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Te Kaporeihana Awhina Hunga Whara

❖ EVIDENCE-BASED BEST PRACTICE GUIDELINE

Traumatic Brain Injury: Diagnosis, Acute Management and Rehabilitation

❖ JULY 2006

STATEMENT OF INTENT

Evidence-based best practice guidelines are produced to help health practitioners and consumers make decisions about health care in specific clinical circumstances. Research has shown that if properly developed, communicated and implemented, guidelines can improve care. The advice in this guideline is based on epidemiological studies and other research evidence. Where no evidence is available, but guidance is needed, recommendations for best practice are developed through a systematic consensus process based on the experience of the Guideline Development Team.

While guidelines represent a statement of best practice based on the latest available evidence (at the time of publishing), they are not intended to replace the health practitioner's judgement in each individual case.

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E iti noa ana, na te aroha

Though my present be small, my love goes with it

Guideline highlights

Traumatic brain injury (TBI), an injury to the brain rather than an injury to the head, is identified by confusion or disorientation, loss of consciousness, post-traumatic amnesia and other neurological abnormalities. Thousands of New Zealanders each year experience TBI. This comprehensive guideline outlines important aspects of the diagnosis, acute management and rehabilitation of children, young people and adults after TBI.

Guideline highlights include:

- a clear definition of TBI, explicitly describing the necessary criteria for this diagnosis
- a clear description of severity levels for TBI
- straightforward descriptions of who should be seen in the Emergency Department and with what urgency
- clear recommendations about who should receive a computed tomography (CT) scan as part of the initial work-up, for both adults and children and young people
- recommendations about when it is safe to discharge adults, and children and young people, from an initial medical presentation
- a description of the types of rehabilitation services available for people with TBI in New Zealand
- recommendations about the organisation of rehabilitation services and approaches to TBI rehabilitation
- where there is enough evidence and/or consensus, recommendations about which interventions for people with TBI are appropriate
- sections dealing with specific issues for Māori, Pacific peoples, consumers and carers as well as a separate chapter dealing solely with issues for children and young people after TBI.

The guideline also points to other resources that come with the guideline. These resources can be found at www.nzgg.org.nz and www.acc.co.nz.

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Purpose

This guideline provides evidence-based recommendations for best practice in the diagnosis, acute management and rehabilitation of children, young people and adults after traumatic brain injury (TBI). It is intended to support informed decision-making about acute management, care and rehabilitative approaches by practitioners working with people who have a TBI, their families/whānau and carers.

This guideline is intended for use primarily by all practitioners involved in the acute management and rehabilitation of those with TBI, including Emergency Departments, primary and secondary care practitioners, rehabilitation and allied health practitioners, providers of residential care, private providers, and case managers and educationalists.

The guideline will also be a resource for the Accident Compensation Corporation (ACC) and District Health Board (DHB) funders and planners as it identifies the necessary aspects of care and services that should be provided. In addition, it identifies where there is a need for targeted research to improve the evidence base.

About the guideline

Foreword

The New Zealand Guidelines Group Incorporated (NZGG) is a not-for-profit, independent organisation established to promote effective health and disability services. NZGG oversees the development and implementation of guidelines across the health and disability sectors in New Zealand. Guidelines make an effective contribution to this aim by reviewing the latest national and international studies and synthesising their findings into practical recommendations for use in the New Zealand setting.

The *Traumatic Brain Injury Rehabilitation Guideline*,¹ published jointly in 1998 by ACC and the National Health Committee, describes essential features of a TBI rehabilitation service, but does not offer guidance on the management and rehabilitation of people with TBI. A *Clinical Guideline for the Acute Management of Traumatic Brain Injury*² was developed in 2001, which defines TBI and provides the main principles for clinical management of acute TBI. However, the previous guideline did not cover the diagnosis, classification or management of people with TBI after the acute phase. ACC is also currently developing generic guidelines for claims assessors, but these will not cover specialised assessments, such as those required for claimants with TBI. ACC commissioned the development of this new guideline for use in the management and care of people with TBI.

Scope

This guideline provides a diagnostic, acute management and rehabilitation framework for the care and management of TBI. It is intended to inform and guide: all TBI acute and rehabilitation treatment providers and specialists throughout New Zealand; funding agencies such as ACC and DHBs; and people with TBI and the people who care for them, including family/whānau and unpaid carers. The guideline will also inform ACC's purchasing strategy and the development of contracts.

This guideline addresses the acute care and post-acute rehabilitation for all levels of severity of TBI, for all ages, and in all locations of care (ie, pre-hospital, hospital and community-based assessment and management).

For the purpose of this guideline, TBI is broadly defined as brain injury resulting from externally inflicted trauma, ie, due to head injury or post-surgical damage. Therefore, the guideline does not specifically address other categories of brain injury, including those resulting from poisoning and anoxia, or stroke and other cardiovascular events. (For current guidelines on brain injury secondary to stroke see *Life after Stroke: a New Zealand guideline for management of stroke*, available at www.nzgg.org.nz.)

This guideline also excludes pre- and peri-natal brain damage resulting from prenatal and birth-related events. The management of TBI-related issues including prevention, drug and alcohol abuse, and family violence is also outside the scope of this guideline. Where other guidelines have relevance to TBI management, they are cross-referenced in the text.

This guideline is not a service framework and does not extend to a detailed analysis of the most effective service configurations to support the recommended assessment and rehabilitation strategies. The section on implementation is similarly intended as a broad conceptual guide. This edition does not specifically address the needs of all minority populations within New Zealand, although they may be considered in future reviews.

The guideline is informed by the International Classification of Functioning, Disability and Health (ICF).³ Therefore, there is a focus on the impact of the TBI on a person's functioning and participation rather than specific impairments.

Terminology

The term ‘head trauma’ or ‘head injury’ is used throughout the guideline to mean the original injury. A head injury does not always cause an injury to the brain, and the terms ‘head’ and ‘brain’ are used to distinguish between the original injury to the head and consequent injury to the brain respectively.

Terms routinely used to describe the severity of the injury, such as the term **mild brain injury**, may be unacceptable to people who have suffered a brain injury that falls within this category, as the impact on their health and functioning that they experience as a result of the injury may be far from ‘mild’. There are also anecdotal accounts that use of this term impacts on the interactions with case managers and health care professionals so that the injured person feels that the professionals are dismissive and do not accept the full extent of their problems. Although classification of the initial severity of TBI is useful in the prediction of some short- and long-term outcomes, the relationship between initial severity of injury and medium- and long-term outcomes has been questioned.⁴

Following recent international practice, the Guideline Development Team has used the terms mild, moderate or severe TBI to describe the initial severity of injury in a few sections of this guideline, particularly in Chapter 1 where the size and impact of the problem of TBI are discussed.

In most other sections of the guideline, the Guideline Development Team has followed the convention of other recent international evidence-based guidelines, and used, where possible, **clinically significant TBI** or **symptomatic TBI** to refer to TBI with a need for intervention or other care or support, irrespective of the initial severity of injury. Additional specific terminology used in this guideline is defined in the Glossary.

Background to the guideline

Current Practice Review

A number of aspects of the rehabilitation and support services delivered to TBI clients in New Zealand are uncertain. There are variations in content and quality for different services operating under the same contract across different regions of New Zealand (eg, urban compared with rural centres). There are also differences in terms of the volume of clients and in client mix (eg, solely TBI compared with TBI and other rehabilitation clients, clients from ethnic minority populations and clients with comorbid conditions, such as mental health disorder or drug abuse). There has been no systematic New Zealand study following large cohorts of people with TBI from onset, documenting the nature and extent of services provided such as would occur with a TBI register. Small-scale studies have been conducted in Auckland, Hamilton and Wellington at various times in the past 10 years. As part of this guideline project, ACC commissioned a review of current practice in TBI rehabilitation from the perspective of TBI providers and consumers. This Current Practice Review was undertaken and completed during 2004, and included a survey of both TBI providers and TBI consumers (people with TBI and carers) throughout New Zealand.⁵ The full report is available at www.nzgg.org.nz.

The evidence base

Many aspects of both adult and paediatric rehabilitation following a clinically significant TBI lack a robust evidence base. For example, in the case of paediatric studies, many group a wide range of ages, where the participants may be at differing developmental stages. The lack of a robust evidence base is also partly due to the heterogeneous nature of the brain injuries and of the people who have suffered the injury. To perform robust randomly controlled trials of interventions would require very large numbers of people to eliminate the confounding effects of individual differences. Therefore, much of the evidential support for the recommendations in this guideline is necessarily drawn from less robust research study designs, or from closely related areas such as the stroke literature. Specific ‘gaps’ in the evidence have been identified (see Appendix A) and it is suggested that research funding bodies consider supporting more research in these areas. It is also suggested that implementation of the guideline recommendations be evaluated to provide stronger evidence for future revisions.

The Wellington School of Medicine and Health Science's Rehabilitation Medicine Department was commissioned by NZGG to conduct an evidence-based comparative review⁶ of psychometric testing and other tools commonly used in the initial assessment of TBI, and in the assessment of outcomes of rehabilitation. This review, *TBI Tools Review for the Development of Guidelines on the Assessment, Management and Rehabilitation of Traumatic Brain Injury*, 2005, is available as a separate document at www.nzgg.org.nz and provides the evidence base for the recommendations for diagnostic and outcomes assessment.

Guideline development process

The TBI Rehabilitation Guideline Development Team first met in March 2004 to undergo training in the guideline development process, and to determine the main topics and questions to be covered by the guideline.

Results of a preliminary literature search (conducted to inform the scope of the guideline) made it apparent that a risk to the effectiveness of any guideline for rehabilitation from TBI would be the impact of treatment recommendations in the acute stage of management. This preliminary literature search also identified a rigorous, evidence-based guideline for care of the acute stage of TBI: *Head Injury: Triage, Assessment, Investigation and Early Management of Head Injury in Infants, Children and Adults*, produced by the United Kingdom's (UK) National Institute of Clinical Excellence (NICE) in 2003.⁷ ACC agreed that this guideline should be adapted for the New Zealand environment to produce a guideline that would cover the entire process of care and rehabilitation from the point of injury. A sub-group with a focus on the adaptation of the NICE guideline was formed from the main Guideline Development Team, with the addition of clinicians with expertise in emergency medicine and the acute phase of care.

Agreed principles underlying the development of the guideline were:

- a consumer focus – evidence and recommendations should be considered in terms of outcomes that matter to people with TBI, their families/whānau and paid and informal carers
- consistency with the World Health Organization's ICF³
- recommendations for diagnostic assessment and rehabilitative interventions should support national consistency in practice
- aspects of service structure and linkages between sectors and services necessary to support the guideline recommendations should be identified.

The specific topics to be covered by the guideline, in addition to those in the NICE acute care guideline, were agreed as follows:

- the epidemiology of TBI in New Zealand
- appropriate assessments (including neuropsychological testing) to confirm diagnosis, classify severity and identify people at high risk of long-term sequelae (including work loss), and to identify important early complications
- effective identification of TBI in a variety of non-clinical settings, such as schools and prisons
- appropriate strategies that minimise subsequent disability and work loss and maximise quality of life, including effective rehabilitative therapies and interventions appropriate to New Zealand clinical settings
- the effectiveness of complementary and alternative medications and therapies, such as osteopathy and acupuncture, in the rehabilitation of people with TBI
- appropriate management strategies for post-acute complications of TBI (including physical, cognitive, behavioural impairments, spasticity, and intervention strategies) that are associated with improved outcomes if recovery is slower than expected
- appropriate follow-up strategies for people with TBI or specific sub-groups of people with TBI
- the most appropriate TBI outcome measurements for New Zealand clinical settings, including assessment of when people can return to sporting, educational, work and leisure activities

- the effectiveness, in terms of improving outcomes for consumers, of:
 - information provided to families, carers, people with TBI, the wider population and/or ACC staff
 - support provided to families and carers of people with TBI
 - application of supported employment for people with TBI
 - care coordination in enhancing the general functional status of people with TBI
- identification of gaps in TBI services and processes to address these gaps, including the need for liaison with mental health services, such as drug and alcohol services
- necessary elements of effective service delivery configuration for the assessment and management of people with TBI.

It was agreed that for each topic, consideration would be given to whether the evidence and recommendations would apply equally well to both adults and children, and to Māori and Pacific peoples, and to provide differing recommendations for these populations, where appropriate.

These topics were operationalised as searchable questions by the NZGG research team, and a systematic hierarchical search for evidence was conducted. The search strategy for the guideline is available online at www.nzgg.org.nz – select ‘Publications’ then ‘Guidelines’ then ‘Neurology/Rehabilitation’ then the guideline title, then ‘Search Strategy’.

Research identified through the search was assessed for relevance by the NZGG research team, and papers identified as potentially relevant were retained to be included in the critical appraisal process.

A number of recent and rigorously produced ‘seed’ guidelines and syntheses of relevant evidence to inform the development of this guideline for New Zealand were identified. The Guideline Development Team acknowledges the help and support received from the authors and editors of these works, which include:

1. *Head Injury: Triage, Assessment, Investigation and Early Management of Head Injury in Infants, Children and Adults*, 2003. Produced by NICE and the National Collaborating Centre for Acute Care.⁷
2. *Rehabilitation following Acquired Brain Injury: National Clinical Guidelines*, 2003. Ed: Turner-Stokes L. Produced by the Royal College of Physicians and British Society of Rehabilitation Medicine.⁸
3. *Management and Prognosis of Severe Traumatic Brain Injury*, 2000. Produced by Bullock MR, Chesnut RM, Clifton GL, et al., for the Brain Trauma Foundation and American Association of Neurological Surgeons.⁹
4. *Evidence Report on Rehabilitation of Persons with Traumatic Brain Injury*, 1998. Produced by Chesnut RM, Carney N, Maynard H, et al., of the Oregon Health Sciences University Agency for Health Care Policy and Research.¹⁰
5. *Rehabilitation for Traumatic Brain Injury in Children And Adolescents*. Evidence report no. 2, supplement, 1999. Produced by Carney N, du Coudray H, Davis-O'Reilly C, et al., of Oregon Health Sciences University Agency for Health Care Policy and Research.¹¹
6. *Joint Framework and Guidelines on Vocational Assessment and Rehabilitation after Acquired Brain Injury*, 2004. Produced by the Inter-Agency Advisory Group on Vocational Rehabilitation after Brain Injury and in association with the British Society of Rehabilitation Medicine Working Party on Rehabilitation following Acquired Brain Injury, British Society of Rehabilitation Medicine.¹²
7. *Concise Guidance for the Use of Anti-depressant medication in Adults Undergoing Recovery or Rehabilitation Following Acquired Brain Injury*, 2005. Ed: Turner-Stokes L. Produced by the British Society of Rehabilitation Medicine and the British Geriatrics Society with the Royal College of Physicians' Clinical Effectiveness and Evaluation Unit.¹³

Guideline Development Team

The following organisations were approached to nominate or endorse members of the multidisciplinary team who developed this guideline:

The Australasian Faculty of Rehabilitation Medicine, The Royal Australasian College of Physicians (RACP)

The Australasian College for Emergency Medicine (ACEM)

The Paediatric Society of New Zealand

The Pasifika Medical Association

The Royal Australia and New Zealand College of Psychiatrists (RANZCP)

The New Zealand College of Clinical Psychologists (NZCCP)

The Royal New Zealand College of General Practitioners (RNZCGP)

The College of Nurses Aotearoa (NZ) Inc

The New Zealand Society of Physiotherapists Inc (NZSP)

The New Zealand Speech-Language Therapy Association (NZSTA)

The New Zealand Association of Occupational Therapists (NZAOT)

Group Special Education in the Ministry of Education

The Head Injury Society of New Zealand (HISNZ)

The Brain Injury Association of New Zealand (BIANZ)

Carers NZ

Ranworth Healthcare

Health Partners Limited

The Disability Resource Centre (DRC), Auckland

The Accident Compensation Corporation (ACC)

The Royal Australasian College of Surgeons

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Declarations of competing interests

Michael Ardagh is a member of the Christchurch Brain Research Group, which received funding for post-head injury assessment. He is also a member of the Emergency Care Research Foundation, a charitable trust which supports emergency care research

Harry McNaughton has received funding for research and fees for consulting from ACC

Kate Hall received funding to attend the Epilepsy Symposium 2002 from Janssen-Cilag

Elizabeth Rowland is a director of a private limited company providing occupational therapy services

Consultation

A draft of this guideline was widely circulated to more than 250 individuals/organisations for comment in June 2005 as part of the peer review process. Comments were received from the following organisations or individuals:

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- Anne Smith, Wilson Centre
- Blair Donkin, Otago DHB
- Bridget Kool, University of Auckland
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Evidence and recommendation grading system

All studies relating to benefits or harms of interventions are graded for quality. Each study has been assigned an overall level of evidence (+, ~ or x). When applicable, the level is listed alongside the citation in the reference list. See Appendix B for details of the grading system. Study details and levels of evidence were summarised in evidence tables, which were used for the formulation of recommendations. Studies with an 'x' level of evidence had questionable validity and were not considered relevant to the formulation of recommendations. Descriptive research, included for information, was not graded for quality.

Chapter 1:

Traumatic brain injury in New Zealand

Overview

- A consumer survey suggests that people with TBI experience significant health disadvantage, in terms of both physical and mental health, compared with their peers. TBI, an injury to the brain rather than an injury to the head, is identified by confusion or disorientation, loss of consciousness, post-traumatic amnesia and other neurological abnormalities.
- The Glasgow Coma Scale score and ‘duration of post-traumatic amnesia’ can be used to classify the severity of TBI.
- Accurate data on the incidence and prevalence of TBI and TBI sequelae is needed to aid the planning and evaluation of service delivery.
- A number of pre-injury, injury-related and post-injury factors have been shown to be associated with better or poorer outcomes.
- Some people with mild TBI will have effects lasting greater than 12 months, while in those with moderate and severe TBI there may be a residual impact on functioning throughout the lifespan.
- Carers of individuals with TBI have a poorer quality of life and increased psychological morbidity compared with the general population.
- Considerable variation currently exists in New Zealand TBI rehabilitation service provision.
- Rehabilitation services are provided by both DHBs and private providers.
- ACC funds a range of residential and non-residential rehabilitation services.

1.1 Defining traumatic brain injury

For the purposes of this guideline, the Guideline Development Team adopted a broad definition of TBI as an injury to the brain resulting from externally inflicted trauma.

The main difficulty with defining TBI is differentiating between those people who have had a head injury (a definite episode of external force to the head, including a deceleration force without actual impact to the head), and those who also have TBI. Most international definitions of TBI require some neurological symptoms or signs such as loss of consciousness, a period of amnesia and/or focal neurological deficit.¹⁴

There is no ‘gold standard’ for the diagnosis of TBI, as some forms of radiological imaging are neither sensitive nor specific for TBI. There are also instances where individuals who do not meet low-threshold criteria for the diagnosis of TBI (those with no loss of consciousness, with a normal Glasgow Coma Scale score [see Section 2.2.1 *Glasgow Coma Scale* for more details] and no amnesia) have evidence of injury to the brain, such as a contusion, on magnetic resonance imaging (MRI) scan.

