

Rehabilitation following acquired brain injury

National clinical guidelines



Royal College
of Physicians

The guidelines were prepared by a multidisciplinary working party convened by the British Society of Rehabilitation Medicine (BSRM). They were drafted and edited by Professor Lynne Turner-Stokes on behalf of the British Society of Rehabilitation Medicine and the Royal College of Physicians.

The guidelines are published in collaboration with the Clinical Effectiveness and Evaluation Unit, Royal College of Physicians

2003

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The British Society of Rehabilitation Medicine

The British Society of Rehabilitation Medicine is the UK professional organisation for practitioners in rehabilitation medicine. It is a young, vibrant organisation devoted to:

- promoting the development and good practice of rehabilitation medicine as a medical specialty
- enhancing undergraduate and postgraduate education in rehabilitation and disability issues
- supporting rehabilitation research
- working with related medical, paramedical and voluntary organisations to further these aims.

Membership is open to registered medical practitioners with an interest in disability and its management.

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Foreword

We are pleased to be publishing these timely national clinical guidelines for *Rehabilitation following acquired brain injury*. They provide a comprehensive framework for the management of an important patient group and complement the guidelines on the management of head injuries, published by the National Institute for Clinical Excellence (NICE) in June 2003.

Whereas the NICE guidelines focused exclusively on management in the first 48 hours after head injury, which is critical in the management of the pathology, the post-acute rehabilitation and longer-term care covered in these RCP/BSRM guidelines are essential to reducing morbidity, restoring function and improving participation – and thus to improving the quality of life for the patients and their families. Together, the two sets of guidelines represent standards for the entire spectrum of care following brain injury.

The present guidelines are evidence based and should be used to underpin the development of rehabilitation services over the next decade, and to inform the forthcoming National Service Framework on Long-Term Conditions.

The guidelines have been developed by a multidisciplinary working party, convened by the British Society of Rehabilitation Medicine and supported by the Royal College of Physicians. There has been extensive contribution from many organisations as well as users and carers, and we wish to congratulate Professor Lynne Turner-Stokes and the members of the working party, and all other contributors for their sterling efforts in producing this essential guidance to improve the care and rehabilitation of individuals with acquired brain injury.

December 2003

Professor Carol Black

President, Royal College of Physicians

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President, British Society of Rehabilitation Medicine

Executive summary

These evidence-based guidelines have been developed by a multidisciplinary working party convened by the British Society of Rehabilitation Medicine, and are published in collaboration with the Royal College of Physicians of London. They have been produced to complement the National Institute for Clinical Excellence head injury guidelines, which focus on management during the first 48 hours after injury. These guidelines address the medium to longer-term needs of patients with acquired brain injury (ABI) and their families/carers.

- The patient group covered by the guidelines is that of adults, primarily of working age, with ABI of any cause, including trauma, stroke, anoxia, inflammation etc.
- The target audiences are healthcare professionals involved in the rehabilitation and long-term care and support of ABI patients, and also purchasers and providers of health and social services for this group.
- The guidance covers general principles of service provision and specific advice on the clinical management of patients with ABI. It has been produced to inform the National Service Framework (NSF) for Long-Term Conditions, which is currently under development by the Department of Health.

There is now good evidence for the effectiveness and cost benefits of rehabilitation, especially where the relevant health and social care practitioners work together as a coordinated interdisciplinary team towards a common set of goals, and where a rehabilitative milieu provides reinforcement of the programme 24 hours a day. Although vocational outcome following severe brain injury is recognised to be poor, there is consistent evidence that specialist brain injury programmes for vocational rehabilitation are effective, and that the initial investment in rehabilitation is repaid in cost benefits.

The principal themes of the guidelines are as follows:

- The small numbers and heterogeneity of ABI patients pose major challenges for service provision:
 - different patients require different services
 - the same patient requires different services at different stages in their recovery.Coordination and communication between these services is of paramount importance.
- Services should be planned in coordinated networks across a geographical area, with joint health and social services commissioning in liaison with other statutory and voluntary services, including employment, education and housing authorities. Not all patients' needs can be met locally; those with complex needs must have access to appropriate specialist services.
- Patients with ABI frequently have complex disabilities which require specialist intervention by professionals with knowledge and experience in the management of brain injury. Staffing provision within rehabilitation and support services must be adequate, in terms of numbers and experience, to meet the requirements of the caseload.
- Rehabilitation should be goal-orientated and planned on an individual basis, taking account of the patient's views, cultural background and pre-morbid lifestyle. ABI patients

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and their families should be offered appropriate information at every stage, and involved as actively as possible in decisions regarding their care.

The effects of ABI are long lasting and patients and their families require continued care and support, often for the rest of their lives. The long-term results of rehabilitation are most successful where ongoing support and supervision is available for those who require it.

**DEVELOPMENT OF
THE GUIDELINES AND
BACKGROUND**

The process of guideline development

The scope of the National Service Framework (NSF) for Long-Term Conditions was announced in 2002. The focus of the framework is on long-term neurological conditions in adults, primarily of working age. Given its wide brief, the NSF will necessarily rely on the parallel development of clinical guidelines and standards within the various conditions that are included.

The National Institute for Clinical Excellence (NICE) and its collaborating centres have begun producing a series of clinical guidelines which address many of the conditions encompassed by the NSF. These include guidelines for multiple sclerosis, Parkinson's disease, epilepsy and head injury. However, the current NICE guidelines for head injury focus exclusively on early management (the first 48 hours after injury) and do not address the needs for rehabilitation and longer-term care. Nor do they encompass non-traumatic forms of acquired brain injury.

In 2002, the British Society of Rehabilitation Medicine (BSRM) set up a multidisciplinary working party to develop guidelines to cover rehabilitation and continued support for patients with acquired brain injury (ABI) and their families/carers. These guidelines will complement the NICE guidance on acute-phase management of head injury.

The working party faced some formidable challenges. The timescale was tight if the guidelines were to be published in time to inform the NSF. Also, the group did not have access to the funding and machinery to perform systematic literature reviews etc which are available to the other national guideline development programmes. All literature searches and reviews were therefore undertaken within the time available by working party members themselves.

The Clinical Effectiveness and Evaluation Unit (CEEU) of the Royal College of Physicians (RCP) utilises the Appraisal for Guidelines for Research and Evaluation (AGREE) Tool¹ for the assessment of clinical guidelines. These *National clinical guidelines for rehabilitation following acquired brain injury* have therefore been developed in accordance with those principles, which are summarised below.

Overall objective

The overall objective of the guidelines is to improve the clinical care and continued support delivered by health and other statutory services to adults with acquired brain injury and their families and carers.

Target audience

The guidelines are targeted primarily towards professionals who work in health and social services including:

- doctors and health/social care professionals involved in the management of people with brain injury
- providers and purchasers of rehabilitation and support services.

Scope

The patients covered by the guidelines are adults, primarily of working age, with acquired brain injury due to trauma, stroke, anoxia, infection or other causes.

The guidelines offer specific guidance on the clinical aspects of care of these patients. They focus mainly on rehabilitation and community integration in the post-acute period during the early years following brain injury. The need for continued access to rehabilitation services and long-term support for patients and their families is also emphasised.

The working party recognised that the longer-term needs of people with acquired brain injury should be the shared responsibility of specialist and local health services in partnership with social services and the voluntary sector, as well as other statutory authorities such as housing, employment, education etc. Detailed guidance in those areas is beyond the scope of this set of clinical guidelines. It is recommended that a further set of guidance should be developed, led by the relevant sectors, to provide more specific advice in those important aspects.

The guideline development group

The guideline development group (GDG) comprised a wide range of professionals involved in the rehabilitation and long-term care of people with acquired brain injury and included representatives of users and carers, as well as the organisations that represent them (see Appendix 1). Official representation was also convened from a broad range of stakeholding organisations.

The GDG was made up of two main groups:

- (a) *Working party members* attended guideline development meetings and were actively involved in drafting the guidelines at every stage.
- (b) *Advisory group members* had the opportunity to comment on and contribute to the draft guidelines during the later stages of preparation.

In addition, an *inter-agency advisory group on vocational rehabilitation* was convened to address the needs for vocational rehabilitation of adults with acquired brain injury.

Conflicts of interest

Competing interests for the working party members were fully declared and are listed in Appendix 1.

Evidence to support the guidelines

The guidelines are based on evidence so far as resources allowed. Extensive use was made of pre-existing reviews, especially those undertaken for the national stroke² and multiple sclerosis guidelines.³ In addition, a new Cochrane systematic review⁴ was used and a systematic search of the literature for review articles and alternative methodologies for research on brain injury rehabilitation was undertaken. This search interrogated all main databases (including Medline, EMBASE, AMED, CINAHL). It included all types of acquired brain injury and a wide range of terms for rehabilitation, therapy, care and support.

Evidence is linked explicitly to the guideline statements using the classification which is currently used in other published guidelines (see Table 1).²

Table 1 Levels of evidence		
Level of evidence	Type of evidence	Grade of recommendation
Ia	Meta-analysis of randomised controlled trials (RCTs)	A
Ib	At least one RCT	A
IIa	At least one well-designed controlled study, but without randomisation	B
IIb	At least one well-designed quasi-experimental design	B
III	At least one non-experimental descriptive study (eg comparative, correlation or case study)	B
IV	Expert committee reports, opinions and/or experience of respected authorities	C

Research in the field of complex disability following ABI poses several major challenges:

- There is marked heterogeneity with respect to the patient group, the intervention and setting, and to the outcomes that are relevant at each stage of recovery.
- The application of randomised controlled trial designs is further confounded by small numbers, and by ethical considerations, since many patients with ABI may lack the mental capacity to give fully informed consent.
- The expanding body of evidence of the effectiveness of multidisciplinary rehabilitation in other conditions (particularly stroke) makes it increasingly unethical to randomise patients to ‘no treatment’ or even ‘standard’ care.
- The length of time over which rehabilitation may have its effects (often months or years) is usually longer than any funded research project and hinders the use of ‘wait-list’ control groups.

The guidelines therefore necessarily rely to a significant degree on expert opinion and on existing consensus-based documents. There are a large number of existing documents in this field which have already been submitted to consensus methodologies (see Appendix 2). They fall into two main categories:

- (a) *Standards or guidelines specifically addressing acquired brain injury* or its subgroups (eg stroke, traumatic brain injury)
- (b) *General standards or guidelines* addressing areas of care which are relevant in this field, such as practice standards produced by the various Royal Colleges or specialist societies.

Documents previously published by the British Society of Rehabilitation Medicine and the Royal College of Physicians which overlap significantly with this set of guidelines include:

- Clinical standards for specialist inpatient and community rehabilitation services in the UK (BSRM Standards*)^{6,7}

*The BSRM standards were modelled on a set of standards produced by the South Thames Brain Injury Rehabilitation Association (STBIRA).⁵

- *National clinical guidelines for stroke* (NCGS)²
- NICE guidelines for multiple sclerosis (NCGMS).³

Areas of overlap with these documents are made explicit. Where recommendations coincide, reference is made to that document with the grade of recommendation quoted, rather than reiterating the original evidence. Two further important documents are also referenced in the same way:

- *Health Select Committee Inquiry into head injury rehabilitation* (Third Report) (HSCR)⁸
- Scottish Inter-Collegiate Guideline Network (SIGN) Guidelines on management for patients with stroke (SIGN guidelines).⁹

Other documents are referenced according to the standard numbering system.

Implementation and cost implications

It is intended that these guidelines will result in improved access to appropriate rehabilitation services for patients with brain injury and their families. Given the current dearth of such services, this cannot simply mean a reorganisation of existing provision. Implementation of the guidelines is likely to require significant investment in rehabilitation services. However, brain injury rehabilitation has already been identified as one of the priorities in the NSF for Long-Term Conditions, so it is intended that the development of these guidelines will be timely in helping to inform effective and coordinated development.

Updating and review

Guideline development is a continuous process, and rehabilitation following brain injury is a field of rapid change and development. These guidelines will therefore be reviewed and updated at three-yearly intervals by the BSRM, subject to the availability of funding.

Terminology

The groups discussed, at some length, the most appropriate term to use for an individual with acquired brain injury for the purpose of these guidelines. The term ‘patient’ has been adopted throughout these guidelines in accordance with advice from the user representatives. This will emphasise the fact that many people do require life-long support following brain injury, and may encourage clinicians to feel a sense of life-long responsibility. For the sake of brevity, the terms ‘patients with ABI’ or ‘ABI patients’ may be used to denote ‘patients with acquired brain injury’.

The relationship between severity of initial injury and the clinical/psychosocial sequelae is poor. The terms ‘significant’ or ‘symptomatic’ brain injury is used to denote ABI associated with needs requiring intervention or support.

Background

Definitions

Rehabilitation: A previous report of the BSRM defined rehabilitation in terms of concept and service:

- *Conceptual definition:* A process of active change by which a person who has become disabled acquires the knowledge and skills needed for optimal physical, psychological and social function.
- *Service definition:* The use of all means to minimise the impact of disabling conditions and to assist disabled people to achieve their desired level of autonomy and participation in society.

These definitions provide a useful framework, although it should be noted that ABI rarely affects an individual in isolation, and the needs of family members and carers should also be addressed as part of the rehabilitation process.

Acquired brain injury (ABI) is an inclusive category that embraces acute (rapid onset) brain injury of any cause, including:

- *trauma* – due to head injury or post-surgical damage (eg following tumour removal)
- *vascular accident* (stroke or subarachnoid haemorrhage)
- *cerebral anoxia*
- *other toxic or metabolic insult* (eg hypoglycaemia)
- *infection* (eg meningitis, encephalitis) or other inflammation (eg vasculitis).

Increasingly, brain injury rehabilitation services in the UK are based on patients' needs, rather than on underlying pathology, and so do not distinguish between the above conditions. The guidelines therefore address the broader spectrum of ABI which actually presents to rehabilitation services.

The functional deficits arising from ABI depend to some extent on the localisation of damage. For practical purposes, acquired brain injury may be categorised as:

- *focal* damage, ie localised, usually from a stroke or direct trauma
- *non-focal* damage, diffuse or multi-focal, from *either*:
 - secondary consequences of trauma (hypotension or raised intracranial pressure); or
 - other acute incidents including hypoxia (eg due to drowning, electrocution, anaesthetic accident), hypoglycaemia, subarachnoid haemorrhage, encephalitis.

Many of the guiding principles that have been so successful in improving outcomes following stroke are equally applicable in other forms of ABI.

Adults of working age: These guidelines are not specifically confined to specific chronological age limits. However, there are certain differences which distinguish younger adults with ABI from the much larger and predominantly elderly stroke population:

- In younger patients ABI often presents in a more varied pattern, which may include any combination of physical, cognitive, behavioural, emotional or psychosocial deficits.

- Younger patients may have rather different goals for rehabilitation, especially in relation to childcare and return to work.
- Younger patients may have greater opportunities for neuroplasticity and they almost always have a longer lifespan over which to glean the benefits of rehabilitation. This may justify significant investment in the initial phases of rehabilitation with demonstrable savings in long-term care.¹⁰
- ‘Life-long’ support for patients and their families may mean *several decades*, and families are often parents and siblings rather than spouses or children.

Epidemiology

Because of the wide range of conditions that make up the population of acquired brain injury, it is difficult to give exact figures for prevalence of ABI in adults of working age.

Stroke and traumatic brain injury (TBI) make up the largest proportion of acquired brain injury in the UK.

- In those aged under 65, there are approximately 20 strokes per 100,000 population per year. Subarachnoid haemorrhage affects 8,500 people each year in the UK, with a significant proportion occurring between the ages of 18 and 65 years (data supplied by the Stroke Association).
- Head injuries requiring hospitalisation occur in the UK at the rate of about 275/100,000 population annually.¹¹ Within this overall figure there is considerable variation in different parts of the country, between urban and rural communities and between age groups, with peaks at 15–24 and >75 years.

