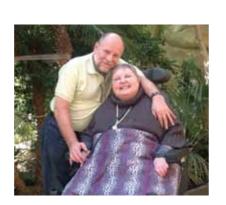
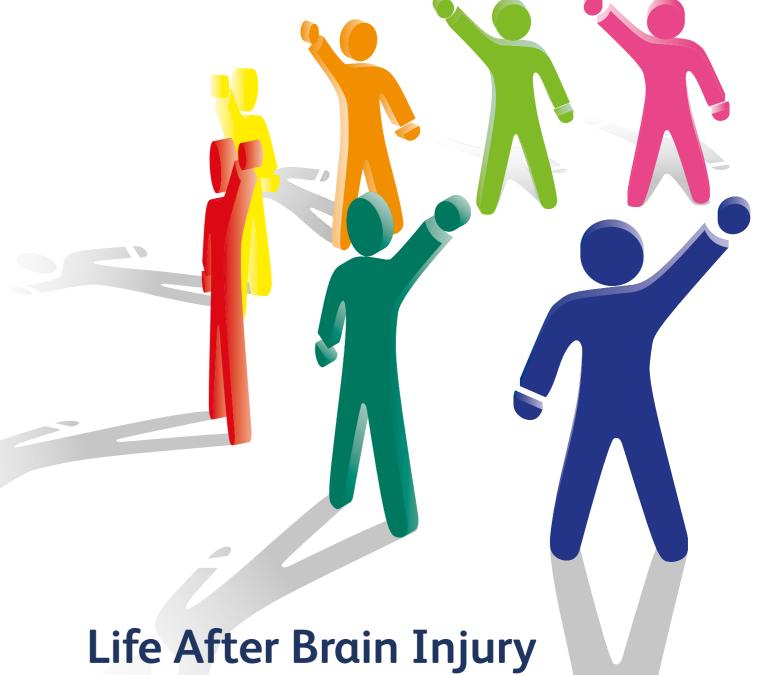


A Way Forward...









Life After Brain Injury
A Way Forward

Manifesto for Acquired Brain Injury July 2012

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Summary

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

- O Appropriate commissioning for specialist brain injury rehabilitation should be made compulsory and each clinical commissioning group should have a named neurological lead
- O 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 *
- O A review is required of The Health Select Committee Report into Head Injury and the National Service Framework (NSF) for Long Term Neurological Conditions.

FACTS YOU NEED TO KNOW

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.

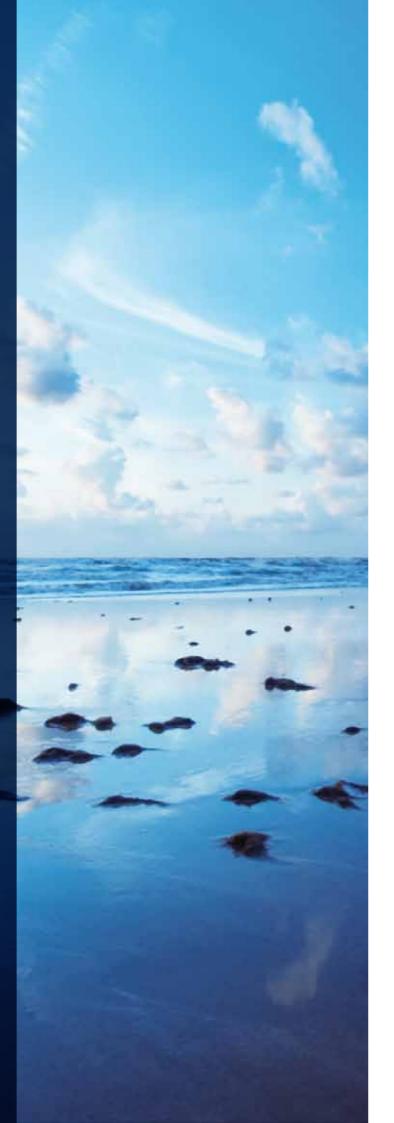
^{*} As implemented with Stroke though Healthcare Emergency Planning and the Care Quality Commission

Introduction

Approximately one million people live with the effects of an acquired brain injury (ABI) in the United Kingdom (UK). People with ABI require specialist rehabilitation services and support both in hospital and the community. Rehabilitation services vary hugely around the UK; this variability is having a detrimental impact on the lives of people with ABI and action is required to change this situation and improve services throughout the UK.