The World Health Organization (WHO) Collaborating Centre Task Force on Mild Traumatic Brain Injury performed a systematic review of explicit case definitions to produce a working definition for TBI and then applied a specific definition for mild TBI.¹⁵ In the absence of a ‘gold standard’ diagnostic test, its definition of TBI is currently the best available, and it has been adapted by the Guideline Development Team to delineate the lower threshold of ‘definite TBI’.

The definition used in this guideline is:

TBI is an acute brain injury resulting from mechanical energy to the head from external physical forces.

Operational criteria for clinical identification include **one** or **more** of the following:

- confusion or disorientation
- loss of consciousness
- post-traumatic amnesia
- other neurological abnormalities, such as focal neurological signs, seizure and/or intracranial lesion.

These manifestations of TBI must not be due to drugs, alcohol or medications, caused by other injuries or treatment for other injuries (eg, systemic injuries, facial injuries or intubation), or caused by other problems (eg, psychological trauma, language barrier or co-existing medical conditions).

TBI can occur in the context of penetrating craniocerebral injuries but in this situation, focal neurological deficits are generally more important than any diffuse element.

1.1.1 Classification of severity

Studies of TBI incidence and prevalence tend to classify the initial severity of injury as ‘mild’, ‘moderate’ and ‘severe’. There are a number of criteria for assessing severity, including:

- the Glasgow Coma Scale score
- loss of consciousness or coma
- post-traumatic or retrograde amnesia.

The most commonly used criterion for classifying severity has been the Glasgow Coma Scale score. This is usually used for assessment when a person with suspected TBI presents to an Emergency Department or general practitioner.¹⁵

The scores are categorised as follows: ‘mild TBI’ 13 to 15 (of a maximum 15); ‘moderate TBI’ 9 to 12; and ‘severe TBI’ 3 to 8 (with 3 being the minimum score).¹⁵ There is some evidence that people with an initial Glasgow Coma Scale score of 13 have worse outcomes than those with a Glasgow Coma Scale score of 14 to 15,¹⁶ with those authors advocating a subset of ‘mild TBI’ called ‘high-risk mild TBI’ for people with an initial Glasgow Coma Scale score of 13 to 14 and/or radiological abnormalities. Nevertheless, current international consensus, including the recent WHO Task Force on Mild Traumatic Brain Injury,¹⁵ supports the severity classification using the Glasgow Coma Scale as described here (ie, initial Glasgow Coma Scale of 13–15 = mild TBI).

See Chapter 2, *Pre-hospital assessment, management and referral to hospital* and Appendix C for more details about the adult and paediatric versions of the Glasgow Coma Scale.

Another useful indicator of the severity of a TBI is post-traumatic amnesia, as it is strongly related to outcomes.^{17–23} Post-traumatic amnesia is calculated from the time of the accident and includes any period of loss of consciousness or coma.

Assessment of post-traumatic amnesia can be inaccurate if trying to determine it retrospectively through clinical interview, and should commence before the resolution of post-traumatic amnesia, where possible.²⁴ There is little difference between particular assessment measures of post-traumatic amnesia, although the Tools Review⁶ concluded there were some qualitative advantages to the Modified Oxford Post-traumatic Amnesia Scale (MOPTAS),²⁵ which is similar to the widely-used Westmead Post Traumatic Amnesia Scale.²⁶

In this guideline, unless otherwise stated, the definitions of severity of TBI used are those given in Table 1.1.

TABLE 1.1:
CRITERIA FOR CLASSIFYING THE SEVERITY OF TRAUMATIC BRAIN INJURY*

SEVERITY OF INJURY	GLASGOW COMA SCALE SCORE [†]	DURATION OF POST-TRAUMATIC AMNESIA [‡]
Mild	13–15	<24 hours
Moderate	9–12	1–6 days
Severe	3–8	7 days or more

* If there is a discordance between the severity level for the Glasgow Coma Scale score and post-traumatic amnesia, it is appropriate to use the more severe category, eg, Glasgow Coma Scale of 14, but mild TBI, post-traumatic amnesia two days = moderate TBI.

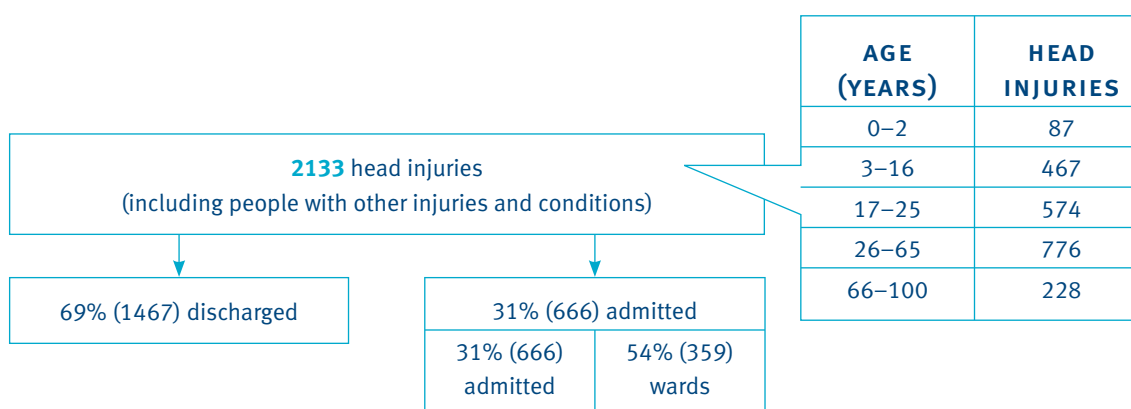
† Teasdale, et al. *Acta Neurochir* (Wien) 1979; 28:13–16.

‡ Carroll LJ, et al. *J Rehabil Med* 2004(43 Suppl):113–25.

1.2 Estimates of the incidence of traumatic brain injury in New Zealand

The problem of inconsistent and inaccurate diagnosis of TBI has been demonstrated in coding of hospital discharges for TBI in New Zealand, with errors in both directions (ie, definite TBI not coded as such and coded TBI not meeting the criteria for definite TBI). Many people with possible TBI, generally at the ‘mild’ end of the spectrum, **do not** seek medical attention. This also means they are unlikely to make a claim to ACC, and therefore will not be identified by ACC statistics. It is not currently possible to identify how many people, who visit an Emergency Department or general practitioner with an injury that is coded as a head injury, actually have TBI. Even so, in 2004, Christchurch Hospital Emergency Department recorded a total of 66,238 presentations,²⁷ including 2133 (3.2%) people with head injuries of all levels of severity, who were assessed and admitted as outlined in Figure 1.1.

FIGURE 1.1:
PRESENTATIONS AND ADMISSIONS FOR HEAD INJURY AT CHRISTCHURCH HOSPITAL EMERGENCY DEPARTMENT, 2004



Reproduced from: MacFarlane, MC. Director, Department of Neurosurgery Christchurch Hospital, New Zealand.²⁷

In the absence of prospectively acquired New Zealand hospital and community data with consistent criteria for the definition of TBI, the Guideline Development Team has been unable to determine the exact extent of TBI in New Zealand. These caveats need to be considered alongside the data in this section.

New Zealand data on hospital presentations for mild TBI found a rate of 437 per 100,000 per year for people aged 15 years and older, and 252 per 100,000 per year for those aged less than 15.²⁸ It was estimated that for every 100 people seen at hospital, 60 were seen and managed by their general practitioner alone. Based on a current New Zealand population of four million, this would give a population estimate of ‘medically attended TBI’ of around 700 per 100,000 per year for those 15 years and older. Data from the United States of America (USA)²⁹ provides a figure for ‘medically attended TBI’ of around 465 per 100,000 per year, which extrapolated to the New Zealand population would suggest a total of 19,000 medical attendances per year.

A systematic review of the literature by the WHO Collaborating Centre Task Force on Mild Traumatic Brain Injury³⁰ concluded that a ‘true’ population-based rate of mild TBI would be more than 600 cases per 100,000 per year. Assuming this is true for New Zealand, this would give an estimate of more than 24,000 cases of mild TBI in New Zealand each year and approximately 60 per 100,000 per year of moderate to severe TBI (an estimated 2400 cases per year in New Zealand). Therefore, the total TBI incidence (including all levels of severity) in New Zealand, projected from the WHO Task Force data, would be approximately 660 per 100,000 per year (ie, 26,400 cases per year).

In reviewing ACC data on TBI incidence, it is important to recognise that ACC uses operational definitions to classify severity. These definitions differ from the classification of severity used in this guideline. An ACC classification of ‘moderate to severe’ TBI thus refers to the need for extensive care, support and lifetime planning. Other categories are aggregated under the heading ‘concussion’. In 2003, ACC recorded 17,514 new cases of ‘concussion’ (about 437 cases per 100,000 per year) and 123 moderate to severe TBI cases in 2002.

Assuming these figures are correct and the proportion of all TBI that is ‘moderate and severe’ is around 10%, there should be 2000 to 3000 cases of moderate and severe TBI per year. It seems probable that the majority of people with moderate and severe TBI are assessed at hospital, and the figure of 8.1% moderate to severe^{4,30} seems conservatively realistic.

Based on the national and international data available, the Guideline Development Team calculates that an estimate of hospital attendance with TBI in New Zealand for all ages would be in the range of 10,000 to 17,000 cases per year, with 8% to 10% of those in the moderate to severe category.^{4,30} A significant proportion (perhaps as high as 25%) of these people may have ‘suspected TBI’, not meeting the criteria for ‘definite TBI’. Our best estimate of all ‘medically attended TBI’ in New Zealand would be 16,000 to 22,500 per year with an even stronger caveat applied regarding the proportion of ‘definite TBI’ in this group. The best estimate of all TBI will, necessarily, have a large range. A total TBI incidence figure for New Zealand, including those people with TBI who do not seek medical attention, is likely to be in the range of 20,000 to 30,000 cases per year.

In order to plan and evaluate service delivery for people with TBI, and test interventions in a TBI population, accurate information about the incidence and prevalence of TBI in New Zealand, together with information about the consequences directly attributable to TBI for those people, is required. Currently that information is not available to a sufficient level of accuracy.

1.3 Hospital-based rehabilitation

In 1999, people with TBI made up 4% of admissions to comprehensive rehabilitation facilities in the USA.³¹ The mean age of individuals was 46 years and the mean length of stay in rehabilitation 23 days. Of this group, 80% were discharged to community settings, including supported and transitional living situations, while 9% were discharged to long-term care facilities. Accurate data to allow comparison with New Zealand is not available.

1.4 Cost

In 2004, ACC figures indicated that it paid over \$100 million a year for post-acute treatment and rehabilitation of claimants with concussion and TBI.³² This excludes costs incurred during the acute phase of care. ACC also supports the operation of Emergency Departments through funds to DHBs. However, it is not possible to identify the proportion of this funding that is used for treating people with TBI. In 2003, 17,514 new cases of concussion led to claim payments of \$12,532,834 for that year alone while in 2002, the 132 new cases labelled moderate to severe TBI led to claim payments of \$3,603,579 for that year. In 2003, there were 1477 ongoing cases of TBI (ie, people with claims originating more than a year previously), which led to claim payments of a further \$93,728,240.

1.5 Demographic characteristics of the traumatic brain injury population

According to 2003 ACC figures, 61.9% of people with concussion were male, in broad agreement with international data suggesting a roughly 2:1 ratio for males:females with TBI.³² The incidence of TBI peaks in the 15 to 30 years age group and again in those aged 60 years or older. ACC figures³² show the highest rate of concussion and TBI occurred in those aged 15 to 19 years of age. In total, 14% of people with concussion identified as New Zealand Māori and 5% as Pacific peoples; slightly less than the proportions of Māori and Pacific peoples in the New Zealand population as a whole (Māori 15%, Pacific peoples 6.5%).

1.6 Causes of traumatic brain injury in New Zealand

ACC data suggests that for people with more severe TBI, approximately 50% were involved in a car crash.³³ This is in keeping with international data.^{29,30}

In those aged under five years at the time of injury, the causes of the injuries (ACC Injury Statistics, 2004)³² were as follows:

- 17% motor vehicle related
- 17.2% 'other loss of balance/personal control'
- 16.1% resulting from being struck by a person, animal or object
- 43% of cases could not be classified according to the criteria used or the cause was unclear.³³

1.7 Prognostic factors

Prognostic factors are those features of the traumatic injury, and of the injured person's life and functioning, which are related to better or poorer outcomes in terms of recovery and rehabilitation from TBI. Although there has been no rigorous analysis of these factors demonstrating their relative importance, consistent evidence has been identified for a number of prognostic factors for adults and children.

1.7.1 Prognostic factors: adults and children and young people

Pre-injury factors

- Pre-injury psychological morbidity is related to poorer outcomes.³⁴
- Age: the likelihood of adverse outcomes increases in those over 35 years, and the risk in those aged 65 years or older is 10 times the risk for those aged 15 to 25 years. The very young and oldest groups have the poorest outcomes; outcomes for children are worst for those aged under seven years.^{11,35-37}
- Sex: on balance, males with TBI have lower morbidity and better outcomes.³⁸⁻⁴⁰

Injury-related factors

- TBI resulting from physical abuse in both adults and children and young people is related to poorer outcomes.⁴¹⁻⁴³

- Both adults and children and young people tend to have poorer outcomes from severe TBI (as measured by the Glasgow Coma Scale).^{11,44,45}
- Direct brain tissue damage in both adults and children and young people is related to poorer outcomes.⁴⁶
- Somatosensory-evoked potentials* (SEPs)/cognitive event-related potentials* (ERPs): in severe TBI, SEPs may be useful in predicting severe negative outcomes, and ERPs are able to predict a wider range of negative outcomes. Both SEPs and ERPs may predict positive outcomes.^{47,48}

Post-injury factors

- Multiple TBIs: there is some evidence that multiple or repeated mild TBI, over an extended period of months or years, may in some cases result in cumulative neurological and cognitive deficits. Very rarely, where the repeated mild TBIs occur within a period of hours, days or weeks, the outcomes can be severe or fatal.^{49,50}
- Social deprivation and lower socioeconomic status are related to poorer outcomes.^{51–53}
- Good or poor family functioning is related to better or poorer outcomes respectively.^{11,54}

1.7.2 Prognostic factors: adults

There are a number of additional factors associated with poorer or better outcomes in adults following TBI. These include pre-injury and post-injury factors, factors related to the injury, and personality and environmental factors.

Pre-injury factors related to poorer outcomes

- A history of alcohol and/or drug abuse.^{34,44,55}
- A history of childhood sexual abuse.⁵⁶
- Genetic vulnerability: people with the apolipoprotein E (ApoE) ϵ_4 allele are more likely to have a poorer outcome than those without the allele (OR 13.93; 95% CI: 1.45–133.97; $p=0.02$).^{57,58}

Injury-related factors

- Mechanism and type of injury influences outcome:⁵⁹ people who have an injury where an object strikes their head have a poorer outcome compared with people whose heads strike an object; the type of injury (ie, motor vehicle collision, fall, assault, motor vehicle-pedestrian collision, falling object, sports/recreation) also has some effect on outcome – people whose injury results from being hit by a falling object, assault or a motor vehicle accident generally have poorer outcomes than people whose injury was due to other causes.
- Better cognitive status as assessed by cognitive testing during the acute stage (inpatient stay) is related to better outcomes.⁶⁰
- In mild TBI, headache, dizziness and/or nausea acutely following injury (ie, in the Emergency Department) is strongly associated with the severity of post-traumatic sequelae six months post-injury.⁶¹
- Serum markers: the specific serum markers S-100B and neurone-specific enolase (NSE) are thought to be markers of cell damage in the human central nervous system, and after damage to brain tissue, increased concentrations of NSE and S-100B can be measured in peripheral blood serum. In mild TBI, one small study found an increase in severity of forgetfulness, dizziness or headache after six months in people with increased early serum NSE or S-100B concentrations. All people with mild TBI without increased serum markers or symptoms in the Emergency Department were symptom free after six months.⁶¹ In TBI of all severities, a serum S-100B concentration of >0.32 mcg/L as measured acutely post-injury (ie, in the Emergency Department) has been shown to predict severe disability as measured by the Glasgow Outcome Scale (GOS <5) at one month post-injury, with a sensitivity of 93% (95% CI: 68–100%), a specificity of 72% (54–79%), and a negative predictive value of 99% (93–100%).⁶² Although these results are interesting, the use of serum markers as a predictive tool is still part of ongoing research rather than of clinical utility.

Post-injury factors

- Development of post-TBI mental illness, such as depression or anxiety, may be related to poorer outcomes.⁶³
- Better social support is related to better outcomes.³⁴

* See Glossary

1.7.3 Prognostic factors: children and young people

For children alone:

- pre-injury behavioural problems are related to poorer outcomes⁵³
- identification of lactate acutely by proton magnetic resonance spectroscopy has a strong relationship with poor, long-term cognitive outcomes.⁶⁴ This is currently a research-only tool.

1.7.4 Factors not related to prognosis

There are a number of factors frequently assumed to be related to better or poorer long-term outcomes from TBI for which the evidence shows no relationship. These include the following:

- premorbid characteristics are not related to personality changes post-TBI⁶⁵
- computed tomography (CT) scan results – in people with a mild TBI, there is no difference in neurophysical status and vocational outcome between those who had positive finding on CT and those who had negative findings⁵⁹
- brief loss of consciousness does not appear to be related to long-term outcomes in people with mild TBI.⁵⁹

1.8 Consequences of traumatic brain injury

1.8.1 Mortality from traumatic brain injury

Data for mortality from TBI in New Zealand is not available. NICE⁷ reports that in the UK, only 0.02% of people attending an Emergency Department with a TBI will die from the injury – about 6 to 10 per 100,000 population per annum. In Sweden, the mortality rate from TBI was found to be 0.7% annually (3.8 per 100,000 per year),⁶⁶ while in the USA the mortality has been reported as 19.3 per 100,000 per annum, although this figure also includes deaths from firearms.