Moderate to severe brain injury is estimated to occur in 25/100,000 people per year of which

- 2–4 (10–20%) patients are likely to have severe disability or prolonged coma
- 18–22 (65–85%) will have had a good physical (but not necessarily cognitive or psychosocial) recovery.

More recent improvements in emergency management and evacuation may have improved outcome overall, but have probably led to an increase in survival of very severely injured and disabled patients who would previously have died at the scene of the accident. Accurate up-to-date figures are not yet available.

The relationship between acute structural damage demonstrated on brain imaging and severity of impairment/disability is weak. Glasgow Coma Scale scores on admission, length of coma or post-traumatic amnesia (PTA) are typically used as proxy measures of severity, but all are only weakly related to actual long-term outcome in individual patients. Some patients categorised as ‘severe’ at the time of injury will go on to make a complete and rapid recovery, while in others an apparently ‘mild’ brain injury will lead to long-lasting and eventually catastrophic effects on family relationships and societal participation.

Sequelae of mild traumatic brain injury

Some 80% of patients with mild TBI are likely to be symptom-free at six months, although the remaining 20% may still experience symptoms such as headache, dizziness, fatigue, lack of concentration, impaired memory, irritability and mood change. The consequences of mild TBI

can impede physical, emotional, social, marital and vocational functioning.¹² Because of the nature of their deficits, this group of patients may become 'lost' to health and social care. However, routine follow-up and rehabilitation for all patients with head injuries may not be the answer. Two randomised controlled trials^{13,14} suggest that the risk/benefit ratio only justifies this approach in patients with more severe injury (ie those admitted to hospital or with PTA lasting >1 hour). Nevertheless, there needs to be some established mechanism whereby all individuals with symptomatic ABI can access the services they need.

Presentation to rehabilitation services

Depending on the nature and location of injury, patients with ABI can present with a wide range of problems. Broadly these divide into the categories listed in Table 2.

Physical	Communicative	Cognitive	Behavioural/emotional
Motor deficits: <ul style="list-style-type: none"> • paralysis • abnormal muscle tone • ataxia/coordination Sensory deficits Visual/hearing loss Symptoms, eg headache, fatigue, pain etc. Dysphagia Seizures	Language deficits: <ul style="list-style-type: none"> • expression • comprehension Dysarthria Dyslexia Dysgraphia	Impairment of: <ul style="list-style-type: none"> • memory • attention • perception • problem-solving • insight • safety awareness • self-monitoring • social judgement 	Emotional lability Poor initiation Mood change Adjustment problems Aggressive outbursts Disinhibition Inappropriate sexual behaviour Poor motivation Psychosis

The deficits shown limit activities and social participation to varying degrees, depending on severity, on the combination of deficits and other injuries, and on background circumstances including environment, support, intellectual background etc. As a result of these deficits, patients with acquired brain injury may face wide-ranging long-term restrictions in their ability to:

- live independently
- drive or use public transport
- return to work or education
- participate in leisure and social activities
- fulfil family roles and maintain personal, sexual and family relationships.

These restrictions are often shared by family members who may be living under considerable long-term strain.

Neurological recovery following ABI occurs over an extended period of many months or years. Fundamental to rehabilitation services is the appreciation that different patients need different input at different stages in their recovery. These are illustrated by the 'slinky model' of rehabilitation,¹⁵ which summarises the phases of rehabilitation (see Fig 1).

The critical point of this model is that, although patients may need to access different services as they progress, their transition between services should be smoothed by excellent

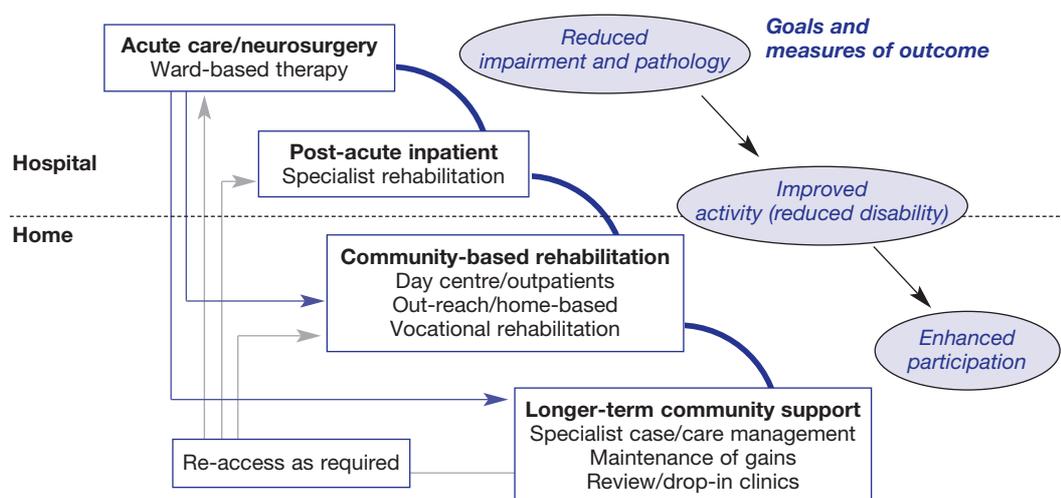


Fig 1 The 'slinky' model of the phases of rehabilitation

communication and sharing of information between services so that (like a 'slinky' toy) they progress in a seamless continuum of care through the different stages.

There has been considerable debate about whether services should be based in the hospital or the community. The answer is clearly 'both' – it is not helpful to consider the benefits of one particular service in isolation. The outcome over 5–10 years will be determined by all the different steps being in place. The important challenge is to make sure that each patient can access the service most appropriate to their needs at the time that they need it.

Main stages of rehabilitation

- Rehabilitation starts as soon as possible, even in the acute stages of intensive care in hospital. Interventions at this stage focus on reducing impairment and preventing secondary complications (pathology), such as contractures, malnutrition, pressure sores, pneumonia etc.
- As the patient starts to recover, intensive inpatient rehabilitation may be required to make the successful transition between hospital and community. Post-acute rehabilitation primarily addresses regaining mobility and independence in self-care to allow the individual to manage safely at home. Interventions focus on improving activity and independence (reducing disability).
- Once back in the community, patients need continued input to maximise their ability to function in their environment. In community-based rehabilitation, the emphasis is usually on more extended activities of daily living (EADL), social integration, and return to work or education. Interventions focus on enhanced participation, improved quality of life, psychological adjustment and carer stress.

Whilst the slinky model provides a useful illustration of the need for different services at different stages, with seamless continuity of care, the real picture is much more complex and three-dimensional. Patients progress through the different stages at very different rates. Many do not require hospitalisation at all and pass straight on to services in the community. A small

minority with very severe injury spend many months in hospital and may never progress to the community. Individuals with brain injury may also need to access services at different points in time as their needs change. This may involve re-access to inpatient services or a review of community rehabilitation and support needs as appropriate.

Within each stage a range of different service providers are involved, which must somehow be coordinated, and these services change according to the stage of rehabilitation. Figure 2 illustrates some of the different components of community rehabilitation.

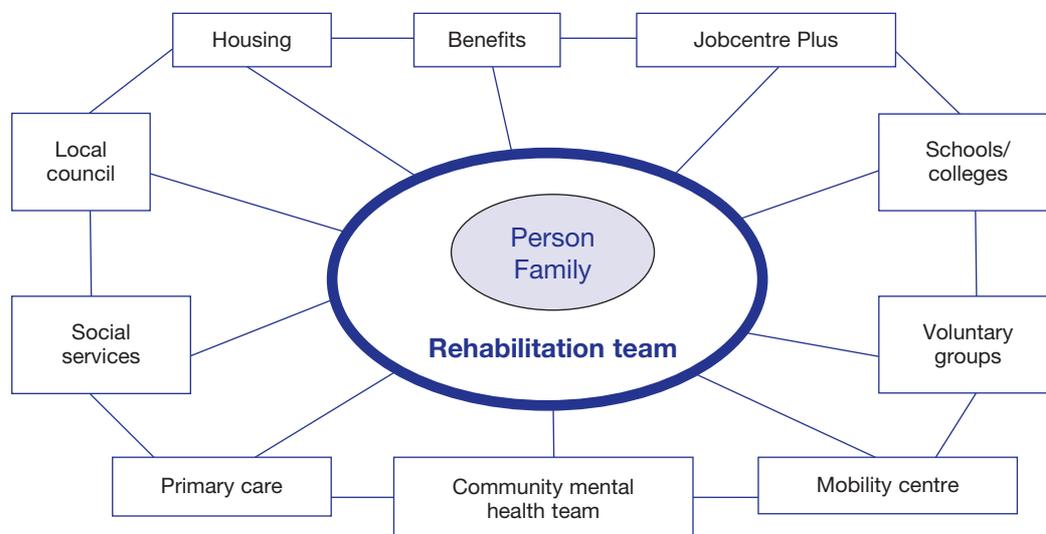


Fig 2 Some of the components of community rehabilitation

Rehabilitation team processes

Evidence, primarily but not exclusively from the stroke literature,¹⁶ suggests that rehabilitation is most effectively delivered by a coordinated team of professionals from the relevant disciplines.

Teams can work together in a variety of different ways:

- Multidisciplinary teams are made up of a group of professionals who work alongside one another to meet the needs of the patients;¹⁷ their interventions run parallel, but not necessarily in close collaboration. Typically, generic therapy services within a district hospital setting may adopt this approach.
- Interdisciplinary teams take a more integrated approach.¹⁸ The team works together towards a single set of agreed goals, often undertaking joint sessions. The majority of inpatient specialist brain injury rehabilitation teams work in this fashion, undertaking a wide range of collaborative interventions over a sustained period.
- Transdisciplinary team working extends the role of individual disciplines. Team members adopt a problem-solving approach, their interventions frequently crossing the traditional boundary lines between disciplines.^{19,20} Community rehabilitation settings may favour

this approach, particularly where constraints of time and travelling may prevent the full team from converging on a single individual.

Whichever method of teamwork is employed, good rehabilitation requires carefully coordinated input from the various professionals involved, and the team also requires clear leadership by a designated individual with the requisite leadership skills.

Coordination and communication

With so many different services and so many people involved, the major challenges of rehabilitation are coordination and communication. This is required at all levels including:

- service planning and commissioning to link health and social services provision with other statutory and voluntary service providers, including employment, education and housing authorities
- coordination within a specific service or programme, by means of whole team dialogue at decision-making points, and a 'key-worker' or equivalent system to act as a central point of communication, coordination and advocacy for the patient within team-based meetings
- individual 'case-management' or equivalent system to support the individual and their family throughout the course of their recovery.

THE GUIDELINES

- 1 Principles and organisation of services
- 2 Approaches to rehabilitation
- 3 Carers and families
- 4 Early discharge and transition to rehabilitation services
- 5 Inpatient clinical care – preventing secondary complications in severe brain injury
- 6 Rehabilitation setting and transition phases
- 7 Rehabilitation interventions
- 8 Continuing care and support

1 Principles and organisation of services

Neurological recovery following acquired brain injury (ABI) occurs over many months or years. Effective management of the brain-injured patient depends upon a well-organised, expert service to provide the full range of rehabilitation and life-long social and psychological support that an individual and their family/carers may need at different stages following brain injury.

1.1 The provision of specialist services

Specialised interdisciplinary treatment programmes are needed to address the particular medical, rehabilitation, social, vocational and educational needs of people with acquired brain injury (BSRM standards^{6,7}),^{11,21} as they are for conditions such as stroke and multiple sclerosis (national clinical guidelines for stroke (NCGS²) and for multiple sclerosis (NCGMS³)).

GUIDELINES

- G1** Every patient with an acquired brain injury should have access to specialist neurological rehabilitation services:
- covering all phases from acute management, through medium-term rehabilitation to long-term support (C) (BSRM standards^{6,7})²¹
 - for as long as required – which may be life-long. (A)^{11,21–23}
- G2** Specialist neurological rehabilitation services for people with acquired brain injury should meet the standards as published by the BSRM^{6,7} and other professional groups as listed in Appendix 2.
- In particular, they should comprise the following:
- a coordinated interdisciplinary team of all the relevant clinical disciplines (A-NCGS²) (BSRM standards^{6,7})^{11,21,22}
 - staff with specialist expertise in the management of brain injury (A-NCGS²) including a consultant specialist in rehabilitation medicine (C) (BSRM standards^{6,7})¹¹
 - educational programmes for staff, patients and carers (A-NCGS²), (BSRM standards^{6,7})^{5,11,24}
 - agreed protocols for common problems (A-NCGS²) such as management of spasticity, epilepsy, depression, etc.

1.2 Commissioning, planning and development of services

The longer-term needs of people with ABI for healthcare and social service support cannot be separated. Joint commissioning arrangements are required to coordinate rehabilitation and care requirements between health and social service agencies and with other statutory, voluntary and private agencies as required (HSCR⁸). Not all patients' needs can be suitably met by local services.²⁵

A wider planning strategy, involving rehabilitation service networks developed across a larger geographical region than a single health district or primary care trust (PCT), will provide a

more cost-effective and comprehensive solution to meet the needs of brain injured people and their families.²⁶ Voluntary services, working in partnership with health and social care professionals, may make an important contribution and help to lessen the load on overburdened statutory services

GUIDELINES

- G3** Commissioning organisations should ensure that arrangements are in place to satisfy all appropriate rehabilitation and supportive care needs for their population of people with ABI, including local inpatient, outpatient and community services and all appropriate specialist services. (C) (HSCR⁸)¹¹
- G4** PCTs should ensure that collaborative commissioning arrangements are in place for the populations served by their local specialised commissioning group.²⁷ The following arrangements should be in place:
- There should be an identified senior manager within the commissioning organisation who has specific responsibility for:
 - commissioning services for patients with acquired brain injury to cover their needs throughout their life (C) (HSCR⁸)
 - working with other agencies and their commissioners to ensure that a seamless service exists. (C) (HSCR⁸)
 - Contractual arrangements should be in place for services with particular specialist skills and facilities for people with very complex problems (low-volume, high-cost cases) such as:
 - severe complex disabilities with physical, cognitive and/or communicative deficits (C)²⁶
 - need for specialised equipment such as electronic assistive technology or communication aids, and specialised seating systems (C)²⁶
 - significant and challenging behavioural problems (C)²²
 - minimally conscious or persistent vegetative states. (C)²²
 - If no suitable services are available locally to meet the patient’s rehabilitation requirements, arrangements should be made to support out-of-area treatment, with monitoring arrangements in place to ensure that patients are transferred back into local services at the most appropriate time. (C) (BSRM standards^{6,7}) (HSCR⁸)
- G5** Social services departments should identify a senior manager who has specialist knowledge and explicit responsibility for the planning and delivery of services for people with brain injury. (C) (HSCR⁸)²⁸
- G6** Services should seek to ensure equitable access for all groups, and should be sensitive to ethnic, cultural, and religious issues. (C)²⁹

1.3 Rehabilitation service networks

These networks should include:

- specialist regional services to meet the needs of more complex cases and provide specialist training and guidance for other professionals involved in care of patients with ABI
- local hospital and community rehabilitation teams

- social services to provide continued support for the individual and their family within the home setting
- voluntary agencies providing support, information and activities
- specialist brain injury vocational rehabilitation services.

GUIDELINES

- G7** Strategic health authorities should ensure that a managed network of specialised rehabilitation services is planned over a geographical area with collaborative commissioning of regional services. (C)¹¹
- G8** Within the network of services, systems should be in place to ensure that:
- patients can be transferred between different services without any bureaucratic delays (C) (BSRM standards^{6,7})^{11,8}
 - there is close communication and collaboration between local hospital, community and regional services to provide a seamless continuum of care (C) (BSRM standards^{6,7})¹¹
 - patients with complex needs are able to regain access to specialised services as their needs dictate by referral through any appropriate agency. (C) (BSRM standards^{6,7})

1.4 Coordination of rehabilitation for individual cases within the network

It is a common experience for patients with brain injury and their families to ‘fall between stools’ as they move between different services, with no-one seemingly responsible for providing long-term coordination and guiding them through the process (HSCR⁸). Life-long contact is needed to meet the changing clinical, social and psychological needs of patients and their families/carers.