This Manifesto outlines the necessity of acute and early access to rehabilitation for adults with ABI to ensure optimal recovery, focussing on the need for specialist neurorehabilitation teams to manage care pathways, the cost implications of not providing adequate rehabilitation and illustrating just some of the issues with the experiences of several people living with an ABI. It is recognised that stroke services are well established in many areas of the UK and are therefore not included in the demands of this document. Children and young people with ABI are outside the scope of this document.

The UKABI Forum (UKABIF) is campaigning for improved rehabilitation services and support for people with ABI. UKABIF has worked with many individuals and organisations to develop this document and has endeavoured to encompass all viewpoints on this diverse and complex healthcare area. This Manifesto recommends a way forward for professionals, service providers, planners and policy makers to maximise the outcome for people with ABI.



Acquired Brain Injury

Definition

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.

Epidemiology

Brain injury is the leading cause of death and disability worldwide. Between 1.0 – 1.4 million people attend hospital in the UK annually with a head injury and of these approximately 135,000 are admitted to hospital. A low estimate is that

Approximately one million people live with the effects of an Acquired Brain Injury in the UK.

approximately one million people living in the UK have had a head injury but this does not include the much higher figures for all ABIs (Health Committee 2000-1).

The lack of accumulated data in the UK means it is not possible to quantify the numbers and proportions of people with ABI in each area.

Causes

Brain injury has a wide range of causes ranging from traumas incurred through falls, assaults, road traffic accidents and sports injuries, to damage caused by stroke and disease. In some cases the brain is damaged due to lack of oxygen, which may occur during a heart attack.

A National Audit of Rehabilitation is required together with the collection and reporting of accurate data on newly acquired brain injuries by all providers along the patient journey, from Acute to Community services.

Consequences

Brain injury can cause many kinds of physical, cognitive, social and behavioural/emotional impairments. They may be either temporary or permanent. Impairments may range from subtle to severe, although the consequences may all be serious.

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

Rehabilitation

Definition

Rehabilitation is a process of assessment, treatment and management by which the individual is supported to achieve their maximum potential for physical, cognitive, social and psychological

Appropriate commissioning for specialist brain injury rehabilitation should be compulsory and each clinical commissioning group should have a named neurological lead.

function, participation in society and quality of living. It is a goal-focussed learning process to optimise functional recovery, disability management and adaptation to loss and change. Patient goals for rehabilitation vary according to the trajectory and stage of their condition (Turner-Stokes *et al* 2008, 2010).

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. Such specialised neurorehabilitation is a front-loaded, high cost treatment but maximum recovery over a lifetime, results in significant savings to the state.

Acute and Early Access to Rehabilitation Services

Acute and early access to specialist neurological services, including specialised neurological rehabilitation at a local level, is crucial to ensure optimal recovery.

When someone has a severe brain injury they are usually admitted as an emergency to hospital where every effort is made to stabilise their condition. Over past ten years resuscitation techniques and emergency care have improved dramatically so many more people now survive severe brain injury and damage. Rehabilitation after an ABI should

start acutely to prevent complications, with the patient's care pathway clearly defined, and referral to a local specialist neurorehabilitation service at the earliest opportunity; this is crucial and often overlooked.

Clinical Evidence

Patients who had 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). In addition a study by Turner-Stokes (2008) demonstrated the effectiveness of early intensive rehabilitation with specialist programmes for those with complex needs, and specialist vocational programmes for those with potential to return to work.

Residential, social and behavioural rehabilitation programmes can decrease the number of care hours needed, which also increases the brain injured person's capacity for independent social activity, however this benefit reduces over time (Wood *et al* 1999). In a study up to two years post-injury, patients showed a 54% reduction in the care hours required compared to pre-admission; clients between two and five years post-injury showed a 33% reduction, and clients over five years post-injury showed a 21% reduction (Wood *et al* 1999).

Rehabilitation Programme

The extent and nature of rehabilitation programmes vary enormously due to the complexity of the brain, nature and severity of injury and time of diagnosis. Damage to the brain affects people in many different ways and therefore rehabilitation should be tailored according to the individual's needs.