1.8.2 Consequences of traumatic brain injury: adults

1.8.2.1 Mild traumatic brain injury

A recent systematic review of the international literature⁶⁷ found that in adults, cognitive deficits and other symptoms are common in the acute stage for those who have had a mild TBI. Most people have recovered fully by somewhere between three and 12 months following the injury. However, in both children and adults a minority will have longer-lasting effects of the TBI. There is also some evidence that adults who sustained a TBI in childhood or adolescence may have psychological impairments in adulthood. For example, one study looking at the effects of TBI in college students found that those who had a 'mild' TBI in childhood or adolescence reported more distress in terms of their emotional and personal functioning than a control group.⁶⁸

1.8.2.2 Moderate and severe traumatic brain injury

A USA National Institute of Health Expert Consensus panel evaluated a comprehensive report of the evidence on TBI. The panel concluded that a person who has had a TBI may have a complex set of neurological and psychological impairments, together with medical problems and physical disabilities that affect not only the person who has suffered the TBI, but also their family/whānau, carers and the wider community. They reported that the consequences of severe TBI often persist in varying forms for the rest of the person's life, and that new problems resulting from the injury may emerge as a result both of the aging process and of new demands on the person.⁶⁹

An evidence report on rehabilitation of people with TBI stated that:

...studies [have] demonstrated that survivors of severe TBI often lose friendships and social support, have limited opportunities to develop new social contacts and friends, have few leisure activities, and have high levels of anxiety and depression for prolonged periods of time. (p. 28)¹⁰

The sequelae of severe TBI vary in individual people and according to the nature and location of the brain injury. The deficits fit broadly into four main categories:

1. physical, including motor and sensory impairment
2. cognitive, including impairment of memory attention, and judgement
3. behavioural, including emotional and mood problems, and inappropriate behaviour
4. communicative, including language expression and comprehension.

These deficits limit the functioning of the person with clinically significant TBI to differing degrees, depending on the severity and combination of the brain injury with consequent deficits, presence of other injuries, and other circumstances such as the person's intellectual background, environment, and family and social support. People who have had a clinically significant TBI may have impairment in their ability to live independently, return to work, education and leisure activities, and maintain relationships. These impairments may impact not only on the injured person, but also on their family/whānau and carers.⁸

Neurological recovery after a clinically significant TBI may take months or years, and people may be left with permanent deficits. Most people with 'mild' brain injuries recover completely over the subsequent few months.⁶⁷ However, some may have symptoms which persist for longer than this, reporting headache, dizziness, concentration and memory problems, mood changes and irritability.

People who have suffered a clinically significant TBI are an extremely heterogeneous group. Thus, rehabilitative care needs to be tailored to the individual, with consideration of individual deficits and rates of progress. Specific recommendations on rehabilitation are contained within Chapter 5, *Rehabilitation following clinically significant traumatic brain injury – assessment* and Chapter 6, *Rehabilitation following clinically significant traumatic brain injury – intervention*.

1.8.3 Consequences of traumatic brain injury: children and young people

1.8.3.1 Mild traumatic brain injury

The WHO Task Force systematic review on mild TBI found that children and young people who have a single mild TBI have a good prognosis; there is little evidence of residual deficits, although there will be a minority who will have longer-lasting effects of the TBI.⁶⁷

1.8.3.2 Moderate and severe traumatic brain injury

Children and adolescents who have a moderate or severe TBI are more likely to survive the injury than adults.¹¹ Many survivors of severe TBI will have a life-long need for support in various ways, so the burden of care and support for the child survivor with TBI is greater as they have more remaining life years. Between 50% and 90% of children and young people who have had a severe TBI will require help in bathing, dressing and walking, proportional to the number of functional deficits they have, for varying periods of time after the injury.¹¹ Of children and young people exhibiting four or more functional deficits, 75% will have impairments in self-feeding, cognition and behaviour; 67% will have speech impairments; 29% impaired vision; and 16% impaired hearing.¹¹ International evidence about the provision of services for children and young people suggests that TBI is underreported and misidentified; and that many interventions developed for other pathologies may be being inappropriately applied.¹¹

A recent UK study of 526 children aged between 5 and 15 years with varying severity of TBI used the King's Outcome Scale for Childhood Head Injury (KOSCHI) to assess outcomes at approximately two years post-injury. Frequent behavioural, emotional, memory and attention problems occurred in one-third of those who had sustained a severe TBI, one quarter of those who had had a moderate TBI, and in 10% to 18% of those who had had a mild TBI. Personality change after TBI was reported for 148 children (28% of the total, of whom 21% had a mild TBI, 46% a moderate TBI, and 69% a severe TBI). Significant associations were noted between injury severity and KOSCHI outcomes, and between social deprivation and poorer outcomes.⁵¹

There is some international evidence that children and young people may not have adequate post-TBI follow-up and treatment. A population study found that at around two years post-injury, 43% of those with mild TBI, 64% of those with moderate TBI and 69% of those with severe TBI had moderate disability (n=252), while 57% of those with mild TBI, 36% of those with moderate TBI and 22% of those with severe TBI made a good recovery (n=270).⁵¹ A total of 30% of children received follow-up, but whereas all of the children who had a severe disability (30%) received appropriate follow-up, 64% of children with moderate disability received no follow-up.⁵¹ Although this study did not analyse the influence of pre-injury factors in measurement of outcomes, it is illustrative of the need for follow-up of children with less severe, as well as more severe TBI.

1.8.4 Consequences of traumatic brain injury for families and carers

Carers of adults or children and young people with TBI are at risk of adverse consequences themselves, and have significantly poorer quality of life and more psychiatric morbidity than the general population.⁷⁰ For example, one study of adult carers of people with severe TBI found that at six months post-injury, about one-third of carers reported clinically significant symptoms of anxiety and depression, and poor social adjustment. By one year post-injury, the same proportion reported significant anxiety and depression, and about a quarter continued to suffer poor social adjustment.⁷¹

Another study of carers in New Zealand found that in addition to distress, many carers reported health problems and a change in roles. Partners who were carers were more likely to report health problems, distress and changes in role than were parents who were carers.⁷² Similarly, a study in South Africa of the effects of caring for a partner with a TBI found that the injured person's altered communication patterns affected interpersonal relationships and quality of life extensively and the carers had decreased income due to the low incidence of return to work.⁷³ Carers also reported changes in family relationships, particularly between the injured person and their children, as well as a deterioration in marital relationships. Most carers reported feeling 'tied down' due to the dependence of the injured person, and loneliness predominated as a social consequence despite the support of pre-injury friendships.

Families who have a child with clinically significant TBI frequently experience work loss and financial difficulties as a consequence of the care needs of the child.¹¹ There is substantial evidence for a negative impact on family functioning when a child in the family has had a TBI, with deteriorating functioning associated with the severity of the child's injury. Families with severely injured children have been shown to be more likely to actively seek help than families of children with less severe TBI, although the latter families are also likely to have need of help.¹¹

1.9 Current practice in New Zealand

1.9.1 Acute phase services

Acute phase care for people with suspected TBI in New Zealand is currently provided by general practitioners, Emergency Departments, accident and medical services, ambulances, sports coaches, teachers at schools and others. Most people with suspected serious brain injury are assessed at the nearest hospital and/or transported (usually by helicopter) to the nearest large hospital providing facilities for assessment and treatment of the immediate consequences of the head injury.

A small number of very severely injured people are transported to tertiary care centres with neurosurgical services (Auckland, Hamilton, Wellington, Christchurch and Dunedin).

Many people with TBI who are assessed in an Emergency Department are not admitted or, if they are admitted, stay only a very short time in hospital (see Section 1.2, *Estimates of the incidence of traumatic brain injury in New Zealand*. Christchurch Hospital data).²⁷

1.9.2 Current traumatic brain injury rehabilitation practice

For people requiring rehabilitation following TBI, various services are currently available. These range from intensive, residential rehabilitation to community rehabilitation aimed at specific issues, vocational rehabilitation programmes, and various support services. ACC contracts for these services with a per-claimant price-agreed fee for service, but with no set volumes.

Most children with TBI are admitted to paediatric wards in general hospitals and are managed by general paediatric teams. For children with severe TBI there is a single specialist residential rehabilitation service, the Wilson Home in Auckland, which accepts referrals from around New Zealand.

Services for people with TBI are available in all major centres in New Zealand. Service provision is restricted to providers who can show a high level of expertise and commitment to rehabilitation following TBI. The service providers tender for each of the services, and through this tendering process must demonstrate to ACC that they have the resources, competence/training and community links to provide rehabilitation matched to the particular needs of the relevant client group.

1.9.2.1 Non-residential rehabilitation services

1.9.2.1.1 Services: mild traumatic brain injury

There is a wide range of non-residential rehabilitation services, from primarily assessment services to primarily intervention services, and from a single operator in a single discipline, to full multidisciplinary team operations. A mixture of DHB and non-DHB services aiming to support people in their own homes or similar 'natural' environments operates in New Zealand. Specific elements of non-residential programmes, including intensity and duration, are currently specified by the ACC case manager, following independent assessment.

The mild TBI service is intended to provide early access and timely assessment and rehabilitation for people who have a mild TBI. The aim of this service is to rehabilitate people to maximum independence through case management and appropriate assessment and rehabilitation. It allows entry for people either early in the post-acute stage of a mild TBI, or later on for people who have persisting symptoms following mild TBI. The service allows for the assessment of people who may have had a TBI and need assessment to establish cover and entitlement.

There are seven mild TBI clinics, sometimes known as 'concussion clinics', around New Zealand. Two further clinics provide specific care for children with TBI. The clinics provide a combination of specialist medical assessment, screening neuropsychological assessment, and assessment and intervention from an occupational therapist, although this is usually limited to a few sessions.

Users of this service fall into three main categories.

1. Those who have definitely suffered a mild TBI and need further assessment and rehabilitation following the acute episode.
2. Those for whom it is unclear whether they have suffered a TBI and who need assessment to establish cover and rehabilitation needs.
3. Those who have established symptoms of more than three months' duration following a mild TBI who need assessment and rehabilitation.

However, most services report also seeing a varying proportion of people with more severe injuries.

1.9.2.1.2 Services: moderate to severe traumatic brain injury

There is a wide range of non-residential services for people with more severe injuries. This range includes established providers, services that provide assessment and rehabilitation (including vocational rehabilitation), and individual providers of specific services (eg, neuropsychologists).

1.9.2.2 Residential rehabilitation

Residential rehabilitation funding for people following a TBI is provided by two main ACC service contracts. These are the *Active Rehabilitation Services Contract* and the *Residential Support Services Contract*. The two service contracts both provide services for rehabilitation, but serve different ranges of claimant need.

Rehabilitation can be provided in a person's own home. Where residential rehabilitation options are being considered, the advantages and disadvantages of living at home, with appropriate inputs and support, need to be discussed. Particular consideration should be given to the needs of family and/or carers in this situation.

Residential rehabilitation services are defined by three features.

1. The person with TBI stays overnight in accommodation provided as part of a rehabilitation package of care.
2. The accommodation provides a 'rehabilitation environment' with an emphasis on education, problem-solving and self-responsibility for the person with TBI, working towards higher levels of independence and participation in the community.
3. In addition to 1 and 2 above, there is rehabilitation and clinician input with an expectation of improvement in functioning over time (although this time-frame can be long).

Almost exclusively, people with TBI who are managed in residential rehabilitation services have had a severe TBI, and/or have a complication of the initial TBI or other injuries. Occasionally there may be significant comorbidities (particularly mental health disorders) which, in addition to a less severe TBI, may require residential placement for rehabilitation. Table 1.2 provides an approximate outline of the current pathway into residential rehabilitation following severe TBI in New Zealand.

TABLE 1.2:
INTERVENTION SETTINGS: THE PROGRESSION INTO RESIDENTIAL REHABILITATION

PHASE	DURATION	LOCATION
1. Acute care	Few days up to few months	Acute hospital ward (generally neurosurgery or surgery)
2. Post-acute but medical problems	Few days to a few weeks	Stay on acute ward, OR transferred to inpatient rehabilitation ward
3. Post-acute, medically stable	Few weeks up to several months	Dedicated residential rehabilitation, usually in community rather than hospital setting
4. 'Plateau' phase, unable to live independently unsupported	Months to years	Community residential setting
5. Independence or able to live in private accommodation with suitable support package	Years	Own home or similar

A decade ago the residential rehabilitation services described were provided almost exclusively in hospitals. The 2004 Current Practice Review⁵ shows that a minority of people with TBI requiring residential rehabilitation are now managed in hospital environments. A common model for these services in 2005 is for small numbers of people with TBI to be managed in a privately owned 'community house', with 24-hour supervision and varying amounts of health-professional input. These environments are more 'real life' than hospital rehabilitation wards, and therefore may facilitate transition back to independent (or assisted) community living.

Elements that vary between different residential rehabilitation environments in New Zealand are:⁵

- the composition of a ‘core team’ that sees every referred person with TBI. This ranges from an occupational therapist and a nurse to a ‘full multidisciplinary team’ including specialist doctor, nurses, occupational therapist, physiotherapist, psychologist, speech-language therapist and social worker
- hours per week of health-professional input
- availability of 24-hour medical cover, which can delay discharge from an acute hospital to a community setting, for example, especially in Phase 2 (see Table 1.2)
- staff who provide 24-hour supervision; generally registered nurses in hospital rehabilitation wards, but varies in community settings.

1.9.2.2.1 Active rehabilitation services

Active rehabilitation services provide rehabilitation for people following a serious injury. Residential services provide a community-based environment and fully inclusive rehabilitation for high-needs claimants by a specialist multidisciplinary rehabilitation team. The contracts for these services are usually held by private providers, although some DHBs also provide the service.

This service is designed for people who have suffered a moderate to severe TBI, and the emphasis on community-based care is to aid the person’s eventual re-integration into the community. People who receive this service usually have substantial cognitive and/or physical needs. From a clinical and rehabilitation management perspective, this client group presents a challenge in that they require 24-hour supervision and care, often with more than one person working with each person at any given time.

The key distinction between ‘active residential rehabilitation’ and ‘residential rehabilitation support’ (described in the following section) is the intensity of rehabilitation input, linked to expectations regarding speed of recovery. Where significant functional gains are possible over weeks to a few months with appropriate input, active rehabilitation (ie, providing a rehabilitation environment and intensive [at least daily] rehabilitation) input is indicated.

1.9.2.2.2 Residential support services

Where gains for people following serious injury are expected to be over a longer period of time (ie, a few to several months), a residential rehabilitation support programme is appropriate. This provides a rehabilitation environment and less intensive rehabilitation input (a few hours per week from rehabilitation clinicians). Residential support services aim to promote a level of independence in a safe environment for people who are unable to live safely, independently. The service provides rehabilitation and support in a home-for-life setting.

This service is aimed at a broad spectrum of people who have TBI long term, and provides community-based rehabilitation of serious injury claimants (most commonly TBI). These claimants may remain in the service in the long term. The service may rehabilitate the person who has had a serious injury into community living with appropriate support. People using this service generally have a need for ‘slower-stream’ rehabilitation.

In residential support services, there is no necessary expectation of improving levels of independence and/or participation in the community; there is monitoring to identify secondary problems, which may lead to deterioration and an ongoing need to provide sufficient support to realise the person’s full ability to function. This includes provision of physical supports (eg, appropriate wheelchair, communication device), social supports (eg, day programmes) and emotional supports (eg, appropriate management of mood, interaction with family/whānau or friends).

A residential environment with people of similar age and interests should contribute to appropriate levels of social and emotional support. However, residential support programmes providing such an environment are not currently available in many parts of New Zealand. In addition, some people with severe TBI can be difficult to manage in existing residential support programmes, due to behavioural difficulties in particular. Such issues

require careful consideration from appropriately trained rehabilitation clinicians, including trial placements, before long-term decisions are made.

Residential support services also provide for people who may not have suffered a serious injury, but are nonetheless unable to rehabilitate to the community (eg, an older person with a relatively minor injury but no carer).

1.9.2.3 Review of current practice

Summary information from the 2004 Current Practice Review commissioned by ACC and completed in 2004 is presented in this section.⁵ This review of TBI rehabilitation included a survey of providers and consumers (people with TBI and carers). The full report is available at www.nzgg.org.nz.

1.9.2.3.1 Provider survey

A total of 49 respondents to the survey of TBI service providers met the criterion of managing at least three people with TBI in the last year or 10 people with TBI in the last five years. Thirty-six of the responses were from providers of non-residential rehabilitation services (managing a total of 4668 clients in the previous 12 months) and 13 were from providers of residential rehabilitation services (managing 452 clients in the previous 12 months).

Key findings of the survey

- Providers were clearly attempting to provide the best possible service they could for people with TBI.
- A range of approaches and variations in structure, staffing and practice was evident. There appeared to be many reasons for this variation including historical factors, local staff availability, contractual requirements and a desire to provide an optimum service.
- Providers supported a need for evidence-based guidelines to help develop best practice.
- There was little or no consistency in the use of standardised assessment and outcome measures and tools.
- Audit and quality improvement initiatives, where present, tended to be at the level of consumer satisfaction and/or audit by funders to ensure contract compliance.
- There was a move away from DHB-provided services, with only 42% of residential clients and 9% of non-residential clients being managed by DHB providers.
- Most providers of TBI services indicated that they provided services targeted to specific sub-groups of the TBI population, such as Māori, Pacific peoples, people with mental health disorders, and people with alcohol or drug abuse problems. However, the extent to which these services met these needs was uncertain.
- The lower age range for acceptance into both residential and non-residential rehabilitation programmes varied, from one specialist paediatric service to others where the lower age limit was between 14 years and 18 years.

Residential TBI rehabilitation services

- Some of these were specialist TBI services (ie, managing clients with TBI only). However, the majority of TBI clients were managed in non-specialist environments (ie, with non-TBI clients as well). Overall, when responses from providers managing across multiple sites were considered, services tended to be low volume, averaging about 16 clients per year.
- TBI rehabilitation provision has been aggregated by a few organisations, often operating across different sites. This allows standardisation of management, staff skill mix and training.

Open-ended responses from providers about effective interventions, barriers to effectiveness, gaps in services and ideas for better services provided further information, and are presented as verbatim responses in the full report. The full report can be accessed at www.nzgg.org.nz.

1.9.2.3.2 Consumer survey

The consumer survey elicited 420 responses from people with TBI and/or their carers across New Zealand. Carers were not separately surveyed.

Survey findings

- About half of the respondents felt that people with TBI got a ‘good deal’ from TBI rehabilitation services, and approximately 60% felt that TBI rehabilitation services focused on goals that were important for them.
- There was considerable support (76%) for the provision of specialist TBI rehabilitation centres in New Zealand.
- In general, people surveyed were ‘happy’ with ACC services. A substantial minority (around 40%) were ‘unhappy’ with these services. Much of their discontent seemed to focus on the training and turnover of case managers.
- Health status of the consumers, measured by a standard instrument, the Short Form 12 (SF12), showed mean values for ‘physical health’ and ‘mental health’ well below (around one standard deviation below the mean) those expected for people of a similar age.

1.10 Major gaps identified

Gaps in knowledge and between existing practice and best practice identified from the Current Practice Review⁵ and in developing this guideline include:

- TBI is a significant health issue in New Zealand. The extent of the problem will remain uncertain until we have better information from prospective studies in a New Zealand population. Such studies would require clear criteria for distinguishing people with a blow to the head who do not meet criteria for TBI from those with definite TBI. Such research should be a high priority for health research funders and ACC
- the consumer survey suggests that people with TBI experience significant health disadvantage, in terms of both physical and mental health, compared with their peers
- there is no uniform approach to standardised assessment and outcome measures
- considerable variation exists in New Zealand TBI rehabilitation service provision, which is probably unacceptable
- providers see a need for clear evidence-based guidelines to help develop best practice for TBI services in New Zealand
- considerable gaps may exist between what is currently being provided and what might be considered to meet the needs of differing groups of people (eg, different ethnic groups or people with specific comorbid conditions, such as mental health disorders, or high drug and alcohol use)
- TBI rehabilitation services in New Zealand are not specialised. It is possible that one or more specialist TBI centres for acute care and early rehabilitation could complement current community-based rehabilitation centres.

