Information for Patients, Relatives and Carers regarding Rehabilitation for Patients with Acquired Brain Injury

Governance Department

Patient Information Leaflet
## Contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>Introduction</td>
</tr>
<tr>
<td>3</td>
<td>Physiotherapy</td>
</tr>
<tr>
<td>4</td>
<td>Psychology</td>
</tr>
<tr>
<td>5</td>
<td>Speech and Language Therapy</td>
</tr>
<tr>
<td>6</td>
<td>Psychiatry</td>
</tr>
<tr>
<td>6</td>
<td>Occupational Therapy</td>
</tr>
<tr>
<td>7</td>
<td>Social Work</td>
</tr>
<tr>
<td>8</td>
<td>Others</td>
</tr>
<tr>
<td>9</td>
<td>Some Local Sources of Information and Support</td>
</tr>
<tr>
<td>13</td>
<td>Further Information on Common Benefits Claimed Following a Brain Injury</td>
</tr>
<tr>
<td>14</td>
<td>Useful Telephone Numbers</td>
</tr>
<tr>
<td>15</td>
<td>After Hospital: Rehabilitation</td>
</tr>
<tr>
<td>16</td>
<td>Nursing / Care Homes Offering Support to People with Acquired Brain Injury</td>
</tr>
<tr>
<td>19</td>
<td>Standard Leaflet Information</td>
</tr>
</tbody>
</table>
Introduction

An **Acquired Brain Injury** (ABI) is an injury caused to the brain since birth. There are many possible causes, including a fall, a road accident, tumour and stroke. The aim of this document is to ensure that people who may require rehabilitation following an acquired brain injury are able to access the services they require and to understand the benefits they are entitled to claim.

It does not matter how the person has acquired a brain injury - but it does matter that the person and their family have help, advice and support.

Information

Following a brain injury a person may need the input of various specialist services. The following information describes some of the available medical and social care services and what they do.

Physiotherapy

Physiotherapists specialise in assessing and treating the disorders of movement and loss of physical skills, which occur following a brain injury. For example, problems with balance, walking, controlling movement of the arms & legs for everyday actions and/or maintaining general fitness.

Physiotherapists can be involved at any point following a brain injury. Treating people when they are still in intensive care, the physiotherapist will carry out chest physiotherapy to help to prevent infections, and passive movements of the limbs to prevent muscles from shortening, limiting movement and forming what are known as 'contractures'. In hospital, physiotherapy might take place on the ward or in a gym where treatment will usually focus on balance, restoring movement and
encouraging independence. A person with a brain injury may be transferred to a rehabilitation unit providing facilities and opportunities for more intensive therapy. Tiredness and lack of stamina are common after brain injury so use of activities and exercises which target improvements in general fitness are also a part of rehabilitation.

In the community, some people will need to continue with physiotherapy to encourage further improvement or maintain gains. Relatives and carers provide crucial support, encouraging the person with a brain injury to do things for themselves or to carry out exercises. Relatives can get involved in using special handling techniques, equipment or applying splints. They greatly assist the physiotherapist as they often notice changes in ability and can make suggestions to improve communication with their brain injured relative.

For inpatients, referral for physiotherapy is made by the doctor or a member of the clinical team. Once discharged from hospital, a GP or Consultant will make a referral to the local NHS hospital Physiotherapy.

**Psychology**

Clinical Psychologists may be involved in assessment and treatment. In hospital and rehabilitation settings they will carry out tests to measure the impact of brain injury upon reasoning, memory, concentration and other mental abilities. Results can then be used to monitor recovery and to design helpful strategies customised to the individual, e.g. problem solving tick-lists, portable memory aids (diaries, notebooks), etc.

Psychologists will also contribute to treating any significant behaviour and emotional changes such as aggression, unexpected behaviour or low mood. Common techniques employed include ‘behaviour modification’ (i.e. environmental changes, use of incentives and systematic feedback about behaviour) and ‘cognitive-behaviour therapy’ (looking at how thoughts about self and situations can be inaccurate and result in 'problem' emotions, e.g. depression, anger, anxiety).

As well as working with a brain injured patient, a psychologist will work with other staff involved in all aspects of care and treatment to ensure that they are helped to understand the effects of reasoning, memory, behavioural and emotional factors that may impact upon brain injured
people. Supporting relatives with information and counselling can be another area of involvement, and sometimes a couple or whole family will be seen together.

