



ACQUIRED BRAIN INJURY AND NEUROREHABILITATION

TIME FOR CHANGE

ALL-PARTY PARLIAMENTARY GROUP ON ACQUIRED BRAIN INJURY REPORT

NEUROREHABILITATION

EDUCATION

CRIMINAL JUSTICE

SPORT-RELATED
CONCUSSION

WELFARE
BENEFITS SYSTEM

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Executive Editor

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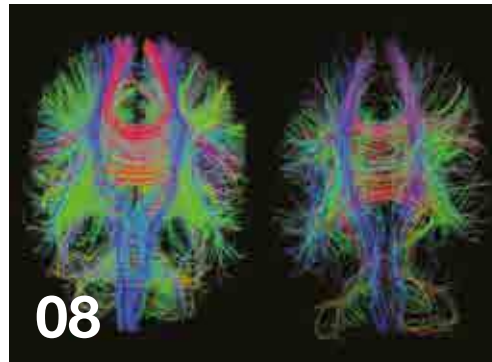
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FOREWORD

Acquired Brain Injury (ABI) is a leading cause of death and disability in the United Kingdom (UK). It is a chronic condition with 'hidden' disabilities and life-long consequences.

The excellent advances in emergency and acute medicine mean that many more children, young people and adults now survive with an ABI, however, many of these individuals require early and continued access to neurorehabilitation to optimise their recovery and maximise their long-term potential.

Neurorehabilitation improves functional independence and reduces the burden on carers, as well as improving the rates of return to work and productivity for those who are able. The economic benefits include a reduced length of hospital stay and associated reductions in staffing costs, a decreased requirement for residential and nursing care and a lower risk of falls in the elderly. However, the number of available neurorehabilitation beds across the UK is inadequate, service provision is variable and, consequently, long-term outcomes for ABI survivors are compromised.

The National Health Service (NHS) is under increasing pressure; funding will continue to be challenging, and service pressures will be relentless. However, neurorehabilitation is not just another service requiring additional funding, it is one of most cost-effective interventions that the NHS provides, and one of the few services in medicine that results in long-term decreased costs to the economy.

The All-Party Parliamentary Group on Acquired Brain Injury (APPG on ABI) was formed in 2017



to raise awareness of ABI, and to seek improvements in support and services for people directly affected by ABI, and also for their families and carers. The APPG on ABI recently held four round table meetings and heard from a large number of experts about the issues surrounding the provision of neurorehabilitation for children, young people and adults with ABI in the UK.

This report outlines the critical role of neurorehabilitation in the ABI care pathway, and the need for Rehabilitation Prescriptions for all brain injury survivors following discharge from acute care. The report reviews the implications for children and young people with ABI when most of their neurorehabilitation takes place in the education system. The high incidence of ABI amongst offenders is discussed, as is the impact of neurorehabilitation on behavioural change and reoffending. The current issues in sport-related concussion are outlined as well as the need for an improved welfare system that is easily accessible.

ABI is a hidden epidemic affecting many hundreds of thousands of people. It impacts on so many government departments, including the Department of Health and Social Care, Department for Work and Pensions, Department for Education, Department for Digital, Culture, Media & Sport and the Ministry of Justice, that the Government has to work in a co-ordinated and consistent way. The Government should bring together a taskforce to address all the issues and recommendations as a matter of urgency. The APPG on ABI intends to unite these departments in driving change for brain injury survivors.

Chris Bryant MP, Chair APPG on ABI



EXECUTIVE SUMMARY

Acquired Brain Injury (ABI) is a chronic condition with 'hidden' disabilities and life-long consequences. Improvements in acute care have substantially reduced the mortality rate but survivors are often left with a considerable burden of physical, cognitive, academic and psychosocial effects.

Neurorehabilitation can avoid or minimise disability and optimise recovery. Early access to specialist and/or community neurorehabilitation are critical components of the ABI care pathway. A Rehabilitation Prescription (RP) documents the individual's neurorehabilitation needs and optimises access to services along the care pathway.

Substantial and robust evidence emphatically supports the clinical effectiveness and cost-effectiveness of neurorehabilitation. It is one of the most cost-effective interventions available to the National Health Service (NHS), with positive financial impacts on both health and social care. However, despite these proven benefits, investment in neurorehabilitation, in-patient neurorehabilitation beds and service provision are all inadequate and hugely variable across the United Kingdom (UK). This resource limitation is compounded by the inconsistent and limited use of RPs. These deficiencies reflect a broader neglect of neurorehabilitation. The 2001 Health Select Committee Report 'Head injury: rehabilitation' made over 20 recommendations. While significant progress has been made regarding many of the recommendations relating to acute care, the recommendations regarding neurorehabilitation have not been substantially implemented. This limited progress over 17 years has had significant and societal consequences.

There are many children and young people with ABI in education, with varying needs and unknown long-term trajectories. They have a wide range of difficulties that can change over time and impact on

their learning ability. Many require bespoke management, regular monitoring and review for the duration of their education.

However, education professionals do not routinely receive training on ABI, and may lack awareness and understanding of the consequences of ABI and the specific support required by children and young people with ABI. Consequently they may be unable to implement appropriate assessment tools, learning and evidence-based strategies. For the majority of children and young people with ABI, most neurorehabilitation occurs in school. On discharge from hospital following an ABI all

children and young people should receive an agreed 'return to school' pathway plan, mapping the return to education. This plan should include the support of a named lead professional to oversee its implementation, with the requirement for regular review and should include the transition to secondary school and further education. This would ensure that

the support is coordinated, collaborative and proactive. Children and young people with Traumatic Brain Injury (TBI) are more likely to develop behavioural problems which can impact on engagement in school, and are linked to an increased propensity to criminal offending. Significant evidence links TBI with an earlier onset of offending, repeat offending and high rates of violent offending. Relative to the general population, there is a high prevalence of brain injury amongst individuals in custody. Despite this evidence, brain injury is rarely considered within any part of the youth or adult criminal justice system, including during police or court interviews, or in determining punishment or assessing rehabilitative needs. This can result in significant barriers in accessing justice, and inappropriate, counterproductive interventions.

Neurorehabilitation is one of the most cost-effective interventions available to the NHS.



Currently those children and young people with ABI who have committed an offence are not generally screened for brain injury, and are therefore not subject to interventions that take account of their needs resulting from their injury, or provided with any neurorehabilitation. Identifying and managing the consequences of ABI at an early stage is a pre-requisite to changing offending behaviour, and an effective way of avoiding the huge individual, social and financial impact of the criminal behaviours they may otherwise continue to display in the longer term.

Sport-related concussion (SRC) has been seen as distinct from other causes of concussion and mild TBI. The distinction is largely driven by sporting bodies who have recognised the need for clear and practical guidelines to determine the management, recovery and safe return to play for athletes with an SRC occurring in either contact or non-contact sports. SRC is an increasingly prominent issue in the UK, and concerns regarding the short, medium and longer term consequences of concussion have been raised by players, their families and researchers.

Better management of SRC and more research into the links between concussion and late degenerative brain disease are required.

Investment in neurorehabilitation, in-patient neurorehabilitation beds and service provision is inadequate and hugely variable across the UK.

An individual with an ABI may not be able to work in the short and long-term, and the loss of income is likely to have an immediate impact on their quality of life, at a time when they are most vulnerable. Welfare benefits, subject to qualifying criteria, are available to support those with ABI who have long and short-term consequences, but the system is complex and can be protracted, and especially challenging to individuals with an ABI. Assessment of Mental Capacity can also be fraught and assessors need a good knowledge base to be able to assess individuals correctly.



SUMMARY OF KEY RECOMMENDATIONS

Neurorehabilitation

- Rehabilitation Prescriptions should be available to all individuals with an Acquired Brain Injury on discharge from acute care, held by the individual with copies made available to the general practitioner
- A national review of neurorehabilitation is required to ensure service provision is adequate and consistent throughout the UK
- The Government should collate reliable statistics for the number of individuals presenting at Accident and Emergency Departments with Acquired Brain Injury, and record the numbers that require and receive neurorehabilitation
- There should be a significant increase in neurorehabilitation beds and neurorehabilitation professionals so that every trauma centre has a consultant in rehabilitation medicine, and individuals with an Acquired Brain Injury have access to neurorehabilitation
- Cooperation between key government departments (i.e. the Department of Health and Social Care and the Department for Work and Pensions) is required to review funding for in-patient and community neurorehabilitation services

Education

- Acquired Brain Injury should be included in the Special Educational Needs and Disability Code of Practice
- All education professionals should have a minimum level of awareness and understanding about Acquired Brain Injury and the educational requirements of children and young people with this condition (i.e. completion of a short online course for all school-based staff). Additional training should be provided for the named lead professional who supports the individual with Acquired Brain Injury, and for Special Educational Needs Coordinators
- The Acquired Brain Injury Card for the under 18s (produced by the Child Brain Injury Trust) should be promoted in all schools, hospitals and Local Education Authorities
- Many children and young people with Acquired Brain Injury require individually-tailored, collaborative and integrated support for the return to school, and throughout their education. An agreed 'return-to-school' pathway plan is required, led and monitored by a named lead professional, to provide a consistent approach and support for the individual, their family and teachers

Criminal justice

- Criminal justice procedures, practices and processes need to be reformed to take into account the needs of individuals with Acquired Brain Injury
- Training and information about Acquired Brain Injury is required across all services including the police, court, probation and prison services
- Brain injury screening for children, young people and adults is required on entry to the criminal justice system and, if identified, an assessment of the effects, deficits, severity and impact is required with the appropriate interventions planned and implemented by a trained team
- All agencies working with young people in the criminal justice system, schools, psychologists, psychiatrists, general practitioners and youth offending teams should work together to ensure that all the needs of the individual are addressed

Sport-related concussion

- The Government should ensure that there is collaborative research to evaluate and improve practical assessment tools, develop objective diagnostic markers and gain a deeper understanding of the recovery process and long-term risks of sport-related concussion
- An enhanced education campaign should be implemented in schools to improve awareness and understanding of sport-related concussion with the support of government departments (i.e. Department for Education and Department of Health and Social Care)
- Sport, government and professional clinical bodies must work collaboratively to improve health professionals' knowledge of concussion management
- The National Health Service should develop better pipelines for the diagnosis and care of sport-related concussion

Welfare benefits system

- All benefits assessors should be trained to understand the problems that affect individuals with an Acquired Brain Injury
- Re-assessment for welfare benefits for people with Acquired Brain Injury should only take place every five years
- A brain injury expert should be on the consultation panel when changes in the welfare system are proposed

OVERVIEW OF ACQUIRED BRAIN INJURY

Defining Acquired Brain Injury:

Definition and types

An Acquired Brain Injury (ABI) is any injury to the brain which has occurred following birth. It includes Traumatic Brain Injuries (TBIs), such as those caused by trauma e.g. from a road traffic accident, fall or assault, and non-TBIs related to other medical conditions, e.g. encephalitis, meningitis, stroke, substance abuse, brain tumour and oxygen deprivation resulting from a cardiac arrest or other causes.