After injury there is a period of spontaneous recovery of the brain, but it can take long periods for the brain to reach its maximum recovery and many people will never recover fully. If rehabilitation does not take place immediately, an individual with a brain injury can still benefit from rehabilitation months or even years after the injury has taken place (see Julie's case study). A 'slow stream' rehabilitation programme is necessary for most people with ABI as it allows adaptation and the development of compensatory strategies over time.

If someone has been assessed as needing rehabilitation they should be referred to a 'post-acute' rehabilitation centre. However, in many parts of the UK there is no suitable rehabilitation facility and people with brain injuries may have to go home too early or go to inappropriate places, such as nursing homes, where insufficient rehabilitation can be provided. In addition, NHS rehabilitation facilities are under severe pressure to move people on as there are a limited number of beds available.

The independent sector provides much of the high quality brain injury rehabilitation available in the UK. A number of organisations offer specialist facilities and

There is significant variation in available services throughout the UK.

provide services to meet the needs of a range of people with ABI including the most difficult cases, which often involve behavioural problems.

Clinical Evidence

Following a specialist rehabilitation programme, ABI patients show significant reduction in dependency at discharge, as measured by the Functional Independence Measure (Turner-Stokes *et al* 2006). More intensive rehabilitation is associated with rapid functional gains once the patient is able to engage (Turner-Stokes *et al* 2011). Highly dependent patients with severe TBI can make sufficient functional gains, but they need longer lengths of stay and more intensive treatment. The study by Turner-Stokes *et al* (2011) concluded that the rehabilitation programme needs to be moulded to the severity of the brain injury.

A systematic review by Cicerone *et al* (2011) of 370 interventions found substantial evidence to support interventions for memory, social communication skills, executive function and comprehensive holistic neuropsychological rehabilitation after TBI. The evidence also supported visuospatial rehabilitation and interventions for aphasia and apraxia after stroke. This review suggests that there is sufficient information to support evidence-based protocols and implement treatments for cognitive disability after ABI. Another systematic review by Guertsen (2010) of comprehensive rehabilitation programmes after severe brain injury provided evidence supporting the effectiveness of day-treatment programmes on daily life functioning and community integration. Other studies on residential treatment have showed positive changes in daily life functioning, community integration, employment and social participation, with functional gains maintained at one-year follow-up. A neurobehavioural treatment programme showed improved functioning in living accommodation, employment and hours of care needed.

Comprehensive holistic neuropsychological rehabilitation i.e. integration of cognitive, interpersonal and functional interventions within therapeutic environment, is effective in improving community functioning and quality of life, compared to standard MDT rehabilitation after moderate to severe TBI (Cicerone *et al* 2008). An intensive cognitive rehabilitation

programme proved effective on the Community Integration Questionnaire and in overall neuropsychological functioning, compared to standard neurorehabilitation after TBI. Satisfaction with cognitive functioning made a significant contribution to post-treatment community integration, potentially reflecting the mediating effects of perceived self-efficacy on functional outcome (Cicerone *et al* 2004).

A social and behavioural post-acute rehabilitation programme substantially decreased the hours of care required by clients, suggesting rehabilitation can effectively increase a brain injured person's capacity for independent social activity (Wood *et al* 1999).

The Role of the Multidisciplinary Team

The person with ABI will require support from a MDT with an expertise in neurorehabilitation comprising a core medical team and additional professionals depending on the nature of the brain injury (see Table 1).

Table 1: Rehabilitation multidisciplinary team Core medical team Additional healthcare team Neurorehabilitation consultant Orthopaedic surgeon Clinical neuropsychologist Neuroendocrinologist Occupational therapist Neurosurgeon **Urologist** Physiotherapist Speech and language therapist Neuropsychiatrist Nurse/professional care staff Assistive technology expert Dietician Employment rehabilitation expert

Integrated services and a MDT rehabilitation programme promote brain recovery and enable people to recover more quickly and efficiently (Turner-Stokes *et al* 2011). The team should be led by Allied Health Professional specialists e.g. a physiotherapist with access to a Consultant in Neurorehabilitation over a timescale that is determined by the patients' progress and gains.

Clinical Evidence

The New Zealand Guidelines Group (2006) showed that the delivery of rehabilitation is most effective when done by a co-ordinated MDT of people from a range of different disciplines. This enables individual 'case managers' to support the individual and their family throughout the duration of recovery.