GUIDELINES

- G9** Within each service network, there should be a case management or equivalent system which gives brain-injured patients and their families/carers an identifiable guide and advocate through the whole care pathway. (C) (HSCR⁸)³⁰
- G10** The individuals or teams providing this ‘case management’ system should:
- register or be aware of patients with symptomatic ABI within their catchment area (C)²⁹
 - take responsibility for coordinating care and providing support and information for patients with acquired brain injury and their families from the time of injury, through the period of recovery and for as long as is required, to ensure continuity of care (C) (HSCR⁸)³⁰
 - have knowledge of all the available resources for these patients and be able to advise patients, families, acute care providers, GPs and commissioners on the options available (C) (HSCR⁸)³⁰
 - be able to access further appropriate professional advice and assessment as required. (C) (HSCR⁸)

1.5 Timing, intensity and duration of treatment

In more severe head injury, early rehabilitation is associated with better outcomes^{31,32} and intensive specialist rehabilitation programmes have been shown to be not only effective,^{33,34} but cost effective.^{10,35–37} Rehabilitation services need to be matched to the needs, strengths and capacities of each person and modified as their needs change over time. Impairments of awareness and insight may affect a patient's ability to engage in rehabilitation in the immediate period following ABI, but this may change. In some cases it may be appropriate keep the patient under review and defer intervention until s/he is ready to engage.

GUIDELINES

G11 Following acute ABI, patients should:

- be transferred as soon as possible to a rehabilitation programme of appropriate intensity to meet their needs (A)^{31,32}
- receive as much therapy as they need, can be given and find tolerable (A-NCGS²)^{33,34}
- be given as much opportunity as possible to practise skills outside formal therapy sessions. (A-NCGS²)

G12 After the post-acute phase, continued rehabilitation in the community should support a balance of activity based on the patient's individual circumstances. This should move progressively from formal therapy to a guided and supported resumption of chosen activities over months or years.

G13 There should be recognition of the need for life-long contact to meet the changing clinical, social and psychological needs of patients and carers. (C)²⁹

1.6 Staffing levels to meet demands for intensive treatment

Previous estimates of staffing levels for rehabilitation services¹¹ largely assumed that services would be planned on the basis of an old district health authority population (approximately 250,000 people) and that each district would have its own more or less free-standing service. The recommendations in these guidelines move away from this rather fragmented style of development to encourage the development of service networks, and a range of different services working in collaboration to provide for a much larger population. Specialist units have an extended role in supporting local community teams, and the same unit may provide several different types of service flexibly from within the same staffing team – for example, inpatient and community outreach services.

Given this extended role, the need for intensive treatment in the early post-acute stages, and the increased survival of very severely injured patients, it is likely that previous estimates of staffing numbers are inadequate to meet the needs of patients with severe complex ABI.

- Patients with very severe brain injury often require two or more people to assist with transfers or to provide therapeutic handling.
- Others who are independently mobile but who are disorientated and confused frequently require one-to-one supervision to ensure their safety.
- Advice, support and intervention for families must be considered independently of the patient's immediate needs.

The numbers and grading of clinical staff required will depend on the demands of the caseload in any particular unit, as well as the setting. The more complex and challenging the caseload, the greater the requirement for highly experienced staff. Validated tools are in development for assessment of dependency in relation to staff numbers and skill mix.³⁸ It is therefore not yet possible to give didactic figures for appropriate staff numbers.

However, Table 3a defines *minimum* recommended staffing levels for a specialist inpatient rehabilitation service for patients with ABI, and Table 3b proposes figures for a specialist community service to support the needs of this group.* The figures are dependent on appropriate access to other relevant services such as neurology, neurosurgery, neuropsychology, neuropsychiatry and mental health services. Based on current epidemiological figures, it is estimated that approximately 60 specialist rehabilitation beds per million are required to meet the needs of younger adults with ABI.

Table 3a Minimum staffing provision for specialist inpatient rehabilitation services		
Nurses	1–1.2 WTE per bed	Plus Trained helper staff Technicians/engineers Other professions as appropriate, eg art and music therapist, counsellor, etc.
Physiotherapists	1 WTE per 5 beds	
Occupational therapists	1 WTE per 5 beds	
Speech and language therapists	1 WTE per 7–8 beds	
Clinical psychologists	1 WTE per 8–10 beds	
Social workers	1 WTE per 10–12 beds	
Dietitians	1 WTE per 20 beds	
Medical staff	A 24–26 bed unit should have: 1 WTE consultant accredited in rehabilitation medicine <i>plus</i> 2 WTE training grades (SpR/SHO) <i>or</i> 1 WTE non-training doctor	
SHO = senior house officer; SpR = specialist registrar; WTE = whole time equivalent		

Table 3b Proposed minimum staffing levels for a community specialist service to support people with brain injury (population 500,000)	
Discipline	WTE
Specialist brain injury nurse	1
Physiotherapists	2.5
Occupational therapists	5
Speech and language therapists	2
Clinical psychologists	2
Specialist social workers	4
Dietitian	0.5
Technical instructors	4
Generic assistants	4
Consultant in rehabilitation medicine	1

*Tertiary services which take on the most complex patients are likely to require consistently higher staffing levels.

GUIDELINES

The figures shown in Table 3a are given with the following provisos:

- G14** Staffing provision, in terms of numbers, qualification and experience in the management of brain injury, should be appropriate to meet the needs of the caseload. (A)^{33,34} (BSRM standards^{6,7})¹¹
- G15** Within any rehabilitation setting, staffing levels should be sufficient to provide: (C)^{29,11}
- safe lifting and handling of heavily dependent patients both for nursing care and in therapy sessions
 - safe supervision for all patients, including one-to-one supervision where required
 - adequate neuropsychological input to support the team in management of patients with cognitive and/or behavioural problems³⁹
 - the full range of services offered by that unit (eg inpatient, outreach, training etc)
 - a permanent staff establishment to ensure continuity of care (ie with the minimum use of temporary and agency staff)
 - a responsive service to support families in parallel to that for patients⁸
 - support and training for carers and rehabilitation professionals both within the service itself and in the community that it supports.
- G16** Senior staff within each discipline should have specific experience in the management of acquired brain injury, and be of sufficient grade and experience to be able to guide and lead the rest of their team. (C)²⁹
- G17** Rehabilitation services taking patients for post-acute rehabilitation, ie directly from neurosurgical or acute medical services, should have appropriate arrangements for 24-hour emergency medical and surgical cover. (C)²⁹
- G18** Services providing community-based or vocational services function largely in the community and require a different staffing pattern with occupational and vocational therapists, as well as close ties with social, employment and education services. (C)²⁹

2 Approaches to rehabilitation

This section refers to patients requiring a coordinated programme of interdisciplinary rehabilitation to achieve change following ABI. It addresses the principles that may help to draw the various disciplines together to provide a cohesive rehabilitation programme.

Level I evidence from the stroke literature¹⁶ suggests that effective intervention is best provided where:

- the relevant health and social care practitioners work together as a coordinated interdisciplinary team towards a common set of goals
- a rehabilitative milieu provides reinforcement of the programme throughout the 24-hour day
- interdisciplinary training and education programmes for staff are in place to ensure consistent standards of care.

2.1 Teamwork and communication

Rehabilitation is a continuous process. Carrying over skills gained in treatment into daily activities is critical to the success of any rehabilitation programme. This involves providing the opportunity for practice in different environments, including the home. Clearly defined systems are required for:

- ensuring coordination of effort between the various different disciplines
- communicating information to patients and their families/carers
- providing education and training to ensure carry-over.

GUIDELINES

- G19** There should be a single interdisciplinary patient record system in which all members of the team record their interventions. (C) (BSRM standards^{6,7})
- G20** A designated member of the team (eg a 'key-worker') should be responsible for overseeing and coordinating the patient's programme and acting as a point of communication between the team and the patient/family. (C) (BSRM standards^{6,7})
- G21** All major decision-making meetings, eg assessment, goal planning, case conferences, discharge planning, should be undertaken by the relevant members of the interdisciplinary team, in conjunction with the patient and their family/carers as appropriate, and should be documented in the case records. (C) (BSRM standards^{6,7})
- G22** Interdisciplinary protocols or integrated care pathways should be in place for management of common problems. (A-NCGS²)
- G23** Rehabilitation programmes should be developed in collaboration with family, carers or nursing staff to ensure that the programme is carried over into daily activities. (C) (BSRM standards^{6,7})

2.2 Goal planning

Goal-orientated programmes have gained widespread acceptance as a means of demonstrating progress and improving communication. If the patient, their family and the treating team are all working towards the same agreed goals, a satisfactory outcome is more likely.^{2,40}

GUIDELINES

- G24 Goal-setting should involve the patient (B) and the family if appropriate. (C-NCGS²)³⁰
- G25 Goals should:
- involve both long- and short-term objectives (C-NCGS²)
 - be meaningful to the patient and challenging but achievable (B-NCGS²)
 - be set at the level of whole team intervention as well as for the individual clinician. (C-NCGS²)
- G26 Programmes and goals should be reviewed at agreed intervals and adjusted accordingly. (C) (BSRM standards^{6,7})⁵

2.3 Assessment and measurement

Monitoring outcome from a rehabilitation programme is important to determine the extent to which the interventions have achieved their aims. An assessment of the attainment of patient-centred goals is essential (NCGS²). There is no single standardised measure which will adequately reflect change at all levels of rehabilitation. However, the BSRM has identified a short-list of validated measures which are in widespread use in the UK.⁴¹ Further instruments are addressed in a special issue of *Neuropsychological Rehabilitation* 1999.⁴²

GUIDELINES

- G27 All rehabilitation programmes should be monitored using tools which are appropriate, timely to apply and relevant to clinical decision-making. (C-NCGS²)
- G28 Outcome monitoring should include analysis of goal attainment for each patient. (B-NCGS²) (BSRM standards^{6,7})
- G29 The team should have an agreed minimum dataset for documenting outcome from the programme, and this should include:
- assessment tools which are shown to be valid and reliable (C-NCGS²)
 - re-assessment at appropriate intervals (C-NCGS²)
 - regular audit and evaluation. (C) (BSRM standards^{6,7})

3 Carers and families

Brain injury rarely involves an individual in isolation and rehabilitation must take account of the needs of the whole family unit. The very nature of acquired brain injury forces a patient's family/carer into dealing with the shock of a totally unexpected event, which is subsequently played out in what is, for them, an unknown and alien set of circumstances.

(Users from the working party)²⁹

Information, counselling, emotional and psychological support can reduce the psycho-emotional sequelae experienced by the family/carer. This support may help them to adapt and come to terms with the attendant life changes, and so result in better long-term outcomes for both the patient and the family.^{43,44} However, it must be sensitively offered as individual families will take their own time to accept and understand what has happened.⁴⁵ Not all families will wish to avail themselves of some, or indeed any, of the available support. The timing of proffered support may be critical to its success and the offer should remain open-ended.

Close family members are likely to experience high levels of stress. As time passes this may diminish a relative's ability to cope, especially if the patient has emotional and behavioural problems. Family members, especially partners, often feel isolated and trapped within a relationship where their own emotional needs are not being met.⁴⁶

Family members are very often a crucial asset to the patient, providing both long-term support and a major contribution to the rehabilitation process. It is also important for the team to recognise that family members often have a special rapport with the patient and may detect subtle communication in advance of the professionals.

Families can provide valuable insights into the patient's character, choices and ambitions, as well as important information on the presentation of difficulties in the home setting. This is essential in initial assessment, and in the monitoring of rehabilitation gain, to minimise under-reporting of difficulties when the brain-injured person lacks insight.⁴⁷

Families, as well as the patient, may be entitled to benefits and may not be aware that certain prescription drugs, eg medication to control post-traumatic seizures, can be available without charge. Early referral to self-help groups, such as Headway or Carers UK (see Appendix 3), may help them to find practical information over and above that which the treating team can offer.

GUIDELINES

- G30** Rehabilitation services should be alert to the likely strain on families/carers and, in particular, the needs of children in the family. (B-NCGS²)
- G31** Patients and their families/carers should be consulted with regard to treatment and care options and should be involved in planning of the patient's specific rehabilitation programme, negotiating appropriate goals, and in decisions regarding their care. (A-NCGS²) (BSRM standards^{6,7})^{11,21,30,45}

G32 Families of ABI patients should be offered timely:

- information and education about the nature of the brain injury, and about local and national services⁴⁸ and support groups (eg Headway) (A-NCGS²) (BSRM standards^{6,7})^{5,11,30,45}
- referral to social services regarding their own needs (C)²⁹
- assistance with the benefits system in relation to brain injury needs, including help to apply for appropriate benefits in relation to their own situation as well as that of the patient (C)²⁸
- support and counselling to reduce distress and to prepare them for dealing with the attendant life changes. This support should be available long-term and be provided by professionals experienced in the management of brain injury (A-NCGS²) (BSRM standards^{6,7})^{11,30}

and, where appropriate:

- the opportunity to learn skills, techniques and routines necessary to maintain rehabilitation gains (B)⁴⁹
- information about the process of compensation for personal injury and approved sources of information concerning legal assistance, eg Headway Solicitor list and Association of Personal Injury Lawyers list. (C)⁸

4 Early discharge and transition to rehabilitation services

The acute management of patients with ABI is addressed in the NICE guidelines on early management of head injury⁴³ and in the *National clinical guidelines for stroke*,² and so will not be further addressed here.

Not all patients require formal rehabilitation following head injury. However, even after mild head injury, a proportion of patients will have cognitive deficits that may impact significantly on work and family relationships, and proactive follow-up and intervention demonstrably improves outcome.^{13,14} Problems may not be immediately obvious, but can become apparent some weeks or months after injury.

Patients who make a rapid recovery following their emergency treatment may be able to go directly home after

- careful review to identify any residual physical, cognitive, emotional, and behavioural deficits
- referral on to specialist follow-up services (hospital based or community) as appropriate.^{23,11,22}

Outreach rehabilitation programmes can support continued gains in independence, self-organisation and psychological well-being even some years after injury.²³

A flowchart summarising the guidelines for early discharge to the community and referral to rehabilitation is provided in Appendix 4.

4.1 Early discharge to the community

GUIDELINES

G33 Once a patient with ABI is conscious they should be assessed for all common impairments (C)²⁹ including:

- limb motor impairments, such as weakness, altered tone and incoordination
- bulbar problems affecting speech and swallowing
- sensory dysfunction which may impact on safety including
 - hearing loss
 - visual problems, including reduced acuity, visual field loss, gaze palsies etc.
- cognitive problems, especially impairments in memory, concentration and orientation
- language problems, especially aphasia
- reduced control over bowels and bladder
- emotional, psychological and neuro-behavioural problems.

G34 Any ABI patient being considered for hospital discharge should not be discharged until the following areas have been assessed by someone familiar with neurological disability, and all identified needs have been documented and met: (A)^{23,11,22}

- presence of common neurological impairments (see above) which should be documented
- safety in the patient's proposed discharge environment
- need for continuing immediate active rehabilitation and how this will be met
- risk to others – especially where children are involved
- awareness of the person and their family or carers of the current problems and how to manage them.

G35 Any ABI patient being considered for hospital discharge, or taking self-discharge, and who has not had an assessment by a member of the specialist neurological rehabilitation team, should be notified to that team (A)^{13,14} and should have:

- preferably a fixed outpatient or domiciliary visit appointment with them
or, if this is impractical and problems are judged to be minor:
- a planned telephone contact from them within seven days.

G36 All patients being discharged after a recent ABI, regardless of follow-up arrangements already made, should: (C)^{13,14}

- be given a card with details of the specialist neurological rehabilitation team and how to contact them
- be warned of any likely problems they may face and how to manage them – including the fact that problems sometimes only become apparent some weeks or months later
- have a family member or friend also informed of the above (with the patient's agreement).

