

Brain tumour treatments: the view of patients and caregivers

Brain tumours need to be given a greater and more urgent focus of attention, say patient groups. Kathy Oliver highlights a campaign for NHS-funded access to promising therapies for this disease

The name of the 16th-century unfortunate pictured in a woodcut illustration published in 1573 is unknown. The man lies face down on an ornately carved bed while a surgeon vigorously cuts into his skull with a wooden-handled instrument (*Figure 1*).

We don't know the names of the three women 'assistants' hovering around the bed either. Could they be some of the first neuroscience nurses? Is one the patient's wife? Or his mother? All wear a look of grim fortitude while a young child (the patient's son?) hangs onto the side of the bed, rapt with horrified fascination as the surgeon drills deeply into the man's parietal lobe. Under the bed lounges a scrawny dog while a plump rat scurries past, anxious to avoid the attentions of a hungry cat lurking somewhere unseen near the make-shift operating theatre.

What we know from a woodcut illustration in Giovanni Andrea Della Croce's book on surgery, *Cirugia Universale e Perfecta* (first published in 1573) is that neurosurgery has come a very long way since then. And as the mother of a brain tumour patient who has successfully undergone two craniotomies, I'm grateful to live in an era of 'high-tech' medicine and where developments in the field of brain tumour treatments, for example, are gathering speed at an impressive rate.

However, the bottom line is that, despite great advances in brain tumour treatments between 1573 and 2007, there remains no cure for this devastating disease.

Nevertheless, there are reasons why

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*Figure 1. The first neuroscience nurses? A woodcut showing a neurosurgical procedure from Giovanni Andrea Della Croce's book on surgery, *Cirugia Universale e Perfecta*, first published in 1573*

patients, their families and caregivers might begin to have some realistic hope for the future when faced with the terrifying diagnosis of a brain tumour.

Advances in treatment

Each day, in places all around the world, 500 people develop a primary, malignant brain tumour, the most lethal of them all. That totals 180 000 per year (personal communication with the Central Brain Tumor Registry of the United States, 2007). A similar number of people develop non-malignant (i.e. so-called 'benign') brain tumours, many of which can also kill them. Many more develop metastatic brain tumours, or secondaries, caused by cancer elsewhere in the body.

While 16th-century neurosurgeons relied on primitive instruments, today operating

theatres are equipped with intra-operative magnetic resonance imaging (MRI) and facilities for image guided surgery, helping enable maximal resection.

Neuroscience nursing for brain tumour patients has changed too, with the emergence of specialist roles—for example, nurse practitioners (in Australia), clinical nurse specialists (in the UK), advance practice nurses (in Canada), and these same three titles accorded to high level neuro-oncology nurses in the USA.

In June 2006 the National Institute for Health and Clinical Excellence (NICE) released new guidelines on *Improving Outcomes for People with Brain and Other CNS Tumours* (National Collaborating Centre for Cancer, 2006). In the key recommendations, the importance of neuroscience nurses was recognized:

Clinical nurse specialists should be core members of the neuroscience brain and other CNS tumours MDT [multi-disciplinary team] and the cancer network brain and other CNS tumours MDT ... They are likely to take on the role of key worker for many patients ...

Centuries ago, radiation and chemotherapies were not even glints in the eyes of doctors.

Today, advances in radiotherapy—for example, external beam radiation, 3D conformal radiation, intensity-modulated radiation therapy (IMRT), stereotactic radiosurgery (SRS), stereotactic radiotherapy and proton beam radiation therapy—offer clinicians a menu from which they can

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choose the treatment most suited to a particular type of brain tumour.

Novel approaches—including chemotherapies (as single agents or combinations), anti-angiogenic therapies, immunotherapies, differentiating agents, gene therapies, targeted molecular therapies and intratumoral therapies—are now the subject of many hundreds of investigations and clinical trials around the world.

And out of all this research there sometimes comes a groundbreaking result.

The NICE experience

An example is the landmark trial data from Dr Roger Stupp et al (2005) on the use of concomitant radiotherapy and a chemotherapy drug developed originally by Cancer Research UK (and subsequently marketed internationally by Schering-Plough) called temozolomide (Temodal/Temodar) for newly diagnosed glioblastoma multiforme.

