

# A MANIFESTO FOR EVERYONE AFFECTED BY A BRAIN TUMOUR

This coalition of brain tumour organisations presents this manifesto on behalf of everyone diagnosed with a brain tumour in the UK each year, and their carers, families and friends.

***We call on Governments throughout the UK to work in partnership with the UK's brain tumour charities to:***

- 1** Ensure early diagnosis and treatment for everyone affected by a brain tumour.
- 2** Implement the best practice guidance for treating people with brain and CNS tumours.
- 3** Significantly increase Government investment in brain tumour research.



## We call on Governments throughout the UK to work in partnership with the UK's brain tumour charities to:

### 1 Ensure early diagnosis and treatment for everyone affected by a brain tumour.

## Introduction

Each year approximately 8,600 primary brain tumours are registered in the UK<sup>1</sup>. It is widely accepted that these figures are an under-estimate of the actual numbers of primary brain tumour cases. The National Institute for Health and Clinical Excellence (NICE) reports that “almost half of intracranial tumours are not recorded by cancer registries”<sup>2</sup> and research by brain tumour charities has suggested the true number of primary tumours could be as high as 16,000<sup>3</sup>.

Secondary tumours in the brain are not recorded in the cancer registries. But research by brain tumour charities suggests that up to 32,000 people may develop secondary cancer in the brain in the UK each year<sup>4</sup>. In many cases the secondary brain tumour, rather than the original cancer, may be the cause of death. The brain is now a major battleground against secondary cancer.

The human cost is alarming. Malignant primary brain tumours take more years off the average person's life than any other cancer<sup>5</sup>. They are the most significant cause of cancer death amongst men under 45 and women under 35, and approximately 400 children are diagnosed with a primary brain tumour each year<sup>6</sup>. Low grade tumours can become malignant and even so called 'benign' tumours can cause serious permanent harm or death.

Anyone diagnosed with a brain tumour will at some stage require acute treatment in hospital. Most will require rehabilitation or palliative care, either to help them return to as normal a life as possible for as long as possible, or to maximise their quality of life.

We recognise that health and social care is expensive and the UK faces major financial constraints. So, whilst this manifesto demands greater investment, the proposed solutions aim to maximise benefits and the efficiency of that investment.

In this document, we have prioritised three key areas for action. We have set out one or more solutions for each area that can be monitored and measured. We believe that each action will make a significant difference to the lives of everyone affected by a brain tumour.

#### The problem:

The diagnosis of a brain tumour is often delayed<sup>7</sup>. GPs and Accident & Emergency teams may not request scans early enough. Or scans showing possible abnormalities may not be promptly referred to a specialist neuroscience team. Not infrequently, GPs and Accident & Emergency teams misdiagnose headaches, nausea and other brain tumour symptoms as migraines, stress or other illnesses.

#### Measurable solution:

Ensure that clear guidelines on identifying the signs and symptoms of brain tumours, and on referring patients for rapid and appropriate assessment, are integrated into General Practice and Emergency Medicine Practice.

#### Benefits:

Early diagnosis and treatment of a malignant brain tumour can significantly improve the prognosis for many patients, resulting in a better quality of life for longer. Early diagnosis and treatment of benign and low-grade tumours can prevent or delay the cognitive and physical impacts of a brain tumour.

<sup>1</sup> This figure includes benign, low grade and malignant brain tumours in the official cancer registries. Sources: Cancer Statistics registrations: *Registrations of cancer diagnosed in 2007*, Office for National Statistics, England. Series MB1 no.38. 2010, National Statistics: London; *Cancer Registrations in Wales 2007*, Welsh Cancer Intelligence and Surveillance Unit, 2010; *Cancer of the Brain and CNS: Scotland: trends in incidence 1985-2007*, ISD Scotland, 2010, Information and Statistics Division, NHS Scotland; *Cancer Incidence and Mortality*, Northern Ireland Cancer Registry, 2010.

<sup>2</sup> *Improving Outcomes for People with Brain and Other CNS Tumours: The Manual*. Guidance on Cancer Services, National Institute for Health and Clinical Excellence, 2006.

<sup>3</sup> *Register my tumour, recognise me*, Brain Tumour UK, March 2009.

<sup>4</sup> *Register my tumour*, op. cit.

<sup>5</sup> Burnet, N., et al., *Years of life lost (YLL) from cancer is an important measure of population burden and should be considered when allocating research funds*. *British Journal of Cancer*, 2005. 92: p. 241-245.

<sup>6</sup> Cancer Statistics registrations: op. cit.

<sup>7</sup> The median time from symptom onset to diagnosis of a brain tumour in children in the UK is 3.3 months, whereas the best currently published results from Poland and USA are less than 5 weeks. Sources: Wilne SC, J. Kennedy, C. Jenkins, A.Grout, J.Mackie, S.Koller, K. Grundy, R. Walker, D. *Progression from first symptom to diagnosis in childhood brain tumours: a multicentre study* (Abstract). *Archives of Disease in Childhood*. 2007;92 (Supp 1):A69; Perek D, Drogosiewicz M, Dembowska-Baginska B, Perek-Polnik M, I F. *Diagnostic problems in children with primary brain tumours treated in Children's Memorial Health Institute*. *Pediatrica Polska* 2005;80(1):29-36; Pollock BH, Krischer JP, Vietti TJ. *Interval between symptom onset and diagnosis of pediatric solid tumors*. *Journal of Pediatrics*. 1991 Nov;119(5):725-32.

