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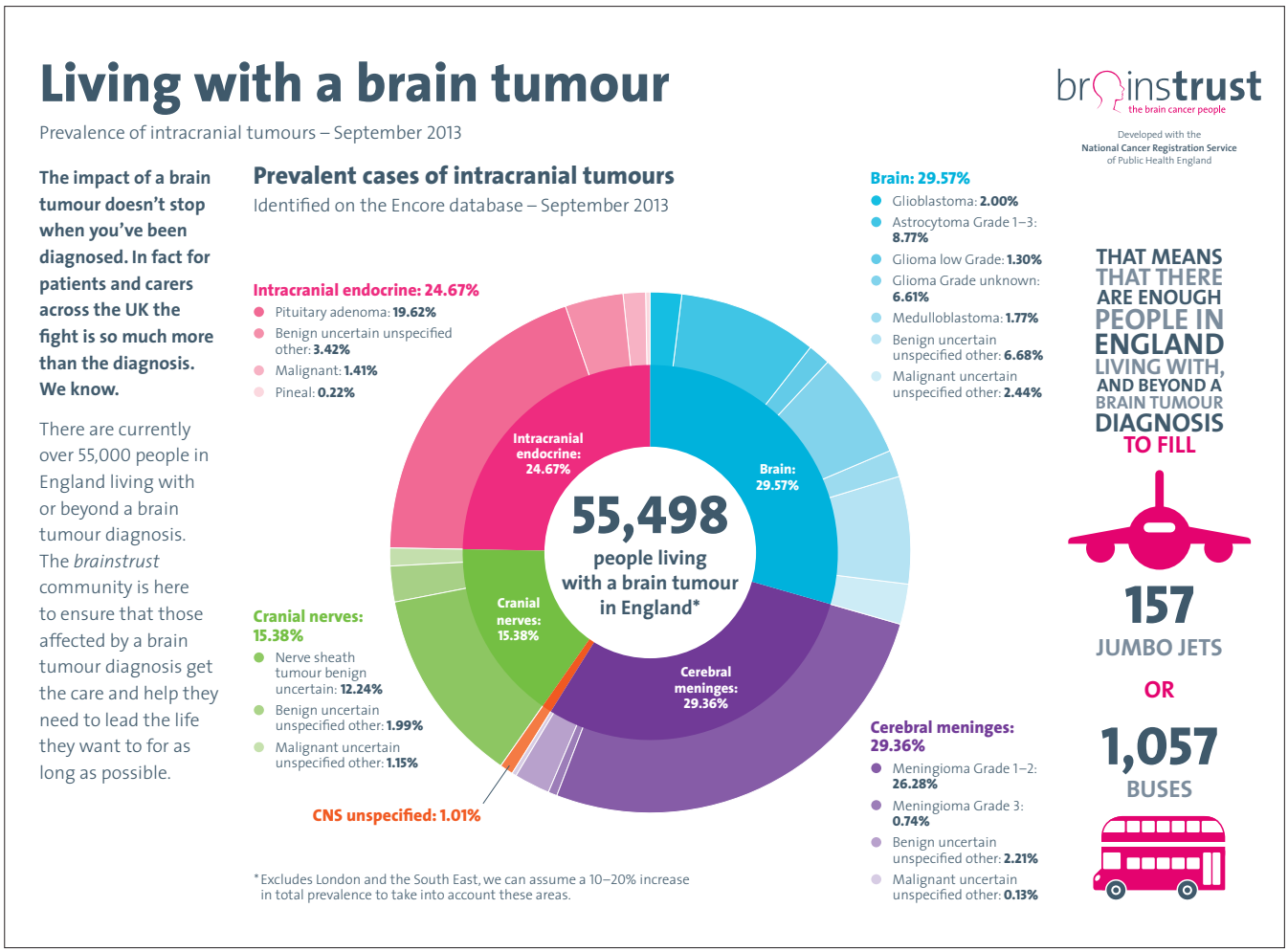
# Malignant Gliomas and long term survivorship – exploring the vital role of the Neuro-Oncology Specialist Nurse

As is well documented, there are around 8,600 patients in the UK each year diagnosed with a primary brain tumour. It is also well accepted that this number is greatly under represented as around half of all brain tumours are not being reported to the cancer registries and furthermore secondary (metastatic) brain tumours are not recorded at all as they are monitored against their primary cancer site [1]. According to the Brainstrust charity, the estimated number of people therefore living with an intracranial tumour in 2013 is currently just under 55,500 [2] (see diagram).