Psychologists that are Full Practitioner Members of the British Psychological Society's Division of Neuropsychology will have had additional training and experience of brain injured people and their relatives. Your GP can usually refer you or your brain injured relative to a psychologist.

**Speech and Language Therapy**

Speech and Language Therapists who specialise in acquired neurological disorders provide assessment and treatment for adults and children who have difficulties with communication, or eating, drinking and swallowing following a brain injury.

The Speech and Language Therapist may be involved at any point from admission to the intensive care unit, inpatient rehabilitation or life in the community. Assessment will aim to identify the needs of the person and inform treatment. Initially support and advice may be given to relatives, carers and medical staff in the early stages on ways to communicate effectively or provide nutrition safely.

In rehabilitation more intensive therapy may be offered with special exercises to improve speech or swallowing or to support affected language skills. Alternative means of communication may be provided e.g. picture based systems or electronic ‘talking’ machines. Group work may be offered to overcome difficulties with conversation and with learning to socialise again. Advice and support may also be given on managing re-entry into the community, e.g. occupational/educational situations.

Relatives and friends play a very important role throughout the process. They can provide information about the patient before the injury, for example, what occupations and interests they had, all of which may assist in decisions about treatment. They may work with the therapist to determine the best way to communicate with the patient or offer help and support with exercise programmes that may need to be carried out daily.
Psychiatry

A Psychiatrist is a medical doctor who specialises in assessment, management, treatment, and prevention of mental, behavioural and emotional disorders. People suffering from brain injury are at increased risk of developing these disorders such as aggression, depression and anxiety.

After a brain injury people can acquire a range of physical health problems such as epilepsy or tremors. They can also develop limitations in understanding others or expressing themselves. Some people may also have sensory deficits such as complete or partial loss of vision or motor problems such as poor mobility.

The combination of mental, behavioural or emotional disorders, along with several of the above mentioned health problems, can make rehabilitation and everyday life even more challenging. Psychiatrists usually work with colleagues from professional multidisciplinary teams to meet the challenge of rehabilitating and returning their patients back to living in the community.

Caring for relatives, partners or friends with a brain injury can be challenging and associated with 'carer distress' and emotional or depressive reactions. A Psychiatrist can help by assessing and identifying sources of distress and supporting relatives with associated mental health problems.

Occupational Therapy

Occupational Therapists (OTs) enable people to achieve health, wellbeing and life satisfaction through participation in society.

Following a brain injury, all activities of daily living can be affected, e.g. personal hygiene (washing and dressing), eating and drinking, managing a wheelchair / seating, home management, community living and work skills. OTs consider the impact the injury has had on people's lifestyles and their ability to participate in society.

Where possible, OTs take a 'person centred approach' to design a programme of treatment based on each individuals' unique lifestyle and
preferences, sometimes modifying the environment surrounding the person (e.g. adapting bathrooms, organising ramps to ease access). Enhancing someone's ability to participate in everyday activities is a central aim of occupational therapy.

The therapy is carried out in in-patient and out-patient settings, working closely with the person and their available support network of family, friends, and carers once they are discharged home.

OTs consider the importance of how a person's physical, mental and social needs will impact on the recovery process and help them achieve the life goals and aspirations that are most important to them. The focus is on working with people to reduce avoidable and unwanted dependency on others.

Social Work

Social Workers aim to provide an effective service based upon non-discriminatory values that recognise the uniqueness of each individual. Social Work can be a key role that requires a range of skills and specialist knowledge pertaining to a particular area of work, e.g. disabilities, etc. Because of the need to have specialist skills, social work teams are often set up to deal with specific areas of service; for example, adult's services and teams that specifically aim to provide a service for individuals with mental health issues and/or learning or physical disabilities.

Social Workers can take on a therapeutic role with individuals as well as advocating for and working closely with carers. They also seek to maintain links with other agencies and professionals relevant to the individual case.