Although there is little robust comparative evidence to demonstrate whether specialisation of services for TBI leads to better outcomes, strong evidence from related conditions and international expert opinion suggests that this would be the case.⁸ One issue that needs to be considered for New Zealand is whether specialist TBI rehabilitation services should be pursued, acknowledging that this would require centralisation and the potential disadvantages that might engender – particularly the difficulties for family and other support. It should be noted that consumers supported the idea of a small number of expert TBI specialist units rather than the current widely dispersed services – that is, they preferred the ‘best possible treatment available’ over the ‘most convenient treatment option’. The ‘centralisation’ model has been applied to spinal injury services for the acute phase of spinal cord injury (SCI) treatment in New Zealand; however, SCI and TBI are not identical conditions.

Chapter 2: Pre-hospital assessment, management and referral to hospital

Overview

- Pre-hospital assessment can be undertaken by a range of trained health care professionals, in order to establish whether a trauma to the brain has occurred and factors associated with serious complications of head trauma are present.
- There are limited, well designed studies on the efficacy of pre-hospital intervention.
- There are a number of risk indicator assessment tools for acute complication of TBI, including the Glasgow Coma Scale.
- The Glasgow Coma Scale is used for immediate, pre-hospital and hospital assessment of the acute complication risk associated with TBI.
- People with symptoms/signs that are defined as risk factors for acute intracranial complications of TBI should be promptly referred to an Emergency Department. Emergency transport services should also be used if the signs of acute complications are more serious, if the person assessing has additional concerns, or for some other circumstances, such as a lack of suitable transport.
- Rapid transfer to an Emergency Department using emergency services is appropriate if there is deterioration in the person's condition, a loss of consciousness, focal neurological deficit, skull fracture or penetrating head injury, seizure, or suspected neck injury.
- People with none of the signs or symptoms for Emergency Department assessment should seek further medical assessment from a general practitioner or accident and medical clinic.
- There is consistent evidence that coordinated trauma systems reduce mortality for serious injury, including serious neurotrauma. A coordinated system of trauma care for TBI that provides an organised and responsive system of care for people is required.

This chapter deals with the pre-hospital phase of assessment and management for people with suspected TBI.

It provides advice about who should be referred for an assessment at hospital and who should be transported by ambulance, along with recommendations about appropriate public health and educational material for the general public.

This chapter is adapted and updated for New Zealand from the NICE Head Injury Guidelines.⁷

There are four important reasons for undertaking pre-hospital assessment, which are outlined below.

1. Identifying actual or potential hypotension and/or hypoxia, which untreated will magnify TBI effects.
2. Identifying risk factors for acute complications of TBI, which may require intervention, particularly bleeding inside the skull and/or brain.
3. Identifying other injuries that may require urgent management.
4. Estimating the severity of any injury to the brain that has implications for subsequent management and follow-up.

2.1 Pre-hospital assessment – acute

RECOMMENDATIONS	GRADE
A person with a suspected traumatic brain injury should initially be assessed and managed according to clear principles and standard practice as embodied in the Advanced Trauma Life Support (ATLS)/Early Management of Severe Trauma (EMST) system and for children the Advanced Paediatric Life Support (APLS) system.	C
The first priority for those administering immediate care is to treat the greatest threat to life and avoid further harm.	C
A person who has sustained a suspected traumatic brain injury should have full cervical spine immobilisation attempted, unless they have all of the following: <ul style="list-style-type: none"> • no alteration of consciousness • no neck pain/tenderness • no focal neurological deficit • no major distracting injury. 	C
A person who has sustained a suspected traumatic brain injury should be transported directly to a centre where traumatic brain injury is managed in entirety. Where this type of facility is unavailable, the person should be transported to a centre that can stabilise the person's condition prior to transfer to a centre where traumatic brain injury is managed in entirety. It is expected that all acute hospitals accepting people who have sustained a suspected traumatic brain injury should have the resources to expeditiously assess and intervene to optimise outcome and that these resources should be appropriate for the person's age.	C
Paramedics should be fully trained in the use of the adult and paediatric versions of the Glasgow Coma Scale and its derived score.	C
Paramedics should have training in the detection of non-accidental injury and should pass this information to Emergency Department personnel when the relevant signs and symptoms arise.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

The first assessment of a person suspected of having sustained a TBI may be performed by a general practitioner or other primary health care practitioner, a sports coach, an ambulance officer, a member of the public, or telephone operator for a telephone health 'helpline'. The aim of this assessment is to establish whether trauma to the head has occurred and whether any of the factors associated with serious complications of head trauma are present.

When assessing a person with a suspected TBI who is apparently intoxicated, it should not be assumed that the signs and symptoms of the person's injury are due to the intoxication from alcohol or drugs. There should be particular caution with people who are vomiting or who may be intoxicated, due to the risk of aspiration and consequent hypoxia.

There are specific questions regarding the very early management of people with severe head injuries (ie, Glasgow Coma Scale score of 8 or less). Recent systematic reviews have examined evidence on the management

of TBI.^{7,74} These reviews found strong evidence for only a small number of interventions and concluded that there was a paucity of well designed studies examining the efficacy of pre-hospital interventions in severe head injury. Management advice in this guideline is based on the UK's NICE guideline recommendations⁷ informed by the New Zealand TBI Guideline Development Team.

A general principle in immediate management is that the first priority for those administering immediate care is to treat the greatest threat to life and avoid further harm.⁷ See also Chapter 3, *Acute phase of traumatic brain injury care*.

2.2 Assessment of need for medical attention

This section details the evidence for using various assessment tools as risk indicators for acute complications of TBI, particularly intracranial bleeding. Factors that might indicate a high risk are also identified.

These tools and factors are used to assess whether a person with a suspected TBI requires assessment at an Emergency Department or other medical assessment and with what urgency.

Recommendations concerning the assessment itself are made in Chapter 5, *Rehabilitation following clinically significant traumatic brain injury – assessment*.

2.2.1. Glasgow Coma Scale

RECOMMENDATION	GRADE
The adult and paediatric versions of the Glasgow Coma Scale should be used to assess people with a head injury.	C
Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.	
GOOD PRACTICE POINT	
A fall in the Glasgow Coma Scale score of two or more points, no matter what the original score, requires urgent investigation and/or referral.	✓
This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.	

The adult and paediatric versions of the Glasgow Coma Scale are widely used to assess and monitor people in the acute phase after a suspected TBI. The Glasgow Coma Scale score gives a useful indication of level of consciousness at a given point in time, allows for serial measurement and provides a useful shorthand for communicating information to ambulance or Emergency Department staff.^{6,7} It is also a familiar tool that enables the collection and comparison of data, both nationally and internationally. Recommended versions are included in Appendix C.

The risk of intracranial complications and the consequent need for surgery increases as the Glasgow Coma Scale score declines.^{7,75} A recent study calculated that the rate of clinically significant brain injury in hospital attenders who had experienced some loss of consciousness and/or amnesia since their head injury, increased from 5% with an initial Glasgow Coma Scale score of 15, to 17% for a Glasgow Coma Scale score of 14, and to 41% for a Glasgow Coma Scale score of 13.⁷ A further study on paediatric head injury found that a Glasgow Coma Scale score of less than 13 was a significant predictor of an abnormal CT scan in children with head injury aged 14 years or younger.⁷

Any fall in a Glasgow Coma Scale score, after an initial recording, is of concern and may represent the development of intracranial bleeding, such as an extradural haematoma. A fall of two or more points, no matter

what the original score, should mandate immediate further investigation and referral (see Section 3.2.1, *Selection of adults for CT imaging of the head*).

The Glasgow Coma Scale is composed of three separate responses: eye opening, verbal and motor. These are summed for a total Glasgow Coma Scale score out of 15. The following is a brief guide on how to use the Glasgow Coma Scale.

- Monitoring and exchange of information about individual people is based on the three separate responses on the Glasgow Coma Scale (eg, a score of 13 based on scores out of 4 for eye opening, 4 for verbal response and 5 for motor response should be reported as E4, V4, M5).
- If a total score is recorded or communicated, it is based on a total possible score of 15, and this denominator should be specified (eg, 13/15) to avoid confusion.
- Describe the eye opening, verbal response and motor response components of the Glasgow Coma Scale in all communications and notes, which should always accompany the total score.
- For the paediatric version of the Glasgow Coma Scale, include a 'grimace' alternative to the verbal score to facilitate scoring in pre-verbal or intubated infants or children (see Appendix C).

2.2.2 Loss of consciousness

RECOMMENDATION	GRADE
Any loss of, or alteration in, consciousness should be recorded and assessed in people with a suspected traumatic brain injury.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT	
People with altered consciousness should have their blood glucose levels checked routinely as part of their assessments.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

A history of loss of or altered consciousness after a brain injury is associated with an increased risk of developing an intracranial complication, such as an expanding haematoma, although the absolute risk remains low.⁷ In most cases, a longer duration of loss of or altered consciousness is associated with greater severity of injury. Momentary loss of or altered consciousness is difficult to measure when no independent observer is available, and there is debate about its importance.

There is some evidence that intracranial complications can occur even when there has been no loss of or altered consciousness. However, as most studies in this area exclude people who have not experienced any loss of or altered consciousness, there is a lack of published research on this aspect of risk. Loss of, or change in, consciousness may have other causes, and blood glucose levels should be checked routinely in all people with loss of or altered consciousness.

2.2.3 Post-traumatic amnesia

RECOMMENDATION	GRADE
Post-traumatic amnesia should be prospectively assessed and recorded when assessing people with a suspected traumatic brain injury, where possible.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT

Services assessing people with traumatic brain injury should choose one of the available validated post-traumatic amnesia measurement tools and ensure all staff are familiar with its use.



This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Post-traumatic amnesia, also known as anterograde amnesia, is the impaired memory for events after brain trauma. It is usually considered the most important amnesic disorder for assessing the risk of acute complications of TBI. However, a recent rigorous study has suggested that retrograde amnesia (ie, impairment of memories before the trauma) is a more important indicator of significant injury.⁷⁵

Even though post-traumatic amnesia is associated with an increased risk of intracranial complications, evidence on the length and type of amnesia is inconsistent.^{7,76} There is some evidence that the duration of post-traumatic amnesia is a more accurate predictor of longer-term outcomes than the Glasgow Coma Scale score.⁷⁷ However, there is a lack of robust evidence to support the use of any particular form of assessment of post-traumatic amnesia.^{76,78} Assessing post-traumatic amnesia is less useful in infants and young children because it is difficult to measure.

The Guideline Development Team recommends the assessment of post-traumatic amnesia in all people with suspected TBI. Measurement should commence prospectively (ie, before it has resolved) to increase accuracy.²⁴ The Tools Review identified three measures of post-traumatic amnesia suitable for use in New Zealand: the Galveston Orientation and Amnesia Test (GOAT), the Westmead Post-traumatic Amnesia Scale, and the MOPTAS.⁶

The Tools Review concluded that while there is no strong empirical evidence to favour one of these measures of post-traumatic amnesia over another, qualitative arguments have been made in favour of the MOPTAS.⁶

2.2.4 Neurological signs

RECOMMENDATION	GRADE
Neurological signs should be assessed and recorded when assessing people with a suspected traumatic brain injury.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

Post-traumatic neurological signs, such as focal neurological deficits or seizure, are highly associated with the risk of an intracranial complication.^{7,76} Consequently, people with these signs are commonly excluded from studies developing clinical decision rules for the management of acute brain injury.

2.2.5 Bleeding disorders and use of anticoagulants

RECOMMENDATION	GRADE
Coagulopathy and the use of anticoagulant medication, or medications and supplements with anticoagulant effect, should be considered when assessing people with a suspected traumatic brain injury.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

People with coagulopathy or who are on anticoagulant medication, such as warfarin, have an elevated risk of intracranial complications but there is no robust evidence that has established this relationship.^{7,76}

Some commonly taken medications (such as aspirin) and supplements (such as *Ginkgo biloba*)⁷⁹ also have an anticoagulant effect. Health care practitioners should be aware of this and ask the person about what alternative or complementary therapies they may be taking, including supplements, when checking their medication use (see Chapter 7, *Complementary and alternative medicines*).

2.2.6 Skull fracture

The risk of intracranial complications is higher in people with a diagnosed skull fracture. The risk of developing an intracranial haematoma is approximately 12 times higher in people with a radiographically detected skull fracture than in people without this diagnosis. This calculation of risk is based on an estimate of 38% sensitivity and 95% specificity reported from a meta-analysis on the value of the radiological diagnosis of skull fracture.⁸⁰

There is variation in diagnostic practice for skull fracture. Some international guidelines advocate a skull X-ray for the diagnosis of skull fracture.⁸¹

Skull X-rays have limited effectiveness in the diagnosis of TBI. Skull X-rays will be normal in many people with clinically significant acute complications of TBI. In addition, skull X-rays are associated with exposure to radiation, and come at a cost in terms of resources and time. Therefore, the routine use of skull X-ray as a decision-making tool cannot be recommended. However, the clinical assessment of signs of skull fracture, including signs of basal skull fracture, such as cerebrospinal fluid leak, periorbital haematoma, depressed or open skull injury, and penetrating injury, should be undertaken.⁷ If an imaging study is indicated in people with suspected TBI, it should be a CT head scan (see Section 3.2, *Primary investigation for people with suspected traumatic brain injury*).

2.2.7 Seizure

A seizure **alone**, with no other neurological signs and full recovery, is almost never a sign of an intracranial haematoma. The difficulty with seizures is that the person may become unconscious as a result of the seizure or from a drug, such as diazepam, used to stop the seizure. This alteration in consciousness level cannot be differentiated from that caused by an intracranial bleeding complication of TBI. Unless recovery is prompt and complete a (further) CT scan is necessary to exclude such a complication.

2.2.8 Mechanism of injury

The widely differing nature of high-energy injury mechanisms makes it difficult to determine the influence on the risk of intracranial complications. Terms such as ‘assault’ or ‘road traffic accident’ cover a great heterogeneity of circumstance. A recent study has proposed the following criteria as high-risk factors for clinically significant brain injuries after head injury: a pedestrian struck by a motor vehicle, an occupant ejected from a motor vehicle, or a fall from a height of greater than three feet or more than five stairs (or less in infants and children under five years).⁷⁵

The height threshold for a high-risk fall is sometimes defined as three feet, and sometimes as one metre. For consistency, this guideline uses the term ‘one metre’. Falls from lower heights may be risk factors with infants and children less than five years of age.

A further study has defined ‘axial load to head’ as a high-risk factor for cervical spine injury after an accident.⁷ This includes: diving; high-speed motor vehicle collision; rollover motor accident; ejection from a motor vehicle; accident involving motorised recreational vehicles; and bicycle collision. In addition, there are many other high-energy mechanism injuries considered to be important which cannot be readily listed (eg, the variety of blunt instruments that could be used in an assault).⁷

2.2.9 Age

An exact age threshold for identifying people at high risk of intracranial complications following a suspected TBI has not been identified, but it is clear that increasing age is associated with an increased risk and a poorer prognosis.⁷ Commonly used thresholds are 60 years⁷ and 65 years.^{7,75}

This guideline adopts a standard age threshold of 65 years and over. An odds ratio of 4.1 (95% CI 2.8–6.1) for clinically significant acute complication of TBI is associated with this threshold when the person has experienced loss of consciousness or amnesia.⁷⁵

There is evidence that the incidence of intracranial complications in children and infants is much lower than in adults.⁷ In young infants (under 12 months) age is inversely related to the risk of intracranial complications requiring intervention, with those under two months old being at highest risk.⁸²

2.2.10 Drug or alcohol intoxication

Drug or alcohol intoxication can result in signs and symptoms that are also risk factors for intracranial complications (eg, vomiting, headache, amnesia, impaired consciousness). Excessive consumption of alcohol can also cause hypoglycaemia, which, in turn, can cause impaired consciousness. This makes a differential diagnosis difficult and could lead to an incorrect diagnosis of a developing intracranial complication. Drug and/or alcohol use have also been identified as independent risk factors for poorer outcomes following TBI,^{7,76} and may impact on rehabilitation from TBI (see Chapter 14, *Special issues*).

Although alcohol intoxication can reduce the Glasgow Coma Scale, it is always safer to assume that such signs are due to TBI or a complication of TBI rather than intoxication and proceed accordingly.

2.2.11 Headache

GOOD PRACTICE POINT

Strong analgesia for headache should be avoided, if possible, until a full assessment has been made in the Emergency Department.



This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Headache – any head pain either diffuse or localised – is a symptom that may be associated with raised intracranial pressure and is a risk factor for intracranial complications.⁷⁶ Headache can, however, be difficult to define in terms of duration and severity, particularly in infants and young children.

Analgesic medications carry a risk of sedation or ‘masking’ symptoms of complications of TBI. If possible, strong analgesics should be avoided until the person has been fully assessed in the Emergency Department, so that an accurate measure can be made of consciousness and other neurological signs. For people with headache alone, simple analgesics, such as paracetamol, may be appropriate. There are situations where strong analgesics are required (eg, fractures) prior to hospital and their use should be clearly documented.

2.2.12 Vomiting

Vomiting is a symptom associated with raised intracranial pressure and is consistently identified as a high risk factor for those with a TBI. However, there is some debate about the number of vomiting episodes required to identify high risk.^{7,75}

Vomiting is quite common in infants and children, and its predictive power is uncertain in this age group. It has been estimated that around 16% of infants and children aged 12 years or under vomit after relatively minor head injury, and the cause of vomiting may be related to individual intrinsic factors (eg, previous tendency to vomit) rather than specific features of the head injury.⁷ However, a recent rigorous systematic review concluded that any vomiting should be considered a risk factor for intracranial complications.

2.2.13 Irritability and altered behaviour

Irritability and altered behaviour are non-specific terms which are sometimes used in clinical guidelines for acute head injury management with little empirical evidence to support their use.⁸¹ However, they are an important sign in young children, where other problems, such as amnesia or headache, cannot be detected.⁸³ Irritability and altered behaviour may also be early signs of deterioration, and should therefore be monitored carefully. Where there is irritability or altered behaviour present, the Glasgow Coma Scale verbal response should be scored at most as 5 (ie, confused). Appropriate action needs to be taken in relation to the overall Glasgow Coma Scale and any change in Glasgow Coma Scale (see recommendations in Chapter 3).