## 2 Implement the best practice guidance for caring for people with brain tumours.

### The problem:

NICE published its Improving Outcomes Guidance (IOG) for Brain and CNS Tumours in 2006. The IOG is a clear set of recommendations designed to provide all brain tumour patients with a high standard of treatment, support and care, within the overall context of the National Cancer Action Plan. It includes low grade and benign tumours, too.

The IOG is designed to be implemented over a three-year period but, in autumn 2010, implementation has barely begun. Furthermore, the IOG only applies to England and Wales. Equivalent standards have not yet been fully adopted in Northern Ireland and Scotland.

Consequently, patients face a postcode lottery in the standards of treatment, rehabilitation and care they can expect. Some struggle to get prompt access to essential chemotherapy and radiotherapy. Others find that no-one takes responsibility for their support and care when they leave hospital and that rehabilitation services are unavailable.

### Measurable solution:

Set a clear timetable in 2010, to fully implement and audit the Improving Outcomes Guidance, or its country equivalent, between 2011 and 2013.

### Benefits:

Everyone affected by a brain tumour will be diagnosed promptly and receive consistently high standards of treatment and care wherever they are in the UK.

People affected by brain tumours, and their carers, will no longer suffer the indignity and isolation that they currently experience when they find that there is no-one taking responsibility for their care.

Effective rehabilitation will help many people affected by a brain tumour, and their families and care-givers, adjust to life after treatment more quickly.

<sup>8</sup> Lammy, D., Research: Leukaemia and brain tumours. *Hansard*, 2009. Written Answers, 27 January, (Column 459W). See: <http://tinyurl.com/267rnks>

<sup>9</sup> In 2008, brain and CNS tumours claimed 492 people under the age of 45, including 88 children; leukaemia claimed 299 people under 45, including 51 children. Across all ages, leukaemia claimed 19% more people than brain and CNS tumours in 2008.

<sup>10</sup> National Cancer Research Network 2010 (NCRN). Each year, approximately 4,670 people are registered with brain cancer in the UK. This figure excludes those patients with benign and low grade brain tumours. Only 2.25% of patients were enrolled in brain tumour clinical trials in 2008-9 and only 2.8% in 2009-10. The percentages enrolled in Randomised Controlled Trials (RCTs) was only approximately 1%.

<sup>11</sup> RCTs give more reliable results in clinical studies. RCTs randomly select patients for the study and then compare the results from treated patients with another 'control' group of patients who have been given an existing, standard treatment or a placebo. This helps to prevent bias creeping into studies and distorting the results.

<sup>12</sup> NCRN op cit.

<sup>13</sup> The *NHS Constitution*, 8 March 2010, promises: "Procedures to ensure that patients are notified of opportunities to join in relevant ethically approved research and are free to choose whether they wish to do so. Research is a core part of the NHS. It enables the NHS to improve the current and future health of the people it serves. The NHS will do all it can to ensure that patients, from every part of England, are made aware of research that is of particular relevance to them."

## 3 Significantly increase Government investment in brain tumour research.

### The problem:

Scientific research into brain tumours is under-funded, both in relation to the number of people affected and the life-limiting nature of malignant tumours in particular. The UK's brain tumour charities and their partners are working hard to increase the amount of scientific research. But we believe that the proportion of Government research funding for brain tumours remains disproportionately small.

In 2007-8, for example, the Medical Research Council (MRC) invested less than £1 million in brain tumour research, compared to £14 million in leukaemia research<sup>8</sup>. Yet brain tumours claim the lives of more children, and young men and women, than leukaemia<sup>9</sup>. There is clearly a deficit in brain tumour research funding that must be urgently addressed.

One way of measuring progress in research is by the number of people diagnosed with a disease who are involved in research as part of their treatment. The National Cancer Research Network (NCRN) was tasked by the Dept for Health with doubling the number of people with cancer recruited to clinical trials. The starting point was 3.75% and for many cancers this figure exceeded 7.5% by 2004. But not for brain tumours.

Of the 8,600 people diagnosed with a brain tumour each year, only 1.5% were involved in clinical trials in 2009-10<sup>10</sup>. Randomised Controlled Trials (RCTs)<sup>11</sup> in particular offer sufficiently reliable results to support an evidence-based approach to healthcare provision. Yet only 1% of patients were involved in an RCT in 2009-10<sup>12</sup>. It is also difficult for patients to find out what clinical trials are available, even though the NHS Constitution promises to make this easier<sup>13</sup>.

We wish to work with Government, and its funding agencies, to:

- measure the total value of Government investment in brain tumour research, quantify the deficit and understand the reasons behind it; and
- develop an appropriate research funding model that corrects the deficit, taking into account the many years of life lost to brain tumours.

### Measurable solutions:

- Publish, in 2011, a detailed breakdown of site-specific brain tumour research funding from the Government.
- Ensure that by 2014 at least 7.5% of adults with primary brain tumours are enrolled in randomised, controlled clinical trials, including international trials, as part of their therapy.

### Benefits:

People affected by brain tumours desperately need new and better treatments to enable them to be fully participating members of society with an improved quality of life and extended survival. Fuller participation in RCTs will not only give patients access to potentially effective therapies but will help others in the future, who will benefit from the proper validation of new treatments.

The causes of brain tumours are not yet known, screening is unrealistic and there are no known lifestyle changes that can prevent a brain tumour. Cures and methods of prevention are the ultimate goals. Research offers the only real hope of dramatic improvements in the management of brain tumours.

Clearly, the level of research in brain tumours falls well-short of the desired minimum standards. Action must be taken to change this.

The Brain Tumour Manifesto coalition involves:



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