G37 For all patients discharged after ABI from an acute hospital, the primary healthcare team (GP) should: (C)⁵⁰

- be notified before or at the moment of discharge, with details of residual impairments and planned follow-up
- be given the details of the responsible neurological rehabilitation service to contact if problems emerge.

G38 Any patient who seeks contact with the NHS with symptoms following ABI should be offered an appointment with a professional trained in the sequelae of brain injury. (C)⁴³

4.2 Transfer to rehabilitation

In more severe head injury, early rehabilitation is associated with better outcomes.^{31,32}

GUIDELINES

G39 Patients still in hospital at more than 48 hours with impaired consciousness or mobility should be reviewed as soon as possible after injury by a rehabilitation team to advise on appropriate referral and interim management techniques to prevent secondary complications such as pressure sores, contractures, malnutrition and aspiration. (C)²²

G40 Severely brain injured patients still in coma should be referred to a specialist acute brain injury unit where their continued acute care may be supplemented by an interdisciplinary team of therapists trained in the prevention of potentially disabling sequelae (see Section 5). (C)^{11,22}

- G41** Those who are unable to go home directly and require a period of post-acute inpatient rehabilitation should be transferred to a specialist post-acute rehabilitation unit as soon as they are medically stable and fit to participate in rehabilitation. (B)^{31,32} (BSRM standards^{6,7})^{11,22}
- G42** Patients transferring to rehabilitation services should be accompanied by their medical records or a full discharge summary (C) (BSRM standards^{6,7}) including:
- a list of investigations undertaken and results
 - details of any surgical procedures/interventions
 - a summary of information given to the patient and their family regarding the nature of their brain injury and prognosis for recovery.

5 Inpatient clinical care – preventing secondary complications in severe brain injury

In the early stages of severe brain injury, patients may be acutely ill or in coma. Complications of brain injury can develop very quickly and may compromise the recovery process, but may be largely avoided by good preventive care. This section describes the principles of early intervention to prevent those secondary complications in patients still requiring hospitalisation for severe brain injury. The role of each professional is further outlined in *Critical care programme: The role of healthcare professionals within critical care services* (Modernisation Agency, 2002).⁵¹

Initial priorities include:

- (1) optimising respiratory function and tracheostomy management
- (2) managing swallowing impairment
- (3) maintaining adequate nutrition and hydration in the face of increased catabolism
- (4) 24-hour positioning/handling to avoid development of contractures, pressure sores and aspiration into the lungs, and to allow satisfactory ventilation
- (5) effective bladder and bowel management
- (6) establishing basic communication
- (7) management of seizures and challenging behaviours if present
- (8) provision of information, counselling and support for relatives (see Section 3).

5.1 Optimising respiratory function

Respiratory function may be compromised by

- poor respiratory effort
- poor cough reflex and inability to protect airway, leading to aspiration of food, liquid or saliva
- upper-airways obstruction, eg due to facial trauma, vocal cord palsy.

GUIDELINES

- G43** The patient's respiratory function should be optimised through early mobilisation, positioning, advice on oxygen therapy and appropriate manual techniques as advised by a specialist interdisciplinary team. (C)⁵¹
- G44** To minimise the risk of aspiration, patients with any significant symptoms, signs or disability should be screened for swallowing impairment before being given food and drink. (B-SIGN guidelines)⁹

Tracheostomy

Patients who have required a tracheostomy require regular reassessment and weaning from their tracheostomy as soon as this is feasible. A published set of guidelines provides detailed guidance on care and weaning (*The care of patients with tracheostomy tubes*, St George's Healthcare NHS Trust⁵²). Having a tracheostomy *in situ* does not necessarily preclude prompt referral to other specialist services.

GUIDELINES

- G45** Patients with a tracheostomy should be reviewed at frequent intervals and a weaning programme instituted as soon as this is appropriate, to facilitate early decannulation. (C)⁵²
- G46** Tracheostomy care and weaning should be undertaken in accordance with the published guidelines. (C)⁵²
- G47** A designated interdisciplinary tracheostomy team including nurses, physiotherapists, and speech and language therapists should take responsibility for setting and reviewing parameters for weaning, effecting good tracheostomy procedures and maintaining care. (C)⁵¹
- G48** Patients with tracheostomy *in situ* should be assessed by a speech and language therapist to determine optimum method of communication, including the suitability of cuff deflation and use of fenestrated tracheostomy tube or speaking valve placement, to achieve speaking voice. (C)⁵²

5.2 Management of swallowing impairment

Dysphagia (abnormality in swallowing fluids or food) is common in patients with acquired brain injury. It may lead to aspiration with an associated increased risk of developing pneumonia.² Prompt bedside assessment of swallowing by a speech and language therapist will usually identify those at risk. Videofluoroscopic examination or fibro-optic endoscopic evaluation of swallowing (FEES)) may provide further objective evaluation of swallowing, especially where there is a high risk of aspiration⁵³ or concern about silent aspiration.⁵⁴ More detailed guidelines on the management and rehabilitation of dysphagia are available from SIGN,⁵³ and also in preparation by the Royal College of Speech and Language Therapists.⁵⁵

GUIDELINES

- G49** Patients presenting with features indicating dysphagia and/or risk of aspiration should:
- receive further clinical evaluation, by a suitably trained speech and language therapist who should assess further and advise the patient and staff on safe swallow and consistency of diet/fluids (A-NCGS²) (SIGN guidelines⁵³)
 - be assessed by the interdisciplinary team for the most suitable posture and equipment to facilitate safe feeding. (SIGN guidelines⁵³)
- G50** Instrumental diagnostic examination (by videofluoroscopy or FEES) should be considered following bedside examination (B) (SIGN guidelines⁵³) where:
- the risk/benefit ratio of proceeding with trial of food is poor
 - there is doubt about future management options or a need for clarification of diagnosis.

- G51 A documented rehabilitation plan, or modified food/drink textures and nutrition plan, should be agreed with and communicated to the patient, carers, and all members of the healthcare team, including domestic staff. (C) (SIGN guidelines⁵³)

5.3 Maintaining adequate nutrition and hydration

Aside from dysphagia, severely brain-injured patients are at risk of malnutrition for a variety of other reasons, eg lack of consciousness, hyper-metabolism and cognitive deficits. Malnutrition is associated with a worse outcome and slower neurological recovery.⁵⁶

Brain injury induces a hyper-metabolic response, which reflects the severity of the injury. It is known to persist for 4–6 weeks. Energy requirements have been measured at 30–35% above normal basal metabolic rate but there is a considerable variation.^{57,58} As the metabolic rate returns to normal, it is also important to monitor weight and nutritional intake as immobility together with increased appetite may result in obesity.^{59,60} Maintaining optimal nutrition and hydration requires close collaboration between medical and nursing teams, speech and language therapy and dietetics.²

GUIDELINES

- G52 All brain injured patients with significant ongoing impairment or disability should have their nutritional status assessed using a validated method, within 48 hours of admission. (B-NCGS²)⁵¹
- G53 Where patients are unable to maintain adequate nutrition orally, nutrition should be provided via nasogastric tube within 48 hours of injury, in collaboration with dietetics and nursing staff. (A)^{56,61}
- G54 Nutrition and hydration must be adjusted to the patient's changing metabolic demand. (C)⁵¹
- G55 A dietitian trained in the management of brain injury should review nutrition and hydration needs regularly at least weekly. This should include weighing the patient weekly. (C)⁶⁰
- G56 If the patient is unable to take adequate nutrition orally for longer than 2–3 weeks after head injury, percutaneous endoscopic gastrostomy (PEG) feeding (or other appropriate stomal route) should be instituted, unless contraindicated. (B)^{62,63}

5.4 Positioning and handling

Therapeutic positioning is widely advocated to discourage the development of abnormal postures, contractures, pain, skin breakdown and respiratory complications – all of which are associated with delayed discharge and poorer outcomes. Prevention of these complications in the early stages is an important element in maximising functional gains and quality of life and in reducing the long-term costs of care (NCGS²).

A 24-hour approach to handling and positioning

GUIDELINES

- G57** All team members handling patients should be taught safe and appropriate ways to handle patients. (C-NCGS²)
- G58** A suitable moving/handling programme for each patient with limited mobility should be:
- instituted through collaboration between physiotherapy and nursing staff within 48 hours of admission (C)¹¹
 - applied consistently by all staff (C)¹¹
 - reviewed and revised as the patient's needs change. (C)¹¹
- G59** Patients unable to protect their pressure areas should:
- have a clinical assessment for risk of pressure sores (B-NCGMS³)⁶⁴
 - be provided with appropriate pressure-relieving equipment (mattress, cushion etc) without delay (A-NCGMS³)¹¹
 - have regular inspection of the skin area at risk to ensure that adequate protection is occurring (A-NCGMS³)⁶⁴
 - have access to specialist advice from special seating teams, tissue viability specialists etc.

Management of spasticity and prevention of contractures

Where spasticity develops despite appropriate preventative positioning, it may lead rapidly to development of contractures and require the input of an experienced team. Guidelines for the use of botulinum toxin in the management of spasticity in adults have been published by the Royal College of Physicians.⁶⁵ Further guidance on splinting and casting has been developed by the Association of Chartered Physiotherapists Interested in Neurology (ACPIN).⁶⁶

GUIDELINES

- G60** Patients with spasticity should be assessed and treated by an interdisciplinary team with experience in the management of spasticity. (C)⁶⁵
- G61** Patients with marked spasticity and/or contractures should have a coordinated plan for interdisciplinary management including:
- elimination of simple causative or aggravating factors such as pain and infection (C-NCGMS³)
 - the use of specific treatment modalities such as serial plaster casts or removable splints if appropriate (B)^{66–68}
 - the use of antispasmodic drugs including botulinum toxin where appropriate. (A-NCGS²)⁶⁵
- G62** The interdisciplinary team should be aware of the possibility of heterotopic ossification (HO) and protocols should be in place for its early detection and management including:
- the use of three-phase bone scans to detect active areas of HO (C)⁶⁹
 - the early use of disodium etidronate 20 mg/kg/day for 2 months and/or non-steroidal anti-inflammatory drugs (NSAIDs) to limit evolution of HO (B)^{70–72}

- surgical excision should be considered at a later stage if the limitation in joint motion hinders the patient's rehabilitation. (B)^{73,74}

Early sitting and standing

Prolonged periods of bedrest may lead to osteopenia, loss of muscle bulk and of normal cardiovascular and autonomic responses.^{75,76} Early sitting and standing is recommended to prevent these problems as well as to promote normal postural tone, proprioceptive information and maintain range and alignment of joints.⁷⁷ Patients who are unconscious or unable to support their own posture against gravity may require assistance and special equipment to achieve this. For further detail on postural support see Section 7.2.

GUIDELINES

- G63** Every brain-injured patient who remains unconscious or is unable to sit themselves up should have a graded programme to increase tolerance to sitting and standing. (C)⁷⁶
- G64** Patients should be stood and sat by adequately skilled staff with appropriately supportive equipment. (C)⁷⁶

5.5 Effective bladder and bowel management

During the acute stages, urinary continence may be maintained with an indwelling urethral catheter. However, prolonged catheter use may be associated with urethral stricture.⁷⁸

GUIDELINES

- G65** Prolonged catheterisation should be avoided where possible. (B-NCGS²) When an indwelling urethral catheter is *in situ*:
- the smallest possible gauge (10–12F) should be used (C)⁶⁰
 - the catheter should be removed as soon as possible and a toileting regimen instituted. (C-NCGS²) (see Section 7.1)
- G66** Patients should have a regular bowel regimen to avoid constipation and to manage faecal incontinence. (C-NCGS²)

5.6 Establishing basic communication

Acquired brain injury can cause a variety of communication deficits. A patient's inability to communicate with staff and family may result in frustration, increased behavioural problems, social isolation and inability to participate fully in the rehabilitation process.⁹ Early intervention should aim to establish a means by which the patient can express their basic needs to other people. For communication with a tracheostomy tube *in situ*, see G48, Section 5.1.

GUIDELINES

- G67** Conscious patients with communication difficulties should be assessed by a speech and language therapist who should work with staff and relatives to delineate appropriate communication techniques. (A-NCGS²) (SIGN guidelines⁹)

- G68 Assessment should include screening tests for hearing and vision, including the restoration of their usual aids such as glasses or hearing aids. (C)²⁹
- G69 Patients with severe communication disability, but reasonable cognition and language, should be assessed for and provided with appropriate alternative or augmentative communication aids. (B-SIGN guidelines⁹) (NCGS²)
- G70 Staff should recognise that patients may communicate at a higher level with family and friends who know them well, than with professional staff. (C)²⁹

5.7 Managing epileptic seizures

Seizures are not uncommon following ABI. When prescribing anticonvulsant prophylaxis, a balance must be struck between preventing seizures which could cause further brain damage, and the sedative and other side-effects of drugs which themselves are a cause of morbidity.

Seizure management has been most closely defined in the case of traumatic brain injury (TBI). Following TBI, seizures may be classified as ‘early’ (within 7 days) and ‘late’ (after 7 days). There is evidence that prophylactic anti-epileptics reduce the incidence of early seizures, but there is no evidence for a reduction in late seizures.⁷⁹ The American Academy of Neurological Sciences (AANS) and the American Academy of Physical Medicine and Rehabilitation (AAPMR) have published agreed guidelines for seizure prophylaxis.⁸⁰

GUIDELINES

- G71 Anticonvulsants may be prescribed during the first 7 days following TBI for the prevention of early seizures. (A)⁷⁹
- G72 Patients who have experienced no seizures or seizures only within the first 24–48 hours should be withdrawn from anticonvulsants after 7 days. (A)⁷⁹
- G73 Protocols should be in place for the management of acute seizures should they occur during rehabilitation. (C)⁸⁰
- G74 If late-onset seizures develop, an appropriate anticonvulsant regimen should be considered, prescribed and monitored, according to the advice of a consultant in neurology or other individual with specialist experience in the management of seizures after brain injury. (C)²⁹

5.8 Emerging from coma and post-traumatic amnesia

As patients regain consciousness, they are likely to be disorientated and confused and they may become agitated and restless. This period of post-traumatic amnesia (PTA), which may last for hours, days or weeks, ends when patients regain continuous day-to-day recall. Once PTA resolves it is then possible to assess longer-term cognitive, emotional and behavioural problems. Drug and alcohol withdrawal are also potential causes of confusion and agitation in the early stages after injury, requiring prompt recognition and treatment. Staff must be aware that brain-injured patients are often particularly sensitive to the central effects of drugs used to control agitation or other symptoms.

GUIDELINES

- G75** Patients who demonstrate confused or agitated behaviour after acute ABI should:
- be assessed fully to establish the diagnosis and especially to rule out treatable causes including drug and alcohol withdrawal (C)¹¹
 - be managed in a quiet environment, avoiding over-stimulation (C)¹¹
 - have an agreed plan for behavioural management which is provided consistently by all staff. (B)⁸¹
- G76** Drugs with sedative side-effects should be avoided where possible. (C)¹¹ However, in the presence of uncontrolled aggressive outbursts, the use of medications such as carbamazepine or olanzepine should be considered in conjunction with psychiatric advice with regular review. (C)^{29,82}
- G77** In the event of severe disturbance, one-on-one supervision should be provided to ensure the safety of the patient and those around him/her, to help to reassure and orientate the patient. (C)¹¹

5.9 Prolonged coma and vegetative states

The vegetative state is a syndrome of being awake but unaware.^{83–85} The minimally conscious state describes a person who has some inconsistent responses above the reflex level, but which are insufficient to allow communication.⁸⁶ Careful clinical assessment is required to distinguish these conditions from ‘locked-in syndromes’ where the patient is both awake *and* aware, but unable to communicate. Management guidelines for vegetative states have been laid out by a working party of the Royal College of Physicians⁸⁷ and by an International Working Party.⁸⁴ These also address some of the ethical issues in managing end-of-life decisions and support for bereaved families.