2.2.14 History of cranial neurosurgical interventions

There is no evidence to indicate previous cranial neurosurgical intervention is a risk factor for intracranial complications. However, expert opinion considers that such intervention is likely to increase the risk of developing a subdural haematoma. Therefore, any intervention should be recorded, particularly if there has been cranial neurosurgery in the six weeks prior to injury, or if there is a shunt for hydrocephalus.⁷

2.3 Referral to Emergency Department

This section covers two clinical questions.

1. For a person with suspected TBI, is assessment in the Emergency Department required?
2. If 'Yes' to (1), is emergency service transport required?

Signs and symptoms that are risk factors for acute intracranial complications of TBI (see Section 2.1, *Pre-hospital assessment – acute*) should initiate referral to the Emergency Department. Promptly transport the injured person to an Emergency Department by emergency services if:

- there are more serious signs
- the person assessing the injured person has concerns
- there are other circumstances, such as the lack of suitable alternative transport.

RAPID TRANSFER TO EMERGENCY DEPARTMENT USING EMERGENCY SERVICES is appropriate if any of the following indicators are present.

- **Any deterioration** in the injured person's condition.
- Unconsciousness, or lack of full consciousness (ie, Glasgow Coma Scale score <15).
- **Any focal neurological deficit** (ie, restricted to a particular part of the body or a particular activity) since the injury (eg, problems understanding, speaking, reading or writing; loss of feeling in part of the body; problems balancing; general weakness; any changes in eyesight; difficulty walking).
- **Any suspicion of a skull fracture or penetrating head injury** (eg, clear fluid running from the ears or nose; black eye with no associated damage around the eye; bleeding from one or both ears; new deafness in one or both ears; bruising behind one or both ears; penetrating injury signs; visible trauma to the scalp or skull).
- **Any seizure** (ie, 'convulsion' or 'fit') since the injury.
- **A high-energy head injury** (eg, pedestrian struck by motor vehicle; occupant ejected from motor vehicle; a fall from a height of greater than one metre or more than five stairs, or less for infants and children aged under five; diving accident; high-speed motor vehicle collision; rollover motor accident; accident involving motorised recreational vehicles; bicycle collision; or any other potentially high-energy mechanism).
- **Suspected neck injury.**
- The injured person or their carer is unable to transport the injured person safely to the hospital Emergency Department without the use of ambulance services (providing any other risk factor indicating Emergency Department referral is present).

In the absence of any of the indicators for emergency services transport, but where review in an Emergency Department is indicated, transport to the Emergency Department could be with a competent adult.⁷

EMERGENCY DEPARTMENT REVIEW NEEDED but **TRANSPORT** could be **WITH COMPETENT ADULT** if any of the following indicators are present.

- **Any loss of consciousness** ('knocked out') as a result of the injury, unless trivial, apparently resolved and alternative observation available.
- **Amnesia** for events before or after the injury ('problems with memory').
Note: The assessment of amnesia will not be possible in pre-verbal children and is unlikely to be possible in any child aged younger than five years.
- **Persistent headache** since the injury.
- **Irritability or altered behaviour** ('easily distracted', 'not themselves', 'no concentration', 'no interest in things around them') particularly in infants and young children (ie, aged younger than five years).
- **Any vomiting** episodes since the injury.
- **History of bleeding or clotting disorder.**
- **Current anticoagulant therapy** such as warfarin, or if the person is taking supplements, such as Ginkgo biloba, or other supplements with anticoagulant effects.
- **Current drug or alcohol intoxication.**
- **Any previous cranial neurosurgical interventions** ('brain surgery').
- **Suspicion of non-accidental injury.**
- **Age** 65 years and older; one year or younger.
- **Concern about the cause of any symptoms** by the person undertaking the assessment.

* Depending on local availability, assessment at an after hours medical clinic or accident and medical clinic may be appropriate for this group of people and this arrangement should be described in local ambulance and hospital protocols.

People who have none of the factors requiring Emergency Department review fall outside the definition of 'definite TBI' used in this guideline (see Chapter 1, *Traumatic brain injury in New Zealand*). Some people whose presentation lies outside this definition, but who have one or more risk factors for acute complications (eg, aged 65 years or older or alcohol intoxication) **should also** be reviewed in the Emergency Department. All people who meet the definition of 'definite TBI' should be referred for an Emergency Department assessment.

2.4 Assessment in hospital not required

People who present with none of the indications for Emergency Department assessment should seek further medical assessment from a general practitioner or at an accident and medical clinic if there are:

- adverse social factors (eg, no one is able to supervise the injured person at home)
- continuing concerns by the injured person or their carer about the diagnosis.⁷

People not meeting the criteria for Emergency Department or other further medical assessment can go home with an information sheet with details of when to seek medical help. The information sheet should state clearly:

- that there are some symptoms (eg, headaches, dizziness, fatigue, difficulty with concentration) that occur fairly commonly after an external force to the head, which resolve over the first few hours and days up to a few weeks
- the specific symptoms and/or signs which, if they occur, indicate the need to seek prompt medical attention.

As these people do not meet the definition of 'definite TBI', there is no need to arrange routine general practitioner follow-up or to arrange time off regular activities, including work. People in whom symptoms persist, worsen or significantly interfere with usual activities should be reassessed by their general practitioner (see Section 2.5, *First assessment – delayed*).

2.5 First assessment – delayed

Not all people who have had an episode of external force to the head present for medical attention on the day of injury. This section refers to anyone presenting to a general practitioner or an Emergency Department more than 24 hours after the injury. People may present weeks or months after the injury. When the first presentation is delayed, it can be more difficult to identify a connection between the reported symptoms and an episode of external force to the head leading to suspicion of TBI.

The key features of this assessment are to:

- document the episode of external force to the head
- document the current presenting symptoms and duration
- try to determine and document acute symptoms (see Sections 2.1, *Pre-hospital assessment – acute* and 2.2, *Assessment of need for medical attention*)
- explain the possibility that some or all of the symptoms may be related to the injury
- if a diagnosis of TBI is probable, consider whether:
 - any of the symptoms are sufficiently serious to consider acute referral to hospital
 - any specialist input is required (see Chapter 5, *Rehabilitation following clinically significant traumatic brain injury – assessment* and Chapter 6, *Rehabilitation following clinically significant traumatic brain injury – intervention*)
- if a diagnosis of TBI is uncertain, decide whether specialist referral or investigation is required to establish a diagnosis
- consider appropriate management of symptoms (see Chapter 5, *Rehabilitation following clinically significant traumatic brain injury – assessment* and Chapter 6, *Rehabilitation following clinically significant traumatic brain injury – intervention*).

2.6 No assessment

Some people with definite TBI never present for an initial assessment. This may be due to a variety of reasons:

- the effects of alcohol and other drugs
- an unwitnessed episode with amnesia of the event
- an accident in the context of sports
- unwitnessed or unreported falls in school playgrounds for children and young people
- unwitnessed or unreported falls for older people
- blows to the head where assault may go unreported (eg, a blow from a family member).

In 1991, one population-based survey of self-reported mild TBI in the USA indicated that 25% of those reporting a brain injury did not seek medical care.²⁹

In a recent New Zealand study, prison inmates reported high rates of previous head injuries.⁸⁴ Given the frequency with which TBI is thought to occur, a degree of suspicion that TBI may be implicated in some instances of otherwise unexplained poor performance is reasonable. However, in the absence of an appropriate initial assessment, it may prove difficult to substantiate such a link.

2.7 Advice to the community sector

The Brain Injury Association of New Zealand provides useful information through its national 0800 helpline (0800 BRAINHELP, 0800 272 464).

New or worsening symptoms indicate a need for the person to seek immediate medical advice.

2.8 Organisation of trauma services

RECOMMENDATIONS	GRADE
Each District Health Board in New Zealand should develop a plan for maximising the coordination of its trauma services to ensure the best possible care for people with severe traumatic brain injury, including timely referral to services provided by other District Health Boards.	C
A system and appropriate protocols for alerting the destination Emergency Department should be developed for all hospitals managing suspected traumatic brain injury.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

There is consistent evidence that coordinated trauma systems reduce mortality in serious injury, including serious neurotrauma. For example, there is good consistent evidence that implementing trauma systems leads to considerable reduction in mortality (by 20–50%) from TBI.⁹ There is similar good evidence of harm; that the initial treatment of severely injured people at local hospitals without good trauma care capability, followed by transfer to ‘trauma centres’ doubles the mortality in both adult and paediatric populations.⁹

A coordinated system of trauma care for TBI requires an organised, responsive system of care for people with severe TBI, which would include:

- planning of pre-hospital management and triage
- transport directly to the trauma centre
- maintenance of appropriate call schedules for staff
- audit and quality improvement reviews
- staff participation in trauma education programmes.⁹

Trauma facilities for treating moderate to severe TBI should ideally include:

- a specialist-led emergency medical service
- a neurosurgery service with a neurosurgeon readily and promptly available
- an in-house surgeon with trauma training
- a continuously staffed and available operating room, intensive care unit and laboratory equipped ‘for’ management of people with TBI
- a continuously staffed and available CT scanner and operating staff.⁹

In areas without access to a neurosurgeon, local surgeons should have competency in:

- performing neurological assessment
- immediate neurotrauma care
- surgical treatment of extracerebral haematoma for people whose condition is deteriorating.⁹

Chapter 3:

Acute phase of traumatic brain injury care

Overview

- Details of good practice and evidence-based guidance for emergency assessment of suspected TBI are provided in this chapter.
- On arrival at the Emergency Department, the person with a suspected TBI should be assessed by a clinician to determine the presence of TBI, and whether a CT scan is necessary. A range of data is needed to assess the person.
- Emergency Department assessment and management of people with a brain injury is focused on the management or avoidance of hypotension and hypoxia, and on determining whether an imaging study is required.
- Early imaging, rather than admission and observation, will reduce the time to detection for life-threatening complications and is associated with better outcomes.
- Skull X-rays are of limited value in determining the presence of acute complications of TBI.
- CT imaging of the head is the primary investigation for the detection of clinically significant acute complications of TBI.
- The Canadian CT Head Rule has been adapted as a guide for New Zealand.
- Early support can help the injured person's family/whānau or carer(s) prepare for the effects of TBI; can reduce the psychological sequelae experienced by the carers; and can result in better outcomes for both the injured person and their family/whānau.
- Careful assessment of the need for rehabilitation during the acute management of people after TBI should take place during hospital care, prior to discharge and if the person has continuing or emergent symptoms of significant brain injury following discharge.

This chapter covers the acute phase of care for people with suspected TBI.

It provides advice about Emergency Department assessment, including selection for CT scanning, and routine observation protocols. Indications for hospital admission and continuation of hospital stay are presented, along with guidance on family and carer support and rehabilitation in the acute phase.

Specifically excluded from this chapter is discussion of the intensive care management of people with severe TBI, which is beyond the scope of this guideline.

3.1 Emergency Department assessment of people with a suspected traumatic brain injury

RECOMMENDATIONS	GRADE
Emergency Department assessments of people with suspected traumatic brain injury should focus on the identification of actual or potential hypotension and/or hypoxia, clinically significant brain injuries and appropriate referral for imaging.	C
Co-existing injuries and other concerns, such as possible non-accidental injury or non-traumatic aetiology, should also receive attention.	C
Imaging (for those meeting selection criteria) should be done early, in preference to admission and observation for neurological deterioration.	C
Data to enable decisions to be made about the probability of traumatic brain injury and the necessity of referring for a CT scan should be collected on admission by a health care practitioner appropriately trained in emergency medicine.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

The priority for all people attending an Emergency Department is the stabilisation of airways, breathing and circulation (ABC) before attention to other injuries.	✓
Anyone presenting to an Emergency Department with a suspected traumatic brain injury should receive a triage assessment by a trained staff member on arrival. Part of this triage assessment should establish whether they are high or low risk for clinically significant brain injury and/or cervical spine injury, using the CT rules in this guideline.	✓
Anyone presenting to an Emergency Department with impaired consciousness (Glasgow Coma Scale score of less than 15) should be assessed immediately by a trained staff member (such as a triage nurse).	✓
In people with a Glasgow Coma Scale score of 8 or less, there should be early involvement of an anaesthetist, emergency physician or critical care physician to provide appropriate airway management and assist with resuscitation.	✓
<p>Anyone found to be high risk on triage for clinically significant traumatic brain injury should be assessed within 10 minutes by a health care practitioner with experience in the assessment of such people.</p> <p>Anyone assessed, on initial triage, as being at low risk for clinically significant traumatic brain injury should be reassessed within a further hour by a doctor with appropriate experience. Junior doctors rostered to the Emergency Department should have training in the assessment of people with traumatic brain injury, and clear protocols detailing when to seek more senior assistance.</p>	✓
Assessment should establish the need to request CT imaging of the head. All Emergency Department health care practitioners involved in the assessment of people with suspected traumatic brain injury should be competent in assessing the presence or absence of risk factors used to select adults, infants and children appropriately for CT imaging. Training should be provided to ensure that this is the case.	✓
In general, people with a suspected traumatic brain injury should not receive strong systemic analgesia until they have been fully assessed, so that an accurate measure can be made of consciousness and other neurological signs. Local anaesthetic should be delivered for fractured limbs or other painful injuries.	✓
Throughout the hospital episode, all care professionals should use a standard 'suspected traumatic brain injury' proforma in their documentation when assessing and observing people with suspected traumatic brain injury.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Many of the people presenting to an Emergency Department with a suspected TBI will have had an initial assessment outside hospital (see Chapter 2, *Pre-hospital assessment, management and referral to hospital*).

For these people there will be some factor present that indicates they need to be referred to an Emergency Department. Others may present without having had any pre-hospital assessment.

There are four important reasons for undertaking an Emergency Department assessment.

1. Identifying actual or potential hypotension and/or hypoxia, which if untreated will magnify TBI effects.
2. Identifying acute complications of TBI that may require intervention, particularly bleeding inside the skull and/or brain.
3. Identifying other injuries that may require urgent management, including injuries to the cervical spine.
4. Estimating the severity of any injury to the brain that has implications for subsequent management and follow-up.

A main focus of Emergency Department assessment for people who have sustained a suspected TBI is the management or avoidance of hypotension and hypoxia, and deciding who needs an imaging study. Early imaging, rather than admission and observation for neurological deterioration, will reduce the time of detection for life-threatening complications and is associated with better outcomes.⁷ See Section 3.2.1, *Selection of adults for CT imaging of the head* and Section 3.2.2, *Selection of infants and children and young people for CT imaging of the head*).

The good practice outlined above should be followed during Emergency Department assessment. Proformas will be developed as part of post-guideline documentation to assist health care professionals when assessing and observing people with suspected TBI.

3.1.1 Data collection on presentation

When a person presents to the Emergency Department with a suspected TBI, a clinician who has appropriate training in emergency medicine should collect data to enable decisions to be made about the probability of TBI and the necessity of referring for a CT scan. This data should include:

- age
- mechanism of injury
- vomiting since the injury
- presence of headache since the injury
- presence of seizures since the injury
- presence of anterograde amnesia since the injury or retrograde amnesia of greater than 30 minutes before the injury
- Glasgow Coma Scale score (on presentation and two hours after injury)
- evidence of suspected or open skull fracture
- signs of basal skull fracture
- evidence of trauma above the clavicles
- evidence of drug or alcohol intoxication.⁶

3.1.2 Alcohol

RECOMMENDATIONS	GRADE
Airways, breathing and circulation (ABC) should be stabilised before attention to other injuries.	C
Signs of possible traumatic brain injury should not be attributed to alcohol intoxication alone when assessing people with traumatic brain injury.	C
Blood alcohol levels should be tested and results recorded for all people with suspected traumatic brain injury and a Glasgow Coma Scale score of less than 15 and/or where alcohol intoxication is suspected.	C
People who present with a suspected traumatic brain injury who are intoxicated following drug or alcohol use should have this recorded as part of their assessment.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

The number of people presenting with suspected TBI affected by alcohol has varied from around 40% to 70% in hospital-based studies.^{4,85} There is considerable similarity in the signs of alcohol intoxication and TBI, making the Glasgow Coma Scale unreliable in alcohol-intoxicated people, particularly where levels exceed about 40 mmol/L.⁸⁶ Conversely, if the blood alcohol concentration (BAC) is below about 40 mmol/L alteration in the conscious level should not be attributed to alcohol alone. Therefore, the presence of alcohol should signal caution in the assessment of people with possible TBI, and a lower threshold for CT scan and admission should be observed.

Routine BAC testing in suspected TBI might allow more accurate risk stratification and eventual diagnosis. An alternative is to use a decision point two hours from admission for people where it is suspected that intoxication may account for the symptoms. If the Glasgow Coma Scale has not returned to 15 by that point, a CT scan is indicated whether or not alcohol is involved.⁷⁵ Any deterioration during the two hours would necessitate immediate intervention.

3.2 Primary investigation for people with a suspected traumatic brain injury

RECOMMENDATIONS	GRADE
The diagnosis of intracranial haemorrhage should not be ruled out on the basis of negative skull X-rays.	C
The primary investigation of choice for the detection of clinically significant acute complications of traumatic brain injury is CT imaging of the head.	A
Skull X-rays may be requested as part of skeletal surveys for the detection of non-accidental injury in children and in addition to a CT scan.	C
Skull X-rays in conjunction with high-quality inpatient observation have a role where CT scanning resources are unavailable.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

A 2004 systematic review of clinical decision rules for the selection of people who have sustained a suspected TBI for CT imaging of the head identified skull X-rays as only being of limited value for three reasons.⁷⁶

Firstly, skull X-rays are only of limited value in assisting the diagnosis of intracranial haemorrhage. A meta-analysis found that the sensitivity and specificity of a skull fracture for predicting the presence of intracranial haemorrhage were 38% and 95% respectively. A recent meta-analysis, in children, found a sensitivity of 59% and specificity of 88%. The equivalent predictive values were 0.41 (positive predictive value) and 0.94 (negative predictive value). These figures imply that if there is a skull fracture diagnosed on radiography, the risk of an intracranial haemorrhage is elevated (about 4.9 times higher than before testing), but one cannot rule out an intracranial haemorrhage in people for whom a skull X-ray does not show a skull fracture.

Secondly, the negative predictive power for a CT scan was 99.7%. People with a negative CT scan and no other body-system injuries or persistent neurological findings can be considered for discharge as they are safe from the risk of having an intracranial haematoma at that time. However, it should be recognised that some of these individuals will be too unwell in terms of headache, vertigo, nausea/vomiting, impairment of cognition, motor performance and coordination to be discharged, despite a normal CT scan. It must also be recognised that there will be a small number (more often older people) who develop a chronic subdural haematoma over the ensuing four to six weeks after the injury.

Thirdly, a strategy of either 100% CT imaging of people who present with a head injury or high-quality inpatient observation for people who have sustained a mild head injury will be 100% sensitive for clinically important acute complications of TBI. Early imaging, rather than admission and observation for neurological deterioration, will reduce the time to detection for life-threatening complications and is associated with better outcomes. Therefore, the task is to derive a more sophisticated clinical decision rule for selection that will improve specificity without impairing sensitivity.