A systematic review by Turner-Stokes *et al* (2008) provided grade A evidence from five studies supporting early co-ordinated MDT rehabilitation leading to better outcomes and a reduced length of stay in hospital. The review also demonstrated evidence for community, milieu-based rehabilitation for residential programmes in transitional units, day care programmes and outpatient programmes: eight studies provided grade A evidence for increased productivity, reduced levels of supervision, improved societal participation and neuropsychological adjustment. The stability of the effects was three years post-injury. Additionally grade A evidence from six studies demonstrated the effectiveness of specialist inpatient rehabilitation and three studies of specialist vocational support programmes provided evidence for the effectiveness of supported employment, achieving improved productivity and return to paid employment in a proportion of clients.

Community Rehabilitation and Support Services

For a significant proportion of people, long-term rehabilitation and support services in the community are required. These services need to be specialist and again involve the MDT (see Table 1). Ideally the rehabilitation services should also be part of an integrated system with social services and include resources and support for the family members/carers providing ongoing care and support. A great deal of work is done by the third sector working collaboratively with the NHS and other providers. They are often able to plug the gap between NHS and social care and provide support and services for people with ABI and their families.

In addition, local Social Services should provide follow-on support ensuring the availability of support workers, increasingly through Direct Payments or Personal Budgets. Headway – the brain injury association, provides important social rehabilitation and long-term peer support to survivors and carers and family members, but limited funding restricts the charity's capacity to provide support services in some parts of the UK.

Some people will need supported accommodation, with knowledgeable support onsite or otherwise readily available. Others, who are unable to be supported in their own homes, will need local specialist residential accommodation. Returning to work is very important, either to previous employment or, if this is not possible, in some other form of productive activity. It provides opportunities to rebuild self-esteem and re-integrate into society, as well as the more obvious potential financial benefits. In addition to the small number of specialist brain injury vocational rehabilitation service providers, which include Headway Centres in some areas, there is scope for community brain injury teams and others to increase such rehabilitation and support.

Neuro Networks

Funded National Neuro Networks should be established to ensure neurological pathways are available throughout the stages of recovery (patient journey). We believe that building Neuro Networks throughout the UK would lead to better commissioning for people with ABI. A good network is commissioning led and 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, networks are able to focus on the major core issues ensuring that appropriate services are routinely commissioned and long-term savings are made. In terms of ABI this means raising the unique needs of people with sudden impact /quick onset brain injury which are so different to degenerative conditions.

Cost Implications

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 are £1 billion for just the acute hospital care and this does not include all types of ABI. 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 (so still an underestimate for ABI) was approximately £4.1 billion (Gustavsson et al 2011).

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

Published studies clearly show that by providing rehabilitation, the savings made offset the costs, even when rehabilitation is not carried out immediately after injury. Over a lifetime, optimal recovery results in significant savings to health care costs.

Clinical Evidence

The cost of high dependency patients on admission to a long stay rehabilitation programme (125 days+) can be offset by an average weekly saving in costs within 36 months (Turner-Stokes 2007). Turner-Stokes et~al~(2006) also showed that high dependency patients incur a reduction in weekly costs of £639 per week following a longer stay, specialist rehabilitation programme and the time taken to offset the cost of rehabilitation was 16.3 weeks. In a separate study by Worthington et~al~(2006) the initial costs of a neurobehavioural rehabilitation programme were offset by savings in care costs within two years, and the cohort were expected to live for another 30-35 years on average with evident long-term benefits of rehabilitation. Assuming inflation, Wood et~al~(1999) calculated that rehabilitation in first two years post-injury saves care costs over a lifetime of £1,350,000. In terms of clinical and cost effectiveness, it is still worthwhile to offer rehabilitation more than two years post-injury (Wood et~al~1999), costs rise and savings projections fall the longer the payee waits post-injury to start rehabilitation. Post- rehabilitation, patients are three times more likely to be able to live in the community.

Information Requirements

Healthcare professionals, commissioners and those with ABI and their families need to know where to find good quality, appropriate and preferably, local services.

Many third sector organisations provide excellent information and support for patients and families. In addition to Headway, others supporting brain injury include The Child Brain Injury Trust, The Children's Trust, The Brain and Spine Foundation, The Meningitis Trust and The Encephalitis Society.