GUIDELINES

- G78** Where there is any doubt whatsoever about a patient’s level of consciousness, assessment should be undertaken by a team with specialist experience in profound brain injury to establish the level of awareness and interaction. (C)⁸⁷
- G79** Where patients remain in persistent coma or minimally conscious states for more than three months, management in a specialist tertiary centre should be considered if the local services are unable to meet their needs for specialised nursing or rehabilitation. (C)^{11,22,87}

6 Rehabilitation setting and transition phases

To maximise new learning and relearning of old skills, evidence suggests that activities should be practised in a naturalistic and realistic environment – ideally at home.^{88,89} However, to reach the stage where that is possible, some patients with ABI will require a period of intensive specialist inpatient rehabilitation. The most appropriate setting for intervention will depend on the individual and their goals for rehabilitation at that particular time (BSRM standards^{6,7}) (HSCR⁸).^{11,90}

Whichever setting is chosen, transfer, discharge and transitions between services must be managed in a way that is safe and therapeutic, and that reflect the needs and priorities of patients and their families/carers.⁹¹

6.1 Referral, assessment and review

Patients with brain injury require timely access to specialist rehabilitation programmes whether in hospital or the community (BSRM^{6,7}) (HSCR⁸).^{11,90} Where they cannot be admitted directly to specialist rehabilitation, defined procedures are required for referral and/or assessment and to minimise waiting times.

GUIDELINES

- G80** Each specialist rehabilitation service should have:
- a written procedure for referral and assessment to ensure appropriate and timely referral (C) (BSRM standards^{6,7})
 - systems to deal with urgent referrals and to minimise waiting times for the service. (C) (BSRM standards^{6,7})
- G81** The initial referral/assessment should routinely include:
- a full review of the patient's needs for rehabilitation and support (C)⁵⁰
 - an interview with the family/carers (C)⁵⁰ in order to:
 - establish their own needs
 - gain further insights into the needs of the individual within the home environment.
- G82** The patient and family should receive:
- clear feedback of the results of the assessment and of the recommendations made (C)⁵⁰
 - continuing education/information about the nature and effects of brain injury. (C) (BSRM standards^{6,7}) (HSCR⁸)^{24,45}
- G83** Following assessment, a written summary should be supplied to the referrer summarising the patient's rehabilitation needs with recommendations for further management. (C) (BSRM standards^{6,7})

6.2 Discharge planning

Standards for discharge planning are set out in the Department of Health publication, *Discharge from hospital; pathway, process and practice*.⁵⁰ Discharge planning involves working with the family/carers to identify the most suitable discharge destination, to process any application and negotiate funding if required. In choosing the destination, careful consideration is required both of the patient's needs for continuing care and rehabilitation, and of the family's needs for accessibility. However, local services will not always be the most appropriate solution.²⁵

GUIDELINES

- G84** Inpatient rehabilitation should continue while the patient requires the facilities, skills and therapeutic intensity of a specialist inpatient rehabilitation unit in order to make progress or while the hospital environment is needed in order to maintain safety. (C)²⁹
- G85** Patients may be transferred back to the community, once any appropriate specialist rehabilitation and support needed can be continued in that environment without delay. (A-NCGS²)
- G86** Planning for community transition should include:
- full preparation of the patient and the family (C-NCGS²)⁴⁵
 - assessment of the discharge destination environment and support available (C)^{21,50}
 - provision of any equipment and adaptations that are required (C-NCGS²)^{21,50}
 - training of carers/family in the use of equipment and in managing the patient to ensure patient safety in the home environment (B-NCGS²)⁵⁰
 - timely liaison with the community teams, primary care teams and social services to guarantee a smooth handover, agree an appropriate package of care and/or continuing rehabilitation programme (C-NCGS²)⁵⁰
 - graded discharge, usually with short-stay or weekend visits at home, to test the suitability of the home care arrangements (C) (BSRM standards^{6,7})
 - giving patients and their families information about, and offering contact with, the appropriate voluntary services and self-help groups that may be useful to them, eg Headway, the Encephalitis Society, Different Strokes (see Appendix 3) etc. (C-NCGS²)⁴⁵
- G87** Transfer to the community should include a written care plan (C)⁵⁰ outlining:
- current needs
 - key contacts
 - responsible services/professionals
 - sources of continued information, support and advice (eg Headway, Patient Advice and Liaison Services (PALS) and social services).
- G88** Care plans should be agreed jointly between the patient and carer and health and social care professionals from the services involved in the transition. The care plan should be accepted by all parties *prior to transition* and a time-frame for review agreed – usually 3–6 months post discharge. (C)^{24,50}
- G89** Upon transfer or discharge, there should be a written report (C) (BSRM standards^{6,7})⁵ which includes:

- the results of all recent assessments
- a summary of progress made and/or reasons for case closure
- recommendations for future intervention.

G90 Copies of both the care plan and the discharge report should be provided to the patient/family where appropriate (C)⁴⁵ and all professionals relevant to the patient's current stage of rehabilitation, especially the GP. (C) (BSRM standards^{6,7})^{24,91}

7 Rehabilitation interventions

The guiding principles of rehabilitation are similar, whether delivered in an inpatient or community setting. This section provides guidelines on the approach to some common clinical problems. Where it is appropriate and relevant to do so, guidelines have been extrapolated from evidence and from guidelines in stroke and other areas of neurological rehabilitation, eg multiple sclerosis.

7.1 Promoting continence

Urinary and faecal incontinence is common following severe ABI. It is distressing, socially disruptive and a major burden to carers once the patient is discharged home. Active management and re-training of bladder and bowel continence is a critical part of the rehabilitation programme, since incontinence can seriously hamper progress in other areas (NCGS)². Further details on general management of incontinence are available from two reports from the Royal College of Physicians:

- *Incontinence: causes, management and provision of services* (1995)⁹²
- *Bowel care in older people: research and practice* (2002).⁹³

Bladder management

GUIDELINES

- G91** Patients who have continuing urinary continence problems should have:
- assessment by a professional trained in continence management in the context of ABI (C-NCGS²)
 - a regular monitoring programme, eg 24-hour voided volume chart, and fluid intake charts (C)⁶⁰
 - access to specialist urologist/continence management and advice, including further investigation (eg urodynamics, ano-rectal physiology etc) (C-NCGS²)
 - effective strategies for alerting carers to the patient's need to pass urine – in cases of communication and mobility problems (C)⁹⁴
 - an established toileting regimen based on reinforcement – in cases of cognitive impairment. (C)⁹⁵
- G92** Anticholinergic medication should only be prescribed after demonstration of an overactive bladder (eg by the passage of small frequent volumes on a 24-hour voided volume chart with a post-micturition residual volume of <100 ml, or by formal urodynamic investigation). (C)^{60,96}
- G93** If a patient has a 'residual volume' of >100 ml, intermittent catheterisation should be considered. (C)⁹⁶
- G94** Long-term catheters should only be used after full assessment and consideration of less invasive forms of bladder management. If necessary they should be used as part of a planned catheter management programme using an agreed protocol. (B-NCGS²)

- The impact on sexual function should be considered, particularly the potential problems associated with an indwelling urethral catheter. (C-NCGS²)
- Supra-pubic catheters should be used in preference to long-term urethral catheters. (C)⁶⁰

G95 Patients with continence problems should not be discharged until adequate arrangements for continence aids and services have been arranged at home and the carer has been adequately prepared. (C-NCGS²)

Bowel management

Constipation is common in patients with ABI due to immobility, use of medications with anticholinergic side-effects, lack of privacy leading to embarrassment, and poor fluid and dietary intake. It may be further exacerbated by other coexisting neurological problems, eg spinal injury. As well as causing discomfort and exacerbating spasticity it may progress to faecal impaction and overflow incontinence if not proactively managed.

GUIDELINES

- G96 An active bowel management regimen should be instituted to establish the patient's normal pattern as soon as possible. This should include: (C)⁶⁰
- ensuring sufficient fluid intake (2–3 litres per day unless contraindicated)
 - the use of natural laxatives, eg prunes or simple bulk laxatives (if fluid intake is sufficient)
 - encouraging exercise and standing, where possible
 - avoiding medications which slow gut motility, such as codeine, tricyclic antidepressants etc
 - careful attention to ensure maximum privacy and comfort during defecation.
- G97 Patients should be supported to sit up for defecation on a toilet or commode at the earliest safe opportunity, and at a regular time each day. (C)⁶⁰
- G98 Daily rectal stimulation (eg with a suppositories or a microenema) should be used where the rectum is full but no spontaneous evacuation occurs despite the conditions above. (C)^{60,97}
- G99 If the rectum is empty for three days running, despite continuing oral intake, the use of an osmotic laxative (eg polyethylene glycol) or a stimulant (eg senna) should be considered. (C)^{60,98}

7.2 Motor function and control

The aim of physical rehabilitation is to increase independence through the facilitation of motor control and skills, and there is strong evidence to demonstrate effectiveness in terms of improved functional independence (NCGS²).

Neuro-physiotherapists need to be not only skilled in the physical management of neurological deficits, but also experienced in recognition and handling of associated cognitive and behavioural deficits which may impact on the patient's ability to engage and cooperate in therapy sessions and to carry over physical gains into daily activities.⁹⁹

GUIDELINES

- G100** A physiotherapist with neurological expertise should coordinate therapy to improve motor function for all brain injured patients. (C-NCGS²)
- G101** Any of the current physical treatment approaches should be practised within a neurological framework to improve patient function but should also take account of associated orthopaedic or musculoskeletal injuries. (A-NCGS²)
- G102** The programme should include a written plan, with illustrations where appropriate, to guide other members of the team in carrying over motor skills into other daily activities. (C)¹⁰⁰

Supportive seating and standing

Postural re-training is an important precursor to gait re-education. The benefits of maintaining an upright posture have been discussed in Section 5.4. In the early stages, supportive systems help to maintain the trunk and head in a good position and free the upper limbs for functional use. As truncal stability improves, systems which encourage more active movement may be introduced to achieve dynamic balance in sitting and standing. More details are provided in the BSRM's *Guidelines for special seating provision*.¹⁰¹

GUIDELINES

- G103** Patients who are unable to maintain their own sitting balance should have:
- timely provision of an appropriate wheelchair and suitable supportive seating package (C)¹⁰¹
 - regular review to ensure continued suitability of the seating system as their needs change. (C)¹⁰¹
- G104** Patients with complex postural needs should be referred to a specialist interdisciplinary team who have expertise in specialist seating. (C)¹⁰¹
- G105** Patients who are unable to stand independently should be provided with a suitable standing aid if appropriate, and this provision should be continued into the community if still required at the time of transfer. (C-NCGMS³)⁷⁷

Aids and orthoses

Orthoses such as an ankle-foot orthoses (AFO) or hand splints may be helpful for some patients to maintain normal posture and stability during function.^{102,103} Care must be taken when fitting orthoses to avoid pressure areas, especially where deformity exists or sensation is compromised.

GUIDELINES

- G106** Patients with mobility problems should be considered for appropriate walking or standing aids to improve stability (C) which may include an ankle-foot orthosis. (B)^{102,103}
- G107** If an orthosis is supplied it should be individually fitted. (C-NCGS²)

Improving motor control

Recovering mobility is an important goal for the immobile patient and is a key factor in regaining functional independence. In addition to neurological impairments arising directly from brain injury, patients who have been unconscious or immobile for significant periods lose muscle bulk and cardiovascular fitness, all of which must be appropriately addressed in terms of the physical capacity of the individual patient.

GUIDELINES

- G108** When planning a programme to improve motor control, the following should be considered to improve motor control and general fitness:
- treadmill training with partial bodyweight support as an adjunct to conventional therapy (A-NCGS²)
 - strength training to improve motor control in targeted muscle groups (B-NCGS²)
 - gait re-education to improve walking ability (B-NCGS²)
 - exercise training to promote cardiorespiratory fitness. (B-NCGMS³)

7.3 Sensory disturbance

Sensory disturbance, including partial loss of hearing or vision, may exacerbate disorientation and confusional states or impact on higher cognitive function.

GUIDELINES

- G109** Patients with visual and/or hearing loss should be assessed and treated by an interdisciplinary team with the appropriate experience or in conjunction with another specialist service able to meet their special needs. (C)¹⁰⁴

In the case of visual loss:

- ophthalmologists should be involved in the assessment of vision
- orthoptists should be involved where there are problems with eye movement or double vision
- rehabilitation workers for the visually impaired should be involved regarding functional use of vision, mobility training and equipment.

In the case of hearing loss:

- audiologists should be involved in the assessment of hearing and suitability of hearing aids
- advice should be sought from a hearing therapist or social worker for deaf people, with regard to rehabilitation and equipment provision.

- G110** Patients presenting with persistent visual neglect or field defects should be offered specific re-training strategies. (A-NCGS²)

Pain

Pain is frequently underdiagnosed in ABI and is associated with poor outcome.¹⁰⁵ Patients with communication and cognitive deficits are often unable to describe sensory symptoms. Specially

adapted assessment tools^{106,107} or the skills of a speech and language therapist and family/carers may be required to elicit symptoms accurately.

Painful musculoskeletal sequelae of ABI include heterotopic ossification (see G62), contracture and deformity. Shoulder pain is particularly common in upper limb paresis, arising from spasticity in the shoulder girdle muscles, malalignment or subluxation due to muscle imbalance or weakness, or secondary damage to soft tissues (eg rotator cuff tears or impingement). An evidence-based integrated care pathway for the management of shoulder pain associated with upper motor neurone weakness and alteration in tone has been published.^{108,109} Neurogenic pain may be associated with local hypersensitivity to touch. Pain may be exacerbated by poor handling and the uncontrolled effects of gravity. Successful management depends on an accurate assessment and intervention depending on the contributing factors, and preventive measures to support the affected limb in all positions.

GUIDELINES

- G111** All patients should be assessed for pain on a regular basis and treated actively in accordance with their wishes. (C-NCGS²)
- G112** Staff should be alert to the possibility of pain in patients who have difficulty communicating and should pay particular attention to non-verbal signs of pain. (C)²⁹
- G113** Staff and carers should be educated about appropriate handling of :
- the paretic upper limb during transfers (B-NCGS²)
 - hypersensitivity and neurogenic pain.
- G114** Protocols should be in place for management of pain which include:
- handling, support and pain relief appropriate to the individual needs of the patient (B)¹⁰⁹
 - review at regular intervals and adjustment in accordance with changing need. (C)¹⁰⁹
- G115** Intra-articular steroids should only be used where there is demonstrable evidence of soft tissue inflammation (eg on T2-weighted magnetic resonance imaging) and injections should be carefully targeted on the identified sites. (C)¹¹⁰

7.4 Communication and language interventions

Acquired brain injury can affect communication in different ways.¹¹¹ Speech and language therapy intervention may target:

- motor speech production and reduced intelligibility
- receptive or expressive language skills (including reading and writing)
- 'high level' abstract language skills and social interaction skills.

GUIDELINES

- G116** Patients with specific communication difficulties should be assessed by a speech and language therapist to assess their suitability for intensive or regular speech and language therapy treatment. (B-NCGS²)

G117 Where achievable goals can be identified, and continuing progress demonstrated, patients with communication difficulties should be offered an appropriate treatment programme, with monitoring of progress. (A-NCGS²) (B-SIGN guidelines⁵³)

G118 The programme should:

- take into account
 - the patient’s premorbid communication style (C)¹¹²
 - any underlying cognitive deficits (C)¹¹²
- give the opportunity to rehearse communication skills in situations appropriate to the context in which the patient will live/work/study/socialise after discharge (C)¹¹²
- include the family and carers in developing strategies for optimum communication within the immediate social circle (C)¹¹²
- consider the need for communication aids including gesture drawing, communication charts and computerised systems. (C-NCGS²) (B-SIGN guidelines⁵³)

7.5 Cognitive, emotional and behavioural management

Cognitive, emotional and behavioural problems are extremely common following acquired brain injury and may be more problematic in the longer term than physical disability. They quite frequently coexist and can be difficult to disentangle from one another. The issues are addressed in more detail in a recent special issue of *Neuropsychological Rehabilitation*.¹¹³

Cognitive management

The nature of cognitive deficit depends to some extent on the severity and location of injury and may include difficulties with memory, concentration, initiation, planning, problem solving etc. Limitations of patients’ insight and awareness of their difficulties in particular may impact on their ability to engage effectively in rehabilitation, and may therefore affect the timing of intervention.