Social Workers aim to ensure that an individual's rights are protected and help and support them to make informed choices. They enable carers to meet people who can support them with their diverse range of needs including those in the social, cultural and spiritual areas. Social Workers also ensure that individuals and carers are aware of their welfare rights, and support them dealing with issues affecting their future. They seek to support choices and decisions that reflect each individual's independence and liberty. Social Workers advise on future life choices based on identified needs, interests and wishes in
collaboration with the individual's family and other agencies as part of a 'whole team approach' 

Others

There are many other health and social care specialists that you may be referred to:

Foremost among these will be registered Nurses. In hospital, nursing staff will be involved from initial assessment of the patient in A&E, to specialist nursing within intensive care, and support on general and rehabilitation wards. Some rehabilitation services will incorporate a range of nursing expertise, including psychiatry, learning disability and general medicine specialists. In the community, the Clinical Nurse Specialists may work with the patient with epilepsy, head injury or one of a growing range of acquired neurological conditions that receive dedicated nursing input. At home, Community Psychiatric Nurses may also be involved if the patient has significant emotional difficulties such as depression or anxiety, offering counselling, support, and supervision.

Healthcare Assistants / Rehabilitation Assistants / Support Workers are also very likely to be encountered providing much of the day to day care or rehabilitation input. They may not be professionally qualified or registered, but will have had comprehensive training specific to their role and work under the supervision of registered colleagues.

Others continued...

It is impossible to be exhaustive, but other professionals the patient may be referred to will include:

- **Neurologists**, doctors specialising in the treatment of conditions of the brain and nervous system;

- **Neurosurgeons**, surgeons that perform operations on the brain and nervous system;
• **Dieticians**, who will work, often in collaboration with Speech & Language Therapist colleagues, to ensure safe and appropriate nutrition;

• **Teachers**, contributing to the development of new skills after a brain injury and supporting individuals into education and training opportunities;

• **Case Managers**, experienced professionals (often Occupational Therapists or Social Workers) that work with individuals and their families to provide packages of care, rehabilitation and support across the full range of needs, usually in collaboration with **Solicitors** representing the Claimant or the Defendant in personal injury or medical negligence cases. It can often be bewildering to have so many people involved in your relative's care, so there should be a ‘**Keyworker**' or ‘**Care Coordinator**' from amongst the care team identified as a single point of contact for you.

• **Benefits Advisors** (sometimes contacted via the Citizen's Advice Bureau) can also be essential to ensure that all financial entitlements are being received in order to attempt to avoid the added burden of debt and to ensure that your relative qualifies for other support and services.

### Some local sources of information and support

**Headway, the brain injury association**

Headway has a network of over a hundred local Headway Groups and Branches across the United Kingdom providing support for people with brain injury, their families and carers, and for those working with them. Each Group or Branch develops its own individual activities and services with local people, in response to local needs. They generally have contact with individual families, offering support, information, guidance and the opportunity for social activities. Through these groups, people with brain injury and those who care for them can meet people in similar situations and share experiences, information on local services, and mutual understanding and support.
About half of the Groups and Branches organise and run Headway House Centres. These provide activities, therapeutic facilities and daily respite care for brain injury survivors, their families and carers. For further information about your local Group or Branch visit: www.headway.org.uk or telephone 0808 800 2244.

Headway South Cumbria meets on the first Thursday of every month during the day at the Castle Street Community Centre, Kendal. The meetings are a mixture of social events and talks on subjects of interest. Those affected by a brain injury, and their families, friends and carers, are all more than welcome. For further details visit: www.headwaysouthcumbria.wordpress.com

Headway Lancaster and Morecambe Bay meets on the third Wednesday of the month in the evening in Lancaster. Speakers on subjects of interest are regularly invited, with some meetings left free for discussion and individual support. Those affected by brain injury in any way, whether directly or indirectly, are always made welcome at their friendly meetings, along with employers and colleagues of people who have suffered brain trauma, and students and members of the caring and statutory services.

Headway Lancaster and Morecambe Bay monthly meeting takes place at The Vale of Lune Rugby Club, Powderhouse Lane, Lancaster, LA1 2TT

Contact Headway Lancaster and Morecambe Bay for further details: 5, Thurnham Street, Aalborg Square, Lancaster, LA1 1XU. Phone: 01524 598339 or 07501 598443

The Neurological Alliance

www.neural.org.uk / Phone: 020 7566 1540

The Neurological Alliance represents a wide range of neurological charities that have come together to make life better for people in the UK with a neurological condition. Its aims are to:
• Raise awareness of neurological conditions and their impact
• Inform and influence policy makers about the needs of people with neurological conditions
• Secure the highest standards of service and improved care for people with neurological conditions
• Promote research and the dissemination of information about neurological conditions
• It is concerned about:
  • The low priority given to addressing the needs of people with neurological conditions
  • The need for nationally accepted standards of care
  • Fragmentation and lack of co-ordination between services
  • Low awareness amongst health and social care and other professionals about the impact of neurological conditions
  • Ensuring that those affected are involved in the management of their condition.