ABI is a leading cause of death and disability

ABI is a leading cause of death and disability in the United Kingdom (UK). Its impact is difficult to quantify due to inconsistencies in definitions and classifications, data collection discrepancies and inadequate reporting. Much of the published data pertains to TBI which means the figures quoted underestimate ABI. (see Figure 1).

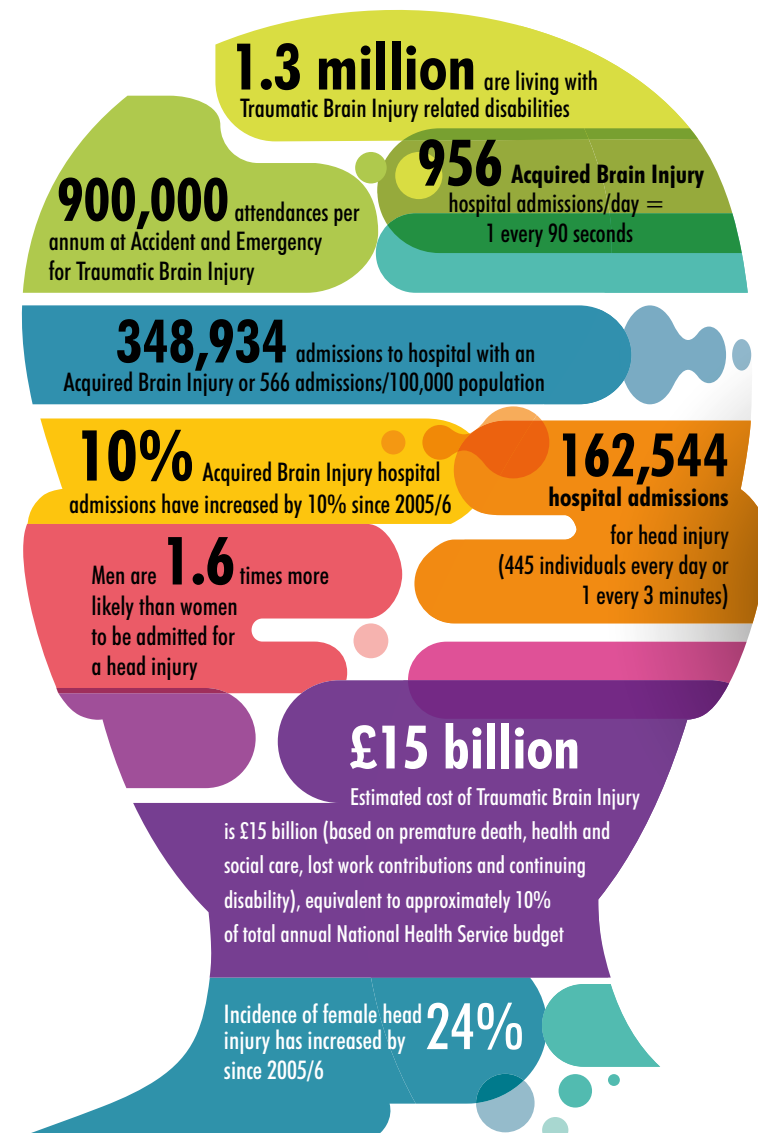


Figure 1: Acquired Brain Injury key facts^{1,2}

A report by the Centre for Mental Health states that 1.3 million people live with the effects of brain injury at a cost to the UK economy of £15 billion per annum, a figure that is equivalent to 10% of the annual National Health Service (NHS) budget². This includes the costs of premature death, health and social care, lost work contributions and continuing disability. International comparisons suggest a similar scale of impact, at least for TBI³.

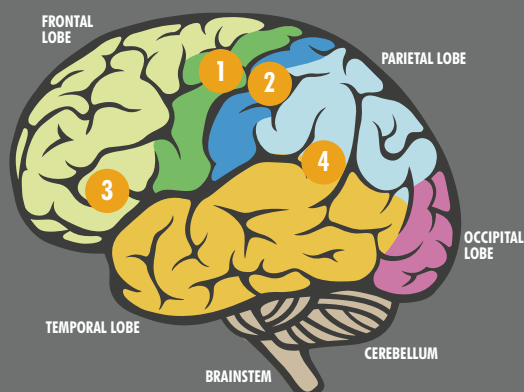
ABI can cause physical, cognitive, behavioural and mental health problems

The consequences of ABI result from injury to specific brain areas (see Figure 2 for some examples), or from damage to connections between brain areas, and can cause physical, cognitive, academic and psychosocial effects, which may be temporary or permanent.

The impact forces in TBI shear nerve fibres ('axons') connecting different brain areas, resulting in abnormalities in the function of neural systems, rather than damage to individual sites. Some of these injuries are not easily seen on routine scans, and may require Magnetic Resonance Imaging for detection (see Figures 3 and 4). An ABI in an adult affects the developed brain; while in children and young people the consequences of the injury will depend on the developmental stage of the child at the time of the injury.

Brain injury is also associated with greater mental health problems, higher rates of depression or mood disorder and/or childhood developmental disorders including Attention Deficit Hyperactivity Disorder or disruptive behaviour difficulties. A head injury doubles an individual's risk of later mental health problems, even if the person had no prior history of mental ill-health². While physical disabilities are more easily apparent, a large majority of individuals with ABI have 'hidden' disabilities which affect memory, judgement, behaviour and other higher functions. Although these are less obvious, they can be as disabling, be misinterpreted by employers and education professionals, and result in loss of employment, relationship breakdown and social isolation (see Table 1).

Figure 2: Functional areas of the brain



Lobes of the brain and location of some specialised brain functions

- 1 Primary motor area – movement of opposite side of body
- 2 Primary sensory area – touch, vibration, body position of opposite side of body
- 3 Regions involved in language production
- 4 Region involved in language comprehension

Brain injury location – functions affected

Frontal lobe: Movement, short-term memory, planning, reasoning, speed of processing, personality, behaviour and judgement, language production

Parietal lobe: Perception and interpretation of touch, position, vibration; integrating sensory information

Occipital lobe: Perceiving and processing vision

Temporal lobe: Sound perception and language comprehension; long-term memory

Cerebellum: Balance and coordination and some cognitive functions

Brain stem: Connections from brain to spinal cord; control of movement of eye, face, swallowing, vocalisation; control of breathing and heart rate; modulating consciousness

Table 1: Long-term effects of Acquired Brain Injury

- | | | |
|--|--|---|
| <ul style="list-style-type: none"> • Impaired memory • Poor impulse control • Mental health problems • Impaired communication skills • Poor initiation and planning | <ul style="list-style-type: none"> • Lack of self-monitoring • Sleep disturbances • Poor judgement • Impaired social skills • Motor and sensory impairments | <ul style="list-style-type: none"> • Other medical conditions
e.g. post-traumatic epilepsy • Reduced concentration and attention • Decreased awareness of one's own
or other emotional state |
|--|--|---|

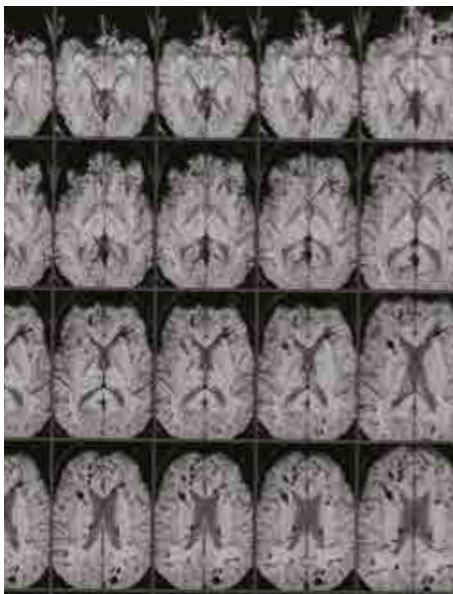
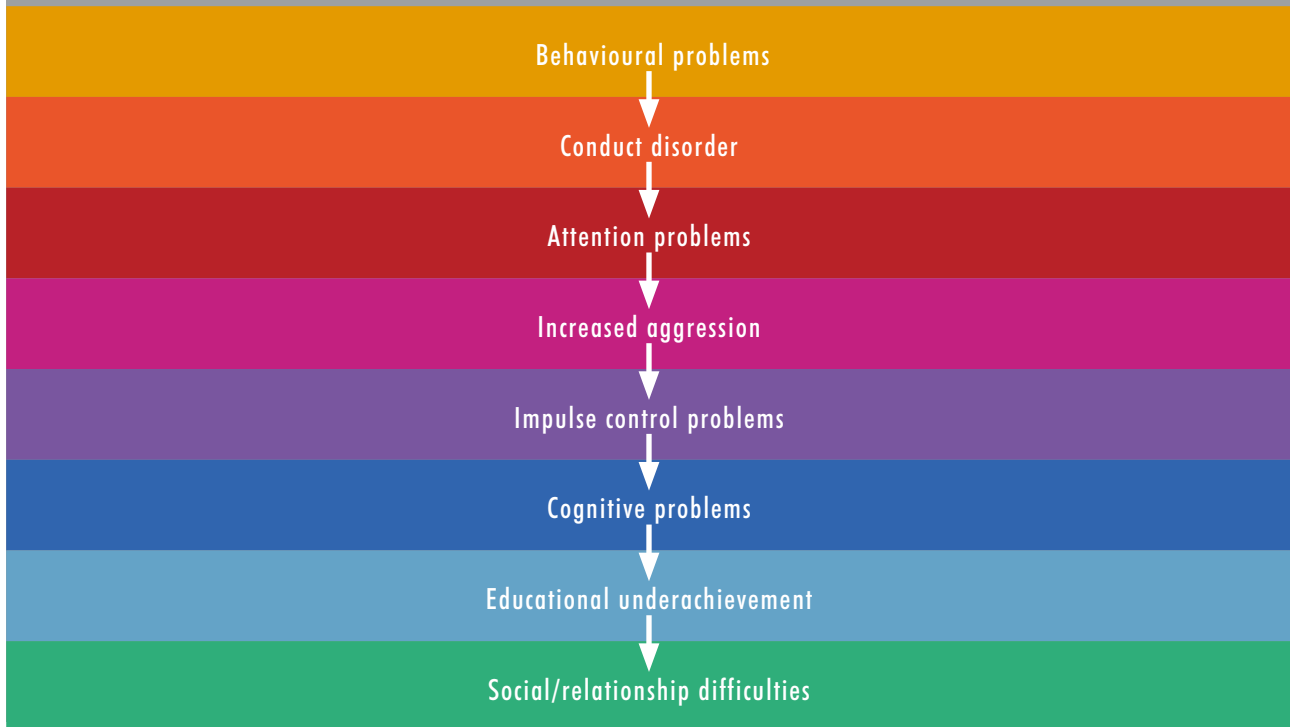


Figure 3: Hidden injuries

Advanced MRI scanning (susceptibility weighted imaging) with dark spots identifying microbleeds in the brain following Traumatic Brain Injury. These are poorly detected by CT scans or conventional MRI.