A detailed neuropsychological assessment will contribute to evaluation of:^{90,114}

- the likely impact of cognitive impairment on the rehabilitation programme
- areas of strength that the patient may be able to build on during rehabilitation
- the patient’s prognosis in terms of their ability to function independently in the community or to return to work or study, and to identify the appropriate areas for effective rehabilitation input.

GUIDELINES

G119 All patients with symptomatic brain injury should be referred for a neuropsychological assessment to evaluate cognitive functioning. (C)^{90,114}

G120 Where cognitive impairment is causing management difficulties or limiting response to rehabilitation, specialist advice should be sought and, if appropriate, the patient referred to a formal cognitive rehabilitation programme. (C)^{90,114}

G121 Patients with persistent cognitive deficits following ABI should be offered cognitive rehabilitation (B)¹¹⁵ which may include:

- management in a structured and distraction-free environment and targeted programmes for those with executive difficulties (ie problems with planning, organisation, problem solving and divided attention) (A)¹¹⁶
- attempts to improve attention and information processing skills (B)¹¹⁵
- teaching compensatory techniques to overcome their everyday problems (C)¹¹⁷
- the use of external memory aids to enhance independence in the presence of memory deficits. (A)¹¹⁸

G122 Trial-and-error learning should be avoided in patients with memory impairment. (B)¹¹⁹

Mental capacity (competence)

Patients with severe cognitive impairment may lack mental capacity and therefore not be in a position to weigh up decisions regarding their own management. Such patients are subject to the Department of Health reference guide to consent for examination and treatment.¹²⁰

Under English law, no one is able to give consent on behalf of an adult who lacks capacity. Therefore parents, relatives or members of the healthcare team are *not* able to consent to treatment on behalf of the patient. However, treatment and examinations may be carried out under common law, if they are agreed to be in the patient's 'best interests'. The key principle is therefore to identify and document those 'best interests' which include not only the patient's medical interests, but their values and preferences when competent, their psychological well-being and relationships. It is good practice to involve family/carers who may be able to provide insight into *the patient's* past values and beliefs, but relatives must not impose their own views or wishes on the decision. Where there is doubt about the patient's capacity or best interests, referral to the High Court may be necessary.

If the patient has significant financial assets and is unable to manage their own financial affairs, the need for and suitability of power of attorney or Court of Protection arrangements are likely to require consideration.

GUIDELINES

G123 Patients should be assessed for their mental capacity to consent to procedures or to interventions which may carry significant risk or cause significant discomfort. (C)¹¹

G124 Where patients lack capacity to consent to a certain intervention, there should be clear procedures for establishing 'best interests' and the process of evaluation should be fully documented. (C)²⁹

G125 Teams should consider the patient's ability to manage their own affairs, finances etc. Appropriate advocacy/legal advice should be arranged for vulnerable patients to protect their best interests. (C-NCGMS³)

Emotional management

Anxiety, depression and other disturbances of affect are common after brain injury and are likely to increase over time if not identified and treated.⁹⁰ However, specific assessment is required to distinguish depression from the somatic and neurobehavioural sequelae of ABI (eg apathy, amotivation). Antidepressants are shown to be effective in the management of

depression following brain injury,^{121,122} but their use must be monitored in ABI because many agents lower the seizure threshold. An evidence-based integrated care pathway has been developed and published for the assessment and treatment of depression in the context of rehabilitation following ABI.¹²³

GUIDELINES

- G126** Assessment of emotional state, including mood, should be undertaken in all patients. (C-NCGS²), if necessary using specially adapted assessment tools.
- G127** Patients should be given information, advice and the opportunity to talk about the impact of brain injury on their lives with someone experienced in managing the emotional impact of acquired brain injury. (B-NCGS²)¹²⁴
- G128** Patients should be provided with access to individual and/or group psychological interventions for their emotional difficulties, adapted to take into account individual neuropsychological deficits. (C)^{125–127}
- G129** Patients in whom depression or emotional lability is diagnosed should be considered for a *monitored* trial of antidepressant medication. (A-NCGS²)¹²⁸
- G130** Mood disorder that is causing persistent distress or worsening disability should be managed by, or with advice from, a clinical psychologist or psychiatrist experienced in the management of emotional difficulties following brain injury. (C-NCGS²)
- G131** Patients should have access to specialist individual or group-based neuropsychological interventions to facilitate long-term psychological, family and social adjustment, including sexual relationships. This need may not arise for many years post-injury. (C)^{90,125,129}

Behavioural management

A variety of unwanted or antisocial behaviours may sometimes develop after brain injury, including verbal or physical aggression, sexual disinhibition and attention-seeking behaviour.¹³⁰ Longitudinal studies⁸¹ suggest that planned behavioural modification programmes, consistently applied, are effective in preventing these undesired behaviours from becoming established.¹³¹ Basic management of agitated behaviour is described in section 5.8 on post-traumatic amnesia. Patients with severe behavioural problems, especially those with a tendency to wander, may require referral to specialist behavioural management services. (C)^{11,22}

GUIDELINES

- G132** Patients with acquired brain injury should be provided with access to specialist psychological assessment and interventions to assist in the management of their behavioural difficulties including substance abuse. (C)^{90,132–134}
- G133** In the event of severe behavioural disturbance, appropriate supervision (including one-on-one supervision when required) by a professional trained in behavioural management should be provided to ensure the safety of the patient and those around him/her, and to provide effective behavioural management. (C)¹¹

- G134** Families should be given specific information and support to help them to understand the nature of cognitive and behavioural problems, and guidance on how to interact appropriately with the patient. (C)¹¹
- G135** If the problems persist or worsen over more than two weeks or if they give rise to severe concern for safety, the patient should be transferred to a specialist unit to provide a safe environment and specific assessment and treatment. (C)^{11,135,136}

Psychiatric management

Mental illness is a risk factor for brain injury,¹³⁷ and may be caused by brain injury.^{138,139} ABI is associated with alcohol and other substance abuse¹⁴⁰ and with increased risk of suicide.¹⁴¹ Close liaison is essential between brain injury rehabilitation services and local psychiatry services. Patients with severe ABI sometimes lack insight into their difficulties and occasionally may require treatment under a Section of the Mental Health Act 1983 if they are unwilling to remain in hospital voluntarily. However, even if patients cannot be admitted under 'Section', staff should be aware of their duty of care to ensure the safety of patients who are unconsciously putting themselves or others at risk.

GUIDELINES

- G136** There should be a named psychiatrist in every health district with special expertise and responsibility for assessing adults with acquired brain injury with significant neuropsychiatric problems. (C)¹⁴⁰
- G137** If a patient has significant neuropsychiatric problems, local mental health teams should be involved in aftercare planning. (C)¹⁴⁰
- G138** All patients whose acquired brain injury is a result of deliberate self injury should have a psychiatric assessment to undertake a risk assessment and consider the need for further intervention from the mental health team. (C)¹⁴⁰
- G139** If a patient is unwilling to stay in hospital yet needs to do so because it would not be safe for them to go home, consideration should be given to the need for treatment under a Section of the Mental Health Act 1983. (C)¹⁴²
- G140** Specialist neuropsychiatric support should be available to support the local mental health teams in the management of patients with complex neuropsychiatric problems following brain injury. (C)²⁹

7.6 Optimising performance in daily living tasks

Activities of daily living (ADL)

The majority of rehabilitation interventions undertaken by the interdisciplinary brain injury team are aimed at minimising impairments and maximising performance in daily living tasks. These tasks include basic self-care and more extended activities of daily living (eg shopping, meal preparation etc), work and leisure activities. To maximise new learning and relearning of old skills, evidence suggests that activities should be practised in a naturalistic and realistic environment – ideally in the patient's own home and local environment.^{88,89}

Independence is achieved through practice, the learning of adaptive techniques, provision of equipment/environmental adaptation.

GUIDELINES

- G141** All patients with difficulties in activities of daily living
- should be assessed by an occupational therapist with expertise in brain injury (A-NCGS²)
 - should have an individual treatment programme that is aimed at maximising independence in areas of self-maintenance, productivity and leisure. (C-NCGS²)
- G142** All daily living tasks should be practised in the most realistic and appropriate environment, with an opportunity to practise skills outside therapy sessions. (A-NCGS²)
- G143** Social services should recognise that provision of ‘care’ for some patients with acquired brain injury may mean the supervision and practice of community living skills, rather than hands-on physical care. (C)^{28,29}
- G144** Family and carers should be involved in establishing the most appropriate routines for activities of daily living which take account of their lifestyle and choices. (C)⁹¹

Provision of equipment/adaptations

Provision of equipment or adaptations provides a unique resolution to the individual’s needs within their own environment, hence research into specific solutions may never be undertaken. Nevertheless, Level I research evidence demonstrates the general benefit and cost effectiveness of equipment provision.¹⁴³

GUIDELINES

- G145** Every patient should be assessed to determine whether equipment or adaptations could increase their safety or independence. (A-NCGS²)
- G146** The need for equipment should be assessed on an individual basis and in the environment in which it will be used. (B-NCGS²)
- G147** Prescription of equipment should take account of any cognitive and behavioural deficits and their constraints on the patient’s ability to use the equipment safely and appropriately. Where this is in doubt the equipment provider should be responsible for ensuring that arrangements are in place for regular review. (C)²⁹
- G148** Once an item of equipment has been identified as required for a patient
- it should be provided as quickly as possible (B-NCGS²) and *before* the patient is discharged to the community
 - the patient, family and/or carers should be thoroughly trained in its safe and effective use (C-NCGS²)
 - its ongoing use and relevance should be reviewed on a regular basis and in accordance with the manufacturer’s guidelines (C-NCGS²)
 - patients should be given clear written information on who to contact for repairs, replacement, or for future help and advice regarding the equipment. (C-NCGS²)

7.7 Leisure and recreation

Engagement in leisure activities is increasingly recognised as an important determinant of quality of life.¹⁴⁴ It is consistently highlighted in user surveys, and is now a recognised health domain in the WHO International Classification of Functioning Disability and Health (ICF).¹⁴⁵

People with ABI who do not resume employment may have more time to engage in leisure activities. However, their ability to engage in these may be inhibited due to:

- the cognitive effects of brain injury such as poor executive skills, problem-solving, and decision-making
- social and behavioural problems leading to difficulties maintaining social relationships
- environmental barriers (eg difficulty accessing public buildings and using public transport).

Targeted problem-solving intervention may be required to help them overcome these difficulties.

GUIDELINES

- G149** Community brain injury services should guide and support persons with significant brain injury in developing alternative leisure and social activities, in liaison with local voluntary organisations. (B)^{144,90}
- G150** All patients should be assessed by a rehabilitation professional or team (C)¹⁴⁶ to identify:
- level of participation in leisure activities (including indoor and outdoor pursuits)
 - barriers or compounding problems which inhibit their engagement in such activities.
- G151** Patients with difficulty undertaking leisure activities of their choice should be offered a goal-directed community-based programme aimed at increasing participation in leisure and social activities. (C)¹⁴⁶

7.8 Computers and assistive technology

Personal computers have increasingly become routine household items. As well as providing a useful adjunct to therapy in some areas,^{147,148} they offer opportunities for sedentary recreation and social interaction (via e-mail).¹⁴⁹ In some cases the acquisition of computer skills may also provide opportunities for employment.¹⁵⁰ Increasing availability of adapted hardware and software can also offer an alternative means of writing for those who are no longer able to hand write;¹⁵¹ this can also provide augmented communication and be linked with environmental control systems.¹⁵²

GUIDELINES

- G152** People with brain injury should be given information and advice about changes in technology and computer use relevant to their needs. (C)¹⁴⁹
- G153** Where necessary, a specialist assessment of each individual's ability to use a personal computer should be arranged and the need for adapted hard- and software recorded. (C)¹⁴⁹

G154 Rehabilitation teams should:

- routinely consider the use of computers as an adaptive source of meaningful occupation for people with brain injury (C)^{149,152}
- collaborate with other agencies (eg adult education schemes, employment schemes, charities etc.) to obtain the provision of adapted hard- and software, and training to enable the individual to develop the appropriate computer skills. (C)^{149,152}

7.9 Driving

There are a number of reasons why patients with acquired brain injury may not be able to return to driving. Prohibiting conditions include seizures, visual field defects or cognitive impairments that affect judgement, attention, reaction times and emotional/behavioural control. However, many people with milder forms of brain injury may be able to return to driving or acquire driving skills following appropriate assessment. Detailed information is available in the *At a glance guide to the medical standards of fitness to drive* published by the Driver and Vehicle Licensing Agency (DVLA).¹⁵³

Although members of the interdisciplinary team may give initial advice to patients about driving, the final decision about fitness to drive lies with the DVLA, supported by medical advice from the treating doctor. Specialist driving assessment centres offer detailed assessment and off-road testing where driving abilities are in doubt; these centres are listed in the DVLA guide.¹⁵³ Accessible information about driving after brain injury is also available in a booklet, *Driving after brain injury*, published by Headway (www.headway.co.uk; see Appendix 3).

GUIDELINES**G155** The interdisciplinary rehabilitation team should:

- advise the patient and/or their advocate that they are obliged by law to inform the DVLA that the individual has suffered a neurological impairment and to provide the relevant information on its effects (A)¹⁵³
- provide information about the law and driving after brain injury (eg the Headway booklet, *Driving after brain injury*) (C)²⁹
- Provide clear guidance for the GP and family, as well as the patient, about any concerns about driving, and reinforce the need for disclosure and assessment in the event that return to driving is sought late post-injury. (C)¹⁵⁴

G156 A doctor with experience of brain injury should screen patients who wish to drive, in accordance with DVLA guidelines, where appropriate in liaison with the multidisciplinary team. (A)¹⁵³

G157 If the patient's fitness to drive is unclear, a comprehensive assessment of capacity to drive should be undertaken at an approved driving assessment centre. (C)¹⁵³

7.10 Vocational/educational rehabilitation*

Vocational outcome after acquired brain injury is recognised to be poor. For example, only about a third of patients with severe traumatic brain injury return to work. However, there is consistent Level II evidence of positive outcomes for specialist brain injury vocational rehabilitation programmes,^{156–160} and the initial investment in rehabilitation pays in terms of cost-benefits.^{161,162} However, long-term successful employment may require ongoing support and supervision.^{159,161}

Jobcentre Plus operates a number of schemes to assist disabled people back into the workplace, which can be accessed through referral to the disability employment advisor (DEA). These schemes include:

- Access to Work (eg help with physical adaptations, specialist equipment or aids, assistance with travel)
- Brain Injury Work Preparation programmes
- WORKSTEP (supported employment programme)
- Permitted Work.¹⁵⁵

The complex vocational needs after brain injury require close liaison between local services including Jobcentre Plus, health and social services and vocational providers, to provide specialist vocational assessment and rehabilitation or suitable alternative occupational provision.¹⁵⁵ Similarly, patients returning to educational or training courses require liaison between rehabilitation services and their tutor/education provider to plan their return including arrangements to support any special needs. **All liaison described below requires the patient's prior consent.**

GUIDELINES

- G158** Clinicians involved in brain injury rehabilitation should consider vocational needs and put patients in touch with the relevant agencies as part of their routine planning, and refer, where appropriate, to a specialist vocational rehabilitation programme. (C)¹⁵⁵
- G159** Patients seeking a return to employment, education or training should be assessed by a professional or team trained in vocational needs following brain injury. (C)¹⁵⁵ Assessment should include:
- evaluation of their individual vocational and/or educational needs (C)¹⁵⁵
 - identification of difficulties which are likely to limit the prospects of a successful return and appropriate intervention to minimise them (C)¹⁵⁵
 - direct liaison with employers (including occupational health services when available), or education providers to discuss needs and the appropriate action in advance of any return (C)^{11,155}
 - verbal and written advice about their return, including arrangements for review and follow-up. (C)¹⁵⁵
- G160** A patient requiring assistance in returning to previous employment should be discussed with the local disability employment advisor (DEA) with a view to a joint evaluation of vocational needs and/or referral on to a suitable vocational provider. (C)¹⁵⁵

*The guidance for vocational rehabilitation has been developed by an inter-agency reference group,¹⁵⁵ convened for the purpose of these guidelines (see Appendix 1).

