

Living with a Neurological Condition

Talk by Angela Collett of the Brain & Spine Foundation
at Spinal Cord Tumour Forum Meeting, 18th October 2014

1. What are we talking about -

Injury or illness to the brain or spine – CNS and peripheral nerves

Most of the causes of these conditions are unknown

No barriers – old, young, rich, poor, culture or ethnicity

2. Neurological Alliance – membership of 80 charities

Report this year – How many people in England have a neurological condition? First time this has been carried out -12.5 million, 19.5% of the UK population

Neuro numbers: <http://www.neural.org.uk/updates/235-New-report-reveals-the-true-impact-of-neurological-conditions>

List of diagnosis is endless but to name a few from each category;

Progressive conditions - MND, MS, dementias, ataxia, Rett syndrome

Sudden onset – meningitis, encephalitis, traumatic spinal injury

Intermittent - Cluster headaches, migraine epilepsy

Stable with changing needs – Transverse myelitis, cerebral palsy, spina bifida

The one area of medicine that has had the biggest impact on diagnosing neurological conditions is the advancement in scanning techniques.

3. Many of you wonder why you had to wait to see a neurologist or neurosurgeon. In the UK, NHS 300 neurosurgical consultants and 500 neurologists. They have been working on this deficiency for some time by training more doctors in this field, but it takes 10 years.

4. Things are moving. Dr. David Bateman June 2013 has been appointed as the 'Neuro Tsar'.

The new CCG's or local commissioning groups are asking for patient representatives in the area of neuro.

5. The Society of British Neurological Surgeons report is due October/November.

88% of all neurosurgeons are members.

Individual consultant's outcomes will be available to the public.

6. NICE have also contacted stakeholder organisations to sign up the review of brain and spine – CNS Tumours which was last up dated in 2006. This will take 1 or 2 years to complete.

7. Neurological Alliance undertook a Patients experience survey, which is the first step to looking at the gaps in research.

8. Brain tumour groups are very active in research. First brain tumour tissue database in UK – which will look at what treatment people receive, how where and when. As the brain has the same cells as the spine, it will have a knock on effect on the treatment of spinal tumours.

9. Research Clinical Trials database shows – 1 result for spinal tumours 10 for brain tumours

1% of Medical research council money goes on brain tumour research.

Brain Tumour Research is a group of 27+ charities raising money and awareness.

10. Treatment - Wait and watch

Surgery

Radiosurgery/cyberknife

Chemotherapy

11. Rehabilitation services – it is well known that there are not sufficient neuro rehabilitation services, more a lack of services, but CCG's are looking at the services and the gaps in provision.

12. But what about after hospital – you go home and get on with life with often limited support.

13. Clinical nurse specialist spinal surgery 4 in UK. 10 Brain tumour CNS.

Physio and OT in community generally offer 6 sessions.

There are GPs with a special interest in neuro, but they are rare.

14. Charities fill a gap in information and support, benefits and grants. Councils compile directories of local support. Neurological Alliance have regional campaign and support groups.

15. Hope this gives you an overview of the advances that are being made, but there is a long way to go.