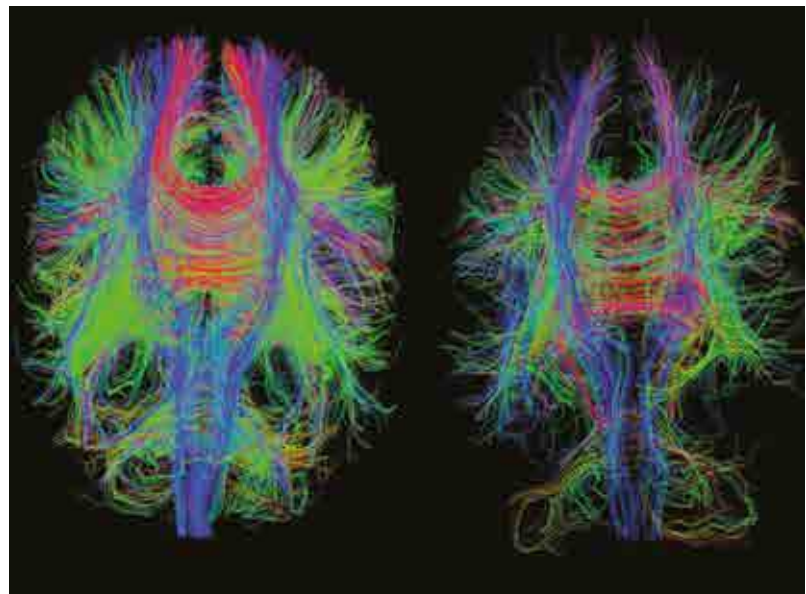


Figure 4: MRI tractography

This image outlines all the nerve tracts in the entire brain as seen from the front. The image on the left is a normal individual. The image on the right is an individual with Traumatic Brain Injury and shows a substantial loss of connecting nerve fibre tracts which are not directly visible on conventional scans but can lead to significant 'hidden' disabilities.



ABI affects the entire family with both short and long-term effects (see Table 2), and appropriate levels of support are required.

Table 2: Psychosocial effects of Acquired Brain Injury

- Loss of role and self-identity
- Changes to relationships
- Change in financial circumstances
- Breakdown of relationships
- Impaired communication and social skills
- Relationship difficulties within the family
- Increased risk of social isolation
- Increased risk of unemployment
- Reduced ability to understand and cope with social interactions

ABI may predispose to late neurodegenerative disease

In addition to the disabilities directly attributable to all forms of ABI, there is increasing evidence that TBI may increase the risk of late neurodegenerative diseases such as Alzheimer's disease (AD) and Parkinson's disease. The risk of AD following TBI may be several times higher than in the general population, and

increases with the severity of the injury⁴. In addition, repeated concussion which is often associated with contact sports, may result in a particular form of neurodegenerative disease – Chronic Traumatic Encephalopathy. This was previously thought to be almost exclusive to former boxers but is increasingly recognised in the post-mortem examinations of athletes from wider sports including American football, association football and rugby. Currently these risks are poorly quantified and more information is essential to be able to balance the risks rationally, against the clear health and social benefits of participation in sport.

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NEUROREHABILITATION

KEY ISSUES

- Early access to neurorehabilitation is imperative to optimise recovery for individuals with Acquired Brain Injury
- There are large variations in the provision and access to neurorehabilitation services across the country, and a lack of neurorehabilitation personnel
- There is a lack of understanding of the role of neurorehabilitation at national and local level, and a reluctance to fund services
- Rehabilitation Prescriptions are not made available to all individuals with an Acquired Brain Injury, and general practitioners rarely receive a copy so cannot facilitate access to neurorehabilitation services post-discharge

RECOMMENDATIONS

- Rehabilitation Prescriptions should be available to all individuals with an Acquired Brain Injury on discharge from acute care, held by the individual with copies made available to the general practitioner
- A national review of neurorehabilitation is required to ensure service provision is adequate and consistent throughout the UK
- The Government should collate reliable statistics for the number of individuals presenting at Accident and Emergency Departments with Acquired Brain Injury, and record the numbers that require and receive neurorehabilitation
- There should be a significant increase in neurorehabilitation beds and neurorehabilitation professionals so that every trauma centre has a consultant in rehabilitation medicine, and individuals with an Acquired Brain Injury have access to neurorehabilitation
- Cooperation between key government departments (i.e. the Department of Health and Social Care and the Department for Work and Pensions) is required to review funding for in-patient and community neurorehabilitation services

Overview

Defining neurorehabilitation and its role

Neurorehabilitation is a process of assessment, treatment and management by which the individual (and their family/carers) are supported to achieve their maximum potential for physical, social and psychological function, participation in society and quality of living. Patient goals for rehabilitation vary according to the trajectory and stage of their condition.

Neurorehabilitation has a key role in the management of individuals admitted to hospital with Acquired Brain Injury (ABI); many of whom have complex rehabilitation needs. The extent and nature of the neurorehabilitation will depend on the nature and severity of the brain injury, and the programme should be tailored according to the individual's needs. It should be implemented after the individual's immediate medical and/or surgical needs have been met in the acute setting in order to prevent complications and maximise outcomes. Each individual's care pathway should be clearly defined, and a referral made at the earliest opportunity to a local specialist rehabilitation service.

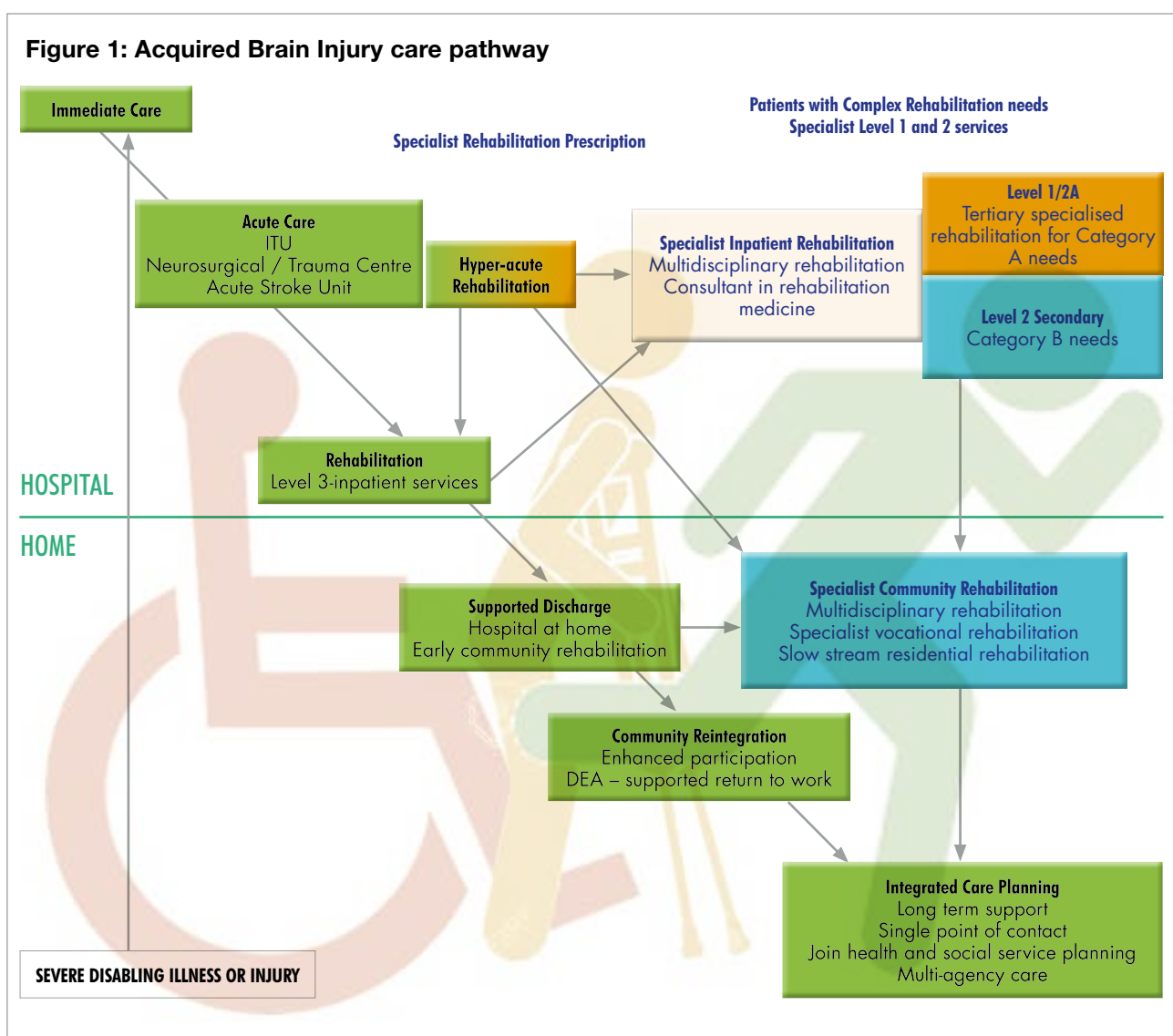
Neurorehabilitation can relieve the pressure on beds in the acute services, and it supports the safe transition of the individual back into the community, where access to ongoing neurorehabilitation is a key requisite to maximising health outcomes. The overall aim of neurorehabilitation is to enable people to reach their maximum potential.