According to the most recent figures for 2011 published by Cancer Research UK, nearly half of all cancer sufferers in England and Wales survive at least a decade, but sadly this is not the case for adults diagnosed with malignant brain tumours, where only 15% survive 10 years [3]. This startling contrast means there remains a lot of work to be done by us as health care professionals to lessen the gap, but how does this survival gap impact on the overall wellbeing of our glioma patients? This article aims to explore some of the shortcomings concerning long term follow up and care of the glioma patient, what is required to change outcomes for the better and why neuro-oncology nurses are pivotal to this process.

Recent research carried out by Brainstrust states people living with a malignant brain tumour face a barrage of uncertainty and feel increasingly isolated and alone [4]. Place this isolation alongside the fact the NHS currently struggles to sufficiently support the increasing number of cancer survivors within its existing service structures and you have a recipe for a disastrous long term follow-up strategy and patient satisfaction [5]. This is further compounded by the fact as many as 1 in 4 brain tumour patients still do not know who to contact for help or support even though The National



Institute of Clinical Excellence (NICE) in 2006 called for all brain tumour patients to have access to a Key worker, likely to be a clinical nurse specialist (CNS) as part of their Improving outcomes guidance [6].

## Access to key workers

Having an authoritative point of contact, such as a CNS, is proven to lessen patient's anxiety and increase satisfaction with regard to their holistic care needs – specialist nurses help improve the patient experience and safety because they have in-depth knowledge of the physical, psychological and social effects of their specific condition and play a key role in the management of patient care [7]. CNS's are pivotal in that we build up a rapport with both the patients and their families, and are able to offer tailored care depending on the patient's level of need. According to Fletcher, CNSs reduce both unnecessary hospital admissions and readmissions, they reduce waiting times, free up the consultant's time to treat other patients, improve access to care, and help support patients in the community [8]. So why is it that as many as 1 in 4 are still not aware of who their CNS / Key worker is when it comes to neuro-oncology [9]?

It is fairly evident that those patients with high grade, primary malignant tumours requiring neurosurgery, chemotherapy and/or radiotherapy will encounter specialist nurses on a near daily basis and will have rafts of information, both verbal and written, given to them [10]. However, those patients with slow growing (low grade) glioma on a "watch and wait policy" are a different scenario completely – they are the ones at risk of slipping through the follow up loop, with no point of contact. In my experience, I've found some patients are followed up by GP's only, others by neurologists, oncologists, neurosurgeons and/or specialist nurses, while some are without follow up at all. Personally, I feel the fragmented and uncoordinated care of these patients should be streamlined at a national level with minimum standards set and clear patient pathways, which should include regular follow-up with surveillance MRI scans and access to a clinical nurse specialist.

## Savings to the health economy

Nurse led telephone clinics, for example, provides an alternative approach to conventional outpatient clinics and ensures the focus is moved away from cancer surveillance to a model of patient centred support, with evidenced high patient satisfaction [11]. Recent studies have shown that referrals from GPs and Consultants to specialist nurse clinics are steadily on the rise with over 100,000 patients on average per year between 2005 and 2010. This proves specialist nurses have a much greater role today in the delivery of healthcare than they did even five years ago [12]. Furthermore, outside of the structured clinic format, it is estimated that specialist nurses field around 100 phone calls per week from patients, relatives and primary care workers. Telephone consultations also save £72,588 per nurse to the national health economy by reducing the number of GP appointments [13].

For the thousands of people across the UK living with long term conditions, including cancer, several studies have shown that specialist nurses are both clinically- and cost-effective [14]. A CNS specialising in cancer care will see an average of 13 follow-up patients per week in an outpatient setting. Matched against Department of Health tariffs this represents £53,040 in income and the potential release of 13 slots to new patients (raising £159,120 per 48 week year). This means CNSs working with cancer patients can speed up pathways, help trusts meet targets, allow new patients to be seen and therefore help generate more income [14].

Having demonstrated the value of the specialist nurse, both financially and in the delivery of healthcare, how can they be best utilised to help shape the healthcare of the future for brain tumour patients and to help improve outcomes?

## Service reconfigurations – The Cambridge Model

In Cambridge, we have successfully streamlined our neuro-oncology service in accordance with the recommendations from the IOG guidance regarding the key aspects of neuro oncology services that needed developing. This included establishing direct referral pathways, implementing a specialist MDT and having a dedicated neuro-oncology clinic headed up by subspecialised neurosurgeons [6]. Resulting from this reconfiguration, our service has evolved from being an unplanned, consultant centric process of care to one which is now mainly out-patient based, consultant led and patient centred [15]. This service reconfiguration, known as the Cambridge model, benefits patients by significantly reducing their length of stay, having a pre-planned surgery date to work towards, having a firm point of contact for the CNS's involved and allowing safe but early discharge home. Clinics headed up by not only the dedicated neuro-oncology consultants but two dedicated neuro-oncology specialist nurses allows for uninterrupted clinics to run on a weekly basis. The CNSs are able to assess the overall holistic wellbeing of patients and there is an opportunity for wound assessment, removal of surgical clips or sutures, steroid reduction and review of anticonvulsant medication. The clinic runs on the same day as the specialist MDT, allowing for patients to be rapidly reviewed the same day as their MDT discussion, thus minimising delays to their patient pathways and any treatment plans. At the core of all this, arranging admissions, discharges, onward treatment referrals, booking of scans and pre- / post-operative review is the specialist nurse. It has been estimated that nurse-led discharges facilitated by a streamlined service supported by the CNSs saves over £1,000.00 per patient in cost of inpatient stay and imaging [15].