The UKABIF is helping to develop a national website called BrainNav which will host an interactive map of all brain injury services, searchable by region. It will include a description of the stage of rehabilitation or service support provision on the neurological pathway (patient journey). Commissioners will instantly be able to find the appropriate local services for all stages of rehabilitation and support provided by the NHS, private and charitable sectors. The information will be provided voluntarily through regional ABI Forums.

Existing Recommendations

Health Select Committee Third Report: Head Injury

In 2001 The Health Select Committee published their Third Report into Head Injury (Health Select Committee 2000-1). A list of 28 conclusions and recommendations were given – most of which have not been acted upon. The following eight points are taken from the list of recommendations.

- O The whole area would benefit from a wider inquiry. NO ACTION
- O The Department of Health 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. NO ACTION
- People with a suspected brain injury should be assessed by specialist staff and nursed in a location appropriate to their needs. **NO ACTION**
- O 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. NO ACTION
- O 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. NO ACTION

The Health
Select
Committee
Report should
be reviewed.

- 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. NO ACTION
- Every head-injured person admitted to hospital to leave with a clear care plan mapped out for him or her. 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. NO ACTION

National Service Framework for Long Term Neurological Conditions

The National Service Framework (NSF) for Long Term Neurological Conditions was a 10-year strategy designed 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 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:

O Quicker and easier to u	0	Quicker	and	easier	to	use
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- O More closely matched to people's needs
- O Better co-ordinated 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
- O 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
- O 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 be expected to deliver each of the quality requirements by 2015. However, no timescales or budgets were allocated to

The NSF for Long Term Neurological Conditions should be reviewed.

the NSF. Many organisations use the framework to guide their work, but with some notable exceptions, there has been very little progress made by the NSF.

Major Trauma Care in England

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.

Extracts from the Major Trauma Study

- Rehabilitation may help to reduce length of hospital stay, minimise re-admissions 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 needs
- 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

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

Case Studies

The following case studies illustrate the different circumstances and experiences of people with acquired brain injury and demonstrate the effectiveness of an early, specialist rehabilitation programme.



James's Story

James Heather was a pilot for British
Airways when he fell eighteen feet over a
hotel balcony onto a marble floor. After an
emergency operation James remained in
a coma for several weeks and took some
time to regain consciousness. He received
some physiotherapy and hydrotherapy in
hospital and was eventually transferred
into a wheelchair. James moved to
Northwick Park – a specialist NHS
Rehabilitation Unit – where he stayed for
almost a year. There he had more intensive
physiotherapy treatment as well as speech
therapy and psychological intervention.

James had severe visual and speech problems and he was told he would never walk unaided again, but he refused to accept this. A year after the accident he took his first steps.

As a transitional step to returning home, James moved to the Transitional Living Unit at The Royal Hospital for Neuro-disability in Putney. He followed a goal-centred programme which focussed on the skills he would need to live independently and the team worked with James, his family and Fulham social care to arrange ongoing support once he was back in his own home. James supplemented his therapy with swimming lessons and he worked hard on his speech, taking various private speech and singing lessons.

Thanks to a good co-ordinated rehabilitation programme and his own drive and determination, James has made a remarkable recovery. He lives in his own flat, can walk almost normally and works voluntarily for a local charity.

"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 and I'd like to be able to carry things with my right hand while I'm walking. Also it's difficult for me to talk in a group when there is background noise. It is hard but it's getting less and less so."



Julie's Story

Julie's brain injury was undiagnosed for two years and during this time she lived in chaos and lost her job. "Life was terribly difficult and I didn't understand why" said Julie.

Julie Curtis has had diabetes for most of her life. In November 1999 she had a diabetic hypoglycaemia episode; her vision, speech and mobility were affected and she experienced pressure and swelling to her head and face. Julie was not hospitalised but endeavours were made to stabilise the diabetes. She spent the following months on her bed at home, with family and friends caring for her. Health professionals were repeatedly asked for an opinion, and on one occasion Julie was told a few brain cells may have been damaged but that the effects would pass.

For two years Julie lived in chaos – her memory was affected and she found it hard to plan and organise her time. She had difficulty with sustaining her attention and the speed at which she was able to process information was very slow. All of this, in addition to severe problems with her sight – and all with no explanation. Work was impossible and she lost her job.