Neurorehabilitation is a key component of the ABI care pathway

Early access to specialist neurorehabilitation is a critical component of the ABI care pathway (see

Figure 1). Depending on the complexity of neurorehabilitation required, individuals with ABI are divided into four categories (A-D), and referred to a range of neurorehabilitation services ranging from Level 1 (tertiary specialist services serving approximately one million population), to Level 3 (non-specialist units). Some individuals with ABI will not need specialist neurorehabilitation but will require timely, community-based, neurorehabilitation post-discharge from hospital.

Figure 1: Acquired Brain Injury care pathway





Delivery of neurorehabilitation services

Neurorehabilitation is delivered by a multidisciplinary team (MDT) who have undergone recognised specialist training, led or supported by a consultant trained and accredited in rehabilitation medicine (see Table 1). A MDT neurorehabilitation programme promotes brain recovery and enables individuals to recover more quickly, efficiently and effectively.

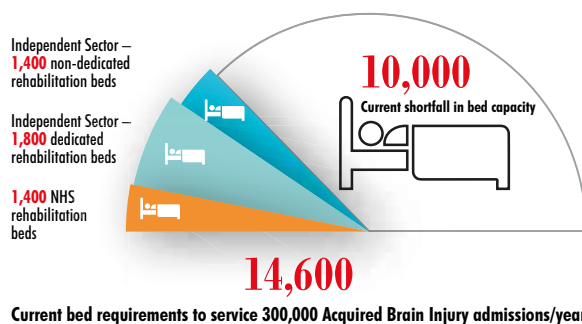
Table 1: Neurorehabilitation multidisciplinary team

- Rehabilitation Medicine Consultant
- Rehabilitation Nurse
- Physiotherapist
- Occupational Therapist
- Speech and Language Therapist
- Dietitian
- Neuropsychologist
- Psychotherapist
- Social Worker

An estimated 14,600 neurorehabilitation in-patient beds are needed for the annual caseload of about 300,000 ABI admissions. Currently there are only 4,600 beds (see Figure 2) available in the United Kingdom (UK), and the independent sector has increased its bed capacity by 700, but the National Health Service (NHS)

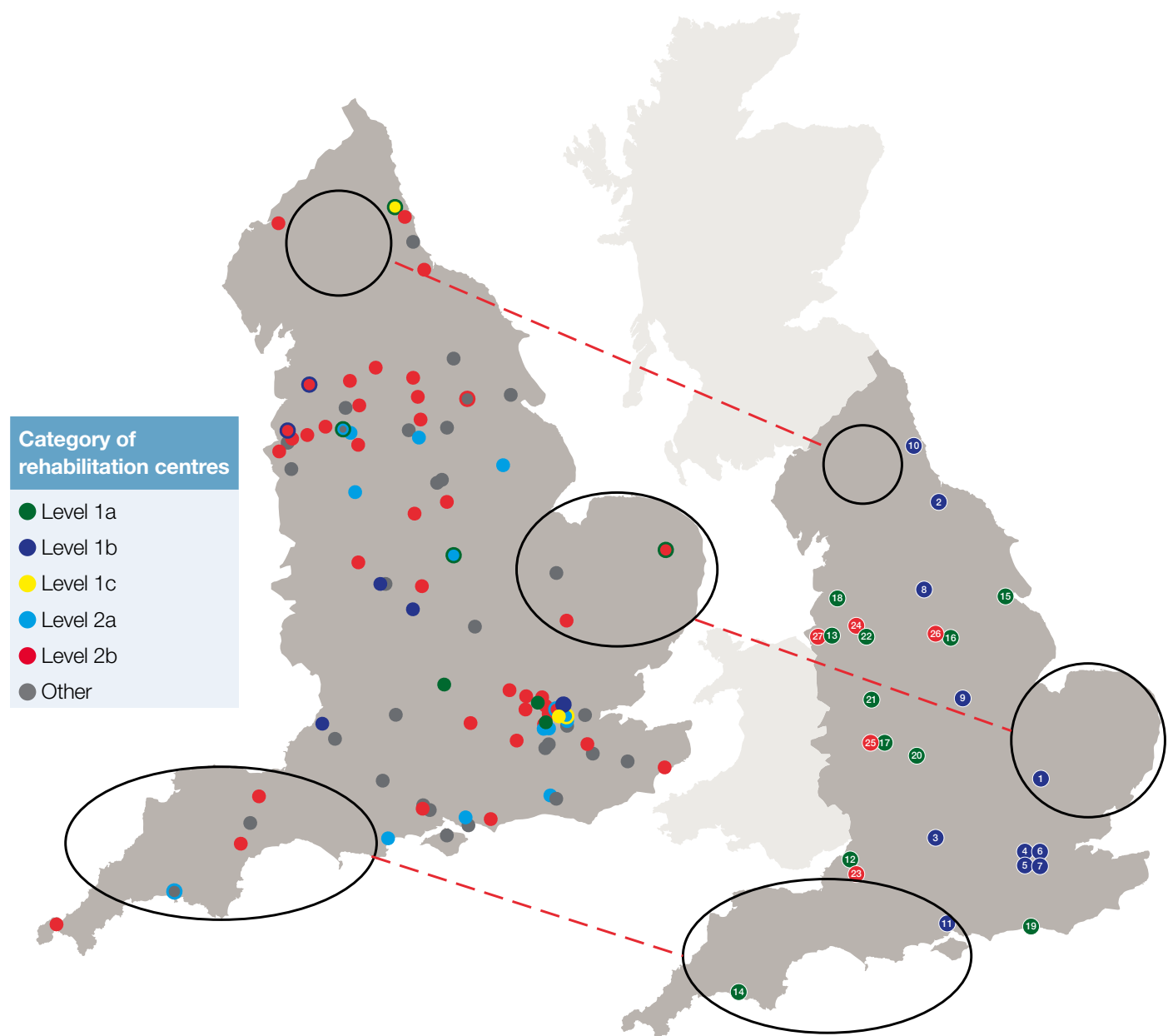
has lost approximately 100 beds since 2013 (data on file). Although the acute care of individuals with ABI has been transformed, many of these patients are let down by deficiencies at subsequent stages of the care pathway, especially with regard to neurorehabilitation, with the result that potential improvements in outcome are never delivered.

Figure 2: Neurorehabilitation bed overview



This overall lack of neurorehabilitation beds is compounded by large variations in provision across the UK, and by the fact that many neurorehabilitation services are not co-located with Major Trauma Centres (MTCs) (see Figure 3). Some parts of the UK such as the East, South West and North have no, or sparse, access to neurorehabilitation services.

Figure 3: Location of neurorehabilitation services (left) and Major Trauma Centres (right) highlighting areas where access is poor or sparse (black circles)



Adult and Children's MTCs	Adult MTCs	Children's MTCs
<ol style="list-style-type: none"> Addenbrooke's Hospital Cambridge James Cook University Hospital Middlesbrough John Radcliffe Hospital Oxford St Mary's Hospital London St George's Hospital London Royal London Hospital King's College Hospital London Leeds General Infirmary Queen's Medical Centre Nottingham Royal Victoria Infirmary Newcastle Southampton General Hospital 	<ol style="list-style-type: none"> Southmead Hospital Bristol Aintree University Liverpool Derriford Hospital Plymouth Hull Royal Infirmary Northern General Hospital Sheffield Queen Elizabeth Hospital Birmingham Royal Preston Hospital Lancashire Royal Sussex County Hospital Brighton University Hospital Coventry University Hospital of North Staffordshire Stoke on Trent Salford Royal Hospital and Manchester Royal Infirmary (Collaborative) 	<ol style="list-style-type: none"> Bristol Royal Hospital for Children Royal Manchester Children's Hospital Birmingham Children's Hospital Sheffield Children's Hospital Alder Hey Children's Hospital Liverpool

Rehabilitation prescription improves communication and service access

A Rehabilitation Prescription (RP) documents comprehensively the rehabilitation needs of the individual with an ABI, and identifies how those needs will be addressed in the longer term (see Table 2). An effective RP improves communication along the care pathway and optimises access to individual services.

A National Clinical Audit in October 2016 highlighted inadequacies in the use of RPs despite the fact that MTCs are incentivised to use them¹. Currently the RP is not always completed in the MTC or Trauma Centre, and the Consultant in Rehabilitation Medicine (RM) is not always involved in assessment of rehabilitation needs. Indeed many MTCs do not utilise the services of an RM Consultant. The RP is rarely given to the individual or to their family or carer, and is not communicated to the General Practitioner (GP) and external agencies. In March 2017 the United Kingdom Acquired Brain Injury Forum (UKABIF) sent a Freedom of Information request to all Clinical Commissioning Groups (CCGs) asking if they logged RPs; the feedback was poor and only four were positive. Most referred UKABIF to the NHS Trust for the information². The use of RPs in primary care is clearly patchy and inadequate.

Currently only MTCs are incentivised to complete RPs; but even in these settings, neither the individual with the ABI nor their GP usually receives a copy, so access to neurorehabilitation services cannot be effectively planned and implemented. The Clinical Reference Group for Major Trauma is currently reviewing the format and use of MTC RPs, and their likely recommendation of tariff-based implementation with a monetary incentive may encourage its completion. However, limitation of this incentive to MTCs means that individuals with an ABI treated outside an MTC are still unlikely to receive an RP.

Skilled expertise is required in community care

When patients cannot be discharged home at the end of their acute care, community support is usually delivered in a nursing home. Although the care provided here is relatively cheap, the absence of skilled neurorehabilitation input compromises the individual's outcome. Unfortunately, CCGs and GPs, who commission community neurorehabilitation services, have a limited understanding of clinical needs in this context. Even when neurorehabilitation is funded,

Table 2: Key criteria for a Rehabilitation Prescription

- Patient held, electronic/updatable, and accessible to all
- Commence 24-48 hours after admission, reviewed weekly till discharge
- Evolving document with input from multidisciplinary team
- Completion by transfer of care/discharge
- Consider psychological/emotional needs
- Accessible/forwarded to General Practitioner
- Clearly document neurorehabilitation plan
- Clearly document future arrangements and responsibilities (who/when/where)
- Provide key contacts (Major Trauma Centre/support agencies)
- Signpost information and expectations
- Can be used for audit and service improvement

it is usually limited to a maximum of six months, regardless of the individual's needs or progress.

