

The day we attended the NICE hearing - London February 8th 2007.

London again. This is the 4th visit to London in the last 5 months. I feel I could get a job for the rough guide to London hotels, hotels been a loose term. Anyway tomorrow is a big day for the Velcade three, of which I am one of them.

Tomorrow we are meeting with members of the NICE team to put forward our issues about the NICE appeal concerning the drug Velcade. It was good of them to grant us 15mins of their time to get our point of view across prior to attending the oral appeal as non-participant observers. Been quiet is not usually associated with me. This meeting and appeal hearing is so important to us as our life's literally hang in the balance of the outcome of the appeal.

The local TV news station, Look North is travelling with us on our journey to London and on the journey of the Velcade 3. Tomorrow we, Janice and I are going to try and get across a humanistic point of view about having an incurable cancer Multiple Myeloma. A cancer that is treatable to an extent with all sorts of drugs but only one drug is actually licensed for MM and that drug, Velcade, is at present been given a negative ruling by NICE, mainly due to cost. What price can you put on a persons life?

We feel we have support of all who have heard about us, through local and national media exposure, friends and family, but now we need to get under the skin of the NICE team in a nice way of course. Amanda from Look North has just finished interviewing Janice and me. We seem to take things in our stride. Who would have thought 6 months ago that we, Jacky, Janice and Marie, 3 cancer women would make the national news headlines and been dubbed the Velcade 3 by the Times newspaper.

The trip to London only consists of Janice and I. Marie is having an operation on her spine, verteoblasty. This is just another side effect of MM, having hot spots in your spine, which can cause vertebrae's to collapse. We are travelling down to London the day before the meeting as the meeting starts too early for us to make the journey there and back in one day, also I don't think either of us have the stamina to do this long trip in one day. We are booked in at Travel lodge. Our choice of hotels previously has been poor. The last hotel had grey nets at the paint flaking windows,

dusty skirting boards and thread bear carpets. One consolation was that the bedding did pass the pubic hair test – thank God.

Last year meeting local TV celebrities like Harry Gration and Christa Achroyd would have only been a dream. Now we are on first name terms with them. But if anyone asked me what I would rather, being a local household name fighting for Velcade or being an unknown midwife and all MM sufferers having access to Velcade at the point of need. The latter wins hands down.

The hotel is clean with adequate facilities and very close to the building where the meeting is taking place. I think we have got the hotel right this time, 3rd time lucky. At last we had chosen wisely. The evening has been spent taking in a show and ensuring our 15 min talk is precise and powerful.

This evening was bizarre. We studied the map and took the underground to the theatre. The walk to view Chicago seemed quite a long way, but I suppose to use that find walking small distances an effort, been breathless at our destination was not unusual. After the performance we needed to head back to the underground. I felt the way back was north – east. We slowly walked about 100 metres in that direction. The shops were not registering, nothing looked familiar. We decided to turn the next corner and hail a taxi, both a little breathless so not communicating with each other. As we turned the corner our hotel was in sight. We had infarct been only a stones throw from the theatre in the 1st place. There was no need to have taken the underground. So much for my map reading.

Its snowing outside, not nice crisp white snow, but slushy mucky grey snow, I hope this does not reflect the mood we are in after today is over. Today Janice and I have to convince some members of the panel that MM sufferers are not just statistics, not just numbers on patients files, but we are people who suffer from MM who have families and live with MM day in and day out, trying to make the best of what life God have dealt us. And we only have 15 mins to convince them.

There has been a minimal advance in the treatment of MM over the last decade and a half. However now this new biological drug Velcade gives hope to mm sufferers and their families and today we want the people listening to make sure that this hope

of prolonged life with good quality of life is not taken away from us just because of not collating all the evidence available and the cost.

It is hard to comprehend that scientists are giving their whole working lives to developing these novel drugs. Rigorous testing has been conducted on the drugs like Velcade in order for them to get licensed in this country. People like you and me give to cancer research so new drugs can be discovered and our aim is that people will live with cancer but not die from cancer. Why then are organisations like NICE able to let us down at the last hurdle? Without access to this drug we will die far sooner than we need to.

