



Nottingham Leads a National Awareness Campaign

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I have been involved in the public and professional launch of the HeadSmart: Be Brain Tumour Aware Campaign (www.headsmart.org.uk). This is an initiative from the Children's Brain Tumour Research Centre at The University of Nottingham, in collaboration with Samantha Dickson Brain Tumour Trust, the Royal College of Paediatrics and Child Health and financially supported by the Health Foundation. This national campaign aims to speed up diagnosis to prevent more serious problems developing. This was the top priority for the recent manifesto launched by the all party parliamentary group on brain tumours at the House of Commons in the autumn of 2010 (<http://www.cbtrc.org>) and also in recent Government cancer documents.

This has come about as a result of the use of public fundraising for research £2.5 million as well as specialist clinical expertise within Nottingham Children's Hospital and the University of Nottingham. Donor funds have been complemented by £5.8 million raised through grant applications so that we now have a major research centre, which has published over 230 papers, chapters and books. There are now six research teams in Nottingham, involving over 60 clinical and scientific researchers tackling problems encountered by the children and their families.

The HeadSmart: Be Brain Tumour Aware campaign is our current flagship national project; it has been developed from a research programme which started in 2003. It evolved from listening to repeated concerns from children, young people and their parents at the time of diagnosis. They said that they had noticed the signs and symptoms for prolonged periods before they were recognised by health professionals, as indicative of brain tumour. When this was many months or even years, they were extremely upset and felt that the health services had let them down.

Speaking with the doctors involved, they were also upset and disappointed - no doctor wants to be involved in such delays. We concluded that the problem lay in a lack of awareness amongst both the public and professionals. The public knew that the symptoms were out of the ordinary but did not know the cause. The doctors, whilst recognising the signs and symptoms, considered them due to more common childhood illnesses and were initially reluctant to change their

opinion until things became significantly worse. UK medical training has not laid emphasis on the relatively high frequency of brain tumour in childhood. Furthermore, doing brain scans in children is more complicated, as it requires a hospital referral, and, in young children, requires sedation or an anaesthetic. However, most of all, it requires the doctor to raise the possibility of a serious diagnosis on the basis of variable symptoms. The reluctance to do this, is undoubtedly fuelled by a lack of awareness of symptom patterns their evolution and the childhood risks of brain tumour to be diagnosed or excluded.

This guidance supporting the awareness campaign was developed from research studying the symptoms at diagnosis from over 2,000 patients published from around the world. We were able to compare the length of time from symptom onset to diagnosis in these reports and compare the UK performance to that in other countries. We found that the UK health system was bottom of the international comparison, it takes about twice as long to make the diagnosis in UK compared to USA or Canada, Israel or Switzerland. We used this information to inform a panel of over 100 experienced health professionals and used their guidance to develop the advice for the symptom cards. This advice was published and endorsed by the Royal College of Paediatrics and Child Health in 2008 (<http://www.rcpch.ac.uk>).

The HeadSmart: Be Brain Tumour Aware campaign aims to create a situation where both the public and the profession are made more aware of brain tumour as a childhood diagnosis as well as the specific signs and symptoms that occur at different ages. Symptoms cards clearly describe these and direct the public and the profession to a website designed to offer guidance for selecting patients for reassurance, referral or review. We anticipate the symptoms cards will be used when the child and parents or young people on their own, meet the doctor to help explain their concerns. They will be directed to the website for easy access to the guidance. We want both partners in this consultation to be supported in deciding whether a scan is required, or not.

The recent very successful media launch is just the beginning of the campaign. We are currently disseminating the campaign message to the public and the profession. We are monitoring the time from symptom onset to diagnosis and measuring the public and professions' awareness through surveys. We are planning an economic evaluation of the impact of the campaign on health service activity.