## Neuro-oncology Nurse Consultant – scope for further improvements

Taking the Cambridge Model of reconfiguration one step further, it is clear to me that significant investments into neuro-oncology specialist nurses need to be made in order to ensure every patient diagnosed with a brain tumour has access to a specialist nurse to help manage not only their pathway as efficiently as possible, but to also provide vital support and information to them and their carers. Currently around 1/3 of all UK based Neuro-oncology CNSs are Macmillan funded [13] – myself included. I strongly believe that access to specialist nurses in the NHS is not something the charitable sector should finance; this is something the Government should fund.

Currently high on the agenda with lobbying groups, neuro-oncology working groups and the charitable sector is the issue of having access to neuro-rehabilitation and enabling timely transition to the community sectors for those patients needing on-going support and care away from the acute hospital environment [4,9]. Allowing patients to recover their maximal neurological potential and / or to die at home instead of in a hospital should be facilitated where feasible. In my opinion, these

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evolving roles are inevitably seen as belonging to the ever increasing remit of the CNS, stretching beyond the hospital environment into the community sector. In reality however, CNS's workload and time constraints prohibits them from fully engaging with this process.

In order to ensure patients fulfil the potential to optimise their neuro-rehabilitation and to be able to lead as long and fulfilling lives as possible, we need to ensure they are adequately assessed regarding their complex rehabilitation needs and in ensuring there is ample involvement with the community sector, even prior to discharge. This needs to be streamlined by someone specialising in neuro-oncology with firm leadership abilities and proven change management, and in my opinion this is the perfect time to consider introducing nurse consultants into the neuro-oncology field. It's time to make brain tumour patients stand head and shoulders above the parapet – so let's ensure neuro-oncology leads by example and let other cancer disciplines follow suit. It's time to make brain tumours count, both statistically and realistically.


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## PROBLEM SOLVED FOR HEART OF ENGLAND CLINICS

When the oncology departments at Heartlands, Good Hope and Solihull hospitals decided it was time to review their complex planning systems, little could executives have anticipated the improvements that lay ahead. Here, Denise Williamson, managing director at BookWise Solutions Ltd (pictured), explains how the software installed in the Oncology Day Units at the clinics in the Heart of England NHS Trust revolutionised facility booking practices, benefiting both staff and patients.

The previous paper-based scheduling system at the Heartlands, Good Hope and Solihull hospitals was very hard to manage, lacked transparency and required heavy user input. When a treatment was cancelled, inputting the change and making the relevant colleagues and patients aware of the cancellation could be painstakingly slow and laborious. Delays in making a cancellation often led to the wastage of expensive chemotherapy drugs, impacting on the patient experience and often resulted in difficulty rebooking facilities.

The working practices within Oncology across the three sites weren't streamlined, leading to unnecessary delays and staff feeling under pressure. Resources clearly could have been better used in improving services for patients.

Following the introduction of user-friendly BookWise software, the units started to make rapid improvements. Greater transparency meant that facility bookings were easier to secure and plan, enabling the streamlining of the patient journey. The reduction in waiting times between arrival and treatment was significant and made for a smoother experience for patients.

Software from BookWise has made the appointment process more efficient. The new booking system instantly recognises the stage in the care pathway of each patient, automatically recommending dates for the next phase of treatment and ensuring the appropriate equipment, staff and resources accompany each chemotherapy booking. The Oncology software has also helped in the reduction of drug wastage as staff can be made aware of cancellations before courses of treatment are prepared.

Oncology staff are happier too. Better scheduling has freed up more of the nurses' time, resulting in less pressure on individual workers and a calmer atmosphere, which has been noted by patients, who are feeling the benefit too.

Julie Bliss, lead chemotherapy and acute oncology nurse at Heartlands and Good Hope hospitals, said:

"I'm delighted to say that our working practices have improved considerably after switching to the new system. Everything's much easier to control now. Planning clinics is much more transparent and quicker than before, and morale has rocketed as a result. The pressure created by uncertainty and lack of co-ordination has been lifted from the staff's shoulders.

"BookWise has delivered positive change. It is simple to use and when called upon, the company's support staff have been excellent. Ultimately, the new software system is saving us time and money and helping create a smoother care pathway for our patients."

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