I relate Velcade to that of the drug insulin. Diabetes was once a terminal illness taking the lives of young adults until advances in medical sciences saw the development and use of the drug Insulin. Now people with diabetes can live a long life with minimal disruption due to administration of insulin injections. What would have happened to diabetics today if the NHS had chosen not to back insulin? Insulin has made diabetes into a chronic illness instead of an incurable disease. I believe Velcade could be a stepping-stone, which aids in transforming MM into a chronic illness instead of a death sentence.

In order to give a humanistic approach to the meeting we needed patient's stories. I knew Velcade was my life savour but for the government organisation team NICE to sit up and listen we had to show I was not an isolated case. We were met at the venue by TV cameras that were eagerly waiting to get an interview from us about how we feel the day would go. How do you put into words my thoughts that today people with good health who do not contemplate their mortality on a daily basis will make decisions about cancer sufferer's treatment? Decisions that would possibly shorten my life and the lives' of many other MM sufferers in England.

Velcade has been instrumental in me returning to the work place, feeling a valued member of society. So why are these people with extended vocabulary able to make decisions about my life. I was taught that God decides weather we live or die not men in posh suits.

I imagined the day to be dull and the atmosphere to be stifled but how wrong I was – I was riveted. The Appeal panel who to all intense and purpose were the jury extrapolated information and evidence from the NICE team and the opponents who

consisted of the charity representatives, health care professionals and drug company executives. The jury asked questions to both sides in succession and in an orderly manner. Each team scored points with the drug reps playing their ace card by promoting risk sharing. This simply means that the drug company would initially give Velcade to the NHS to administer to patients. If patients responded to therapy then the NHS would pay for the treatment, however if patients didn't respond then the drug company would foot the bill. On average 25% would not respond to treatment, which allows the NHS to purchase Velcade for 3/4s of the price. The risk sharing is a novel idea and really excites me. I was finding it difficult stopping myself from standing up in the room and applauding the drug company reps. I had to sit with my hand under my bottom. I had already become so excited, I clicked my fingers when the charity Myeloma UK was trying to respond to a question. God it was so difficult to keep quiet but I had to remember that we were invited as non-participant observers. Five years of living with the disease, reading all available literature had given me a really solid grounded knowledge base. I wanted to be vocal and put my case forward, me who was living with the illness not just reading up about it. Issues which Janice and I discussed while on the train going to London like a stopping rule, which simply means stopping giving the drug to patients who fail to respond after three cycles was actually discussed at the appeal. Also the matter of Velcade been given as a combination therapy instead of been given in isolation was discussed by us prior to the meeting and was brought up as a very important issue at the meeting. I felt good that the Velcade three could identify the same issues as the knowledgeable people in the room. However, then I reflect upon the years I spent going through the education system resulting in attaining an MSc Masters in health professional education. It was paying off again.

No matter where you sat in the meeting, no one disputed this clinical effectiveness of this treatment. However, in today's economical society, been clinically effective is not enough, the jury had to be convinced that the treatment was cost effective, which was more difficult with the QALY been set at £33,800. This sits on the cusp of been deemed too costly. What kind of society puts cost before life? At present when relating to cancer care, England does.

Networking at the meeting was a real bonus. Talking again to Adam, a TV documentary producer, other MM patients and the NICE chairperson was stimulating and thought provoking. Breaking bread with these people and listening to their points of view on the subject only enhanced our knowledge that everyone believe that this

biological drug was really effective treatment for MM sufferers. The cost appeared to be the problem that needed to be addressed. I felt that the risk sharing and stopping rule would address the cost issue.

Feeling post meeting was one of cautious optimism. We hoped people in the room listened to the evidence presented throughout the hearing. If they did then no one could now dispute the clinical and COST effectiveness of this wonderful life-prolonging drug.

A car was booked to take Janice and I to the London TV studio, but that's another story.