

## **PERSONAL STATEMENT: LEONARD RHYS EVANS**

I was diagnosed with Colorectal Cancer (Dukes B) in November 2003. I subsequently underwent an Anterior Resection and Ileostomy in Jan 2004 and a 6 monthly Mayo regime course of chemotherapy. Reversal of the Stoma followed in November 2004 and more recently repair of a large incisional hernia in March 2006.

### **Comments on the proposed technology**

As someone who has experienced the diagnosis and treatment of colorectal cancer, I welcome any further developments in the treatment of this cancer. My concerns centre on how such treatments are communicated to patients/carers and how available such treatments will become given the current postcode lottery experienced in other treatments.

### **Specific issues and concerns include:**

#### **1. Information on the proposed technology**

One of the main issues facing patients and carers is obtaining sufficient in depth information on various treatments and technologies. Often what is available on health information sites, such as Cancer Bacup and Macmillan, is fairly basic and related to how to live with, rather than fully explain current treatments and developments. Such information quickly becomes out of date. Information on current developments and proposals is mainly restricted to professionals rather than the public. It therefore becomes difficult to access specific knowledge. Internet searches all too often discover American information whose approach is quite different to the UK personal experience. In addition, such information contains treatment regimes that are not available or used in the UK.

Fundamental to all the information provided and for which patients require reassurance, is the risk assessment underpinning new technology. This is the principle of and foundation for informed consent.

It is therefore essential for patients and carers to receive clear and explanatory advice outlining the technology and those other issues, which I raise in this statement.

#### **2. Communications on the benefits and harmful effects of the technology**

During the treatment journey, especially if treated in specialist centres, patients and their carers can anticipate a number of requests to participate in various research projects. I have been requested to participate in two different trials, one of which was discredited the day after my acceptance. From my personal experience, I would want considerable reassurance that the experience of undergoing this additional treatment would have clear benefits and no harmful short or long term effects.

My experience of the pressure to accept further treatment following the diagnosis and initial surgery suggests that drip feeding of information stage by stage creates anxiety and a loss of confidence contributing to feelings of distrust between patients and clinicians. This combined with the way in which information is provided indicates that good communication is vital.

It is essential that information is not only communicated orally but in writing and that time is given for questions to be asked and fully explored. The inclusion of the carer/support partner at the consultation stages is vital as messages often become distorted or misheard. Whilst this is well known and taught to all health professionals it is surprising how often this is not practised when confronted with the reality of busy ward rounds or outpatient clinics.

It is also essential that feedback is sought from patients to check their understanding and any additional questions that might have arisen.

It is also important that communication between the hospital and the patients' General Practitioner occurs at an early stage. This sharing of information on new technologies, including the dangers and side effects as well as the benefits, between all members of the health care team enhances patient care. From my personal experience, it was my own GP informed me of the withdrawal of VIVOX and provide advice discontinue my involvement with the study.

### **3. Potential benefits in life expectancy**

Medical staff are quite rightly concerned with trying to improve the quality of the patients' experience during their cancer journey and unwittingly may overstate the benefits to patients. What does it mean to suggest that a particular course of treatment might add a 3 or 7% increase to their survival rate? What is required is a clearer explanation of how life will be altered if they undergo this treatment, what actual benefits can be expected, what reduction of pain or symptoms can be looked for. What activities can be undertaken during the treatment phase and post treatment period?

### **4. Potential benefits in the quality of life.**

The one key benefit that individuals will be looking for is how this treatment is going to increase life expectancy and the quality of life during that time. Treatments that cause distress and have little alteration on the quality or quantity of time produce little benefit for individuals and palliative care might be a more appropriate treatment plan than subjection to aggressive treatments causing distress without producing life-enhancing benefits.

### **5. Possible side effects**

As with any treatment there would be concern regarding the range of potential and actual documented side effects and what treatments are available to support individuals experiencing such problems. It is also important to provide realistic information on the likelihood of any individual experiencing any or all of the known side effects.

It should be remembered that possible side effects will also include the emotional issues as well as the more recognised physical ones. Both will exert their influences at different times during the treatment cycles as well as varying between individuals. Making efforts to know the individual and their coping mechanisms will enable appropriate individualised care to be provided.

Clinical support from both medical and nursing staff should be made available especially at night or during weekends when problems become increasingly more distressing and access to specialist information is not readily accessible.

The need for out of hour's advice is one that has been sadly neglected in recent times.

## **6. Methods of administration, hospital v home administration**

A key issue for patients with metastatic cancer will be how locally will the treatment be available. The need for further hospital attendance with the associated costs in time and money may well mitigate against acceptance of the treatment. Memories associated with unpleasant treatments create barriers, which increase stress levels. Even with a good experience of my own chemotherapy the fact that I regularly pass the treatment centre evokes memories that have not lessened in the last two years.

The possible availability of community administration of this treatment would enhance the quality of life experience and reduce stress at a difficult time.

It is not clear from the information supplied if this treatment is an oral or intravenous preparation, reflecting my earlier comment on the need for clear communication and replication of points made earlier in this statement.

## **7. Ongoing research into effectiveness of treatment regime**

As a patient, I would want to be aware of what current updating research is ongoing and how I would be made aware of this. I especially would wish to be kept informed of the effectiveness of any treatments I have had or am having in the light of the current public debates on medical research and drug development. The influence of newsworthy medical items on patients' perceptions should not be ignored.

## **8. Geographical availability of the technology**

Perhaps one of my key concerns after the effectiveness of the treatment revolves around its availability. The persistent debate in the press or television on PCT funding denials/rationing is very worrying and would be a prime concern. Knowing that there is a potentially effective treatment technology available, but not yet funded, when you have a prognosis of metastatic cancer, is a worry that you do not need.

## **CONCLUSION**

The possibility that a treatment might exist to relieve symptoms and provide an enhanced life experience is worthy of adoption. However, it is important that all aspects of potential benefits and side effects are fully explained at the outset of the treatment process.

The importance of truthful communication between the health professionals, patient and carers is vital and must not be overlooked. Support during and after the treatment phase is important and needs to be available at all times especially during the out of hours periods.

Communication from the various self-help groups and research charities needs to be enhanced.