She received Incapacity Benefit, but she desperately wanted to return to the career

she loved in horticulture. Eventually Julie saw a Disability Employment Advisor who by pure chance had attended a training day on ABI at the Queen Elizabeth Foundation for Disabled People (QEF) in Surrey. He arranged for Julie to join their Vocational Rehabilitation Programme.

"Attending the QEF was an utter relief.
From the outset they understood me
and what I was going through. It was
explained to me that my brain had been
affected by the hypoglycaemia. I began
to learn about what had happened to me
and I began to face it. With support from
the QEF I started to learn how to deal
with my condition."

The rehabilitation programme included voluntary work experience, as a stepping stone to getting back to work.

Julie would like to return to work but the complexities of the welfare system make this very difficult for her. When she finished her Vocational Rehabilitation Programme she continued working as a volunteer, increasing her hours slowly and building up her stamina. After four months her employer suggested she should be paid for the hours she worked. "'I was delighted with the response – what a confidence boost!" she said.'

Attending the QEF was an utter relief. From the outset they understood me and what I was going through. It was explained to me that my brain had been affected by the hypoglycaemia. I began to learn about what had happened to me and I began to face it. With support from the QEF I started to learn how to deal with my condition.

Information contributed by Julie's GP enabled her to receive the Therapeutic Earnings Benefit which enabled payment for some of the hours she worked, whilst continuing to receive Incapacity Benefit. The paperwork and forms to be completed were difficult to understand and Julie was conscious that as she increased her hours at work, eventually up to the maximum of 14 hours per week, she was becoming more exhausted and had no energy for anything else.

In March 2002 she was informed that 'Therapeutic Work' was being replaced by 'Permitted Work.' The paperwork which was sent to her was confusing. She approached the Disability Employment Officer for help, and was told that the support organisations were unable to start work with her 'due to a full caseload of candidates.' The Benefits Agency did not have email addresses and had no comprehension that as a brain injured person, Julie's processing is very slow – so telephone conversations were not possible.

Julie was given a time limit but became exhausted by the complexity of what she was being asked. She did not submit the information which was needed and her Incapacity Benefit was stopped. A very difficult period followed – she was told rules were rules, and there were no exceptions. "I pleaded for help and tried to explain that I had a brain injury and have difficulty processing words. I really needed help and support and I wanted to get off benefits, but I could not do so within the time frame" she said.

Eventually Incapacity Benefit was reinstated and Permitted Work was extended. A space arose with a support organisation called Status Employment and they became Julie's Access to Work Advisor. They assisted with the paper work element of Julie's job for a few hours each week. But the time limit on Permitted Work meant Julie reached a point where it could not be extended. It was acknowledged this was wrong for those with ABI who generally need more time. Ultimately The Benefits Agency presented Julie the choice of either staying on or coming off benefits. Julie didn't see how she could live on the pay from 14 hours work per week. and physically she could not increase the number of hours. All the information she found was confusing and she didn't know where to go for the assistance she needed.

"It felt that I had to take the easiest, but heart breaking, option of returning to Incapacity Benefit alone."

Heather & Ron's Story

In June 2001, Heather and Ron Payne had just returned from a holiday in Spain when Heather noticed a pain in her left leg. On investigation it became clear that this was a circulation problem and deep vein thrombosis was diagnosed.

In hospital a catheter was inserted into Heather's neck to stop pieces of the blood clot breaking off and travelling round the system. The procedure did not

go smoothly and a haematoma (collection of blood) formed around the neck punctures which began to swell. By the next day Heather was finding it hard to swallow and could only take water by letting ice cubes melt in her mouth. During the night Heather's airway was compromised and she suffered a respiratory and cardiac arrest.

After a few worrying weeks Heather began to respond and slowly improved, although major difficulties resulted

from the hypoxic brain damage (lack of oxygen to the brain). In September 2001 Heather was transferred to a rehabilitation unit and the physio team worked her hard but sympathetically through a painful routine in the gym and the therapy pool.

After six months Heather returned home. At first, daily home carer support and visits to the hospital day unit were provided. But many facilities, such as hydrotherapy, were

> not accessible and visits to the day unit became a wasted effort as she often sat alone with a magazine open on the table in front of her, possibly unable to read and definitely unable to turn the pages.