When referring to the DEA, brain injury services should: (C)¹⁵⁵

- provide summary information and explanation about the brain injury and its effects and about the rehabilitation input received to date
- attend the interview with the DEA to assist the patient in explaining about their work-related difficulties and to contribute to the development of an agreed joint plan of action.

- G161** A patient who is considered to be capable of employment but unable to return to previous work or training should be referred, via the DEA, for employment assessment by a Jobcentre Plus work psychologist or other suitably trained professional experienced in assessment of vocational needs after brain injury. (C)¹⁵⁵
- G162** Patients considered to require a programme of vocational rehabilitation prior to return to work or training, should be referred (C)¹⁵⁵ either:
- to the DEA for assessment of suitability for referral under contract to a specialist brain injury work preparation provider, *or*
 - direct to a brain injury vocational rehabilitation programme.
- G163** In setting up a voluntary trial in the workplace, arrangements need to ensure the following: (C)¹⁵⁵
- the requirements of the job match the skills of the patient
 - the needs of the patient are communicated clearly to the employer
 - health and safety training and insurance cover are provided by the employer
 - there is appropriate support, including on-site job coaching when required
 - the patient is guided and supported in adapting strategies to the workplace
 - the trial is monitored closely through contact with patient and employer.
- G164** In setting up placement into a long-term job, monitoring should be provided for at least six months to respond to any emergent difficulties, with a follow-up thereafter to establish the long-term viability of the placement. (C)¹⁵⁵
- G165** Patients who are unable to return to employment or training should be provided with alternative occupational provision or adult education appropriate to their needs, as identified through joint assessment by NHS and social services or college of further education. (C)¹⁵⁵

8 Continuing care and support

As stated in the introduction, the working party recognised that the longer-term needs of people with acquired brain injury should be the shared responsibility of specialist and local health services in partnership with social services and the voluntary sector, as well as other statutory authorities such as housing, employment, education etc. Detailed guidance in those areas is beyond the scope of this set of clinical guidelines. It is recommended that a further set of guidance should be developed, led jointly by health, social and voluntary sectors, to provide more specific advice in those important areas. In the meantime, this section provides an outline of principles.

Following ABI, the needs of patients and families change over time and for some may increase significantly. Many require long-term counselling and emotional support to assist understanding and adjustment to altered family roles and circumstances.^{44,48} Families also report the need for information, practical support, continued education and easy access to health and social care systems to combat isolation, emotional distress, stress and practical overload. Ongoing support is required in the community in order to maximise independence and quality of life for what may be the next 50 years or more of their lives.

It is impossible to separate the needs for healthcare and social services in the long-term management of the effects of ABI on the injured person and their family; joint planning and provision of services are essential to maintain and extend gains made in rehabilitation. The Department of Health guidance, *Fair access to care services*,¹⁶² stresses the need for health and social services to work together to ensure that long-term needs are met and gaps in services are filled. Coordinated teams cost no more to implement than an ad hoc approach and are more likely to enhance societal participation in young adults with complex disabilities.¹⁶⁴

The aim of long-term services should be to enable and sustain optimal societal participation, with personal choice, and will involve helping the person – and family – to adjust to the new situation. Services will need to be delivered in a whole range of settings and, importantly, will involve adapting and developing a range of specialised professional skills and attitudes to working with this client group. A social/educational model of care is appropriate, and effective services will place great emphasis on collaboration between rehabilitation specialists and people involved in the everyday life of the person with the brain injury.

8.1 General principles

GUIDELINES

- G166** Patients with significant ABI should have long-term access to an individual or team with experience in management of ABI that: (C) (HSCR⁸)³⁰
- takes responsibility for their continuing care and support needs
 - has knowledge of the various specialist and local services available
 - coordinates appropriate referrals, assessments and reviews as required
 - works across the range of statutory, voluntary and independent services to meet the needs of patients and their families.

- G167** Care services should be provided by skilled workers, trained in the needs of ABI patients, to ensure that:
- the support is relevant and appropriate to meet needs (C)³⁰
 - care provision takes into account the needs of those with cognitive and communication problems. (C)³⁰
- G168** Family and carers should be: (C)¹⁶³
- involved in assessment and subsequent decisions about help that is required
 - offered assessment to establish their own needs and to increase the sustainability of the caring role.
- G169** For patients with complex needs following brain injury, there should be joint assessment by health and social services, followed by continued communication, review and re-assessment. (C)¹⁶³ This should include:
- a clear agreement of who will provide which services
 - a plan detailing specific arrangements, which should be communicated to patients and their families/carers, and includes:
 - the identification of individuals responsible
 - details of services to be provided
 - agreed carers' contributions to care needs
 - contingency plans to manage emergency situations
 - an agreed review date
 - continued support from specialist rehabilitation services where local services are unable to meet the needs of patients and/or their families.

8.2 Joint health and social services provision

GUIDELINES

- G170** Community health and social services managers should work in partnership to ensure that an adequate range of services exists to meet the specific needs of those with ABI and their carers. (C)³⁰ These should include:
- assistance with care (C)²¹
 - provision for respite care (C)²¹
 - supported living arrangements, care home facilities, day centres etc
 - equipment provision and maintenance (C)²¹
 - assistance with claiming the relevant benefits for both patients and their families/carers (C) (HSCR⁸)
 - access to continued healthcare and rehabilitation through regular review or through open access by self-referral (C)⁴⁵
 - brain injury education for families including information written specifically for children and siblings (C) (HSCR⁸)
 - guidance and support for families in managing specific brain injury difficulties (C)^{30,90}
 - sexual and relationship counselling (C)²⁹
 - peer group support (C)²⁹
 - opportunities for purposeful activities including leisure and voluntary work. (C)²⁹

G171 There should be explicit pathways for collaborative working between the various statutory and voluntary services including: (C) (BSRM standards^{6,7}) (HSCR⁸)³⁰

- primary care trusts
- social services
- housing departments
- education authorities
- employment authorities (eg Jobcentre Plus)
- benefits agencies
- advocacy services
- voluntary agencies
- driving assessment centres
- probation and the criminal justice system.

9 The need for further research

There is increasingly good published research evidence for the overall effectiveness of rehabilitation. However, there is still a need for further research to strengthen the evidence base and tease out which interventions are most effective for which groups.

Epidemiological data

Service planning is critically dependent on a clear understanding of the size of the problem. The assimilation of epidemiological data for acquired brain injury is confounded by poor record-keeping and coding in acute hospital practice. Epidemiological studies are required to provide accurate information and to develop robust and feasible minimum datasets by which to record and classify patients presenting with acquired brain injury.

Service mapping

Information is also needed to map existing services and models of good practice. Due to chronic under-investment in the UK, and a relative decline in establishment over the last two to three decades, many specialist rehabilitation services have been forced to close beds and reduce their numbers to remain within budget. Relatively modest investment to re-open beds and services at marginal cost, and restore existing services to critical mass, is likely to prove more cost-effective in some areas than starting service developments anew. However, it is first necessary to identify existing service provision, the likely gaps and potential for re-expansion.

Timing and intensity

Existing research supports the notion that early and intensive rehabilitation is associated with favourable outcomes. However, this interpretation may be overly simplistic and timing of rehabilitation input may be critical to a successful outcome. Patients still in post-traumatic amnesia are frequently confused and disorientated. This may compromise their ability to adopt new coping strategies and participate in rehabilitation. Intensity of rehabilitation must be matched with the patient's capacity to engage and benefit, and reliable methods are required for determining these attributes.

Staffing needs, in terms of number, qualification and experience, will depend on the complexity of the patient load and the type of rehabilitation planned. Standard tariffs may have a place among common surgical procedures, but in rehabilitation could lead to preferential selection of cases likely to recover spontaneously, to the detriment of patients with profound and complex disabilities. Validated tools for assessment of nursing and therapy dependency in rehabilitation settings are needed to determine staff needs in relation to caseload, and to plan services appropriately.

Outcomes

Determination of the effectiveness of rehabilitation relies on the existence of valid outcome measures which are reliable, clinically relevant and sensitive to the level of change which is likely to result from rehabilitation intervention. Meta-analysis and other assimilations of rehabilitation outcome data are frequently confounded by the lack of consistency in outcome measurement. A number of well-validated generic tools are now in existence. Whilst no single outcome measure is suited to all circumstances, it may be appropriate to choose at least one or two global outcome measures, both for research and for routine clinical services, which over time will provide a common dataset against which different populations, programmes and practices can be compared.¹⁶⁵

On the other hand, global outcomes are frequently insensitive to specific interventions leading to more focal change. Further research is required to develop specific outcome measures for different interventions and to describe changes at the level of participation or quality of life which, by their very nature, vary from person to person. Goal achievement⁴⁰ and goal attainment scaling¹⁶⁶ may provide a solution to measurement of individualised outcomes in a standardised format, but have yet to achieve full acceptance in rehabilitation research.

Cost effectiveness of rehabilitation

In the current climate, it is not sufficient to demonstrate merely that rehabilitation interventions are effective or lead to improvements in quality of life. They must also be demonstrably cost-efficient. Health economics is itself a costly and time-consuming branch of research. Accurate costings can be provided, but the techniques are not practical for application in the course of routine clinical practice. Ideally, rehabilitation outcomes should be measured in terms that can be costed directly – for example by demonstrating that reduced dependency can result in reduction of the costs of long-term care in the community. Simple costable outcome measures do exist for use in routine practice in the context of severe physical dependency,¹⁶⁷ but further refinement is needed to adapt such tools for patients with predominantly cognitive and behavioural deficits, and to demonstrate validity in different settings.

Assessment of cost-effectiveness in terms of quality of life introduces a whole new dimension of complexity. Quality Adjusted Life Years (QALYs) have become the standard currency of health gain against which to assess cost-effectiveness of intervention, but have yet to be fully explored in the context of ABI. An ‘extra year of perfect health’ as the QALY is defined, would be beyond expectation for most individuals with ABI, and more work is required in the context of chronic neurological conditions to develop appropriate ways of capturing meaningful health gain for patients and the families, as well as the impact of intervention on utilisation and costs of health and social care.

Summary

There is an expanding research base confirming the effectiveness of rehabilitation in acquired brain injury, and some evidence for cost benefits. However, there is much to be done in defining what works, for whom and under what circumstances. Also to determine the optimum use of resources to maximise benefit for this vulnerable and often traumatised group of patients and their families.

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Guideline development group membership

Working party membership

<i>Working party member</i>	<i>Representing</i>
Lynne Turner-Stokes (<i>Chair</i>) Herbert Dunhill Professor of Rehabilitation, King's College London; Director, Regional Rehabilitation Unit, Northwick Park Hospital	British Society of Rehabilitation Medicine (BSRM)
Jill Dawson Clinical Specialist in Occupational Therapy, National Hospital for Neurology and Neurosurgery, Queen Square	Occupational therapy College of Occupational Therapists (COT) National Association of Neurological Occupational Therapists (NANOT)
Pam Enderby Professor of Community Rehabilitation, Sheffield University	Speech and language therapy Community Rehabilitation Teams Network
Simon Fleminger Consultant Neuropsychiatrist, Lishman Unit, South London and Maudsley Hospital Trust	Neuropsychiatry British Neuropsychiatry Association Royal College of Psychiatrists/Special Interest Group for Neuropsychiatry
Jenny Garber Brain Injury Social Worker, Sheffield	Social work British Association of Social Workers (BASW) Brain Injury Social Work Group (BISWG)
Steve and Ann Harris Carers: for a son with acquired brain injury	Users/carers
Angela Hicks Carer: for a partner with acquired brain injury	
Kit Malia Cognitive Rehabilitation Therapist, Headley Court Charity, Ministry of Defence	Independent sector
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Pat Salt Rehabilitation Services Manager, Oxford Centre for Enablement	Rehabilitation service management Institute of Health Care Managers
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<i>Working party member</i>	<i>Representing</i>
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Andy Tyerman Consultant Clinical Neuropsychologist, Community Head Injury Service, Vale of Aylesbury PCT	Clinical psychology/vocational rehabilitation British Psychological Society
Maureen Vallon Patient Advice and Liaison Manager, Horsham and Chanctonbury PCT (previously Continuing Health Care Coordinator, West Sussex)	PALS service/continuing care West Sussex ABI Network
Derick Wade Consultant in Neurological Disability, Oxford Centre for Enablement	Neurology Association of British Neurologists; Royal College of Physicians
Judy Watkin Acute Brain Injury Clinical Nurse Specialist, National Hospital for Neurology and Neurosurgery, Queen Square	Nursing
Barbara Wilson OBE Professor of Rehabilitation Studies, Clinical Neuropsychiatrist, MRC Cognition and Brain Sciences Unit, Cambridge	Neuropsychology British Psychological Society

Advisory group membership

<i>Advisory group member</i>	<i>Representing</i>
Maggie Alexander Director, Brain and Spine Foundation	Brain and Spine Foundation
Keith Andrews Director, Royal Hospital for Neurodisability, Putney, London	Independent sector
Louise Chance Project Manager, Lancashire Teaching Hospitals Trust	British Association of Brain Injury Case Managers
Shoumitro Deb Professor of Neuropsychiatry and Intellectual Disability, Birmingham University	Royal College of Psychiatrists: Special Interest Group for Neuropsychiatry
Ava Easton Support Services Coordinator, the Encephalitis Society	The Encephalitis Society – Action for Support, Awareness and Research
Jeff Graham Medical Officer, Department of Health	Department of Health
Camilla Herbert Consultant Clinical Neuropsychologist, Brain Injury Rehabilitation Trust	Brain Injury Rehabilitation Trust
Barbara Howe Director of Specialist Commissioning, London SE Sector	Health Services Commissioners
Jane Johnson Consultant Nurse, Neurorehabilitation, King's College Hospital, London	Royal College of Nursing: Rehabilitation and Intermediate Care Nurses Forum

Rehabilitation following acquired brain injury: national clinical guidelines

<i>Advisory group member</i>	<i>Representing</i>
Nikki Joule Policy Officer, the Neurological Alliance	Neurological Alliance
Norman Keen Carer for son with ABI	Carer representative of External Reference Group, National Service Framework for Long-Term Conditions
Judy Lavery Stroke Information Service Manager, Stroke Association	Stroke Association
John Pickard Professor of Neurosurgery, Clinical Director, Wolfson Brain Imaging Centre, Cambridge	Society for British Neurological Surgeons
Laura Waite RNIB Multiple Disability Service Coordinator	Royal National Institute for the Blind
Leyla Ziyal Consultant Neuropsychologist	Partnerships in Care

Conflicts of interest

All working party and advisory group members signed a form to declare any potential conflicts of interest with the guidelines. These are summarised as follows:

- 1 Nearly all professionals worked for an organisation whose work is related to the guidelines. Details of appointment and affiliations are therefore listed above.
- 2 Twelve members of the working party and advisory group were also directly involved in the National Service Framework for Long-Term Conditions, sitting either on the External Reference Group or one or other of its working parties.
- 3 Three individuals had undertaken paid consultancy work within commercial organisations which could potentially be involved in the guidelines. Those individuals abstained from discussion of guidelines wherever this could represent a source of conflict.
- 4 No individual had any personal commercial interest (such as personal shares) with any companies that could be involved with the guidelines.

