

VELCADE: The latest treatment for Multiple Myeloma

The most effective drug introduced into the treatment of this disease for decades, giving phenomenal results in the majority of patients who have already been treated with the drug. As I have a friend who has just recently been given the drug in a trial situation I have seen for myself the astonishing results which can and have been achieved by Velcade - she has literally been given back some semblance of "normality" in her life, not just in her physical condition her mental attitude has been given such a huge boost to know that if or when she relapses again there will an effective and beneficial treatment available to her. This drug has given hope to all myeloma sufferers in dealing with a disease for which now and into the foreseeable future there is no known cure. We have to "learn to live" with Multiple Myeloma - not an easy task in itself as the nature of the disease is truly erratic as it does not run a normal or obvious course, throwing up problems in all kinds of guises to each individual patient, life truly becomes a case of living on the edge of a volcano, wondering at each regular blood test what the results would show up and, if treatment was shown to be needed, WHAT treatment? Having already been through chemotherapy at Airedale General Hospital and a stem cell transplant at L.G.I (no picnic believe you me) I have nothing but admiration for the doctors and nursing staff, especially at Airedale's H.O.D.U. who had all the time and patience in the world in dealing with a frightened middle aged woman who had been totally traumatised and had her whole world turned upside down by this diagnosis - after all I had only gone to my doctor (after being constantly nagged to go by son and his girlfriend) complaining of feeling generally unwell and with slight breathlessness. I was certain I would be sent home with just an inhaler and hey ho carry on with life as normal. I will admit I had to see four doctors before finally seeing one who asked for blood tests, and as soon as she saw the results realised I had a big problem. I'm so thankful that she did as who knows how or where I would be today if she hadn't realised the seriousness of the situation.

Within just over a week I was in treatment - and found myself in a totally alien world of hospital rooms, blood tests, bone marrow aspirates, hickman lines, medication etc. looking back all of which I initially reacted to like a zombie. I really found it difficult to come to terms with and accept the diagnosis. I couldn't have got through all this if not for the unfailing support of my husband and family. Even though they must have been falling apart inside when I gathered everyone together - my husband and best friend since the age of 15, our two sons of 33 and 28, and the "baby" of the family our

daughter of just 19, and told them what was happening and about to happen, they were each and every one - though i'm sure shaken and shocked at this time bomb that had exploded in their midst - totally supportive and encouraging towards me - "You'll be fine Mum, I KNOW you'll get through this" – "No problem mum you'll be O.K. I'm sure". Whilst being nothing but positive towards me I know that once they had left the house they all fell apart, each one in their own way. During the worst times they were all there for me, encouraging me forward and out the other side.

My husband became in effect my carer, giving up his job as a long distance driver which took him away from home so much and spending all his time looking after me and keeping me going. I'm certain I would not be here now if he hadn't been there continually urging me forward and encouraging me to keep going - even when i'm sure I turned into the most awkward, irrational and ungrateful person to deal with - but that's what illness, medication and fear does to a person - mainly fear, fear of the unknown and what happens next. "What happens next" in my case is just taking one day at a time, enjoying life as it is at the moment and being grateful to still be here and lucky enough to be able to do that. I count myself extremely fortunate to be in the position I am as I'm very aware of the effects this disease has and is having on fellow sufferers, and lets face it, however kind and sympathetic people are towards someone in our situation it is truly IMPOSSIBLE for anyone to really understand the impact of this diagnosis and treatment unless they have (god forbid) been faced with such a diagnosis themselves.

It was during treatment that I first met up with Jacky who later introduced me to Marie. I don't think I would have had the nerve or the energy to attend any support group but these two have been an unbelievable source of support to me these past five years, e-mails, cuppas at one another's homes and **LONG** telephone conversations (for which I should apologise now to Gary and Sean!) have been a big help and comfort to all of us I think. We're always there for one another and find it such a help to talk things through, whether its just a hiccup or something major, between us we always manage to cope and help one another find a way through, so when we became aware of the controversy and threatened withdrawal of the drug Velcade from its availability on the NHS it just seemed a natural progression for the three of us to band together as "The Velcade Three", so dubbed by the Times newspaper, and fight for this drug to be put into the realm of all Myeloma sufferers, after all don't we all have a basic human right to life?