The current primary investigation of choice for the detection of clinically significant acute complications of TBI is CT imaging of the head.

For safety, logistic and resource reasons, magnetic resonance imaging (MRI) is not currently indicated as a tool for primary investigation, although it is recognised that additional information of importance to the person's prognosis can sometimes be detected using MRI.⁷

MRI is contraindicated in head investigations unless there is absolute certainty that the person does not harbour an incompatible device, implant or foreign body. There should be appropriate equipment for maintaining and monitoring the person within the MRI environment and all staff involved should be aware of the dangers and necessary precautions for working near an MRI scanner. MRI safety, availability and speed may improve in the future to the point where it becomes a realistic option for primary investigation for people with suspected TBI.⁷

3.2.1. Selection of adults for CT imaging of the head

RECOMMENDATIONS	GRADE
<p>CT scans should be immediately requested for adults who have sustained a head injury, if they have any one of the following risk factors:</p> <ul style="list-style-type: none"> • any deterioration in condition • a Glasgow Coma Scale score of less than 13 when assessed, irrespective of the time elapsed since the injury • a Glasgow Coma Scale score of 13 or 14 two hours after the injury • a suspected open or depressed skull fracture • any sign of basal skull fracture (haemotympanum, 'panda' eyes, cerebrospinal fluid otorrhoea, Battle's sign) • post-traumatic seizure • focal neurological deficit • more than one episode of vomiting • amnesia for more than 30 minutes for events before the injury. 	B
<p>CT scanning should be immediately requested for adults with any of the following risk factors who have experienced an injury to the head with some loss of consciousness or amnesia since the injury:</p> <ul style="list-style-type: none"> • age 65 years or older • coagulopathy (history of bleeding, clotting disorder, current treatment with warfarin) • high-risk mechanism of injury (a pedestrian struck by a motor vehicle, an occupant ejected from a motor vehicle, or a fall from a height of greater than one metre or five stairs). 	B

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

A number of decision rules have been developed for CT imaging in an attempt to identify those at a high risk of TBI complications (usually intracranial haemorrhage).⁷ However, the purpose of scanning those who may be at high risk varies, from the wish to identify any injury requiring medical and/or surgical intervention, through to attempting to identify any injury to the brain of any degree of severity, sometimes for purposes other than determining appropriate treatment, such as support for litigation.

For the purposes of this guideline, the Guideline Development Team has considered the balance of risks and benefits, and recommends that CT scanning be used to identify the need for medical and/or surgical intervention, or to confirm, where there is doubt on clinical assessment, the safety of discharging a person with a head injury.

The UK's NICE *Head Injury* Guideline Development Team based its decision rules for CT scanning following head injury on the seven-point Canadian CT Head Rule.⁷⁵ The Canadian CT Head Rule reported a 50% (95% CI 48–51) specificity rate for detecting clinically significant brain injury.

This section of the guideline is based on the NICE guideline.⁷ Since the NICE guideline, there has been further work on developing clinical decision criteria for determining those who require CT scanning following apparently mild TBI. One example of such work is the criteria identified by the WHO Collaborating Centre Task Force on Mild Traumatic Brain Injury.

These criteria were derived from a systematic review of the literature on diagnostic procedures and selection rules for imaging of people with head injury.⁷⁶ However, the WHO criteria were specifically developed to identify people who could be quickly and safely discharged from hospital Emergency Departments.

The team developing this guideline for New Zealand considered that if the WHO criteria were adopted, it would result in a large increase in the number of people unnecessarily receiving CT scans. The public and peer consultation for this guideline confirmed that these criteria were considered too broad and demanding of resources to be appropriate for the New Zealand setting.

In order to provide comprehensive guidance, the seven-point Canadian CT Head Rule⁷⁵ has been adapted for the New Zealand setting as follows:

- deterioration in condition at any time is a strong indicator for an immediate CT scan
- people with post-traumatic seizure, focal neurological deficit or coagulopathy, meet selection criteria for CT scanning
- drug or alcohol intoxication should not be assumed to be the cause of an altered Glasgow Coma Scale score. The decision to CT scan should be applied regardless of the influence of intoxication
- people with non-symptomatic risk factors (ie, aged 65 years or older, coagulopathy, high-risk mechanism of injury) should at least have had an injury to the head and an instance of loss of consciousness or amnesia (ie, the main signs and symptoms used to screen people for inclusion in the Canadian CT Head Rule study) before receiving a CT scan. This is to prevent the possibility of people with no signs or symptoms receiving a CT. For consistency, falls from three feet have been changed to falls from greater than one metre.

3.2.1.1 Observation of adults

Some adults who have had an injury to the head may be observed in hospital for 24 hours as a safe alternative to a CT scan, although it should be remembered that early imaging (compared with observation) is associated with better outcomes.⁷

The Guideline Development Team acknowledges that for clinicians in rural centres with limited access to CT, it can be difficult to weigh up the pros and cons of transfer for a CT scan, when the risks of a complication of TBI are fairly low versus the very real difficulties of managing such a complication at a distance from a neurosurgical centre. In some situations, observation for 24 hours rather than CT scan is a reasonable compromise.

People with the following factors must be referred for CT scan as observation may not be a safe and effective alternative for these people:

- any deterioration in condition
- a Glasgow Coma Scale score of less than 13 at time of assessment irrespective of time elapsed since the injury or Glasgow Coma Scale score of 13 to 14 two hours after injury
- any sign of basal skull fracture (haemotympanum, ‘panda’ eyes, cerebrospinal fluid otorrhoea, Battle’s sign)
- focal neurological deficit.

People without these signs and symptoms, but with any other of the factors indicating a CT scan, may be admitted for observation for 24 hours, as an alternative to early CT scan.⁷⁶ It is recommended that the presence of factors that would normally indicate a need for CT scanning (eg, post-traumatic seizure with full recovery and no focal signs; amnesia greater than 30 minutes; age of 65 years or older; high-risk mechanism of injury) be discussed with the relevant neurosurgical centre regarding the appropriateness of observation and possible need for transfer before making the decision not to transfer for CT scan.

3.2.2 Selection of infants and children and young people for CT imaging of the head

There is some evidence that the prevalence of intracranial complications in children and infants is much lower than in adults,⁷ but it is important that any complications requiring neurosurgical intervention are detected as early as possible. CT scanning in infants and children carries a greater risk than for adults, both from the increased risk of lifetime fatal cancer from the radiation exposure (see Appendix D for a link to a supplementary resource) and from the sedation and anaesthesia frequently needed in younger children for the scanning procedure. Therefore, it is important to ensure that the balance of benefits and harms of CT

scanning is considered. For this reason, the criteria in this section are aimed at detecting the possible need for neurosurgical intervention only and not to gain information about the existence of TBI.

There are several recent robust studies that have derived clinical decision rules from large study populations, which can be used to select candidates in the paediatric setting for imaging of the head.^{87,88} These include rules developed for use specifically with infants under the age of two years.

Although at the time of writing none of these decision rules has been independently validated, there is considerable concordance between studies on the factors identified, and therefore the validity of these factors can be inferred.

Current evidence supports the following factors indicating a need for imaging in children aged 0 to 16 years (see Figure 3.1):

- post-injury adverse events or signs, including focal neurological deficits, seizures, loss of consciousness, altered mental state, more than one episode of vomiting
- a paediatric Glasgow Coma Scale score of 13 or less, particularly an initial or 'field' (pre-hospital) Glasgow Coma Scale score of 13 or less, or any decrease in Glasgow Coma Scale score
- skull fracture, either obvious or suspected on the basis of clinical signs
- injury resulting from a fall from one metre or five stairs, or less in the case of younger children
- non-accidental cause of injury
- younger age
- lethargy or irritability on examination.^{76,82,83,87-89}

3.2.2.1 Infants aged 24 months or less

In infants aged two years or younger, there are additional risk factors for TBI indicating CT scanning, which include:

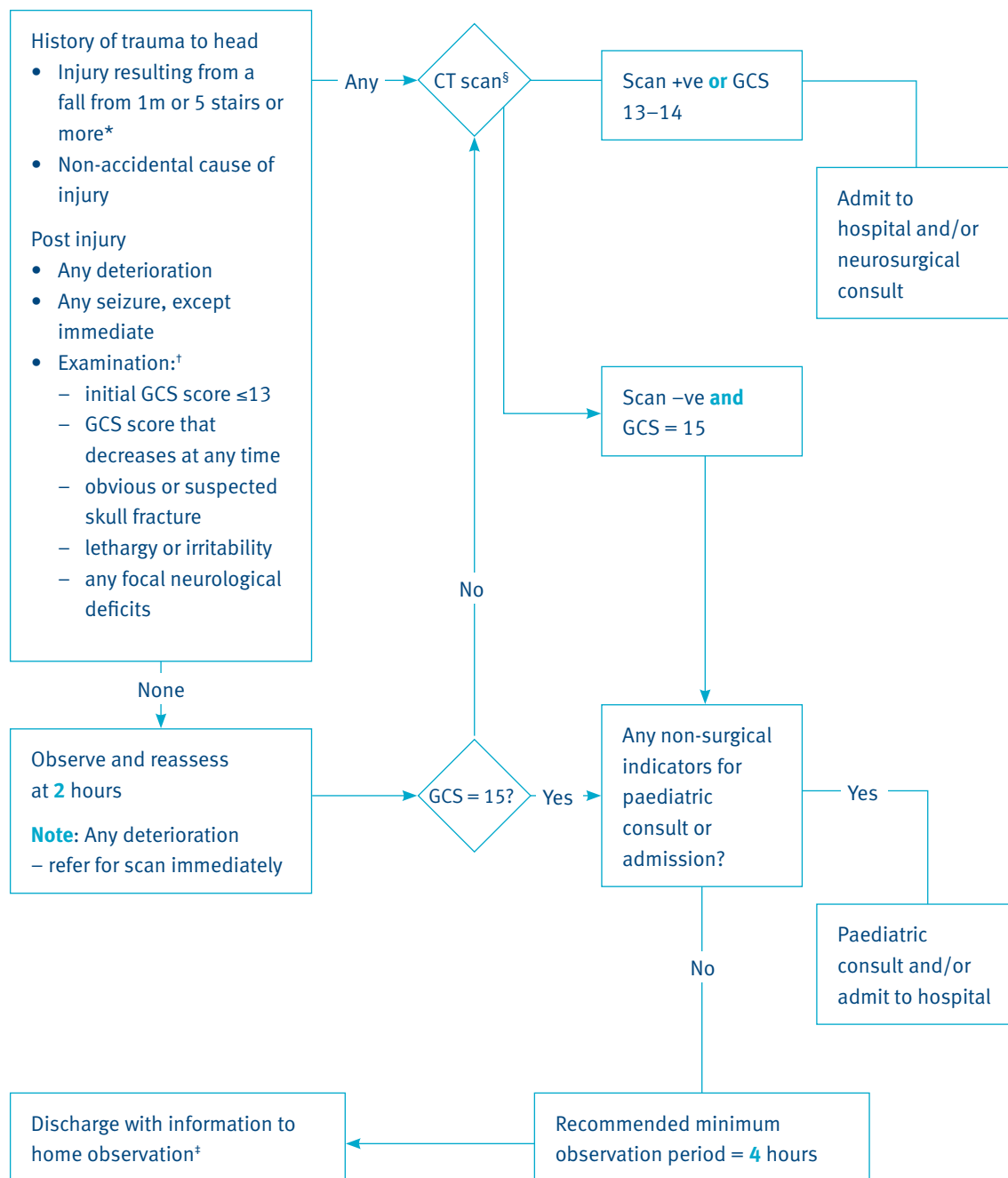
- soft tissue injury such as swelling or haematoma
- occipital or temporal/parietal location of injury
- age under one year.

Taken together, these suggest a lower threshold for scanning if a large scalp swelling is present, if the haematoma is temporal/parietal or occipital rather than frontal, and the age is younger.

3.2.3 Skull X-rays in infants and children

The literature on skull X-ray in children and infants indicates that, as with adults, the sensitivity of skull X-ray is too low to be the primary investigation (ie, the absence of skull fracture does not predict the absence of intracranial complications).^{7,87} In studies which have included both children and adults, there is evidence that adult rules for selection for X-ray can be safely applied to children, but these studies have suffered from statistical power problems.⁷ The evidence regarding the safety of adult rules with infants is inconclusive.⁷

FIGURE 3.1:
DIAGNOSTIC MANAGEMENT AND SELECTION FOR IMAGING OF CHILDREN AND YOUNG PEOPLE AGED <17 YEARS



* In younger children, falls from lesser heights may have a high risk of intracranial complications.

† Use paediatric version of GCS.

‡ Children and young people with a head injury should only be discharged home if they have a responsible adult who can observe them for any deterioration.

§ CT scanning of infants and children can be difficult and may require anaesthesia and pose a significant radiation risk. If uncertain about benefits of CT scan versus risks of scan, seek specialist advice (Emergency Department specialist, intensive care unit specialist, neurosurgeon, paediatrician) before scanning.

GCS = Glasgow Coma Scale

3.3 Non-accidental injury in children

The acute management of non-accidental injury is outside the scope of this guideline. However, it is important that health practitioners are aware that the head injury examination is an important opportunity to identify this problem. There is evidence that a distinct pattern of brain injuries is associated with non-accidental injury in children. This results from the different mechanisms of injury in accidental versus non-accidental head injury. Non-accidental head injuries are more likely to involve inertial forces (eg, shaking) whereas accidental injuries are more likely to involve blunt trauma.⁷

Due to the distinct pattern of injuries involved, skull X-ray as part of a series of plain X-rays (skeletal survey), along with other well established examinations (eg, ophthalmoscopic examination for retinal haemorrhage, examination for pallor, anaemia, tense fontanelle) and additional investigations (eg, CT and MRI imaging), has a role in detecting non-accidental head injuries in children (ie, aged less than 12 years).⁷

Work on the derivation of clinical decision rules to predict non-accidental injury, based on imaging patterns, has recently started.⁹⁰ However, decision rules in this area will require substantial validation before they can inform clinical practice.

3.4 Imaging of people with a suspected traumatic brain injury

GOOD PRACTICE POINTS

All CT scans of the head should be reviewed by a clinician who has been deemed competent to review such images.	✓
A full or interim written report for the person's notes should be provided within an hour of all imaging procedures performed on people with head injury.	✓
Neurosurgical or anaesthetic referral for people with severe head injury should not be delayed for imaging of any kind.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

It is assumed that clinicians will adhere to general principles of good practice in imaging as outlined by the Royal College of Radiologists.⁷ Where necessary, transport or transmission of images should be used to ensure that a competent clinician reviews the images.⁷

There may be occasions where the CT scan needs to be repeated, in addition to the recommendation regarding imaging during observation. For example:

- if an initial scan shows an abnormality, such as a small intracranial haematoma and there is clinical deterioration
- to check that an original small lesion has not progressed (often scan repeated the next day)
- to check that an initial small lesion has resolved spontaneously (often scan repeated a week or two later).

3.5 Use of corticosteroids in acute traumatic brain injury

RECOMMENDATION	GRADE
Avoid corticosteroids in the management of people with acute traumatic brain injury of any severity.	A

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

A 2004 trial recruited 10,008 participants with acute TBI and a Glasgow Coma Scale of 14 or less in over 40 countries. Participants were randomised to receive 48 hours of intravenous methylprednisolone or placebo. Results showed that two-week all-cause mortality was 18% higher in the methylprednisolone group. This is strong evidence to avoid corticosteroids in people with acute TBI of any severity.⁹¹

3.6 Involving neurosurgical care

Information in this section has been adapted for New Zealand from the NICE guideline on head injury.⁷ A small number of people with TBI will require an operation or invasive monitoring. Apart from situations where the person is far from a neurosurgical centre and has a life-threatening complication requiring urgent intervention, decisions about surgery will normally be made by, or in consultation with, a neurosurgeon. There are no absolute rules for deciding which people should be discussed with, and/or managed by, a neurosurgeon. Rules will vary depending on local availability, preference of neurosurgeons and other factors.

Although local centres will need to decide on their own criteria, in general, the person's condition should be discussed with the nearest neurosurgeon, with a view to their taking over their care in the following clinical situations:

- the person is deteriorating, particularly regarding level of consciousness (documented Glasgow Coma Scale score fall of two or more), has developed pupil dilation or other new neurological deficit
- the person has had a severe TBI (Glasgow Coma Scale score 8 or less), especially if they have remained unconscious from the time of injury
- the person has a significant neurological deficit following the TBI
- the person has a 'surgically significant lesion' on imaging, which may include:
 - a mass lesion with >1 cm midline shift or with acute hydrocephalus. Such lesions include acute extradural and acute subdural haematomas, cerebral contusions and traumatic intracerebral haematomas
 - open/compound skull fracture
 - obvious brain wounds visible at the bedside
 - diffuse brain swelling/cerebral oedema.

A list of examples of abnormalities not considered 'surgically significant' was produced by a survey of neuroradiologists and emergency physicians in Canada.⁷⁵ However, a survey conducted in the UK in 2003 by the Society of British Neurological Surgeons found substantial concern about these Canadian criteria.⁷

Further situations where a neurosurgeon should be consulted, not necessarily with a view to their taking over care, would be:

- a cerebrospinal fluid leak
- definite or suspected penetrating injury
- a seizure without full recovery.

The exact nature and timing of the neurosurgical interventions are beyond the scope of this guideline. It is assumed that best practice will be followed once neurosurgeons have become involved with a particular person. Details of best practice in neurosurgical management for adults are given in an evidence-based guideline⁹ available from the Brain Trauma Foundation, at www2.braintrauma.org/guidelines/ and an evidence-based guideline for infants, children and adolescents⁹² is available from www.ohsu.edu/news/2003/neuroGuidelines/.⁸¹

3.7 Transfer from secondary to tertiary care settings

RECOMMENDATIONS	GRADE
There should be designated consultants in both the referring hospital and the tertiary care facility (generally a neurosurgical unit but may be an adult or paediatric intensive care unit) with responsibility for the transfer and receipt of people (adults and children) with suspected traumatic brain injury.	C
Local guidelines, consistent with national guidelines, on the transfer of people with suspected traumatic brain injury, including the transfer of the responsibility for care, should be drawn up between the referring hospital and the tertiary care facility.	C
Resuscitation and stabilisation of the injured person should be completed before transfer. A person persistently hypotensive despite resuscitation should not be transported until stabilised.	C
All people requiring transfer to tertiary care with Glasgow Coma Scale scores of 8 or less should be intubated and ventilated.	C
A person with suspected traumatic brain injury should be accompanied by a doctor with at least two years' experience in an appropriate specialty, who should: <ul style="list-style-type: none"> • be familiar with the pathophysiology of traumatic brain injury, drugs, equipment and working in the ambulance or helicopter • have received specialist training in the transfer of people with traumatic brain injury • have an adequately trained assistant • be provided with appropriate clothing and medical indemnity and personal insurance. 	C
The transfer of a child or infant to a tertiary care facility should be undertaken by staff experienced in the transfer of critically ill children.	C
The transfer team should have a means of communication with their base hospital and the tertiary care facility during the transfer.	C
Appropriate resources for education, training and audit should be provided.	C

Continued...