Neurorehabilitation is effective and saves money

Neurorehabilitation is one of most cost-effective interventions available to the NHS. Substantial and robust evidence supports the clinical and cost-effectiveness of neurorehabilitation³⁻⁸. Although individuals with complex needs may require a longer hospital stay, the front-loaded cost of providing early specialist neurorehabilitation for these individuals is rapidly offset by longer-term savings in the cost of community care, making this a highly cost-efficient intervention^{9,10}. These savings are substantial and have been estimated at £500 per week for each ABI survivor requiring specialist neurorehabilitation, or over £5 billion of annual savings for the 300,000 individuals who need this service each year.

These cost savings are accompanied by better physical, cognitive, behavioural and emotional outcomes and these improvements extend across the outcome spectrum. Where recovery is incomplete, neurorehabilitation improves functional independence and reduces the burden on carers; and where outcomes are better, it improves the rates of return to work and productivity^{11,12}. These benefits are amplified when neurorehabilitation is followed through in the community, and the costs of early specialist neurorehabilitation for individuals with an ABI and complex needs are rapidly offset by longer-term savings in the cost of community care¹³.



CASE STUDY: **JAMES**

In January 2011, 39-year-old James set out for an ordinary Sunday morning drive with this family. After 30 minutes on the road a nail punctured the car's tyre, causing the vehicle to spin off the road and smash into a tree. The whole accident took less than a minute; just a few seconds in time that would change James' life in an instant. Thankfully, James' three children were not injured, but his wife was tragically killed and he was left unconscious with a serious traumatic brain injury.

James was flown 60 miles by air ambulance to Addenbrooke's NHS Hospital in Cambridge and was in an induced coma for five days. Following a period

of intensive and acute care he was moved to Norwich NHS Hospital where he received many months of neurorehabilitation. James has made great progress in the years following his accident, but has had to come to terms with some long-term aspects of his brain injury. He has had to lower his expectations of himself; he has learnt to cope with fatigue and is better at avoiding situations which will leave him very tired. He has also had to change the way he lives and accept that aspects of his life take longer to achieve. However, he has been able to return to his part-time job as a science communicator.

CASE STUDY: JOSH

Josh was 18 years of age when he was in the front seat of a car involved in road traffic accident. He was taken to a Major Trauma Centre with a severe brain injury and other serious trauma. As soon as Josh's injuries were stabilised he commenced intensive rehabilitation which continued on an in-patient basis for 12 months, and on discharge he was able to walk, albeit with the use of a Zimmer frame. He now lives with his parents and brother in the family home. He has no care input, but does have 2.5 hours of physiotherapy and occupational therapy each week in the community brain injury service. He has outpatient neuropsychology reviews at 3-6 month intervals and has been discharged from speech and language therapy with exercises and advice.



Josh has made huge progress and regained some independence as a result of the neurorehabilitation he received and his reliance on carers is now much reduced. The time to offset the costs of Josh's treatment have been calculated (see Table 3).

Table 3: Cost of Josh's neurorehabilitation

	In-patient	Community	
Length of stay	40 weeks	50 weeks	
Episode cost	£127,224	£21,150	
	Admission date 03/05/2016	Discharge date 06/02/2017	Follow-up date 01/2018
Northwick Park Nursing Dependency tool	64	16	3
Care hours/week	66.5	35	14
Care cost/week	£2,768	£1,612	£800
Reduction in care costs		£1,156	£812
Time to offset costs		27 months	6 months

Table 3 illustrates that although the NHS spent a considerable amount on Josh's neurorehabilitation, both in hospital and in the community, the costs were offset within 27 months (in-patient) and six months (community) due to the reduced amount of care that he would

otherwise have needed, and the state would have had to fund. Assuming Josh has a life expectancy of 52 years then the lifetime savings without community rehabilitation are £3 million and further savings with community rehabilitation would be £2.2 million.

2001 – 2018 Political aspirations but limited progress

While improvements in the quality of neurorehabilitation are a widely shared and long-standing aspiration, its implementation has been considerably neglected over the last two decades. This can be illustrated by attempts to improve neurorehabilitation following Traumatic Brain Injury. In 2001 the parliamentary Health Select Committee published a report 'Head injury: rehabilitation' containing over 20 recommendations. The committee examined the availability, organisation and resourcing of rehabilitation services for head-injured adults following medical stabilisation. It also considered rehabilitation services in hospital and in the community, and looked at the extent to which agencies in the statutory and non-statutory sectors collaborate to provide seamless care.

Whilst many of the recommendations relating to acute care have been implemented to some extent, the last 17 years have not seen any of the recommendations regarding neurorehabilitation achieve substantial implementation (see Table 4).

The call for evidence attracted such a large quantity of material for such a short inquiry that it became obvious that this was an area of some considerable concern to a great many people. The committee concluded: 'We have managed to look at some key issues, but we believe that this is an area which would benefit from a wider inquiry'. No wider inquiry took place.

In 2010 the NHS Clinical Advisory Group for Major Trauma (Trauma CAG) reported to the Department of Health (DoH) and recommended the establishment of services in Major Trauma Centres (MTC) to provide coordinated pathways of care. Subsequently 22 MTCs were established for adults following major trauma. As a result of this reorganisation, advances in emergency and acute medicine, the availability of hyper-acute stroke units and defibrillators in public places, survival rates for individuals with an ABI have increased by approximately 50%, or 500 individuals per year. While many of these individuals experience good outcomes, the number of survivors with significant disability or catastrophic brain injury has also increased, with long-term consequences. Unfortunately this reorganisation made no formal provision for neurorehabilitation services.

National guidelines and standards documents, including those from the DoH, NHS England, the British Society of Rehabilitation Medicine, the Royal College of Physicians and the National Institute for Health and Care Excellence, have made recommendations for improving the consistency and quality of care for brain injury survivors. However, without fundamental changes in the provision of neurorehabilitation services these documents are redundant.

Table 4: 2001 Health Select Committee Report

‘Head injury: rehabilitation’ (abbreviated recommendations classified according to the progress made since publication)

Substantial progress

1. Acute assessment and management by specialist staff appropriate to head injury severity
2. Explicit allocation of responsibility for planning different levels of head injury rehabilitation

Partial progress

1. Improved data collection on epidemiology and consequences of TBI – acute incidence and severity data available but no reliable data on prevalence and disability to inform service planning
2. Involvement of families in recovery, rehabilitation and support services – inconsistent progress
3. Timely post-acute rehabilitation in appropriately resourced rehabilitation services – remains a target, but with incomplete and variable implementation
4. Acute sector to take responsibility for planning onward care journey and provision of information on this to patients and families – variable implementation
5. Clear plans for care pathways for serious head injury, including tertiary services – achieved in acute stage, but skilled assessment for, and delivery of, specialist neurorehabilitation remains inconsistent
6. Each individual to have a clear care plan for rehabilitation post-discharge from hospital – universal target, but implementation incomplete, especially outside Major Trauma Centres
7. Improved provision of information on head injury to patients and families from hospitals and GP, with inclusion of information provided by Headway – inconsistent implementation
8. Targeted mental health services for TBI – variable implementation, especially in post-acute phase
9. Trusts, Health Authorities and Local Authorities to have a case management system to help guide carers and patients through whole care pathway
10. Every NHS Trust should have a named manager for head injury rehabilitation who can liaise with patients, carers, and services; and is responsible for coordinating care
11. Recognition of contributions by independent sector, and collaboration with the statutory sector

Little or no progress

1. Greater allocation of Department of Health (DoH) research budget to TBI rehabilitation
2. Learning lessons of vocational rehabilitation from other complex neurological disorders, and providing flexible support in this area to be of real help to individuals with head injury
3. Assessment for disability living allowance should be by individuals who have specialist skills and understanding of head injury, with input of a patient advocate
4. DoH should take responsibility for providing community rehabilitation for both physical and cognitive disability, with service design in consultation with rehabilitation professionals
5. Social Service departments should have an additional classification of user group in planning services for complex neurological conditions including TBI, included in the Community Care Plan
6. DoH should help charitable organisations which provide core services
7. There should be allocation of rehabilitation responsibilities between health and social services, with identified managers, clear responsibilities and close collaboration. There should be arrangements to provide out-of-catchment area specialist care, when unavailable locally
8. There should be a government subsidised publication which provides an inventory of resources available for head injured people, for circulation to health authorities
9. Health Improvement Plans and Community Care Plans should include a section on planning rehabilitation for complex neurological conditions – including head injury
10. Clear plans to improve rehabilitation services for head injury, with implementation before 2005
11. Urgent formulation of policy for long term rehabilitation of head-injured people; Intermediate Care, National Institute for Health and Clinical Excellence guidelines and National Service Framework on long-term conditions do not provide a satisfactory solution



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EDUCATION

KEY ISSUES

- There is a lack of awareness and understanding amongst education professionals about Acquired Brain Injury, its consequences and its impact on learning
- Education professionals have difficulty identifying what specific educational support is needed following Acquired Brain Injury, in terms of assessment tools, learning strategies and interventions
- There is a lack of liaison, including information sharing regarding assessment and support, between health and education professionals, as well as a lack of involvement and communication with the family

RECOMMENDATIONS

- Acquired Brain Injury should be included in the Special Educational Needs and Disability Code of Practice
- All education professionals should have a minimum level of awareness and understanding about Acquired Brain Injury and the educational requirements of children and young people with this condition (i.e. completion of a short online course for all school-based staff). Additional training should be provided for the named lead professional who supports the individual with Acquired Brain Injury, and for Special Educational Needs Coordinators
- The Acquired Brain Injury Card for the under 18s (produced by the Child Brain Injury Trust) should be promoted in all schools, hospitals and Local Education Authorities
- Many children and young people with Acquired Brain Injury require individually-tailored, collaborative and integrated support for the return to school, and throughout their education. An agreed 'return-to-school' pathway plan is required, led and monitored by a named lead professional, to provide a consistent approach and support for the individual, their family and teachers

Overview

Despite pockets of good practice regarding Acquired Brain Injury (ABI), too many children and young people with ABI encounter issues in the education system that are identical to those experienced decades ago, and do not receive the tailored education needed to maximise their potential.

