Personal Statement on the use of temozolomide in the NHS in preparation for the Health Technology Appraisal being held on 23rd November 2005 at NICE, London

Written and submitted by Tina Mitchell
on 14th November 2005

Background:-

Paul Mitchell – Patient, diagnosed with a brain tumour (grade iv glioblastoma) at the age of 35, died at the age of 37

Tina Mitchell – Wife and former full-time carer for Paul Mitchell, husband

John Mitchell – Son

Sitting in the Consultant's room in March 2002, it is apparent to even the non-medical eye that Paul has only a few weeks to live.

Back at our home in Bristol, his Mum is busy making tea for when we get in and our son John, four years old, is in the playroom with his brio train set, tired after a busy day at school.

In the Consultant's room, Paul's Dad appears calm and I am numb with disbelief as our fears are confirmed. Paul does indeed only have a few weeks to live. As we sit there together, we are given three options:-

1. Palliative care
2. A chemotherapy treatment called temozolomide which has a success rate of one in ten
3. Take time to consider the above two options

We are not sure how much of this Paul has taken in, but he remains full of determination and ready to fight for his life. Trained as a Chartered Accountant, it is clear that Paul has retained his ability to understand figures and without a moment's hesitation, he has worked out that statistically 10% is not good (although with hindsight, I guess that all statistics are relative to the condition). However, he also very quickly concludes that he wants to start this treatment as soon as practically possible.

Paul, a devoted family man, a committed Christian and a talented sportsman developed a grade iv glioblastoma brain tumour in his right temporal lobe at the age of 35. His diagnosis shattered our entire world and on that day, we boarded the most painful rollercoaster ride imaginable. Following emergency surgery initially to remove as much of the tumour as possible, Paul was left with peripheral vision, weakness in the left hand side of his body and a change in his personality. This resulted in Paul being severely restricted in his normal every day activities, a loss of independence and the family having to re-adjust to a completely different way of life. Paul's Mum and Dad moved from Hastings to live with us in Bristol in order to help us cope with this adjustment. Paul demonstrated obsessive behaviour and talked much more than he ever had before, so it was very difficult for us all to learn to live with someone who was quite different from the person we knew before.

Paul received post surgery radiotherapy, debulking of the tumour and three cycles of PCV chemotherapy which had little, if no effect at all, so by the time we were told Paul only had weeks left to live, he was very weak and was struggling to do everything. He could barely walk and had extreme difficulty in feeding and dressing himself. It was heartbreaking to see this 6ft 2" Father struggle to even give his own son a cuddle. At this stage, we could not possibly have contemplated any future family life together.

Paul began taking temozolomide in March 2002 and from this very first cycle he showed improvements in his physical being. The peripheral vision, the fact that a large proportion of his brain had been taken away during surgery and the differences in his personality remained unchanged. However, the outcome of starting this treatment allowed him to join in activities, which a month earlier, we could only ever have dreamt of.

As a direct result of taking temozolomide, Paul was able to do the following:-

- Rough and tumble on the floor with his son
- Take part in and help celebrate John's 5th birthday pirate party
- Hold a party for over 150 people to celebrate our 11th wedding anniversary
- Be the best ever "best man" at his only brother's wedding
- Go on a much longed for camping holiday with the church
- Return back to work part-time
- Follow through building work he had planned before his diagnosis
- Write and run a sports quiz at the local leisure centre
- Stand up at fundraising events to talk about brain tumours
- Walk his son to and from school (without someone watching over him)

Temozolomide was administered in a five day cycle and unlike previous treatments, we were able to give him the pills at home. There was nothing complicated about the timings of the drugs and the course fitted well into the routine of his other drugs. The side effects were minimal compared to other treatments he had been through, so although the chemotherapy was highly toxic, he didn't experience any sickness or headaches. He had bouts of constipation, but all in all, Paul experienced six months of vastly improved health. After the second cycle, Paul had a routine MRI scan and the scan result, just days before his brother's wedding, showed the first decrease ever in the size of the tumour. All the previous scan results had only ever shown an increase. How amazing was that!

Our lives are built upon memories and these memories can make a difference to our future. Memories that you build up throughout your childhood affect how you are as an adult today and I firmly believe that the extension of life given to Paul by temozolomide has had a lasting impression, not only most importantly on our only son, but also upon all our family and friends around us. Parent-Child relationships are important at any stage in a child's life, but particularly during the first five years of their life. Obviously we cannot categorically say what effect Paul’s illness has had upon John, but I am sure that both Paul and John’s lives were enriched by the extra “quality” time they had together. Paul was a man of integrity. His values and the things that were important to him were still part of John’s experience during this traumatic time - this was made even more apparent when Paul was feeling better. Children bank memories unconsciously as well as consciously and, without temozolomide, Paul could have gone from being poorly to dead. However, the “improved” time between diagnosis and death meant that amidst all the bad memories of his illness, there were also good ones which we have all stored for the future.

However, with regards to Paul’s long-term health and well being, it had little effect. As the treatment continued and his physical and mental state improved, it made it more difficult for Paul to accept that although he was making an improvement, he would never be restored to his former self. For example, taking temozolomide meant he went from hardly being able to walk and move unaided to actually being able to jog quite adequately several times around a field. However, Paul had been a footballer all his life and prior to his illness, had played football to a good standard. He therefore believed that given time and a bit of practice, he would be playing for his club once again. Understandably, he got terribly frustrated as he couldn’t even play a short game of football and ultimately it led to the onset of a mild depression. For the family, it was devastating to see him achieve such a lot and yet to know that it was his need and desire to do more which, due to the severity of the grade of brain tumour, was never going to be achievable. This was very hard to reconcile and although the quality of life given and the memories that John has been able to retain, are important, the side effects are perhaps less physical and more emotional.

In summary, if Paul hadn’t been offered temozolomide, good memories wouldn’t exist and I would never have been able to write this statement.

n.b. Carmustin, administered as gliadel implants weren’t available at the time of Paul’s illness. In my line of work, however, I have met patients who have successfully had this form of treatment without side effects and seemingly a good result.

END