RECOMMENDATIONS	GRADE
<p>Indications for intubation and ventilation in people with traumatic brain injury: immediately.</p> <ul style="list-style-type: none"> • Coma (Glasgow Coma Scale score of 8 or less). • Loss of protective laryngeal reflexes. • Ventilatory insufficiency: <ul style="list-style-type: none"> – hypoxaemia (PaO₂ less than 65 mm Hg on air or less than 95 mm Hg on oxygen) or – hypercarbia (PaCO₂ greater than 45 mm Hg). • Spontaneous hyperventilation causing PaCO₂ less than 30 mm Hg. • Respiratory arrhythmia. 	C
<p>Indications for intubation and ventilation in people with traumatic brain injury: before the journey.</p> <ul style="list-style-type: none"> • Significantly deteriorating conscious level, even if not coma. • Bilateral fractured mandible. • Copious bleeding into mouth. • Seizures. 	C
Carers and family/whānau should have as much access to the injured person during transfer as is practical.	C
Carers and family/whānau should be fully informed about the transfer.	
Service provision in the area of paediatric transfer to tertiary care should also follow these principles.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

The risk of a further injury to people with TBI during transfer to tertiary care is well established.⁷

Recommendations in this section have been adapted for New Zealand from the NICE guideline on head injury.⁷

3.8 Indications for hospital admission

RECOMMENDATIONS	GRADE
<p>Criteria for admission to hospital following traumatic brain injury:</p> <ul style="list-style-type: none"> • a deteriorating Glasgow Coma Scale score • clinically significant abnormalities on imaging • a Glasgow Coma Scale score of less than 15 after imaging • when criteria for CT scanning are met but it is not possible • focal or abnormal neurological signs • early post-traumatic seizure • skull fracture • a major force of injury • continuing signs of concern to the clinician (eg, vomiting, severe headaches, amnesia) • other reasons for clinician concern (eg, drug or alcohol intoxication, other injuries, shock, suspected non-accidental injury, meningism, cerebrospinal fluid leak, where a scalp laceration overlies a fracture, or due to the injured person's age) • when there is no responsible family member, caregiver or close friend under whose care the person could be discharged • 'mild' head injuries with symptoms such as headache, photophobia, nausea and vomiting, or amnesia requiring management. 	C
People who require an extended period in a recovery setting due to the use of sedation or general anaesthetic during CT imaging should not normally require admission.	C
Resuscitation and stabilisation of the injured person should be completed before transfer. A person persistently hypotensive despite resuscitation should not be transported until stabilised.	C
People with multiple injuries should be admitted under the care of the team appropriate to their most severe and urgent problem.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

The recommendations are based on the NICE guideline on head injury.⁷ Although most of the criteria concern injuries at the more severe end of the spectrum of TBI, a significant number of people with 'mild' TBI may also need admission so as to better manage symptoms of headache, photophobia, nausea and vomiting, amnesia and other post-concussion sequelae. Admission allows for appropriate input and advice from a neurosurgeon, neurosciences nurses, and other members of the multidisciplinary team, including occupational therapists and social workers. Such input and help at this time can be of considerable assistance in the recovery and rehabilitation process and the benefits should not be underestimated.⁹³

This guideline places emphasis on the early diagnosis of clinically significant brain injuries, using a sensitive and specific clinical decision rule with early imaging. Admission to hospital is intrinsically linked to imaging results, on the basis that people who do not require imaging are safe for discharge to the community (provided no other reasons for admission exist) and those who do require imaging can be discharged following negative imaging (again, provided no other reasons for admission exist). However, observation of the injured person still forms an important part of the acute management phase, for people with abnormal CT results who do not require surgery, and/or for people with unresolved neurological signs, and/or for some people with initially abnormal Glasgow Coma Scale scores who are observed, without CT, for two hours.

Neurosurgical and intensive care management of severe TBI is outside the scope of this guideline.

3.9 In-hospital observation of people with traumatic brain injury

RECOMMENDATIONS	GRADE
OBSERVATION: GENERAL	
In-hospital observation, including all Emergency Department observation, of a person with traumatic brain injury should be conducted only by health care practitioners competent in the assessment of traumatic brain injury.	C
Observation of infants and young children with traumatic brain injury should only be performed by units (including normal paediatric observation settings) with staff trained and experienced in their observation.	C
TYPE AND FREQUENCY OF OBSERVATIONS	
Minimum documented neurological observations should be: <ul style="list-style-type: none"> • Glasgow Coma Scale score • pupil size and reactivity • limb movements • respiratory rate • heart rate • blood pressure • temperature. 	C
Observations should be performed and recorded every 15 minutes, or more frequently in some cases, until the person has achieved a Glasgow Coma Scale score of 15 on two consecutive occasions.	C
For people with an initial Glasgow Coma Scale score of 15, or who have returned to a Glasgow Coma Scale of 15 on two consecutive observations, the minimum frequency of observations following the initial assessment should be: <ul style="list-style-type: none"> • half hourly for the first two hours, then • one hourly for four hours, then • two hourly thereafter. 	C
NEED FOR REASSESSMENT/OTHER ACTION	
If a person with a Glasgow Coma Scale score of 15 deteriorates at any time after the initial two-hour period, observations should revert to every 15 minutes or more frequently if necessary and follow the original frequency schedule.	C
An urgent reappraisal should be done by the supervising doctor if any of the following signs of neurological deterioration occur: <ul style="list-style-type: none"> • development of agitation or abnormal behaviour • a sustained (ie, ≥ 30 minutes) drop of one point in the Glasgow Coma Scale score • any drop of more than two points in the Glasgow Coma Scale score • development of severe/increasing headache or persisting vomiting • new or evolving neurological symptoms or signs. 	C

RECOMMENDATIONS		GRADE
NEED FOR REASSESSMENT/OTHER ACTION CONTINUED		
An immediate CT scan should be considered if any of the above signs of neurological deterioration occur.		C
Further CT or MRI scanning should be considered in the case of a person who has had a normal CT scan but who has not achieved a Glasgow Coma Scale score of 15 after 24 hours' observation.		C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT	
TYPE AND FREQUENCY OF OBSERVATIONS Post-traumatic amnesia and focal neurological signs should be assessed at regular intervals.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Observation should occur throughout the person's stay in the Emergency Department or after admission following abnormal imaging results. All clinicians should use a standard 'suspected TBI' proforma in their documentation when assessing and observing people with suspected TBI. Separate adult-specific and child and infant-specific proformas should be used. The adult and paediatric Glasgow Coma Scale and derived scores (see Appendix C) should form the basis of observation, supplemented by other important observations.

There is some evidence from the UK that Emergency Department observation wards are more efficient than general acute wards in dealing with people admitted for short-stay observation, with more senior supervision, fewer tests and shorter stays.⁷ There have also been concerns about the experience and skills of staff on general and orthopaedic acute wards in head injury care.⁷ This resulted in a recommendation by the Royal College of Surgeons of England in 1999 that adults needing a period of observation be admitted to a dedicated observation ward within or adjacent to an Emergency Department.⁷

Where the optimal management of other injuries necessitates management in an orthopaedic or general surgical ward, the observations and responses described in the recommendations must continue.

It is recommended that in-hospital observation of people with a TBI, including all Emergency Department observation, should only be conducted by professionals competent in the assessment of TBI.⁷ The service configuration and training arrangements required to ensure that this occurs are beyond the scope of this guideline, but best practice demands that this issue be addressed by future policy.

Observation of infants and young children (ie, those aged less than five years) is a difficult exercise and therefore should only be performed by units with staff experienced in the observation of infants and young children with a head injury. Infants and young children may be observed in normal paediatric observation settings, as long as staff have the appropriate training and experience.

Medical, nursing and other staff caring for people with suspected TBI admitted for observation should all be capable of performing the observations recommended in this guideline. The acquisition and maintenance of observation and recording skills require dedicated training and this should be available to all relevant staff. Specific training is required for the observation of infants and young children.

3.10 In-hospital support for families/whānau and carers

Early support can help the injured person's family/whānau or carer(s) prepare for the effects of head injury. This support may reduce the psychological sequelae experienced by the family/whānau or carer(s) and result in better long-term outcomes for both the injured person and their family/whānau or carer(s). For the family/whānau or carer(s) thrust into a hospital acute care setting, the shock can be overwhelming and cause additional tension or stress. It can be a particularly traumatic experience for a child visiting a sibling or parent with a head injury.

Measures to make the experience less daunting should be put in place.⁷ There should be a protocol for all staff to introduce themselves to family/whānau members or carers and briefly explain what they are doing. In addition, a photographic board with the names and titles of personnel in the hospital departments caring for people with head injury can be helpful.

Consumer information sheets detailing the nature of head injury and any investigations likely to be used should be available in the Emergency Department.⁷ Staff should consider how best to share information with children and introduce them to the possibility of long-term complex changes in their parents or siblings. Literature produced by consumer groups may be helpful. Fact sheets prepared for people and their families with TBI are being prepared (see BIANZ www.brain-injury-nz.org or ACC www.acc.co.nz).

The presence of familiar friends and family/whānau at the early stage following admission can be very helpful. The person recovering consciousness can easily be confused by unfamiliar faces and the unfamiliar environment in which they find themselves. Family/Whānau or carers are often willing to assist with simple tasks, which, as well as helping nursing staff, helps friends and family/whānau to take an active role in the recovery process.

Family/Whānau or carers should be encouraged to talk and make physical contact (eg, holding hands) with the injured person, although it is important to ensure family/whānau, carers and friends do not feel that they have to spend many hours at the bedside, and to ensure they also have breaks and sleeps from time to time. This may be an opportune moment to mention consumer support organisations and introduce their literature.

Voluntary consumer support groups can speak from experience about the real-life impact that follows head injury and can offer support following discharge from hospital. This is particularly important where statutory services are lacking. There should be a board or area displaying leaflets or contact details for consumer support organisations, either locally or nationally, to enable family members to gather further information.

3.11 Discharge from hospital

RECOMMENDATIONS	GRADE
<p>A person with suspected traumatic brain injury may be discharged if:</p> <ul style="list-style-type: none"> the person has a Glasgow Coma Scale score of 15 (or in children, normal consciousness as assessed by the paediatric version of the Glasgow Coma Scale) and CT is not indicated <p>or</p> <ul style="list-style-type: none"> head or cervical spine imaging is normal and the person has returned to a Glasgow Coma Scale score of 15 (or in children, normal consciousness as assessed by the paediatric version of the Glasgow Coma Scale) <p>and</p> <ul style="list-style-type: none"> no other factors are present that would warrant a hospital admission there are appropriate support structures for safe transfer and subsequent care and supervision. 	C
<p>People with suspected traumatic brain injury who have been admitted to hospital may be discharged to the community if:</p> <ul style="list-style-type: none"> there is resolution of all significant symptoms and signs there are appropriate support structures for their safe transfer and subsequent care and supervision. 	C
<p>Infants or children presenting with suspected traumatic brain injury who require imaging of the head or cervical spine should not be discharged until assessed by a clinician experienced in the detection of non-accidental injury.</p>	C
<p>All personnel involved in the triage and assessment of infants and children with suspected traumatic brain injury should have training in the detection of non-accidental injury.</p>	C
<p>All people with any degree of suspected traumatic brain injury who are discharged should receive verbal advice which:</p> <ul style="list-style-type: none"> outlines the risk factors in their community setting explains that some people make a quick recovery, but may later experience complications gives instructions on contacting community services in the event of delayed complications. 	C
<p>People who initially presented with drug or alcohol intoxication and are being discharged should receive information and advice on alcohol or drug misuse.</p>	C
<p>People with any degree of suspected traumatic brain injury with no carer at home should be discharged only when there is negligible risk of late complications, or when suitable supervision arrangements have been organised.</p>	C
<p>People with mild traumatic brain injury may be advised in their discharge information that bed rest may temporarily help alleviate excessive dizziness, but will not aid recovery.</p>	B

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

People discharged from hospital after a traumatic brain injury should have had their general practitioner notified either before or at the point of discharge, with details of any residual impairments and details of the planned follow-up.



People who are discharged after a suspected traumatic brain injury sustained after a self-harm or suicide attempt should have a risk assessment performed and should be referred as appropriate.



This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

These recommendations have been reproduced from the NICE guideline.⁷

All people discharged from hospital after a TBI should have had their general practitioner notified either before or at the point of discharge, with details of any residual impairments and details of the planned follow-up.

People who are discharged after sustaining a suspected TBI from a self-harm or suicide attempt should have a risk assessment performed and should be referred as appropriate (also see Chapter 14, *Special issues*). For more details of management of people after a suicide attempt, see the guideline, *The Assessment and Management of People at Risk of Suicide* available at www.nzgg.org.nz.

3.11.1 Discharge and Glasgow Coma Scale status

People presenting with suspected TBI should not be discharged to the community until they have achieved a Glasgow Coma Scale score of 15.

3.11.2 Bed rest

People should not be routinely recommended bed rest, but may be advised that if they suffer excessive dizziness, bed rest may help. A controlled trial randomised people with mild TBI to bed rest for six days post-injury or no bed rest. They found that bed rest had no effect on the speed of resolution of symptoms. However, there was significantly less dizziness reported by the intervention group, and it was concluded that bed rest may have some palliative effect on dizziness in the first two weeks post-injury.⁹⁴

3.12 Referral to rehabilitation in the acute phase after traumatic brain injury

The information in this section refers to the rehabilitation issues in the acute phase after TBI. More detailed information about identifying clinically significant TBI and rehabilitative needs is provided in Chapter 4, *Rehabilitation services*. Rehabilitation may begin in hospital, be organised to commence following discharge from hospital, or begin when the person re-presents with symptoms after discharge. Careful assessment of the need for rehabilitation during the acute management of head-injured people should take place during hospital care, prior to discharge and if the person has continuing or emergent symptoms of significant brain injury following discharge.

A small number of people will also develop late complications despite normal CT results and an initial absence of signs and symptoms. A well designed system of high-quality discharge advice and post-discharge observation by a carer is required to ensure that people receive appropriate care as needed, as soon as possible. The role of carers at home in the early post-discharge observation of people with TBI is important and should be guided by clear and detailed information. There should be clearly defined pathways back to hospital care for people who show signs of late complications.^{7,8} For more details of post-discharge follow-up see Chapter 8, *Management of persistent symptoms and activity limitation following mild traumatic brain injury*.

Early rehabilitative intervention in clinically significant TBI improves outcomes.^{95,96} Therefore, rehabilitation should start as soon as possible.

3.12.1 Assessment for rehabilitation in the acute stage

Once a person with TBI has regained consciousness, it is important to determine what neurological damage they might have sustained in order to determine their need for immediate rehabilitative interventions. The assessment should be done by someone with expertise in assessment of neurological impairment and disability, and results and required actions should be documented accurately. The following areas should be assessed:

- motor impairments, such as weakness, altered tone and lack of coordination in the limbs
- problems with speech and swallowing
- sensory impairment, including visual problems such as reduced visual acuity, loss of visual field, gaze palsies and hearing loss
- cognitive impairments, especially of memory, concentration and/or orientation
- language problems, particularly cognitive communication disorder or aphasia
- reduced control over bowels and bladder
- emotional, psychological and neurobehavioural problems.⁸

With more severely injured people, the first stage of rehabilitation may occur at the acute stage of intensive care in hospital, where interventions focus on reducing impairment and secondary complications. As the person starts to recover, they may need rehabilitation in a hospital inpatient or community residential environment to enable their successful discharge to the community.

If a person with TBI is still in hospital (including intensive care unit) 48 hours following the injury, the advice of and a review by a rehabilitation team should be sought as soon as possible. The purpose of this review is to determine appropriate referral and interim management to prevent the development of secondary complications.⁸

3.12.2 Post-acute referral to rehabilitation

Before discharge is considered for people who have had a clinically significant TBI, an assessment of the need for immediate inpatient or outpatient rehabilitation must be undertaken. People who require post-acute inpatient care should be transferred to a specialist rehabilitation unit as soon as they are medically stable and able to participate in rehabilitation.^{95,96}

Before a person with TBI is discharged following emergency care, there should be an assessment of their need for rehabilitation, and referral if necessary. They should be assessed for any residual physical, cognitive, emotional or behavioural deficits which are negatively affecting their functioning and referred to specialist follow-up services (hospital based or community) as appropriate.⁸

The awareness of the person, their family/whānau and carer(s) of the current problems and how to manage them should also be assessed. All people being discharged after a TBI should be given details of who to contact if they have any concerns and how to contact them. They should also receive information about any problems they are likely to face and how to manage them. A member of the person's family/whānau, or a friend or carer, with the injured person's consent, should also be given this information.^{8,97}

3.12.3 Criteria for referral to rehabilitation

People with TBI will need referral to a specialist rehabilitation service which is familiar with the problems of people with TBI, if they have:

- difficulty with body functions
- difficulty with activities that they were able to complete prior to the injury
- difficulty participating in their usual social roles (pre-injury, or as it would have been had the injury not occurred).⁸

People should be referred to a service that can assess the nature and severity of difficulties in these areas and includes access to a multidisciplinary team. The service should have the capacity to identify appropriate interventions to aid recovery or compensation.

Ideally, rehabilitation will take place in the person's usual environment. This does not exclusively mean their home environment, but also includes other settings in which their usual social role requires them to function. Where this is not practical, rehabilitation is undertaken in an environment conducive to intervention, and intervention strategies are generalised (with active support) into the usual environment. See also Chapter 4, *Rehabilitation services*.

Chapter 4:

Rehabilitation services

Overview

- Over the past 20 years there has been a significant change to the rehabilitation model. Rehabilitation services for people with TBI should be based on achieving well-being rather than on a model of deficit and dependency.
- In order for TBI rehabilitation to be effective, rehabilitation services should:
 - approach people with TBI from a participation perspective
 - have the necessary skills and experience to provide appropriate and context-specific assessments and interventions for people with TBI.
- Rehabilitation for people with clinically significant TBI has been shown to be effective in terms of improving outcomes for adults and children with TBI, and their carers, and is cost effective.
- Rehabilitation services must acknowledge that different people require different input at different stages in their recovery.
- There are distinct stages of rehabilitation and each has a different aim in relation to TBI. The four stages are:
 1. acute care/neurosurgery
 2. residential rehabilitation
 3. non-residential rehabilitation
 4. longer-term community support.
- The transition between the stages of TBI rehabilitation should be seamless, which requires effective communication and sharing of information.
- There is substantial evidence of the effectiveness of community-based rehabilitation.
- People with TBI may be referred to different types of residential services for rehabilitation. There are specific criteria for referral to these residential services.
- Coordination of services and communication between them, both potentially difficult, are a very necessary part of effective TBI rehabilitation.
- There is international agreement (both research and expert opinion) on the benefits of individual ‘case managers’ to support the individual and their family throughout the course of their recovery.
- Delivery of rehabilitation is most effective when done by a coordinated, multidisciplinary team of people from a range of different disciplines, taking an interdisciplinary approach.