Potential solutions to these problems are complex because of significant changes in health and education systems, reduced funding, regional differences, changes in teachers' roles and responsibilities, the impact of technology, and changes in the way training and professional development are delivered. Education professionals are already overstretched,

but the incidence and long-term consequences for children and young people with ABI warrant proactive measures in the education system.

The functional impact of ABI is affected by the age and developmental stage at the time of injury. ABI frequently disrupts the process of learning, and consequences may be delayed for years. Children and young people spend a relatively short time in the acute hospital setting, dedicated neurorehabilitation facilities are rare, and other rehabilitation services patchy. Consequently, most neurorehabilitation for children and young people occurs in schools.



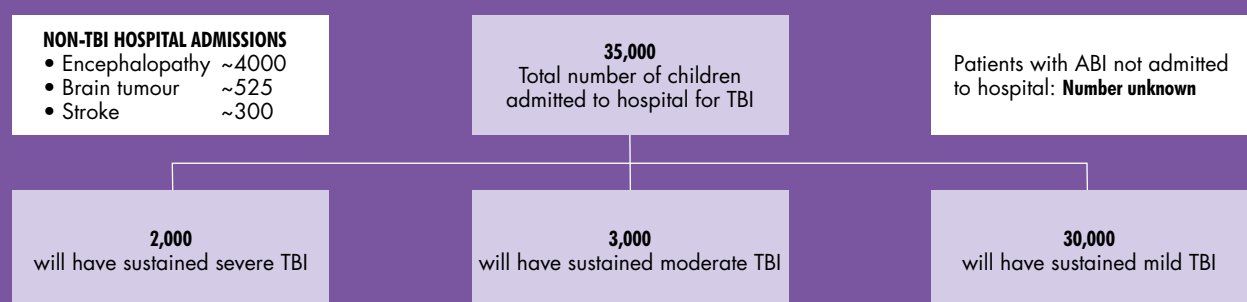
Burden of ABI in the education system is not widely recognised

Figure 1 shows the statistics for the annual incidence of TBI in children that results in hospital admission. The incidence figures for ABI from causes other than TBI, or ABIs that do not result in hospital admission, are

less easily available, but approximate figures are provided¹. ABI is difficult to quantify due to inconsistencies in definitions and classifications, data collection discrepancies and inadequate reporting, and consequently the prevalence of ABI in children and young people is unknown, but likely to be much higher.

Figure 1: UK annual incidence of Acquired Brain Injury in children¹

Detailed data are available for TBI (in purple boxes) but best estimates have been provided for other conditions, and indications of areas with no data provided (in white boxes)



ABI has long-term consequences for learning

Although children and young people may appear to make a good physical recovery after the acute phase of the ABI, the long-term effects may arise many months or even years later, when the injured part of the brain reaches a key stage of development, and they are unable to demonstrate some of the skills they otherwise would have had (see Table 1).

Table 1: Effects of Acquired Brain Injury that may impact on learning

- Limb weakness and poor mobility
- Fatigue
- Reduced concentration and attention
- Difficulties processing information
- Impaired memory
- Visual and visuo-perceptual impairments
- Hearing difficulties
- Difficulties understanding and using language
- Mental health problems e.g. anxiety and depression
- Difficulties with organisation and planning
- Changes in behaviour e.g. irritability, behaving impulsively or inappropriately
- Social difficulties including a lack of empathy and awareness about their own or other people's emotional situation

'Neurocognitive stall' – a halting or slowing in later stages of cognition, social or communication development – may occur beyond a year after brain injury². The individual may 'hit a wall', or plateau after initial improvement, and consequently not meet later developmental milestones. The implications for education professionals are that the individual may begin to struggle in class and, because information about an earlier ABI may not be readily available, the reason for these difficulties is not understood. At best the individual's struggle goes unnoticed, at worst it can be attributed to lack of effort or laziness.

Behaviour issues may bring the individual with ABI to a teacher's attention (see Table 2). In school, these issues may be labelled as not learning, oppositional behaviour, impulsivity, poor self-control, disorganisation or low motivation. When resources are stretched, poor motivation or withdrawal may lead the individual to being overlooked in a busy classroom.

Table 2: Common behavioural problems after Acquired Brain Injury^{3,4}

- Overactivity
- Apathy
- Demanding behaviour
- Disinhibition and impulsivity
- Sexual acting out
- Rigidity or perseveration
- Immature behaviour
- Social awkwardness
- Verbal and physical aggression
- Irritability, lowered frustration tolerance, reduced anger control
- Egocentrism, insensitivity, impaired social perception
- Unawareness of impact on others, gullibility
- Reduced judgment and motivation
- Sleep disturbance and eating problems (over/under eating)
- Depression, anxiety, increased emotionality, social withdrawal



Children and young people with ABI are more likely to be excluded from school, and those who are excluded are more likely to commit offences. If education professionals understand, recognise and can support young people with an ABI, they can reduce the likelihood that the individual will enter the youth and criminal justice system.



Teams managing special education needs provide an opportunity for improved care

Children and young people are described as having Special Education Needs (SEN) when they have learning or behavioural difficulties, or disabilities that make it more difficult for them to learn than most students of the same age. For children and young people with ABI this might be because they struggle to process information, have difficulty remembering things, find it hard to concentrate and/or have sensory or physical difficulties.

In England, Northern Ireland and Wales, Special Education Needs Coordinators (SENCOs) are responsible for the day-to-day operation of the school's SEN policy. Scotland has Special Needs Assistants, also known as special needs auxiliaries, SEN auxiliaries or support for learning assistants,

who work in schools helping children with a variety of SEN. Educational Psychologists (EP) in the UK help children and young people with difficulties in learning, behaviour or social adjustment in school. However, EP numbers are limited, and schools have variable access to an EP.

An education, health and care (EHC) plan is available up to 25 years of age for children and young people who need more support than is available through the usual education or health resources. The EHC identifies educational, health and social needs and sets out the additional support needed. The family can request a Local Authority (LA) assessment if they think their child needs an EHC plan, but requests for assessment can be rejected and unfortunately families may have expectations that are seldom met.

Support is required throughout the course of education

Education professionals do not routinely receive training on ABI, and may therefore lack awareness and understanding its consequences^{5,6}. They may have difficulty identifying what specific support is required and may consequently use inappropriate assessment tools, learning strategies and interventions, and monitor and review the individual's progress less frequently than appropriate. Often education professionals who lack knowledge about ABI fill their knowledge gap with strategies they have used for children and young people with other disabilities; this lack of recognition of the developmental complexities of brain injury can lead to children and young people receiving inappropriate and potentially detrimental support. Education professionals require accurate information and awareness training about ABI, and support from SENCOs and external professionals to select and make effective use of the most appropriate assessment tools, learning strategies and evidence-based interventions.

While some excellent support is available to aid the transition from hospital back to school, this is limited and inconsistent. LA involvement at hospital discharge can be sporadic, LA advisors are not always in the loop and potential funding needs may not have been identified, addressed or agreed. In addition the individual's condition at the point in time that they return to school may be very different from the assessment at hospital discharge, or the school may not have read or implemented the recommended guidance.

Many of these individuals require bespoke management, regular monitoring and review for the duration of their education. Additional support and planning will also be required to address transitions between primary, secondary and further education. A 'return to school' pathway plan e.g. the Sam White Pathway, from hospital back into education, and, crucially throughout their education, is a 'must-have' for many children and young people with ABI⁷. A key professional is also required to provide consistent, face-to-face support and monitor/support the individual on their journey along the entire pathway. This ensures that all the required support is in place, co-ordinated, collaborative and pre-emptive.

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CASE STUDY: **EDEN**

In March 2011, six-year-old Eden had a seizure at home and became unconscious. She was rushed to hospital and, after many tests, was treated for encephalitis. Eden regained consciousness and initially the condition affected her vision, hearing, speech and mobility. By the summer she was discharged from hospital, albeit with an Acquired Brain Injury (ABI) and some complex needs. Her mother said: "I've still got my daughter in physical form, but I've got a different child emotionally, physiologically, behaviourally and intellectually".

Eden is very aware of her differences in comparison to her peers. The simplest task is a huge challenge; what used to take Eden an hour, now takes at least a day. What used to take her a day, now takes her at least a week. She gets fatigued so quickly and there are some things that she is unable to do which results in frustration and behavioural effects.

Two and a half years of school were lost, and even now Eden is not able to go back full time. When she did return to mainstream school the challenges were

enormous and overwhelming for both Eden and her parents. The education professionals knew nothing about ABI or the 'new' Eden, and were unable to provide the required support. Her peers did not understand the impact of this 'invisible' condition and Eden quickly became very isolated.

Preparation for Eden's return to school was essential to create the right learning environment. In the absence of trained professionals, Eden's parents briefed the teachers and developed and managed a coordinated plan to reintegrate Eden, irrespective of funding. They had no choice but to address the issues themselves, and prepare the school and Eden for her return.

Although Eden's mother provided as much information as possible, it was often misunderstood by teachers, SENCO and peers, which added to the continuous challenges faced by Eden and her family. Eden's mother concluded: "Every day was a battle. We just wanted to help the school understand Eden's needs and get the right people involved". As a consequence Eden's mother established The Eden Dora Trust for Children with Encephalitis to provide help and support for children and their families.

