

15th July 2011

Bowel Cancer UK: Cetuximab, Bevacizumab and Panitumumab monotherapy for the treatment of metastatic colorectal cancer that has progressed after first line chemotherapy (review)

I am a patient who has lived through NICE's expert judgements and decisions. I was diagnosed with terminal cancer of the bowel, which had spread to the liver in November 2006.

Having been given only 3-5 months to live with only conventional drugs, I researched the drug 'Avastin' (Bevacizumab) and asked for it.

Although backed strongly by my oncologist and my surgeon, through the MDT, funding was still refused on the NHS.

I had to go through a dreadful process of appeals, completing paperwork and spending precious time on matters when the end of my life could have been very near, all to no avail.

With no time to waste, we paid the £21,000 ourselves with the help of my 86 year old mother.

November: 2006: Diagnosis - No chance of survival, prognosis of 3-5 months

January 2007: Oxaliplatin/5FU - 4 treatments, no success, tumour grew to 15 x 10cm in left liver

March 2007: Irinotecan/5FU - 6 treatments, some shrinkage of tumour. Not sufficient for resection. Told continued treatment of the same would not be effective

August 2007: Addition of Avastin to previous regime. 4 treatments. Dramatic result after two treatments only in **2nd line treatment**

October 2007: Resection of left liver and ascending colon

Needless to say, I am still alive as Avastin shrank the tumour sufficiently so that resection of the entire left liver was possible.

Since my last opportunity of speaking to the NICE committee, I have had a fabulous life:

I have seen my youngest son graduate and also qualify as a teacher. I had tears in my eyes at the ceremony; this was an event I never dreamt of seeing. I had written a letter to my son on the night I was told that there was 'no hope' and I told him that I could imagine him doing this and for him to know how proud of him I would be.

I was actually there and witnessed it all.

I have spent weeks in France doing all the things I love doing during the last two years.

I celebrated my Mum's 90th birthday.

I have been speaking out for availability of drugs such as Avastin on the NHS.

If I died tomorrow, I would feel that I have had real quality time with my family.

I speak because I was told that there was 'no chance' for me in November 2006. I am alive and still in remission four years later. I am not unique; there are others who would also benefit from these drugs. I have been amongst them in the hospice at Worcester. They could have had the chance to live, like me. What does that feel like? Isn't it immoral?

The cost of Avastin as part of my treatment prior to resection was £4,000. I had four treatments which enabled my resection. The other £6,500 was for the treatment I was already having on the NHS i.e. irinotecan 5FU. These are not the figures that the NHS claims they cannot afford.

I was present at the first World Patient Conference in Barcelona in June of this year. It stunned me to see the statistics. There is no denying that, in the UK, we have more 'rights' than most places in the world. However, more shocking is that our use of monoclonal drugs stood on the baseline for years while patients in France, Italy and Germany were benefitting tremendously from them. It is not surprising then that survival rates in England for colorectal cancer are among the lowest in Europe.

In conclusion, I beg that we listen more to our clinicians. I had the best doctors and surgeons but the NHS is restricting what they are allowed to do. They are not being allowed to do what they believe is the best treatment for each individual. Isn't that against their Hippocratic Oath?

NICE always says that one cannot prove it is Avastin that is effective and not the chemotherapy. I can categorically say that it was the addition of Avastin to my second line treatment which shrank my tumour and allowed resection. Without that, I would not be alive today; my doctor and surgeon have certified this. My first chemotherapy did not work as my tumour grew.

My second line treatment had little success and its effect was diminishing with prolonged use. I am living proof of someone who has benefitted from the addition of Avastin to second line treatment with its dramatic results. If it can do this for me, it can also work for others.

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