



### Box 1 World Health Organization classification of central nervous system tumours

- Tumours of neuroepithelial tissue.
- Tumours of the meninges.
- Tumours of cranial and paraspinal nerves.
- Lymphomas and haematopoietic neoplasms.
- Germ cell tumours.
- Tumours of the sellar region.
- Metastatic tumours.

(Louis *et al* 2007)

tumour types, but these are the most challenging. Some patients are impaired physically and mentally. They can lose the use of an arm or a leg. Sometimes if the cancer is near an optic nerve then patients can lose their sight. They can have complete personality changes, perhaps because of problems with speech or understanding, or they have difficulty balancing. We have some patients who are bed bound.'

She adds: 'You need to have resilience to work in this field although that probably isn't quite the right word because it makes you sound quite hard. But you have to have the skill. There are some horrifically sad cases among the patients. I meet with other neuro-oncology clinical nurse specialists - you have to be able to support each other.'

### Guidelines for all

The LCA guidelines are designed for use by all healthcare professionals, and cover initial assessment, investigation and management of patients. An important aspect is to reduce the time to diagnosis. There are sections on criteria for referral for possible early diagnosis, radiology, multidisciplinary team (MDT) membership and function, the role of the neuro-oncology clinical nurse specialist and palliative care. There are also sections on the use of chemotherapy and radiotherapy.

Each patient should have a named neuro-oncology nurse specialist, the guidelines state. This specialist nurse should be involved in 'all aspects of the disease journey, from diagnosis to end of life care, in both outpatient and inpatient settings.' Other aspects of the role include holistic needs assessment, communicating significant news, pain control and symptom management in collaboration with palliative care, carer support and assessment, referral for benefits and financial advice, and giving patients end of life choices.

A patient's nurse specialist should assign him/her a key worker, who co-ordinates care and promotes continuity, and ensures that the patient knows who to go to for information and advice. The LCA also argues that the first cycle of chemotherapy

Table 1 Brain, other central nervous system and intracranial tumours, UK, 2011

All people	New cases	Incidence rate per 100,000 people
England	7,490	12.0
Wales	669	17.2
Scotland	895	14.0
Northern Ireland	311	15.5
UK	9,365	12.5

(Cancer Research UK 2014)

should be performed by a consultant or specialty registrar, but that a nurse specialist who has passed the physical assessment and independent nurse prescribers' course can authorise subsequent cycles.

The guidelines emphasise that sometimes nurses who typically practise outside cancer need to be called on for advice. An epilepsy nurse specialist or consultant neurologist should be involved if a patient experiences seizures, for example, and diabetes nurses will be required if a patient develops raised blood sugar levels.

New drugs and treatments are being developed. Ms Johnson says: 'There are an increased number of trials testing new chemotherapy drugs. In other cancers, such as breast, there have always been a host of trials, but our branch has been the poor relation. It's rare and difficult to treat because there is a blood brain barrier that separates circulating blood from the brain extracellular fluid. This means it has been difficult to design drugs that can get into the brain to attack the tumours. Treatment options are very limited because of this.'

In 2009, Stupp and colleagues found patients with glioblastoma treated with concomitant and adjuvant temozolomide and radiotherapy had improved survival rates throughout five years of follow up.

'Radical surgery', which involves multiple operations to debulk tumours, is also improving patient outcomes, says Ms Johnson.

'What we can do as nurses and health professionals is to work together to improve the lives of patients, give them hope, and a fighting chance.'

### References

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