CRIMINAL JUSTICE

KEY ISSUES

- Individuals with Acquired Brain Injury are more likely to have contact with the criminal justice system and are significantly over-represented within it with major personal, social and economic consequences. Addressing this over-representation can result in significant cost-savings and reduce reoffending rates
- Acquired Brain Injury falls within the healthcare and offender management/police/court systems and requires an integrated approach
- Individuals with Acquired Brain Injury are typically failed by the criminal justice system because of barriers to access justice, lack of recognition of the impact of impairment on offending and limited specialist service provision
- Despite the strong recognition of its disproportionate prevalence in the youth justice system, young people who commit offences are not screened routinely for an Acquired Brain Injury before they enter a secure estate, by which time a cycle of re-offending may be triggered; neither male or female adult offenders are screened, resulting in similar consequences

RECOMMENDATIONS

- Criminal justice procedures, practices and processes need to be reformed to take into account the needs of individuals with Acquired Brain Injury
- Training and information about Acquired Brain Injury is required across all services including the police, court, probation and prison services
- Brain injury screening for children, young people and adults is required on entry to the criminal justice system and, if identified, an assessment of the effects, deficits, severity and impact is required with the appropriate interventions planned and implemented by a trained team
- All agencies working with young people in the criminal justice system, schools, psychologists, psychiatrists, general practitioners and youth offending teams should work together to ensure that all the needs of the individual are addressed

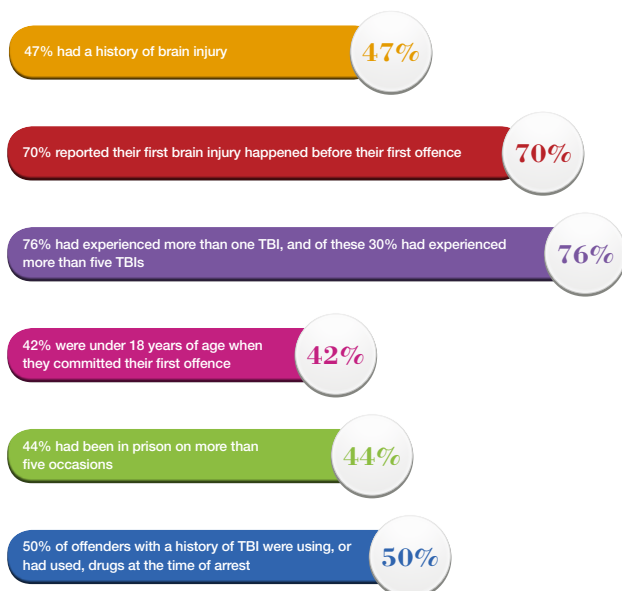
Overview

High incidence of ABI amongst offenders

Evidence now emphatically links Acquired Brain Injury (ABI) to offending in young people, with prevalence rates for Traumatic Brain Injury (TBI) as high as 60% among prisoners¹. A systematic review reported prevalence rates of brain injury amongst incarcerated youth of between 16.5% and 72%². The largest United Kingdom (UK) study (which involved 613 adult male prisoners) showed that almost half (47%) reported a history of TBI when screened on admission to HMP Leeds³. The majority (70%) of offenders reported receiving their first injury prior to their first offence, reinforcing previous studies that TBI may be a risk factor for offending (see Figure 1).



Figure 1: Incidence of Traumatic Brain Injury in prison³



The criminalisation of Acquired Brain Injury

The criminal justice system (CJS) discriminates against those with ABI from arrest to court to initial interventions. The lack of recognition and understanding within the CJS about the 'hidden' disabilities of ABI results in many barriers

to accessing justice. When encountering the CJS, individuals with ABI may have difficulty understanding the terminology and the language used, communication may be challenging especially in interview situations, and their behaviour misinterpreted.

A lack of recognition of ABI can result in the inappropriate use of standard criminal justice interventions that do not address the causes of behaviour related to an injury, and therefore are ineffective in preventing ongoing offending. This may also mean individuals have difficulty engaging with, and completing, court orders, resulting in an increased risk of breach and a return to court for further sentencing. The limited specialist service provision, and consequently a failure to identify and appropriately support individuals with ABI, results in a higher risk of custody and reoffending.

However, if professionals are aware of the symptoms of brain injury, contact with the CJS can provide an opportunity for screening and referral for specialist assessment

and support. More effective early identification and intervention in the CJS has the potential to greatly improve outcomes for those with an ABI. This could include referral to liaison and diversion services to enable specialist health-related interventions, and the application of the recent Sentencing Council guidelines to courts, to address experiences of brain injury when considering the welfare needs of young people at the time of sentencing^{4,5}. Taking account of an individual's brain injury could help deter repeat offending in those affected and/or manage the factors that contribute to criminal behaviour.

Living with a brain injury in prison has consequences for the individual

The behaviour of an individual with ABI in prison can often be misinterpreted, resulting in ineffective neurorehabilitation and management. It can also result in an increased risk of rule breaking and violence, and therefore additional penalties and adjudications (see Table 1). The disruptive and/or aggressive behaviour, poor memory and other cognitive problems that result from ABI and impact on learning all require specialist management in prison.

Table 1: Misinterpretation of Acquired Brain Injury related behavioural deficits in a prison setting

Behaviour	Misinterpretation in prison	Underlying cause due to ABI
Frequently misses appointments	Avoidant and irresponsible	Impaired memory functioning
Talks about the same things repeatedly	Trying to wind you up	Slow information processing
Makes inappropriate personal comments	Rude and disrespectful	Poor impulse control
Says they will do something but never gets round to it	Trying to manipulate the situation	Diminished executive skills

When an ABI has not been recognised earlier in the CJS, prison provides an opportunity to identify the underlying needs of the individual (see Table 2), and to then provide the required neurorehabilitation.



Table 2: Prison environment and neurorehabilitation – an opportunity?

- Provides a structured environment
- Rules and boundaries are clear
- Increased insight and awareness can motivate change
- Increased understanding can reduce conflict and lead to co-operation
- Individual with an ABI knows what to do, when and where
- If they have an executive impairment they often respond well
- Effective rehabilitation can result in effective learning

Screening and assessment are essential

Standardised screening for brain injury is essential when individuals come into contact with the CJS, particularly pre-sentencing and in custody. Screening can be carried out by a range of criminal justice professionals such as police officers, court staff, probation officers and prison reception teams.

There are assessment tools that can be used in prison, during probation, and community and rehabilitation settings to establish whether an individual has a brain injury, e.g. the Comprehensive Health Assessment Tool (CHAT) and the Brain Injury Screening Index (BISI®). CHAT was developed by the Offender Health Research Network for children and young people, and facilitates standardised holistic screening and assessment, early identification of needs, improved continuity of care and reduced duplication during transition periods within the YJS. The BISI® was developed by the Disabilities Trust Foundation and is an 11-question screening tool which also gives an indication of the brain injury severity level.

Management and support services are required

Following identification of a brain injury, interventions are required to manage the health, cognitive and behavioural issues. Following a recent pilot of BISI®, a Brain Injury Linkworker (BIL) Service was established for prisoners in HMP Leeds and young offenders in Wetherby and Hindley, to work with individuals identified as having a brain injury, address their problems and assist in their engagement with rehabilitation programmes (see Figure 2). Early evaluation suggests positive results with this approach and this service has now been delivered at over 10 custodial sites⁶.

The core BIL team comprises a BIL, Clinical Neuropsychologist and Project Manager, and provides one-to-one support including education about brain injury and its effects, as well as cognitive strategies involving functional intervention aids (e.g. a diary to aid memory, attention and thought records). Behavioural management plans and guidelines are developed with individuals and support is provided in the form of psychological approaches to emotional regulation. The BIL participates in the care planning process and provides information and supports referrals for

further assessment or treatment. BILs also deliver staff training to raise awareness of brain injury and to support service delivery.

Figure 2: The Linkworker care pathway



Near the end of their sentence, an individual's interventions are adapted to prepare them for release and maintain improvement; links and referrals are also made to appropriate professionals.

This service aims to contribute towards decreasing reoffending, and work is underway to assess the outcomes for BIL service users and prison staff.

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SPORT-RELATED CONCUSSION

KEY ISSUES

- There is inadequate knowledge regarding all aspects of sport-related concussion including the underlying mechanisms, assessment, diagnosis, recovery and long-term risks
- There is poor awareness of the management of sport-related concussion in schools, colleges and universities
- There is a lack of knowledge regarding clinical management of sports-related concussion amongst health professionals
- Current National Health Service provision is insufficient to address the (currently unmet) clinical needs in this context

RECOMMENDATIONS

- The Government should ensure that there is collaborative research to evaluate and improve practical assessment tools, develop objective diagnostic markers and gain a deeper understanding of the recovery process and long-term risks of sport-related concussion
- An enhanced education campaign should be implemented in schools to improve awareness and understanding of sport-related concussion with the support of government departments (i.e. Department for Education and Department of Health and Social Care)
- Sport, government and professional clinical bodies must work collaboratively to improve health professionals' knowledge of concussion management
- The National Health Service should develop better pipelines for the diagnosis and care of sport-related concussion

Overview

Defining of concussion

Concussion is a traumatically induced, usually transient, disturbance of brain function that involves complex pathophysiological processes.

Sport-related concussion (SRC) is a complex, emotive subject with a rapidly evolving knowledge base. It can occur in both contact and non-contact sports.

Incidence figures are problematic

Obtaining good data on the incidence of SRC is problematic because different methods are used to carry out epidemiological studies and there is an over-reliance on subjective measures. Concussion is not reported reliably in hospital, and there is confusion regarding terminology and definition which have changed over the last 50 years. In the

United Kingdom (UK) English rugby union has the best data collection of all sports, with low levels of SRC reported until 2011/2012, after which figures start to increase. This increase is thought in part to reflect an increase in awareness and the developments in pitchside concussion management.

The incidence of SRC is highest in horse racing (jumps), followed by rugby union (professional), American football, horse racing (flat), boxing, rugby league, ice hockey, rugby union (amateur) and football.



Sport-related concussion has a wide range of features

The common features of SRC are outlined in Table 1.

Table 1: Common features of sport-related concussion

- Direct blow to the head, face, neck or elsewhere on the body with an impulsive force transmitted to the head
- Rapid onset of usually short-lived impairment of neurological function that resolves spontaneously
- Symptoms may be prolonged in some cases
- Signs and symptoms may evolve over minutes/hours
- Neuropathological changes occur
- Acute clinical signs and symptoms are not associated with structural brain abnormality on conventional brain scans
- Range of clinical signs and symptoms that may or may not involve loss of consciousness
- Clinical and cognitive features may follow a sequential course



Conventional Computerised Tomography and Magnetic Resonance Imaging (MRI) usually show no abnormalities in SRC, but recent research suggests that advanced MRI scans may show subtle abnormalities in some subjects¹, and scans of brain function or brain blood flow may be abnormal^{2,3}.

Knowledge regarding sport-related concussion is poor

A great deal of progress has been made in raising awareness of SRC, particularly in rugby (amongst the sports common in the UK). However, there remains a lack of awareness and understanding amongst health and education professionals of the potential seriousness of SRC and how to manage it. Awareness is also poor about the importance of 'return to learn', before 'return to play', and the need to make adjustments for the student with SRC in the classroom.

