



The United Kingdom
Acquired Brain Injury Forum

Manifesto for Acquired Brain Injury Rehabilitation

For further information please contact:

Chloë Hayward
UKABIF Executive Director
PO Box 355
Plymouth
PL3 4WD

Tel: 01752 601318
Email: ukabif@btconnect.com
Website: www.ukabif.org.uk

Index

- 3 Summary
- 3 Definition
- 3 Epidemiology
- 4 Causes, Consequences and Costs
- 5 What is Brain Injury Rehabilitation?
- 6 Previous recommendations on the need to focus on rehabilitation after ABI
- 8 What is needed to maximise the potential outcome for people with acquired brain injury?

Summary

When someone has a brain injury early access to local, specialist rehabilitation is crucial. Early treatment and support ensures the maximum recovery which, over a lifetime, makes significant savings to the state in health care costs.

Rehabilitation services for people with acquired brain injury in the UK are not good enough. There is unacceptable variation in access to services and their geographical availability.

Without rehabilitation the need for ongoing care or access to crisis management increases. Untreated affects of brain injury may be physical, social and emotional and may result in the need for other forms of care and support or may lead to offending behaviour.

Brain injury rehabilitation commissioned as a specialist service by people who have knowledge of the area and are working to provide co-ordinated services will reduce costs, relieve the burden on health, social and prison services and provide the best quality of life for thousands of people.

Previous recommendations in governmental and parliamentary reports and studies have not been acted upon.

Acquired Brain Injury - Definition

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

Acquired Brain Injury - Epidemiology

Brain injury is the leading cause of death and disability worldwide. Between 1- 1.4 million people attend hospital in the UK each year with a head injury and of these around 135,000 people are admitted. A low estimate is that approximately one million people living in the UK have had an acquired brain injury.¹

¹. Health Committee Third Report Head Injury: Rehabilitation, House of Commons Session 2000-1 HC307

Causes, Consequences and Costs

Causes

- Road Traffic Accidents account for 50% of all traumatic brain injuries.
- The leading causes of traumatic brain injuries vary by age: falls if 65 and older; transportation if less than 65 years.
- Sports related brain injury accounts for close to 300,000 injuries each year of which winter sports such as skiing account for close to 20,000.
- Assaults.
- Infection, disease and stroke also cause a large number of acquired brain injuries. Estimates for encephalitis alone amount to 4,000 new cases per year

Consequences

Brain Injury can cause many kinds of physical, cognitive, and behavioural/emotional impairments as shown below. They may be either temporary or permanent. Impairments may range from subtle to severe.

While some people may be physically disabled, the large majority have only 'hidden' disabilities, which are less easy to observe and, as a result, lead to misunderstanding, loss of employment, relationship breakdown and social isolation.

Costs

The costs to the state of acquired brain injury are difficult to estimate due to problems with the accuracy of the figures. An approximation is:

Assume admission for 2 days to an ordinary ward (£300/day) X 130,000 (see above) = £78 million/year.

Include high dependency (£2,000/day) and rehabilitation (£400/day). Add the costs of lost employment and social security to the State.

Total cost of brain injury in the UK = at least £1billion/year.

What is Brain Injury Rehabilitation?

Good quality rehabilitation is vital for proper recovery/maximum improvement after brain injury. There is very good evidence that a proper multidisciplinary rehabilitation programme promotes brain recovery and enables people to recover more quickly and more efficiently².

Typically someone will need a clinical neuropsychologist, neurological rehabilitation physician, occupational therapist, physiotherapist and a speech and language therapist. Sometimes other disciplines, such as an assistive technology expert, dietician, or employment rehabilitation expert will be involved and often a whole variety of medical professionals, such as an orthopaedic surgeon, neurosurgeon or urologist are needed. All these professions need to be properly coordinated so there is an interdisciplinary model of rehabilitation.

For many people the recovery period lasts many months and indeed the brain can take up to three years to recover naturally. For many people a 'slow stream' rehabilitation programme is necessary and ideally this should be provided by the same team with the same principles over a longer timescale.

When and where should rehabilitation be carried out?

- As soon as possible after the injury once the individual is medically stable.
- At an NHS 'post acute' rehabilitation centre though they are under severe pressure to move people on as there are a limited number of beds which are much in demand. Regrettably, in many parts of the UK there is no suitable rehabilitation facility and they may have to go home too early or go to inappropriate places, such as nursing homes where insufficient rehabilitation can be provided.
- Once at home or in new independent accommodation further rehabilitation may be needed for several more months and, for those with the most severe disabilities, lifelong support may be needed. This support is best managed by a brain injury case manager to coordinate the team. Sometimes support workers are needed to carry out the routine work of care and therapy under the supervision of the rehabilitation team.

It should be noted that services for those who have a medico-legal case often vary hugely from those whose brain injury had not been caused by negligence, with the latter often receiving slower and less appropriate care.

² Evidence of the effectiveness of MDT rehabilitation following brain injury Lynne Turner Stokes 2008

Previous recommendations on the need to focus on rehabilitation after ABI

Health Committee Third Report: Head Injury

In 2001 The Health Select Committee published their Third Report into Head Injury³. A list of 28 conclusions and recommendations were given. In almost every case these have not been taken forward.

The whole area would benefit from a wider inquiry (paragraph 2). No action.

DoH should find ways of improving the methods of data collection on incidence, prevalence and severity of head injury and subsequent disability, as a matter of urgency. In particular, they recommended that all health authorities should be required to collect data on head injury (paragraph 12). No action.

People with a suspected brain injury should be assessed by specialist staff and nursed in a location appropriate to their needs (paragraph 24). No action.

