

# Rehabilitation following acquired brain injury: concise guidance

Lynne Turner-Stokes and Derick Wade

**ABSTRACT** – The national clinical guidelines for *Rehabilitation following acquired brain injury* were 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 (2003). They have been produced to complement the National Institute of Clinical Excellence head injury guidelines, and to address the medium- to longer-term needs of patients with acquired brain injury and of their families/carers. This article serves as an introduction to make physicians aware of the guidelines, and to highlight in particular the advice to doctors in the acute services regarding early discharge and referral to rehabilitation.

**KEY WORDS:** brain injuries, clinical guidelines, rehabilitation

## Background

The National Service Framework (NSF) for Long-Term Conditions is currently in development and will focus on 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 to produce a series of clinical guidelines for patients with multiple sclerosis, Parkinson's disease, epilepsy and head injury. However, the current NICE guidance for head injury<sup>1</sup> focuses exclusively on early management during the first 48 hours after brain injury and does not address the needs for rehabilitation and longer-term care, nor does it encompass non-traumatic forms of acquired brain injury.

The national clinical guidelines for *Rehabilitation following acquired brain injury*<sup>2</sup> have been developed to complement the NICE guidance and to address the medium- to longer-term needs of patients with acquired brain injury (ABI) and their families/carers. Principal themes from the guidelines are shown in Box 1.

## Evidence for effectiveness and cost-effectiveness

There is now good evidence for the effectiveness<sup>3–5</sup> and cost benefits of rehabilitation.<sup>6</sup> In more severe head injury, early rehabilitation is associated with better outcomes<sup>7,8</sup> and is demonstrated to repay the initial investment and result in cost-savings overall.<sup>8–11</sup> Rehabilitation appears to be most effective where the relevant health and social care practitioners work together as a coordinated interdisciplinary team<sup>12</sup> towards a common set of goals, and where a rehabilitative milieu facilitates reinforcement of the programme throughout the 24-hour day. Outreach rehabilitation programmes can support continued gains in independence, self-organisation and psychological well-being even some years after injury.<sup>13</sup>

## The process of guideline development

The guidelines were developed in accordance with the principles laid down by the AGREE Collaboration (Appraisal of Guidelines for REsearch and Evaluation).<sup>14</sup>

## Key Points

Even after a mild head injury, a proportion of individuals will have cognitive deficits that may impact significantly on work and family relationships

Problems may not be immediately obvious, but can become apparent some weeks or months after injury

Proactive follow-up and intervention demonstrably improves outcome

The challenge facing acute physicians is therefore to identify those individuals in who are in need of rehabilitation and refer them appropriately

This concise guidance offers practical advice to determine who may be safely discharged home (and with what precautions) and who should be referred on to specialist neurological rehabilitation services

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*Clin Med* 2004;4:61–65

### Scope and purpose

*Overall objective of the guidelines.* The overall objective was 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.

*The patient group covered by the guideline.* The patient group covered comprised adults, primarily of working age, with acquired brain injury due to trauma, stroke, anoxia, infection or other causes.

*Target audience.* The largest audience was 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.

*Clinical areas covered.* The guidelines offer specific guidance on the clinical aspects of care. 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.

### Stakeholder involvement

The Guideline Development Group (GDG) ( $n=18$ ) included a wide range of professionals involved in the rehabilitation and long-term care of people with acquired brain injury and had direct representation of users and carers, as well as the organisations which represent them. An Advisory Group ( $n=15$ ) provided additional comment and constructive criticism. Official representation was also convened from a broad range of stakeholding organisations ( $n=11$ ) and specialist societies ( $n=11$ ) and the Royal Colleges ( $n=4$ ). Guideline development was funded through grants from the Department of Health and the British Society of Rehabilitation Medicine (BSRM). Any conflicts of interest among the GDG were fully declared.

### Rigour of development

*Evidence gathering.* The guidelines were based on evidence so far as it was available and resources allowed it to be found. Research in the field of rehabilitation and complex disability poses a number of challenges to traditional research methodologies, and the guidelines necessarily relied to a significant degree on expert opinion and on existing consensus-based documents.

- Extensive use was made of pre-existing reviews, especially those undertaken for the national stroke<sup>15</sup> and multiple sclerosis guidelines.<sup>16</sup>
- In addition, a new Cochrane Systematic Review<sup>17</sup> and also a systematic search of the literature for review articles and alternative methodologies for research on brain injury rehabilitation were undertaken. This search interrogated all main databases (including Medline, EMBASE, AMED, CINAHL). It included all types of acquired brain injury and

### Box 1. Principal themes of *Rehabilitation following acquired brain injury: national clinical guidelines*.<sup>2</sup>

- The small numbers and heterogeneity of ABI patients pose major challenges for service provision. Different patients require different services. Moreover, the same patient requires different services at different stages in their recovery. Coordination and communication between these services are 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 referred.
- 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 and their families should be offered appropriate information at every stage, and be 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 are available for those who require it.

a wide range of terms for rehabilitation, therapy, care and support.