Heather was assessed as needing 24/7 support – she received 45 minutes help in the morning, 30 minutes in the evening and nothing at weekends. She was provided with a bed, a hoist and a commode.

Heather was doubly incontinent and required hoisting onto a commode several times each night. There was a 12 month waiting list for a stair lift. The social worker from the hospital relinguished responsibility for Heather as soon as she was discharged and there was no follow-up from the local authority or the neurologist.

Through family contacts Heather's husband Ron was put in touch with the Northumberland Head Injury Service (NHIS) who arranged a meeting to assess Heather's needs. The approach of NHIS is simple. They provide everything under one roof, through one specialised team, in one package controlled by a dedicated case manager – to client, family and carer. Ron and Heather lived in Staffordshire but the idea of this package of care sounded so good that they 'upped sticks' and moved to Northumberland.

The difference was incredible. Overnight, in addition to carers, Ron and Heather had access to: physiotherapy, occupational and speech and language therapy, a psychologist, an accessible and approachable consultant, day centre activities, welfare and benefit advice and a cup of tea and someone to talk to.

Within two weeks Heather had a stair lift and, during the interim, two volunteers to carry her up to bed at night. After Heather's claim was settled, Ron and Heather set up their own team of carers and they are now their friends, family and confidants.

"Heather's improvement was miraculous and it felt like getting at least part of the old Heather back again. If Heather could have been discharged into the care of such a Service earlier, life could have been so much better."

New Zealand Guidelines Group. Traumatic brain injury: Diagnosis, acute management, and rehabilitation. 2006.

References

Cicerone K D, Langenbahn D M, Braden C et al. Evidencebased cognitive rehabilitation: Updated review of the literature from 2003 through 2008. Archives of Physical Medicine and Rehabilitation 2011; 92 (4): 519-530.

Cicerone K D, Mott T, Azulay J et al. Community integration

and satisfaction with functioning after intensive cognitive rehabilitation for traumatic brain injury. Archives of Physical

Cicerone K D, Mott T, Azulay J et al. A randomized controlled trial of holistic neuropsychologic rehabilitation after traumatic brain injury. Archives of Physical Medicine and

Geurtsen G J, van Heugten C M, Martina J D and Alexander C

H. Comprehensive rehabilitation programmes in the chronic phase after severe brain injury: A systematic review. Journal

Health Committee Third Report Head Injury: Rehabilitation,

Major Trauma Care in England, NAO, 2010, H213 section 12.

National Service Framework for Long-Term Neurological

Medicine and Rehabilitation 2004; 85 (6): 943-950.

Rehabilitation 2008; 89 (12): 2239-2249.

of Rehabilitation Medicine 2010; 42 (2): 97-110.

Gustavsson A, Svensson M, Jacobi F et al. Cost of

disorders of the brain in Europe 2010 European

House of Commons Session 2000-1 HC307.

Conditions. 2005. Department of Health.

Neuropsychopharmacology 2011;21(10):718-779.

Wellington (New Zealand): New Zealand Guidelines Group. NICE Clinical Guideline 56. Head Injury: Triage, assessment,

investigation and early management of head injury in infants, children and adults. Sept 2007.

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. Cost-efficiency of longer-stay rehabilitation programmes: Can they provide value for money? Brain Injury 2007: 21 (10): 1015-1021.

Turner-Stokes L. Evidence for the effectiveness of multidisciplinary rehabilitation following acquired brain injury: A synthesis of two systematic approaches. Journal of Rehabilitation Medicine 2008; 40 (9): 691-701.

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.

Turner-Stokes L, Paul S and Williams H. Efficiency of specialist rehabilitation in reducing dependency and costs of continuing care for adults with complex acquired brain injuries. Journal of Neurology, Neurosurgery & Psychiatry 2006; 77:634-639.

Wood R L, McCrea J D, Wood, L. M et al. Clinical and cost effectiveness of post-acute neurobehavioural rehabilitation. Brain Injury 1999; 13 (2): 69-88.

Worthington A D, Matthews S, Melia Y et al. Cost-benefits associated with social outcome from neurobehavioural rehabilitation. Brain Injury 2006; 20 (9): 947-957.