The immediate management of SRC is to establish a diagnosis, based on history, examination and approved assessment tools. If SRC is suspected then it should lead to a decision to remove the sportsperson from the action, monitor them, and then if necessary, refer them to an Accident and Emergency department; 'if in doubt, sit them out'. Many contact sports are played at a fast pace, in a disorganised environment, where the view of on-field incidents is often obscured and the symptoms of SRC are diverse. These factors add to the challenge of identifying suspected SRC. In addition, evolving and delayed-onset symptoms of SRC are well documented, and highlight the need to consider follow-up evaluation after a suspected SRC, regardless of a negative sideline screening test or normal early evaluation.

The ongoing management of SRC requires early recognition, 24-48 hours of rest, followed by gradual resumption of everyday activity, remaining below the threshold at which symptoms are provoked, and then a graduated return to cognitive and physical activity. If symptoms (see Table 2) such as excessive tiredness or headache return on increasing exertion, then the period of rest should be extended and a reduction in

Table 2: Symptoms of concussion

- Transient loss of consciousness (not obligatory)
- Amnesia
- Visual disturbance
- Sensitivity to light
- Confusion/disorientation
- Inability to process or retain information
- Excessive tiredness
- Headache
- Dizziness/nausea

the level of activity recommended. Individuals with symptoms lasting more than three weeks should be referred to specialist services for clinical assessment and, if required, formal neuropsychological input.

The Sideline Assessment Concussion Tool (SCAT5), endorsed by key sporting organisations, is a standardised tool for evaluating SRC and designed for use by physicians and licensed healthcare professionals⁴. If a more serious head injury is diagnosed then the National Institute for Health and Clinical Excellence Guidelines (2014) are relevant⁵.

The long-term prognosis for concussion is generally good, with most individuals recovering completely given time; 80% tend to resolve in 7–10 days. The post-concussion syndrome of persistent symptoms can last weeks or months but even this is self-limiting in most individuals.

There are considerable risks in returning to the field of play too early after sustaining an SRC. If an individual sustains another blow to the head before the brain has had a chance to recover from the initial concussion, the damage can be exacerbated to the point that it can be – on rare occasions – fatal. This is known as the Second Impact Syndrome and, although it is rare, it is believed to be most common among children and young people. In addition to putting themselves at risk of sustaining a more serious brain injury by returning to the field of play following a SRC, players are also more susceptible to other injuries.

Guidance is available and thorough implementation essential

Formalised protocols do exist for many sports to guide a 'return to sport' but they are often not understood or implemented adequately. There is also a lack of evidence-based guidelines or objective markers for recovery. A personalised approach is essential, based on the player, the level of performance and the rules and practicalities of the sport. The key is 'recognise, remove, recovery and return'.

All guidelines recommend that individuals with symptoms and signs of SRC should not return to play until these resolve. The Scottish Sports Concussion Guidance represents one cross-sport national approach to standardising SRC advice and

management⁶. The Sports and Recreation Alliance produced concussion guidance for professionals working in the education sector and, while it is aimed at school-aged children, it can also be applied to the over 18s in the absence of any other advice⁷. The 2017 Concussion in Sport Group consensus statement is an expert-consensus based approach to guide clinical practice, developed for physicians and healthcare providers who are involved in athlete care, whether at a recreational, elite or professional level⁸. As the science of SRC evolves, individual management and return-to-play decisions remain in the realm of clinical judgement, and the consensus document will need to be modified as new knowledge develops.

There is a legal requirement for professional sport to manage the risk of all injuries including concussion. However, if the sport is voluntary then the legal requirement does not apply.



More knowledge is required regarding long-term impact

The impact of SRC on late dementia and other chronic neurological conditions is uncertain. The impacts associated with boxing have been known for many decades to be associated with chronic neurological disease termed *Dementia Pugilistica*. However, more recently, evidence is accumulating that athletes involved in other contact sports including former footballers and rugby players, may also be at risk of what is now termed Chronic Traumatic Encephalopathy (CTE). A 2017 study of 202 deceased former American professional football players who were part of a brain donation programme, showed a high proportion with neuropathological features of CTE⁹. The severity of CTE pathology appeared to be linked to the level of exposure, with those exposed to the highest number



of brain impacts or SRC having the greatest amount of pathology. Behaviour, mood and cognitive symptoms were commonly associated with mild CTE pathology, while dementia was more commonly associated with severe CTE pathology. However, the numbers described are still relatively small (300-400 cases worldwide), the mechanisms by which CTE is related to SRC are unclear and further research is required.

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WELFARE BENEFITS SYSTEM

KEY ISSUES

- An individual with an Acquired Brain Injury may not be able to work in the short or long term, and the loss of income is likely to have an immediate impact on their quality of life, at a time when they are most vulnerable
- The welfare system is complex, has detailed application processes and can be protracted with repeated and frequent re-assessment
- Assessment of mental capacity can be a fraught process for individuals following an acute brain injury and a sound knowledge base and empathy about the consequences of Acquired Brain Injury are essential for all assessors

RECOMMENDATIONS

- All benefits assessors should be trained to understand the problems that affect individuals with an Acquired Brain Injury
- Re-assessment for welfare benefits for people with Acquired Brain Injury should only take place every five years
- A brain injury expert should be on the consultation panel when changes in the welfare system are proposed

Overview

An individual with an Acquired Brain Injury (ABI) may not be able to work in the short or long-term, and the loss of income is likely to have an immediate impact on their quality of life, at a time when they are most vulnerable. Some individuals may have workplace sickness schemes or insurance policies, but that does not apply to everyone. Even those who do have financial support from their employer or receive compensation payouts may still be entitled to welfare benefit payments from the Department of Work and Pensions (DWP). A brain injury survivor may also be entitled to benefits to assist with care and mobility.

Welfare benefits, subject to qualifying criteria, are available to support those with ABI who have long and short-term consequences. However, the welfare benefits system is complex, with detailed application processes, and can be protracted. An individual with an ABI and their family need to apply as soon as possible in order to obtain a regular income that will meet living costs in the short and long term, as well as care and mobility support. There are numerous benefits available (see Table 1).



Table 1: Wide range of benefits available to individuals with Acquired Brain Injury

Statutory Sick Pay	Available for a limited period for those still employed but unable to work
Employment and Support Allowances	Main benefit for those unable to work through illness or disability
Income Support	Available in certain cases for those with substantial caring responsibilities or have young children
Disability Living Allowance (DLA)	For children who have mobility problems or extra requirements for care
Attendance Allowance	For those of state pension age who have care needs
Personal Independence Payment (PIP)	Replaces DLA for new claimants of working age. Qualifying criteria includes the effects of the condition, rather than the condition itself, and is reviewed regularly. People of working age who currently receive DLA will be migrated to PIP; people over 65 years will continue to receive DLA/PIP as long as they qualify
Carer's Allowance	For anyone who has substantial caring responsibilities for a person with a disability
Housing and Council Tax Benefit	Both are means-tested and contribute towards the cost of rent and Council Tax
Child Tax Credit	For those with dependent children up to a certain age
Universal Credit	Being phased in to provide one payment to cover a range of welfare benefits and is expected to replace Jobseeker's Allowance, Housing Benefit, Working Tax Credit, Child Tax Credit, Employment and Support Allowance and Income Support by 2022

There may also be additional help for mortgage relief, local authority care and certain national health services. There is also support available for those who are working and on a low income in the form of Working Tax Credit.

The three key benefits are the Personal Independence Payment (PIP), Employment and Support Allowance (ESA) and Universal Credit. PIP is paid to individuals who have difficulty with everyday living and/or moving around, and ESA is paid to people who have difficulty working due to illness or disability. Universal Credit is paid to individuals who have difficulty working due to illness or disability and is partially replacing ESA.

Navigating a complex system is a difficult challenge

Individuals with ABI frequently have cognitive problems which makes the application process extremely challenging, from understanding the information required, through to communicating the answers. Often the assessors have inadequate knowledge and

understanding of ABI, and lack empathy with both the individual and their family. In 2015, Thompsons Solicitors and Headway, the brain injury charity, conducted a focus group with brain injury survivors, to learn more about their experiences of navigating the welfare benefits system (see Table 2)¹.

Table 2: Welfare system and Acquired Brain Injury: a first-hand perspective¹

- 93% of people found the benefits assessment process difficult and/or unsatisfactory
- Over 90% agreed that benefit assessors did not have good insight into the challenges, symptoms and impact of ABI. Assessors had little knowledge of the issues
- 1 in 4 thought they/their loved ones were receiving adequate levels of welfare benefit to meet their needs
- Over 90% agreed that benefit application forms were not a good measure of an ABI individual's needs and they focussed on physical illness, neglecting cognitive issues

Individuals with ABI found the welfare system difficult to understand and inadequate for their needs. The assessors had a poor knowledge of ABI and the application forms were long, difficult to complete and much too complicated¹.

In Headway's report 'Right First Time' the charity is calling for urgent changes to disability assessments to reduce the number of vulnerable people forced to go through stressful and often unnecessary appeals processes².

The frontal lobe paradox and its implications for Mental Capacity assessment

The Mental Capacity Act (MCA) is designed to protect and empower individuals who may lack the mental capacity to make their own decisions about their care and treatment. It is a law that applies to individuals aged 16 and over. There is a group of individuals with ABI that have prefrontal cortex (PFC) damage who perform well in interview and test settings, despite marked impairments in everyday life. This is known as the 'frontal lobe paradox' or the 'knowing-doing dissociation'^{3,4}. Failure to take account of this when conducting MCA assessments can result in disastrous consequences for individuals with ABI⁵ (see Table 3).

Table 3: Frontal lobe paradox in formal assessment settings

- Can perform tasks which are externally prompted by an assessor but lack ability to self-initiate those tasks
- Perform adequately in well-structured situations but have difficulty with complex behavioural organisation in non-routine situations
- Lack insight into their impairment and so fail to use compensatory strategies
- Long-term 'rule maintenance' may go undetected as the testing process is short
- Testing may fail to highlight the effort required – they may perform normally but it is exhausting
- Few demands on social cognition

Opinions on how test performance is likely to influence everyday behaviour should not be made without carefully interviewing those with direct experience of the person's real-world behaviour over a period of time⁶. The interview setting may mask an individual's care and support needs. A change to the MCA assessment process is required to ensure that information about patients' adaptive behaviour is gathered as a matter of routine.

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ACQUIRED BRAIN INJURY AND NEUROREHABILITATION

TIME FOR CHANGE

ALL-PARTY PARLIAMENTARY GROUP ON ACQUIRED BRAIN INJURY REPORT

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