



Life After Brain Injury A Way Forward

Summary of the Manifesto for Acquired Brain Injury | July 2012

Approximately one million people live with the effects of an Acquired Brain Injury (ABI) in the United Kingdom (UK).

When someone has a brain injury, acute and early access to specialist neurological services, including specialised neurological rehabilitation at a local level, is crucial to ensure optimal recovery.

Over a lifetime, optimal recovery results in significant savings in health care costs.

There is significant variation in the available services throughout the UK.

Recommendations documented in previous government and parliamentary reports and studies have not been acted upon.

To improve the lives of the one million people with ABI in the UK, the people affected, their carers and the professionals working in this field are asking for the following:

- Appropriate commissioning for specialist brain injury rehabilitation should be made compulsory and each clinical commissioning group should have a named neurological lead
- Funded National Neuro Networks should be established to ensure neurological pathways are available throughout the stages of recovery (patient journey)
- A National Audit of Rehabilitation should be carried out and the collection and reporting of accurate data on newly acquired brain injuries made compulsory by all providers along the patient journey, from Acute to Community Services *
- A review is required of The Health Select Committee Report into Head Injury and the National Service Framework (NSF) for Long Term Neurological Conditions.

* As implemented with Stroke through Healthcare Emergency Planning and the Care Quality Commission



James: “There are a lot of things I still want to improve on – I can’t really crack jokes because I can’t talk quickly enough. It is hard but it’s getting less and less so.”

James, a pilot for British Airways fell 18 feet over a hotel balcony onto a marble floor. He subsequently received a good co-ordinated rehabilitation programme.



Julie: “Life was terribly difficult and I didn’t understand why.”

Julie had a diabetic hypoglycaemia episode; her resulting brain injury was undiagnosed for two years. Eventually, on a vocational rehabilitation programme, it was explained that her brain had been affected. **“I began to learn about what had happened to me and I began to face it.”**



Heather: “If Heather had been discharged into the care of such a Service earlier, life could have been so much better.”

Ron’s wife had a deep vein thrombosis; the subsequent hypoxic brain damage left Heather needing 24/7 support. The couple moved to a different county to receive much needed rehabilitation and support which has made a huge difference to both their lives.

Acquired Brain Injury (ABI) is non-degenerative injury to the brain which has occurred after birth. It includes traumatic brain injuries (TBIs) such as those caused by road traffic accidents and non-TBIs, such as those caused by strokes and other vascular accidents, tumours and also infectious diseases.

Specialist Neurorehabilitation is the total active care of patients with a disabling condition and their families, by a multidisciplinary team (MDT) who have undergone recognised specialist training in neurological rehabilitation, supported by a consultant trained and accredited in neurorehabilitation medicine.

- **Accurate and reliable data is limited relating to the provision of healthcare services for ABI in the UK. In 2007 the National Institute for Clinical Excellence (NICE) estimated that the annual costs for TBI (not all types of ABI) are £1 billion for just the acute hospital care. The costs of rehabilitation and community care are difficult to estimate but probably total many multiples of the figure provided for acute care. In 2010 the cost of TBI in the UK was approximately £4.1 billion (Gustavsson *et al* 2011).**
- **Patients who have an early referral programme in the acute stages of recovery have significantly better social integration, emotional well-being and vocational functioning than those individuals receiving rehabilitation services later in recovery, despite having greater functional limitations upon entry (Reid-Arndt *et al* 2007).**
- **Integrated services and a MDT rehabilitation programme promote brain recovery and enable people to recover more quickly and efficiently (Turner-Stokes *et al* 2011).**

References:

Reid-Arndt S A, Schopp L, Brenneke L *et al*. Evaluation of the traumatic brain injury early referral programme in Missouri. *Brain Injury* 2007; 21 (12): 1295-1302.
Turner-Stokes L, Nair A., Sedki I *et al*. Multi-disciplinary rehabilitation for acquired brain injury in adults of working age (Review). 2011. The Cochrane Library 1.
Gustavsson A, Svensson M, Jacobi F *et al*. Cost of disorders of the brain in Europe 2010. *European Neuropsychopharmacology* 2011; 21(10): 718-779.
NICE Clinical Guideline 56. Head Injury: Triage, assessment, investigation and early management of head injury in infants, children and adults. Sept 2007.