really quite poorly for the four days that the cassette was running. I would even pass out! I once passed out in the shower. My poor husband couldn't get me out as he couldn't open the door! I passed out behind the sofa once. It was a few minutes before I was found. My husband was worried about it and called the H O D U unit at the hospital. They told him to get me there A S A P. There I was in my P Js being pushed in my wheel chair to H O D U as fast as he could. When we got there they took my blood pressure. It was in my boots!! 50/48, I had to have geli-fusion (two bags) before my B P was anything like normal. My doctor rang the drug company to try and find out which if any of the drugs I was taking could have caused it. They said it could be the doxorubicin: but who knows with all that crap they pump into your body to make you better, or worse before you get better!

Christmas came and went. I did have a break from my chemo and started to feel a little better. Happy New Year, goodbye and good riddance 1999: hello 2000, new year, new millennium, new start back on chemo.

It wasn't long before I was neutropenic and back on a busy ward. I rang for some anti-sickness treatment, Jan 2000 at 3pm. I am still waiting! I just wonder if some of the staff nurses know what it's like to feel noxious for hours on end. If they did we might get a quicker response.

It is now February finally we were talking about transplant! Well stem cell collection. I needed to have a bone marrow aspiration. I forgot to mention this before, this would be my third. Another very painful procedure but it has to be done to see what's happening to your bone marrow. There has to be 5% or less myeloma cells in your marrow before they give you something to kill off your bone marrow so it starts to produce new cells.

Great news, the test results are ok so I can start chemo. I will have it in H O D U. I will be there for a day. It's now Monday; we are going to the L G I in Leeds for blood test every day this week to monitor the growth of my new stem cells. It takes a week to get them to the right level. I can now have them removed and stored ready for my transplant. This was one of the easy parts of the continuing treatment. They attach a line to your groin and pump your blood through a machine which separates the stem cells out of the blood and stores them until a bed is available.

It will be nice to have a break from the chemo and hospitals. It's now the beginning of summer, the end of May; I have a date for my transplant.

I was admitted on the 6th June. The next day they gave me chemo to kill off my immune system. It felt like it was going to kill me: that's how it felt to me anyway. On Friday the 8th I had my stored stem cells given back to rescue me.

It's Saturday! I thought I was going to die I could hardly lift my head off the pillow. I had no immune system left. I stayed in bed all that day except when sitting on the loo with a vomit bowl!

On Monday my bloods were taken. I had a chart in my room so I could keep a track of the results. I can go home when my white cell count gets to 5!

It was now Friday. They have given me two bags of blood and two bags of platelets I started to feel better. I picked up really quickly. I was allowed home after 18 days

It was great to be home away from the hospital environment. One of the worst things to deal with was the chronic fatigue. I had to crawl up stairs on my hands and knees. You don't realise how bad it is until you are at home. It seemed to take ages before I felt human again, but it was only three months. I went back to work on the 9th of October. Back to some sort of normality, away from hospital, only attending clinic, GREAT!

It is now three years down the road and I have started having chronic back pain and terrible muscle spasm. I went to my GP who, knowing my history sent me to a physiotherapist. After a few sessions which didn't do a scrap of good, she put too much pressure on my back producing a loud crack and great pain. It made me cry it was that bad. I couldn't move for the pain. The physiotherapist was so concerned she phoned to make sure I was ok. I said I was ok but I was far from it. I spent a lot of my own money seeing an osteopath which had no effect.

I knew in my own mind by this time that it was my myeloma that was behind this. So I went to see my consultant. To my surprise she said it wasn't and sent me to see an orthopaedic surgeon. I was in agony for at least three months before I got to see him.

When I eventually got to see the orthopaedic surgeon he offered me a M R I scan to find out what was going on. After a week I went to see him to get the results of the scan. I was shocked when he showed me the scan results. I had a collapsed vertebra which was a direct result of my myeloma. So I was sent back to my 'so called' haematologist.

The collapsed vertebra was causing spinal compression. I was in agony. I could hardly walk. I couldn't climb stairs. I had to drag myself up steps and stairs. We had to sell our home and go into debt for a bungalow but I find it much easier now we don't have stairs to climb.

It was now time for my yearly follow up appointment at Leeds with the Myeloma specialist. We had a good chat about my back. He said he knew someone who might be able to help by doing a verteoplasty on my vertebra. This is a new procedure where they

fill the damaged bone with (for want of a better word) cement. But before I could have this done I had to have five courses of radiotherapy to kill the myeloma cells which were doing the damage. This helped with the pain a little. I could now see the neurosurgeon. He showed me the damage to my spine and explained how he could help. I had the procedure done as a day patient it worked wonders! No pain 'great stuff'.

Twelve months later the same happened higher up my spine and the whole thing started again but again it was treated with good effect.

In November 2006 I went on a Caribbean Cruise I had a wonderful time, but was in constant pain despite using 100mg fentanyl patches and I had no stamina what so ever but despite it all it was great, on coming home I had to have a gynaecology operation which all went to plan.

It was February 2007. I could not believe it! I had another collapsed vertebra, this time in my neck. I have my own pain relief nurse from Manor Lands Hospice. I have had to increase my fentanyl patches to 200mg. I also have to take oramorph as and when required but I am never pain free. I often wonder when it will ever end

I am now starting to have problems in my left rib cage

I was sent to Cookridge Hospital in Leeds for more radiotherapy but they have now decided that radiotherapy isn't an option anymore. I was sent home without treatment.

Today 24th April I have been to Dr Cook at my Leeds clinic. It has been decided that I have to start chemo again. I will be given C T D (cyclophosphamide thalidomide dexamethazone) starting in a few weeks time!! This will treat all my bones rather than just the hot spots.

My Husband and daughter have helped me through this. They have been my rock and have kept me going through anything that's been thrown at me. I don't know what the future holds but my husband and daughter are there for me and will help and support me through the bad times, of which there will be plenty.

Life is a learning circle and I have learnt a lot about myself and my family. I'd never heard of myeloma back in 1999 but I know a little more now (not by choice I might add). I have managed to fight this debilitating illness for eight years. I hope I can fight it for many years to come

These are some of the things I can remember about my journey, although there are things I have failed to mention! It is difficult for me to write about myself, but I hope you find this story interesting and helpful.

Marie Morton