Collaborating organisations

<i>Organisation</i>	<i>Representative</i>
Association of British Neurologists	Derick Wade
Brain and Spine Foundation	Maggie Alexander
Brain Injury Rehabilitation Trust	Camilla Herbert
British Association of Brain Injury Case Managers	Louise Chance
British Association of Social Workers (BASW) Brain Injury Social Work Group	Jenny Garber
British Dietetic Association	Ella Segaran
British Neuropsychiatry Association	Simon Fleminger
British Psychological Society	Andy Tyerman Barbara Wilson
British Society of Rehabilitation Medicine (BSRM)	Lynne Turner-Stokes Ajoy Nair Derick Wade
Chartered Society of Physiotherapists (CSP) Association of Physiotherapists Interested in Neurology (ACPIN)	Annie Meharg
College of Occupational Therapists (COT) National Association of Neurological Therapists (NANOT)	Jill Dawson (Chair NANOT)
Community Rehabilitation Teams Network	Pam Enderby
Department of Health	Jeff Graham
The Encephalitis Society – Action for Support, Awareness and Research	Ava Easton
Headway – The Brain Injury Association	Graham Nickson
Independent Sector	Keith Andrews Kit Malia
Institute of Health Care Managers	Pat Salt
Neurological Alliance	Nikki Joule
Partnerships in Care	Leyla Ziyal
Royal College of Nursing: Rehabilitation and Intermediate Care Nurses Forum	Jane Johnson
Royal College of Physicians	Derick Wade
Royal College of Psychiatrists: Special Interest Group for Neuropsychiatry	Simon Fleminger Shoumitro Deb
Royal College of Speech and Language Therapists: Speech & Language Therapy Head Injury Special Interest Group	Shana Taubert
Royal National Institute for the Blind	Laura Waite
Society of British Neurosurgeons (BPS)	John Pickard
Stroke Association	Judy Lavery

Inter-agency advisory group on vocational rehabilitation

In view of the required joint working across the NHS, Jobcentre Plus and independent vocational providers, it was recommended by the BSRM/RCP working party that an inter-agency advisory group be set up to recommend guidelines to the working party. The group produced a document which will be published separately, but from which selected guidance has been extracted for this document.

Inter-agency advisory group members

Representing health professionals

Andy Tyerman (<i>Chair</i>)	Consultant Clinical Neuropsychologist, Working Out Programme
Sue Gillmer	Occupational Therapist in Work Practice and Productivity Group
Kit Harling,	NHS Plus, Department of Health, Skipton House, London
Ajoy Nair	Specialist Registrar in Rehabilitation Medicine; Member, BSRM Working Party
Doreen Rowland	Head Occupational Therapist; Chair, NANOT Brain Injury Group

Representing Department of Work and Pensions; Jobcentre Plus

Mick Meehan	Senior Work Psychologist, Jobcentre Plus, London Region
Rob Murdoch	Disability Service Manager, Jobcentre Plus, Bucks and Oxford District
Wendy Needham	Disability Employment Advisor, Milton Keynes
David Stuart	Department of Work and Pensions, Disability Services

Representing independent vocational providers

Jim Weir	Director, Rehab UK
Ellen Pedley	Employment Business Manager, Remploy Interwork

Representing social services

Jan Clark	Social Services Inspectorate, Cambridge
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Representing education

Linda Napoleoni	ABI Programme Co-ordinator, Warwickshire College, Warwick
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Appendix 2

Standards documents

Standards for acquired brain injury and related disorders

British Society of Rehabilitation Medicine (BSRM), 1998

Rehabilitation after traumatic brain injury

www.bsrm.co.uk/Publications/Publications.htm

South Thames Brain Injury Rehabilitation Association (STBIRA), 2000

Minimum recommended standards for post-acute brain injury rehabilitation

www.stbira.freewire.co.uk

South Thames Brain Injury Rehabilitation Association, UK

Royal College of Surgeons (RCS), 1999

Report of a working party on management of patients with head injury

www.rcseng.ac.uk/services/publications/publications/index_html?pub_id=6

National Institutes of Health, 1998

Rehabilitation of persons with traumatic brain injury. Consensus development conference statement. No 109

http://consensus.nih.gov/cons/109/109_statement.htm

Royal College of Physicians (RCP), 2000/2002

National clinical guidelines for stroke (includes Concise Guide and update)

www.rcplondon.ac.uk/college/ceeu/ceeu_stroke_home.htm

Royal College of Physicians (RCP), 2003

The vegetative state: guidance on diagnosis and management

www.rcplondon.ac.uk/pubs/brochures/pub_print_veg.htm

Royal Hospital for Neurodisability, Putney, 1995

International working party report on the vegetative state

www.rhn.org.uk/institute/doc.asp?catid=225&docid=242

National Institute for Clinical Excellence (NICE), 2003

NICE guidelines for head injury (first 48 hours)

www.nice.org.uk/pdf/cg4niceguideline.pdf

National Institute for Clinical Excellence (NICE), 2003

Multiple Sclerosis management in primary and secondary care

www.nice.org.uk/cat.asp?c=20094

Department of Health, 2001

Health Select Committee inquiry into head injury rehabilitation

www.parliament.the-stationery-office.co.uk/pa/cm200001/cmselect/cmhealth/307/30702.htm

Department of Health, 2002

Specialised Services National Definition Set No 7: Brain injury rehabilitation

www.doh.gov.uk/specialisedservicesdefinitions/index.htm

Rehabilitation following acquired brain injury: national clinical guidelines

Scottish Intercollegiate Guidelines Network (SIGN), 2002

Management of patients with stroke: rehabilitation, prevention and management of complications and discharge planning

www.sign.ac.uk/guidelines/published/index.html#CHD

Scottish Intercollegiate Guidelines Network (SIGN), 2002

Management of patients with stroke III: identification and management of patients with dysphagia

www.sign.ac.uk/guidelines/published/index.html#CHD

College of Occupational Therapists NANOT, 2002

Standards in practice: for OTs working with people with traumatic brain injury

Not available on-line.

College of Occupational Therapists, 106, Borough High ST London SE1 1LB
(Tel: 020 7357 6480, www.cot.org.uk)

British Psychological Society (BPS), 1989

Working party report: services for young adults with acquired brain damage

www.bps.org.uk

British Psychological Society (BPS), 2002

Briefing Paper: psychological services for stroke survivors and their families

www.bps.org.uk

American Academy of Physical Medicine and Rehabilitation (AAPMR), 1998

Practice parameter: anti-epileptic treatment of post-traumatic seizures

Archives of Physical and Rehabilitation Medicine 1998;79:594–7

National Institute for Clinical Excellence (NICE), 2001

Pressure ulcer risk assessment and prevention

www.nice.org.uk/pdf/clinicalguidelinepressuresoreguidancenice.pdf

Scottish Head Injury Forum, 2001

Service standards for the rehabilitation of adults with acquired brain injury

Scottish Head Injury Forum 1650, London Road, Glasgow, G31 4QF (Tel: 0141 554 8822)

Social Services Inspectorate (DHSS), 1996

A hidden disability: report of the SSI traumatic brain injury rehabilitation project

Department of Health, PO Box 410, Wetherby, LS23 7LN

Standards for general conditions of relevance to the guidelines

AGREE Collaboration, 2000

Appraisal of Guidelines for Research and Evaluation (AGREE) instrument
www.agreecollaboration.org/draft.html

Association of Chartered Physiotherapists interested in Neurology (ACPIN), 2001

Guidance on manual handling in treatment
 Not available online.

Chartered Society of Physiotherapy, 14 Bedford Row, London WC1R 4ED (Tel: 020 7306 6666)

Association of Chartered Physiotherapists interested in Neurology (ACPIN), 1998

Clinical practice guidelines on splinting adults with neurological dysfunction
 Not available online.

Chartered Society of Physiotherapy, 14 Bedford Row, London WC1R 4ED (Tel: 020 7306 6666)

British Society of Rehabilitation Medicine (BSRM), 2002

Standards for specialist inpatient and community rehabilitation services
www.bsrn.co.uk/ClinicalGuidance/standards.PDF

British Society for Rehabilitation Medicine (BSRM), 2003

Guidelines for specialised wheelchair seating
www.bsrn.co.uk (when complete)

Chartered Society of Physiotherapy (CSP), 2000

Standards of physiotherapy practice: core standards
 Chartered Society of Physiotherapy

Department of Health, 2001

Reference guide to consent to examination or treatment
www.doh.gov.uk/consent/refguide.pdf

Department of Health, 2003

Discharge from hospital: pathway, process and practice
www.doh.gov.uk/publications/index.html

Department of Health, 2003

Community care policy (draft)
www.doh.gov.uk/jointunit

Department of Health, 2003

Fair access to care services: guidance on eligibility criteria for adult social care
www.doh.gov.uk/scg/facs/

Driver and Vehicle Licensing Agency, 2003

'At a glance' guide to the medical standards of fitness to drive
www.dvla.gov.uk/at_a_glance/content.htm

Neurological Alliance, 2001

In search of a service: the experiences of people with neurological conditions
www.neurologicalalliance.org.uk/pages/publications/service_search.asp

Rehabilitation following acquired brain injury: national clinical guidelines

Neurological Alliance, 2002

Levelling up

www.neurologicalalliance.org.uk/pages/publications/levelling_up.asp

NHS Modernisation Agency critical care programme, 2002

The role of healthcare professionals within the critical care services

www.modern.nhs.uk/scripts/default.asp?site_id=20&id=6511

Royal College of Physicians: Clinical Effectiveness and Evaluation Unit, 2002

Botulinum toxin in the management of spasticity in adults: concise guidance to good practice

www.rcplondon.ac.uk/college/ceeu/ceeu_stroke_home.htm

Royal College of Speech and Language Therapists, 1998

Clinical guidelines by consensus for speech and language therapists

Update on dysphagia management to be posted in 2003 on website: www.rcslt.org

Royal College of Speech and Language Therapists, 1996

Communicating quality, Vol 2

www.rcslt.org

St George's Healthcare Trust, 1997

Care of patients with tracheostomy tubes

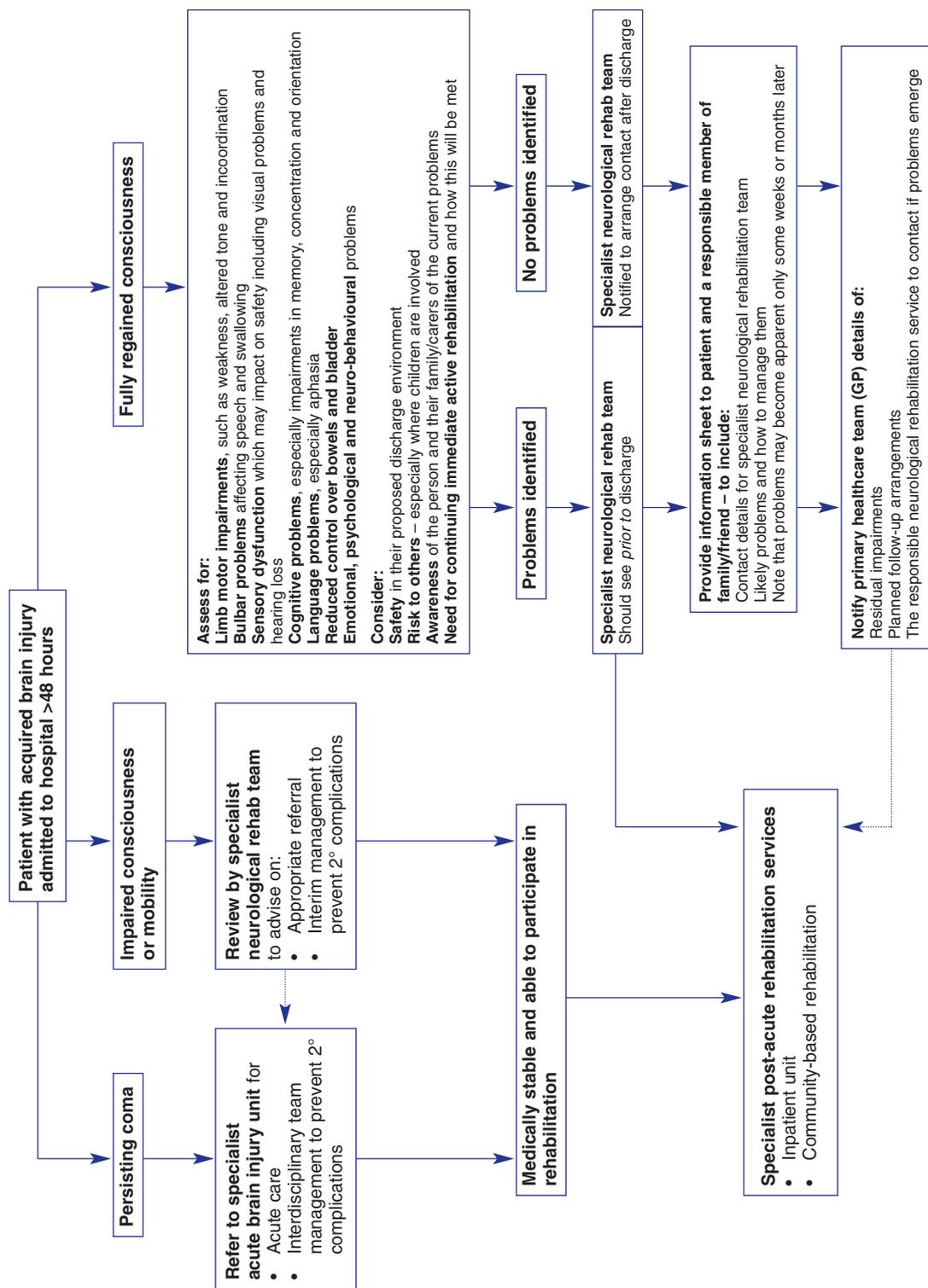
Available through SIMS Portex Ltd, Hythe, Kent, CT21 6JL (Tel: 01303 260551)

Appendix 3

Useful addresses

<i>Organisation/address</i>	<i>Contact details</i>
Brain and Spine Foundation 7 Winchester House Cranmer Road Kennington Park London SW9 6EJ	Tel: 020 7793 5900 www.bbsf.org.uk Email: webenquiries@brainandspine.org.uk
Carers UK 20/25 Glasshouse Yard London EC1A 4JT	Tel: 020 7490 8818 Fax: 020 7490 8824 www.carersonline.org.uk Email: info@ukcarers.org.uk
Different Strokes 9 Canon Harnett Court Wolverton Mill Milton Keynes MK12 5NF	(UK) Tel: 0845 130 7172 (Outside UK) +44 1908 317618 www.differentstrokes.co.uk Email: info@differentstrokes.co.uk
Headway 4 King Edward Court King Edward Street Nottingham NG1 1EW	Head Office: Nottingham Tel: 0115 924 0800 London Tel: 020 7841 0240 www.headway.org.uk Email: enquiries@headway.org.uk
Partnerships in Care Kneesworth House Bassingbourn-cum-Kneesworth Royston Herts SG8 5JP	Tel: 01763 255600 Fax: 01763 247494 www.partnershipsincare.co.uk Email: info@partnershipsincare.co.uk
The Encephalitis Society 7B Saville Street Malton North Yorkshire YO17 7LL	Tel: 01653 699599 www.encephalitis.info/ESG/Support/Default.asp Email: mail@encephalitis.info
The Neurological Alliance PO Box 36731 London SW9 6WY	Tel: 020 7793 5907 Fax: 020 7793 5939 www.neurologicalalliance.org.uk/ Email: info@neurologicalalliance.org.uk
The Stroke Association Stroke House 240 City Road London EC1V 2PR	Tel: 020 7566 0300 Fax: 020 7490 2686 Helpline Number: 0845 30 33 100 www.stroke.org.uk Email: info@stroke.org.uk
Rehab UK Communications Department Rehab Group, Beach Road Sandymount Dublin 4	Tel: 01-2057200 Fax: 01-2057202 www.rehab.ie/uk/rehabilitation.htm Email: dara.duffy@rehab.ie

Summary guidelines for early discharge



Summary guidelines for early discharge to the community and referral to rehabilitation