- Evidence was reviewed by members of the GDG, and was linked explicitly to the guideline recommendations using the same standard classification as the *National clinical guidelines for stroke*.<sup>15</sup>
- The draft guidelines were submitted for independent review by the BSRM Executive Committee and by the Royal College of Physicians prior to publication.

### Implementation and cost implications

It is hoped that these guidelines will result in improved access to appropriate rehabilitation services for patients with brain injury and their families. The biggest potential barrier to implementation is likely to be funding and the availability of services. Given the current dearth of rehabilitation services, implementation cannot be accomplished simply through reorganisation of existing provision; significant investment will be required. However, some of the costs will undoubtedly be offset by:

- avoidance of bed-blocking and delayed discharges in acute services
- improved independence of brain-injured individuals, leading to long-term savings in the cost of providing continuing care in the community.

**Box 2. Guidelines for early discharge to the community.**

Recommendation	Grade
<p><b>1 Once a patient with ABI is conscious they should be assessed for all common impairments including:</b></p> <ul style="list-style-type: none"> <li>● <i>limb motor impairments</i>, such as weakness, altered tone and incoordination</li> <li>● <i>bulbar problems</i> affecting speech and swallowing</li> <li>● <i>sensory dysfunction</i> which may impact on safety, including visual problems and hearing loss</li> <li>● <i>cognitive problems</i>, especially impairments in memory, concentration and orientation</li> <li>● <i>language problems</i>, especially aphasia</li> <li>● <i>reduced control over bowels and bladder</i></li> <li>● <i>emotional, psychological and neuro-behavioural problems.</i></li> </ul>	(C) <sup>2</sup>
<p><b>2 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:</b></p> <ul style="list-style-type: none"> <li>● <i>presence of common neurological impairments</i> (see above) which should be documented</li> <li>● <i>safety</i> in the patient's proposed discharge environment</li> <li>● <i>need for continuing immediate active rehabilitation</i> and how this will be met</li> <li>● <i>risk to others</i> – especially where children are involved</li> <li>● <i>awareness</i> of the patient and family of the current problems and how to manage them.</li> </ul>	(A) <sup>13,18,19</sup>
<p><b>3 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 and should have:</b></p> <ul style="list-style-type: none"> <li>● preferably a fixed outpatient or domiciliary visit appointment with the team</li> </ul> <p><i>or, if this is impractical and problems are judged to be minor:</i></p> <ul style="list-style-type: none"> <li>● a planned telephone contact from them within seven days.</li> </ul>	(A) <sup>20,21</sup>
<p><b>4 All patients being discharged after a recent ABI, regardless of follow-up arrangements already made, should:</b></p> <ul style="list-style-type: none"> <li>● be given a card with contact details of the specialist neurological rehabilitation team</li> <li>● 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</li> <li>● have a family member or friend also informed of the above (with the patient's agreement).</li> </ul>	(C) <sup>20,21</sup>
<p><b>5 For all patients discharged after ABI from an acute hospital, the primary healthcare team (GP) should be notified before or at the moment of discharge of:</b></p> <ul style="list-style-type: none"> <li>● details of residual impairments and planned follow-up</li> <li>● details of the responsible neurological rehabilitation service to contact if problems emerge.</li> </ul>	(C) <sup>22</sup>
<p><b>6 Any patient seeking contact with the NHS with symptoms following ABI should be offered an appointment with a professional trained in the sequelae of brain injury.</b></p>	(C) <sup>1</sup>

Brain injury rehabilitation has already been identified as one of the priorities in the NSF for Longer-Term Conditions, so it is intended that the development of these guidelines will be timely in helping to inform effective and coordinated development of services.

### Updating and review

Guideline development is a continuous process, and this is a field of rapid change and development. These guidelines will be reviewed and updated at three-yearly intervals by a group convened by the BSRM, subject to the availability of funding.

As yet there are no formal tools for auditing compliance with the guidelines. However, many of the recommendations are reflected in the BSRM standards for inpatient and community rehabilitation services which are available on the BSRM website

([www.bsrm.co.uk](http://www.bsrm.co.uk)), together with questionnaires for assessing compliance with the standards.

### Guidelines for early discharge to the community and referral to rehabilitation

Not all patients require formal rehabilitation following head injury. The need is often most apparent where patients have severe brain injuries resulting in significant physical disabilities. Patients who make a rapid recovery following their emergency hospital treatment may be able to go directly home after:

- (a) careful review to identify any residual physical, cognitive, emotional, and behavioural deficits
- (b) referral on to specialist follow-up services (hospital-based or in the community) as appropriate.<sup>13,18,19</sup>

**Box 3. Guidelines for transfer to rehabilitation.**

Recommendation	Grade
1 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) <sup>18</sup>
2 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 these potentially disabling sequelae.	(C) <sup>18,19</sup>
3 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) <sup>7,8</sup>
4 Patients transferring to rehabilitation services should be accompanied by their medical records or a full discharge summary including: <ul style="list-style-type: none"> <li>● a list of investigations undertaken and results</li> <li>● details of any surgical procedures/interventions</li> <li>● a summary of information given to the patient and their family regarding the nature of their brain injury and prognosis for recovery</li> </ul>	(C) <sup>23,24</sup>

However, even after mild head injury, a proportion of individuals will have cognitive deficits that may impact significantly on work and family relationships, and proactive follow-up and intervention demonstrably improves outcome.<sup>20,21</sup> Problems may not be immediately obvious, but can become apparent some weeks or months after injury. The challenge facing acute physicians is therefore to identify those individuals who are in need of rehabilitation and to refer them appropriately.