**The Child Brain Injury Trust (CBIT)**

The Child Brain Injury Trust (CBIT) supports anyone in the United Kingdom affected by childhood acquired brain injury. They can provide information, support and training to families and professionals.

The CBIT helpline has been set up to provide information and support for families of children who have an acquired brain injury.

Telephone 0845 6014939 10.00am - 1.00pm (Mon, Tues, Weds, Fri) 24 hour answer machine.

Outside of these hours you can ring 01865 552 467

Calls are charged at local call rate.

Email: helpline@cbituk.org
Benefits

A brain injury is likely to have an effect on a family's finances, and claiming benefits can help to ease the pressure. The system is complex and can be confusing, so it is important to get professional advice and to apply as soon as possible so you don't lose money.

There are different types of benefits available and these can affect other benefits that you may be receiving. Below are the different types of benefits that you may be able to claim.

Means-tested benefits

These benefits are based on your current income, and any savings that you may have:

- Income-related Employment and Support Allowance
- Pension credit
- Housing benefit
- Council tax reduction

Non means-tested benefits

These benefits are based on the National Insurance (NI) contributions that you may have made:

- Contributory Employment and Support Allowance
- Statutory sick pay (if employed immediately before your brain injury)

Benefits on assessment of your disability
With these benefits, the level of support you are entitled to depends on the extent of your disabilities:

- Disability living allowance / Personal Independence Payment
- Motability
- Attendance allowance
- Industrial injuries disablement benefit
- Constant attendance allowance
- War disablement allowance

**Further Information on Common Benefits Claimed Following a Brain Injury:**

**Disability Living Allowance (DLA)**

Please note that DLA has been replaced by Personal Independence Payment (PIP) for adults aged 16 - 64.

**Personal Independence Payment (PIP)**

PIP is a tax-free benefit that helps with the extra costs associated with having a long-term illness or disability. It replaces Disability Living Allowance (DLA) for adults aged 16 to 64.

You can make a claim for PIP if you have a long-term health condition or disability that causes difficulties with daily living and mobility. You must have experienced these difficulties for over 3 months, and they must be expected to last for at least 9 months. People who are terminally ill and expected to live for less than 6 months may also qualify.

PIP acts as a 'passport' to certain other benefits, such as Carers' Allowance, the Blue Badge scheme and leasing a car from Motability. Many people with a brain injury will qualify for PIP, as the cognitive, behavioural and physical effects of the condition often cause difficulties with activities of daily living and mobility. The criteria for PIP have
changed from DLA, so it may be worth making a claim even if you have been turned down before.

To claim PIP you will need to contact the Department for Work and Pensions on telephone: 0800 917 22 22

**Employment and Support Allowance (ESA)**

Employment and Support Allowance is paid to people who have difficulty working due to illness or disability. It replaces Incapacity Benefit, Severe Disablement Allowance and Income Support paid on the grounds of disability.

ESA is designed to support people with disabilities and help them find work if they are capable. It is not designed to force people into work if that is not realistically possible. People with severe disability can claim without having to seek employment.

**Useful Telephone Numbers**

**Benefits Enquiry Line Dept. for Work and Pensions**
0800 917 2222 / www.dwp.gov.uk

**Carers UK Helpline**
0808 808 7777 / www.carersuk.org

**Child Brain Injury Trust (cbit)**
0845 601 4939 / www.cbituk.org

**Headway UK**
0808 800 2244 / www.headway.org.uk
After Hospital Care: Rehabilitation

After hospital care you may need further care in relation to rehabilitation. Contact your local Social Services Department or Health Care Provider for a full list of Brain Injury Rehabilitation Units.

Examples are listed below, although this list is not exhaustive.

Rehabilitation Units Offering Support to People with Acquired Brain Injury:

Brain Injury Rehabilitation Trust (BIRT) - Liverpool

Located in Liverpool, Redford Court, and its dedicated Transitional Living Unit, Redford Court Lodge, are specialist neuro-behavioural rehabilitation centres for people with acquired brain injury. The service forms part of the nationwide network of rehabilitation support services provided by The Brain Injury Rehabilitation Trust (BIRT).