They recommended that guidance should be issued to all acute Trusts to ensure that head-injured people are treated, as soon as possible after medical stabilisation, in appropriately resourced rehabilitation beds where specialist rehabilitation staff could care for them and begin their rehabilitation interventions: this would yield long term savings, as well as benefits to patients (paragraph 25). No action.

All health authorities and trusts to plan care pathways for head-injured people to enable them to move through the system as quickly as is appropriate, releasing acute beds for other patients and increasing their own potential to improve (paragraph X). No action.

Health authorities and trusts to improve their data on the incidence and prevalence of head injury in their catchment area, by better collation and maintenance of data (paragraph 26). No action.

Every head-injured person admitted to hospital to leave with a clear care plan mapped out for him or her (paragraph Y) No action

The Government should spell out clearly what steps it will take to improve the situation in the provision of rehabilitation services for head-injured people (paragraph Z). No action

National Service Framework for Long Term Conditions - 2005

The national service framework (NSF) for long-term conditions was a 10-year strategy to transform the way health and social care services support people with long-term neurological conditions to live as independently as possible.

The framework aims to improve care and to ensure that effective and high quality services are available uniformly across England by giving local NHS and social care organisations clear

³ Health Committee Third Report Head Injury: Rehabilitation, House of Commons Session 2000-1 HC307

Brain Injury Rehabilitation Manifesto November 2011

standards and quality requirements as well as supporting them through sharing good practice and evidence about what care works best for patients.

The NSF was developed to ensure that services are:

- Quicker and easier to use.
- More closely matched to people's needs.
- Better coordinated so that people do not have to see a lot of different professionals and repeat the same information about themselves.
- Provided for as long as people need them, so that treatment continues without the need for a referral every time the person has a new problem.
- Better at helping people with neurological conditions and their carers to make decisions about care and treatment.
- Provided by people with knowledge and experience of specific conditions.
- Giving people with long-term neurological conditions better results from their treatment.
- Planned around the views of people with long-term neurological conditions and carers.
- Able to give people more choice about how and where they get treatment and care.
- Better at helping people to live more independently.

NHS and social care services were expected to deliver each of the quality requirements by 2015. However, no timescales or budgets were allocated to the NSF and although many organisations use the framework to guide their work recent guidance from the Government is that if health authorities cannot afford to deliver the quality requirements in the suggested timeframes they should not worry about it.

The Major Trauma Study - 2010

In 2010 The Major Trauma Study was published. The study strongly advocated that appropriate rehabilitation services are paramount to the smooth running of the trauma network and best outcomes for the patient. Professor Keith Willett, Director of Trauma Services in the UK has spoken several times on the need for efficient rehabilitation and has undersigned this manifesto.

Extracts from the Major Trauma Study

- *Rehabilitation may help to reduce length of hospital stay, minimise readmissions and reduce the use of NHS resources following the initial period of hospitalisation.*
- *There is a widely perceived lack of capacity for the specialist rehabilitation of major trauma patients, but with little hard evidence about what services are currently available and how well they are arranged to meet patient needs⁴*
- *If the regional trauma networks which are now planned are to be successful, Trusts need to have appropriate funding arrangements that facilitate easy transfer of patients to more specialist care and rehabilitation'*

⁴ Summary of Major Trauma Care in England, NAO, H213 section 12

What is needed to maximise the potential outcome for people with acquired brain injury?

Appropriate Specialist Commissioning for Rehabilitation

- Each Clinical Commissioning Group to include a named neurological lead/champion who should ensure that people with Acquired Brain Injury have early access to local, quality neuro-rehabilitation services.
- Neuro Networks throughout the UK would lead to better commissioning. A good example of a network is the North East Neuroscience Network (NENN) which works collaboratively across agencies, professional groups, user and carer groups and the voluntary and independent sector to help develop a more integrated service. By bringing together commissioners and care providers the NENN have:
 - been able to focus on the major core issues
 - ensure that appropriate services are routinely commissioned
 - make long term savings

Use of Accessible and Up To Date Information

Commissioners, clinicians and those with ABI and their families need to know where to find good quality, appropriate and preferably local services. As an example UKABIF is with the financial assistance of a private sponsor developing a national website which will host an interactive map of all services available in a localised and easy to use format. It will:

- include a description of the stage of rehabilitation or support the service provides on the neurological pathway (patient journey).
- mean that commissioners are immediately able to find appropriate local services for all stages of rehabilitation provided by the NHS, private and charitable sector.
- run on information provided voluntarily through regional acquired brain injury fora.

A National Audit of Rehabilitation

In the same way that Trauma services were audited in 2010 the National Audit Office should research the need for the costs of and the availability of rehabilitation services for acquired brain injury in England.

A Review of the Health Select Committee Report and the National Service Framework (NSF) for Long Term Conditions

The 2001 Health Select Committee report should be reviewed and the actions revisited.

The NSF should be reviewed within the current reorganisation of the health care system. (see supporting evidence)

Screening of Offenders

ABI has a high incidence amongst offenders and may lead to reoffending behaviour. Brain injury rehabilitation is not provided in the prison service and screening is inadequate. Early screening should be introduced with access to appropriate rehabilitation will reduce re-offending.^{5,6}

⁵ Williams, W.H., Cordan, G., Mewse, A., Tonks, J. & Burgess, C (2010) Self-Reported Traumatic Brain Injury in Male Young Offenders: A risk factor for re-offending, poor mental health and violence? *Neuropsychological Rehabilitation*, 20 (6), 801 - 812.

⁶ Traumatic brain injury in a prison population: Prevalence and risk for re-offending
W. H. Williams, A J. Mewse, J Tonks, S Mills, C N. W. Burgess, & G Cordon
School of Psychology, University of Exeter, Exeter, UK
Received 14 December 2009; revised 5 May 2010; accepted 12 May 2010) *Brain Injury*, 2010