Boxes 2 and 3 list the guidance on early discharge and referral to rehabilitation services, and this is summarised in Fig 1.

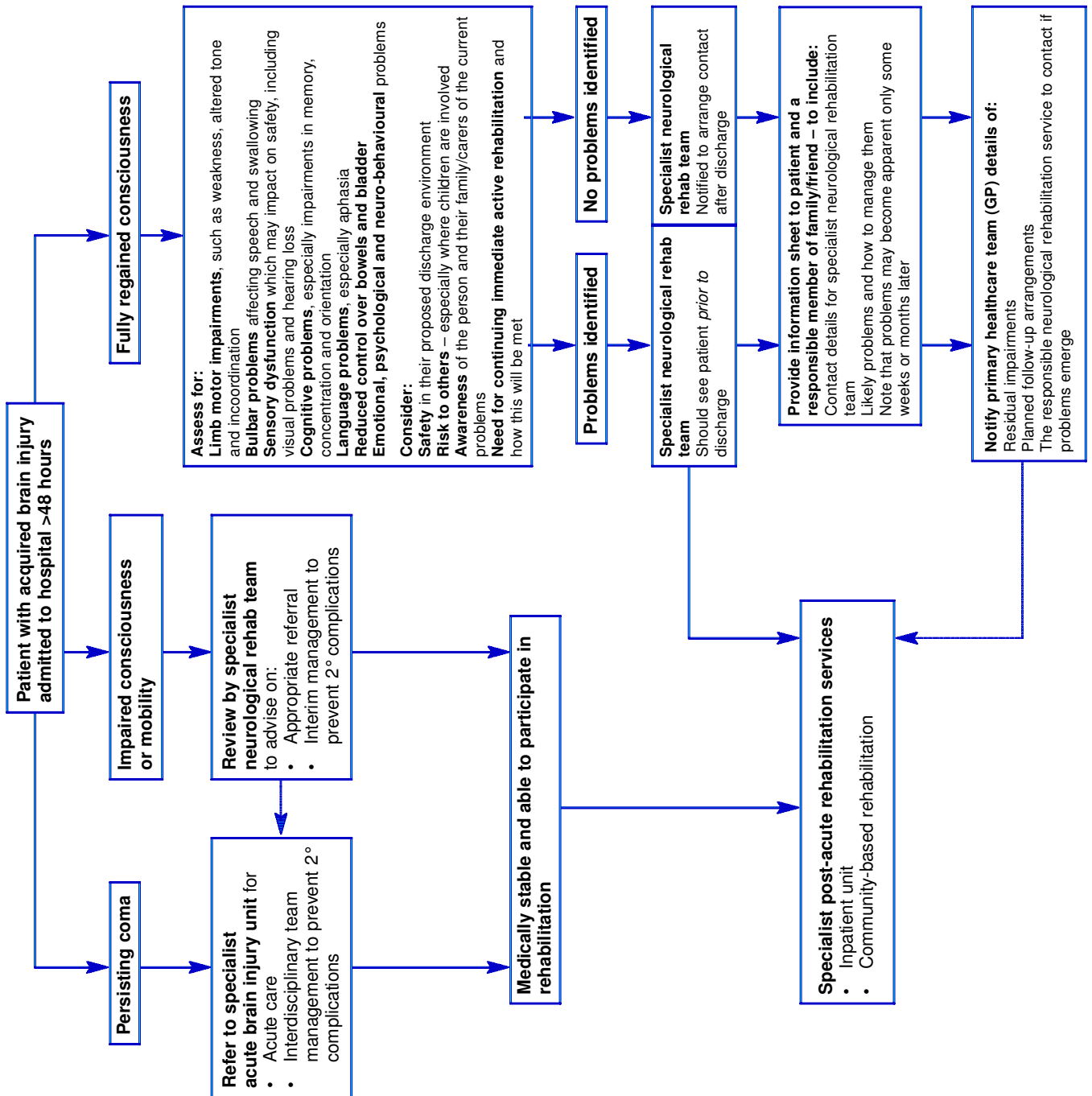
### Acknowledgements

The authors would like to acknowledge the members of the Guidelines Development Group, Advisory Group and all users and professionals who provided comment and constructive criticism. We are indebted to the BSRM and the Department of Health for funding the guidelines development and to the Luff Foundation for financial support in preparation of this manuscript.

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Fig 1. Summary guidelines for early discharge to the community and referral to rehabilitation.



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