Redford Court works with people from all walks of life who have to cope with a range of cognitive, physical and/or emotional symptoms following a severe brain injury.
Rehabilitation is based on the neuro-behavioural model and focuses on enabling people to function more independently and to participate in as many of their previous roles and activities as possible, while developing their lives as they choose.

For further details please go to the website: www.thedtgroup.org

---

**St George Healthcare Group - St Mary's Hospital - Warrington**

St Mary's Hospital, Warrington is a purpose built facility, providing 58 inpatient beds, for the rehabilitation of:

- Male patients with a brain injury within medium, low and open settings
- Deaf people with mental disorders requiring a medium secure environment.
- Male and female patients with Autistic Spectrum Conditions (ASC).

For further details please go to the website: www.stgeorgehealthcaregroup.org.uk

---

**The Priory Highbank Centre - Bury**

The adult neuro-rehabilitation service at the Priory Highbank Centre specialises in the assessment, rehabilitation and care of individuals who have an acquired brain injury or neurological illness. The intensive rehabilitation site caters for 19 patients aged 16 years or over.

For further details please go to the website: www.priorygroup.com

---

**Nursing / Care Homes Offering Support to People with Acquired Brain Injury**
For further details please go to the website: www.carehome.co.uk

**Applegarth Nursing Home**
243 Newtown Road, Carlisle CA2 7LT
Matron: Caroline Whitehead

**Heron Hill Care Home**
Esthwaite Avenue, Kendal LA9 7SE
Registered Home Manager: Michael Bowles

**Silloth Nursing & Residential Home**
Silloth, Wigton CA7 4JH
Matron: E Blair

**Risedale at St George's Nursing Home**
Albert Street, Barrow-in-Furness LA14 2JB
Nurse Manager: Paula Edge

**Croft Village**
Croft Care Trust, The Croft, Hawcoat Lane, Barrow-in-Furness LA14 4HF
Manager: Wendy Coward

**Croft Nursing Home**
Hawcoat Lane, Barrow-in-Furness LA14 4HE
Manager: Colette Hibbert
For further details please go to the website: www.carehome.co.uk

**Applegarth Nursing Home**
243 Newtown Road, Carlisle CA2 7LT
Matron: Caroline Whitehead

**Heron Hill Care Home**
Esthwaite Avenue, Kendal LA9 7SE
Registered Home Manager: Michael Bowles

**Silloth Nursing & Residential Home**
Silloth, Wigton CA7 4JH
Matron: E Blair

**Risedale at St George's Nursing Home**
Albert Street, Barrow-in-Furness LA14 2JB
Nurse Manager: Paula Edge
Croft Village
Croft Care Trust, The Croft, Hawcoat Lane, Barrow-in-Furness LA14 4HF
Manager: Wendy Coward

Croft Nursing Home
Hawcoat Lane, Barrow-in-Furness LA14 4HE
Manager: Colette Hibbert

Leaflet Details

Reference Number: PIL/001
Approved by: PD & ILG
Author: Patient Information Officer
Date of Publication: 09/12/2014
Review Date: 01/12/2017
Other formats
If you would like to receive this information in an alternative format, then please contact: 01539 795497.

Travelling to our hospitals
For the best way to plan your journey visit our website: http://www.UHMB.nhs.uk/ or contact Patient Advice and Liaison Service (PALS): 01539 795497.

Useful Contact Details
NHS 111 (for 24 hour urgent health advice): telephone 111

Your Information
If you would like to know how we use, share, disclose and secure your information and your rights of access to the information we hold about you, visit the Trust’s website: http://www.UHMB.nhs.uk/ or contact Patient Advice and Liaison Service (PALS) on 01539 795497.

Evidence
Details of the evidence used in writing this leaflet are available on request from: Patient Information Officer at 01524 512476.

Feedback
We appreciate and encourage feedback. If you need advice or are concerned about any aspect of care or treatment, please speak to a member of staff or contact PALS on 01539 795497.

UHMBT is a no smoking Trust. Smoking is not permitted on any of the hospital sites. You can contact the NHS North Lancashire Stop Smoking services on the number below:

NHS Quit Squad - 0800 328 6297

If you live in Cumbria, please call 0300 013 3000 to find a local pharmacy who are offers 1-2-1 support and nicotine replacement therapy.

University Hospitals of Morecambe Bay Trust: a great place to be cared for; a great place to work.