Data from the Stupp trial (conducted worldwide in 85 centres with 573 patients) show that the addition of temozolomide to radiotherapy significantly increases patients’ chances of extended survival. Specifically, the trial results reported an increase in the number of patients living

2 years from 10.4% to 26.5%, among those who benefited from it. The Stupp trial findings have been described as the biggest breakthrough in brain tumour treatment in 30 years.

Subsequent to release of the Stupp data, treatment with this concomitant therapy (which also includes an adjuvant 6-month period of temozolomide on its own), quickly became the standard of care for glioblastoma multiforme in developed countries around the world.

Ironically, it is the ‘home of temozolomide’, the UK, where brain tumour patients have had a singularly frustrating and excessively long wait for the concomitant therapy to be funded on the NHS.

On the basis of cost-effectiveness, NICE originally rejected temozolomide and another brain tumour therapy, Gliadel wafers, which are impregnated with the chemotherapy carmustine and inserted during neurosurgery.

Many brain tumour specialists were so opposed to NICE’s negative recommendation that they signed a joint letter to Secretary of State for Health, Patricia Hewitt.

Brain tumour patient groups mounted a rigorous and sustained campaign to reverse NICE’s decision. A formal appeal hearing was granted but then cancelled by NICE. This was because a mistake in the way NICE calculated the cost-effectiveness of one of the therapies was discovered and prompted NICE to re-analyse its appraisal of both temozolomide and carmustine implants. This resulted in a reversal of its original guidance. Both therapies are now recommended for NHS funding.

The UK brain tumour community was relieved at NICE’s U-turn. But patient groups now raise concerns that the two therapies may still not reach those who need them because of funding squeezes in primary care organizations. They say it will be a cruel blow if treatments for one of the most lethal of all cancers were further delayed owing to insufficient funding. They also express concern at the adoption by NICE of pre-conditions for eligibility which could exclude certain groups of patients.

The NICE appraisal of temozolomide and carmustine implants has taken more than 2 years. During this time, fears were also expressed that, if NICE eventually rejected the two therapies, the UK would fall very much behind Europe and the rest

of the world in its treatment of malignant brain tumours. There were also concerns that brain tumour research in the UK would stagnate if the country was not conducive to readily adopting new treatment modalities and moving forward with progress.

From the perspective of brain tumour patients and caregivers, NICE’s change of heart is a step in the right direction. But the road ahead remains long and challenging.

Cutting edge therapies for relatively rare diseases like brain tumours are far from cheap. However, when these therapies bring extended survival and good quality of life, can cost-effectiveness really be the only yardstick by which these treatments are measured? And might it not be fairer,

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when considering therapies for funding on the NHS, that the caregivers’ role is also economically evaluated? Legions of caregivers provide 24-hour care and support to those whose lives have been touched by a brain tumour. There is an element of cost-effectiveness in that which should be considered during funding appraisals.

Hope

There is one constant in the patient experience which probably has not changed over the centuries. Even that anonymous 16th-century man in the Della Croce woodcut depicting neuroscience’s frontier days would have experienced hope.

In his book, *The Anatomy of Hope*, Dr Jerome Groopman says:

Although there is no uniform definition of hope, I found one that seemed to capture what my patients had taught me. Hope is the elevating feeling we experience when we see—in the mind’s eye—a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion. Clear-

eyed, hope gives us the courage to confront our circumstances and the capacity to surmount them.

In a study by Burnet et al (2005), brain tumour patients were found to have the highest ranking of ‘average years of life lost’, a measure of the burden of cancer to the individual patient. Yet brain tumours attract one of the lowest levels of research spending in the UK from the National Cancer Research Institute, at 1.5% (Burnet et al, 2005).

In dealing with this ugly, impossibly persistent disease, we must all—patients, caregivers, medical professionals, government—ensure that brain tumours are given a greater and more urgent focus of attention. We must also advocate equal access to promising therapies, as happened with the NICE appraisal of the two brain tumour treatments.

All of this will bring hope—and hope is an important therapy too.

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KEY POINTS

- Guidelines from the National Institute for Health and Clinical Excellence (NICE) on improving outcomes for people with brain and other CNS tumours recognize the importance of the role of neuroscience nurses
- Patients, caregivers, medical professionals and government need to ensure that brain tumours are given a greater and more urgent focus of attention
- Equal access to promising therapies for the treatment of brain tumours must be advocated

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Table 1. Further information

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