4.1 The rehabilitation process

Before describing rehabilitation services, it is necessary to be clear about what constitutes best practice rehabilitation in the 21st century. In the past 20 years there has been a sustained move away from a deficit-based, clinician-dominated rehabilitation model. That model was based on the premise that all that was required to deliver good outcomes for people was to identify deficits caused by the disease process and provide interventions that ameliorated those deficits either through functional recovery or adaptation. This linear model of rehabilitation was represented by the International Classification of Impairments, Disabilities and Handicaps⁹⁸ and tended to reinforce existing hospital-dominated structures where hospital services focused on impairments, and people with disabilities were left to look after themselves or were considered substantially later in the rehabilitation process.

Modern rehabilitation practice is based around five key points.

1. The process is non-linear (see Figure 4.1).
2. There is an early focus on participation. Impairment and activity restriction are assessed and interventions planned in the context of the individual's participation goals.
3. The person's strengths and wishes are acknowledged, as well as those of their support team, rather than the focus being solely on deficits.
4. The majority of the rehabilitation process occurs in a community context and in the absence of health professionals. The role of the health care professional is to facilitate, problem-solve, educate and identify, and remove barriers to full community integration for the individual. They also have the role of ensuring that the person and their support team can take on as much control of the rehabilitation process as they are happy and able to handle at that time. This is a continually iterative process.
5. Rehabilitation is a process that includes four core components:
 - i. assessment – to determine the relevant rehabilitation approach
 - ii. planning – that involves the development of meaningful and collaboratively determined goals
 - iii. interventions – that are specific, measurable, attainable and time-limited to meet these goals
 - iv. evaluation – of that intervention, before further iterations of this cycle.

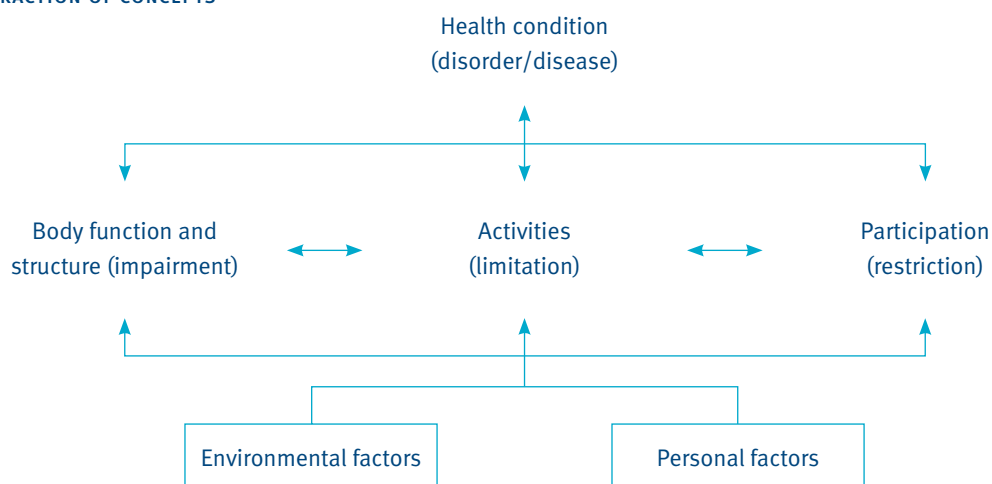
These points apply to TBI rehabilitation as well as rehabilitation in general. In order to practise effective TBI rehabilitation in the current environment, the following approaches are recommended.

1. Approach people with TBI primarily from a participation perspective, considering issues around their ability to:
 - live independently
 - drive or use public transport
 - return to work or education
 - participate in leisure and social activities
 - fulfil family roles and maintain personal, sexual and family relationships.

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

2. Have the necessary skills and experience to provide appropriate and context-specific assessments and interventions for people with TBI that are likely to contribute to enhanced participation and/or quality of life. Despite a primary focus on participation, the ICF model acknowledges that intervention at the level of pathology and impairment may have substantial benefits for the person. Too rigid a focus on participation (eg, that issues around pathology and impairment are missed) can have devastating consequences, for example failing to make a diagnosis of depression or seizures post-TBI or failure to prevent contractures. This means that the rehabilitation team needs to have the necessary skills to undertake assessment and management at all levels of health for people following TBI but with an emphasis on the level of participation.

FIGURE 4.1:
INTERACTION OF CONCEPTS



Reproduced from: World Health Organization. *Towards a Common Language for Functioning, Disability and Health: ICF*. Geneva: WHO; 2002.

Rehabilitation for people with clinically significant TBI has been shown to be both effective in terms of improving outcomes for adults and children with TBI and their carers, and cost-effective.^{10,11,99–103}

Rehabilitation for people with clinically significant TBI may differ from rehabilitation in general due to the influence of executive deficits on the rehabilitation process. Executive deficits refer to limitations associated with primarily frontal lobe damage, which influences attention and concentration, initiation and goal direction, judgement and perception, learning and memory, speed of information processing and communication and other cognitive skills, such as planning and organisation.^{104,105}

Rehabilitation services for individuals after TBI must attend to the following issues for the person with TBI:

- a compromised ability to set goals, plan and organise and initiate behaviour to achieve these goals, and difficulty inhibiting behaviour incompatible with these goals. The individual with frontal lobe injury may have reduced ability to apply strategies or actions flexibly to new situations and to think clearly under stress. Thus, individuals with TBI are more likely to respond to an **antecedent** approach to intervention. An antecedent approach is one that is proactive (ie, identifying potential challenges and barriers for the individual in advance rather than relying on consequences and rewards applied after the event, as in some traditional approaches to behaviour management)¹⁰⁶
- a compromised view of the individual's world and evaluation of self, which may 'take the form of perplexity regarding one's lack of ability, frank unawareness of deficits, active denial of the effects of the injury or some combination of these'¹⁰⁷
- cognitive and physical fatigue, which frequently accompanies the condition.¹⁰⁸ Note that the individual may be restless, distractable, disorganised or abnormally loquacious. Mood may be exaggerated with ready laughter or tears. The individual may be swift to argue, difficult to reason with, and may deny fatigue
- a lack of correspondence between the results of conventional assessment of structured tasks and performance in everyday life.

Neurological recovery following TBI can occur over an extended period of many months or years. Fundamental to rehabilitation services is the appreciation that different people need different input at different stages in their recovery, and that sometimes lifelong support may be required. The carers of people with significant TBI may also require support over long periods of time.

4.2 Stages of rehabilitation

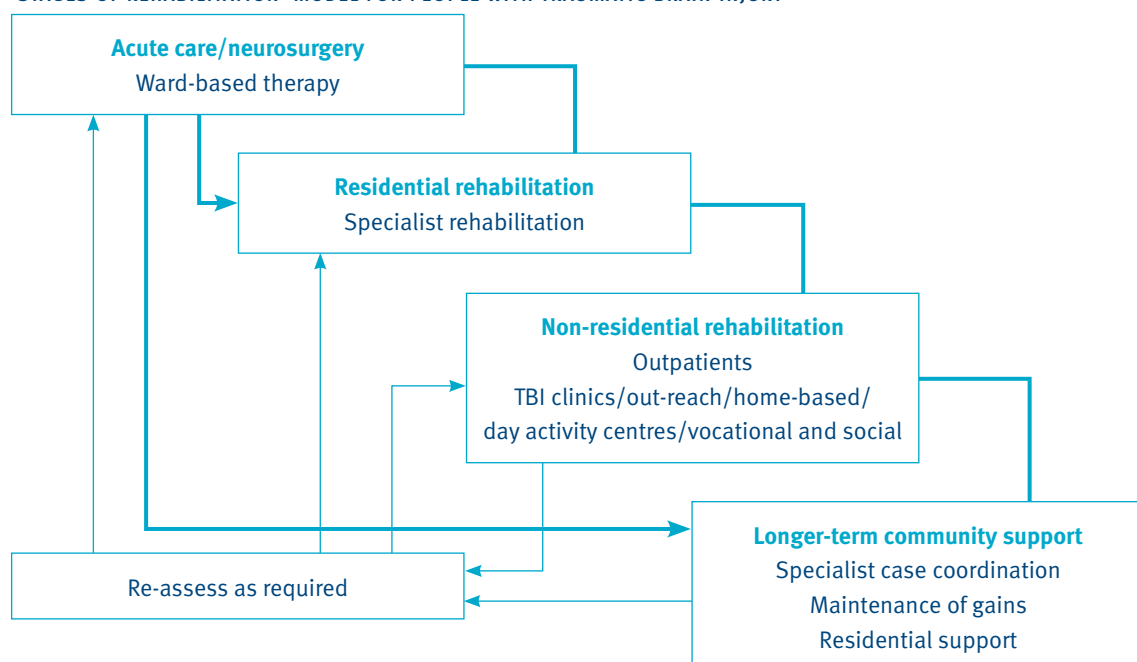
This section addresses needs for rehabilitation for people at the moderate to severe end of the spectrum of injury and those with prolonged unresolved symptoms.

Rehabilitation starts as soon as possible, even in the acute stages of intensive care in hospital. Interventions at this stage focus on reducing impairment and preventing secondary complications (pathology), such as contractures, malnutrition, pressure sores and pneumonia. As the person starts to recover, intensive residential rehabilitation may be required to make the successful transition between a residential environment and home. Post-acute residential rehabilitation has traditionally focused on regaining mobility and independence in self-care to allow the individual to manage safely at home. This needs to be placed in the context of participation goals so that discharge to home is not seen as an end in itself but a milestone on a much longer journey. Discharge home can occur very early, even following very severe injury. Those involved in the rehabilitation process (particularly the person with TBI and their family/whānau and carer(s)) need to be able to consider all possible options and choose the most appropriate option for them.

Once back in a home-based setting, people with TBI may need continued input to maximise their ability to function in their environment. Interventions focus on enhancing participation, improving quality of life, promoting psychological adjustment and minimising carer stress. These stages are illustrated in the 'stages of rehabilitation' model (see Figure 4.2).

The critical point of the 'stages of rehabilitation' model is that people with TBI may need to access different services as they progress through the different stages. Their transition between services should be smoothed by effective communication and sharing of information between services so that they progress in a seamless continuum of care through the different stages.

FIGURE 4.2:
'STAGES OF REHABILITATION' MODEL FOR PEOPLE WITH TRAUMATIC BRAIN INJURY



Adapted from: Turner-Stokes L. *Head Injury Rehabilitation – How Should it be Provided?: Head Injury Rehabilitation – a Parliamentary Select Committee*; 2001.

There has been considerable debate about whether services should be based in the hospital or the community. The answer depends on the mix of clinician skills and environment; these may be able to be delivered best in a non-hospital environment and this is certainly the trend in New Zealand for people with TBI requiring residential rehabilitation. There is substantial evidence of the effectiveness of community-based rehabilitation.^{109–112} The outcome over five to 10 years will be determined by all the different steps being in place. The important challenge is to make sure that each person can access the service most appropriate to their needs at the time that they need it.

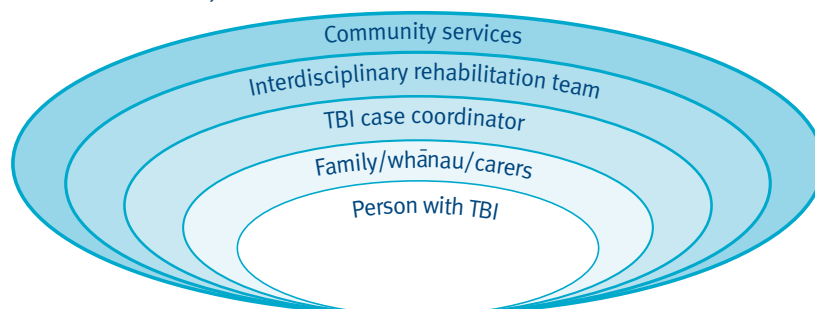
Rehabilitation within the community is supported by a number of New Zealand policies, including the Public Health and Disability Act 2000¹¹³ that establishes the New Zealand Health Strategy (www.moh.govt.nz/publications/nzhs) and the New Zealand Disability Strategy (www.odi.govt.nz/nzds/) as guides for health care planning and funding. The vision of the New Zealand Disability Strategy is for ‘a society that highly values the lives and continually enhances the full participation of disabled people’. It recognises that this will be realised when disabled people are integrated into community life and community-based services ensure that disabled people (and their families/whānau or carers) are supported. The Code of Health and Disability Services Consumers’ Rights¹¹⁴ prescribes that health services are delivered that enhance respect, dignity, and independence. In addition, the Injury Prevention, Rehabilitation, and Compensation Act 2001 reinforces ACC’s responsibility to provide rehabilitation ‘to the maximal extent practicable’.

Whilst the ‘stages of TBI rehabilitation’ model provides a useful illustration of the need for different services at different stages, with seamless continuity of care, the reality is much more complex and three-dimensional in practice. People with TBI progress through the different stages at very different rates. Many may not require hospitalisation at all and pass straight on to services in the community. A small minority with very severe TBI spend many months in hospital. People with TBI may also need to access services at different times as their needs change. This may involve re-access to inpatient services or a review of community rehabilitation and support needs as appropriate.

4.3 Organisation of services

Rehabilitation services for people with TBI should be based on achieving well-being and independence rather than on a model of deficit and dependency. Within each stage of rehabilitation, a range of different service providers is involved, which must somehow be coordinated, and these services change according to the stage of rehabilitation. Figure 4.3 represents community-based rehabilitation, developed around the ICF model of functioning.¹¹⁵

FIGURE 4.3:
A MODEL OF FUNCTIONALLY ORIENTED, COMMUNITY-BASED REHABILITATION



Reproduced from: Bilbao A, Kennedy C, Chatterji S, et al. The ICF: Applications of the WHO model of functioning, disability and health to brain injury rehabilitation. *Neurorehabilitation* 2003;18(3):239–50.

There are a number of different services and supports involved in rehabilitation of people with TBI. Because TBI rehabilitation is a dynamic process, the involvement of various organisations, services and people may change over time. Coordination of the different services, although potentially difficult, is a very necessary part of effective TBI rehabilitation.

4.3.1 Residential services

There are different types of residential service to which people with TBI may be referred for rehabilitation (also see Section 1.9.2.2, *Residential rehabilitation*). The first of these is residential rehabilitation, where the person both lives and undertakes rehabilitation in these facilities; the second is residential support services, where the person needs a sympathetic place to live (such as with a landlord who understands TBI and the chronic problems associated with the condition). Each type of residential rehabilitation has a different focus and specific criteria for referral, although for the rehabilitation environments there will be considerable overlap in the services provided. These include:

- hospital inpatient rehabilitation:
 - a need for ongoing medical treatment
- a secure facility replicating as much as possible a typical environment (this could include mental health services/drug and alcohol services):
 - a need for 24-hour supervision due to the risk of possible harm to self or others
- a residential facility replicating a typical environment:
 - a need for 24-hour environmental manipulation that promotes rehabilitation, such as an ordered household, ie, support for executive dysfunction issues with managed lighting, noise, visitors and communication, support to complete everyday tasks and establish and maintain a routine and supported reduction of assistance towards independence
 - a need for preparation for independent living, including gradual support to take over all the tasks for independence
 - a requirement for services that are not normally available in a typical environment (eg, percutaneous endoscopic gastrostomy feeding, wheelchair access, meals prepared, ongoing assistance with everyday activities)
- residential support:
 - when the person cannot take up rehabilitation until they are in a stable environment or they cannot maintain function without a stable environment
 - when the person may be mobile but is cognitively compromised
 - in order for the person to retain normal social roles as far as possible (eg, not being dependent on parents in adulthood)
 - when supervision (of various levels) is needed.

4.3.2 Coordination and communication

With so many different services and so many people involved, the major challenges of rehabilitation are coordination and communication. Service planning and commissioning is required to link health and social services' provision with other statutory and voluntary service providers, including employment, education and housing authorities.

4.3.2.1 Case coordination

RECOMMENDATIONS	GRADE
People with traumatic brain injury who require rehabilitation should have a case coordinator/key worker appointed.	B
A paediatric case coordinator/key worker should be appointed for children and young people with traumatic brain injury.	B
The case coordinator/key worker should: <ul style="list-style-type: none"> • be focused on the needs of the person with traumatic brain injury and their carer(s) • have specialist training • provide continuity and good communication • be the key point of contact. 	B

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT

Any change of case coordinator or ACC case manager should be immediately advised to the person with traumatic brain injury and their carer(s).	✓
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This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Case coordination is a concept with an established history in both adult and paediatric rehabilitation, although the label can vary. For example, it can be called key working or case management. Case coordination implies a role for a specified individual who takes responsibility for coordinating the assessment, management and support activities for a specified client. These terms are used interchangeably here.

Following consultation on the draft guideline, the Guideline Development Team has suggested that the term ‘case coordinator’ or ‘key worker’ is generally used in New Zealand to describe the person who undertakes this role. The Guideline Development Team acknowledges that this person may be an ACC case manager (or lifetime planner), the person’s general practitioner or a member of an established multidisciplinary rehabilitation team, depending on the individual circumstances of the client. Ultimately it is a matter of finding the right person to fulfil the role of case coordinator in the context of the person’s life at that time. The roles of the case coordinator are specified below, following a discussion of some of the relevant literature on effectiveness.

Apart from the obvious logistic need for coordination in multidisciplinary rehabilitation, a controlled study showed that participants receiving coordinated care showed greater gains throughout the study period and maintained the treatment effect after treatment ended, and that their carers exhibited less distress compared with the control group.¹¹⁶

There is international support from both the research evidence and experts in the rehabilitation field for the benefits of individual ‘case management’ or an equivalent system to support the individual and their family throughout the course of their recovery.⁸ A 1998 systematic review found that studies of the effectiveness of case management show that the clearest demonstration of benefit is in vocational status, with studies using different models of case management showing similar improvements.¹⁰ It reported conflicting evidence on other effects of case management, such as improvements in disability, living status and family well-being, although particular benefits were identified in one study where a single case manager administered insurance benefits.¹⁰

The systematic review also reported that participants receiving the case management showed significantly more improvement, as measured by the Disability Rating Scale (DRS), than the control group, and suggested that pre-settlement of permanent disability advances for economic assistance helps people with TBI, possibly because it helps them to focus on rehabilitation. It concluded that although present evidence is mixed, use of several case management models should be continued and evaluated to identify which model is most effective.¹⁰

A more recent study found that case management for people with TBI also improves the rate of unexpected outcomes.¹¹⁷

A quasi-randomised study of case management for people with severe TBI in the UK, published in 1994, was unable to show a difference in important endpoints.¹¹⁸ The case-managed group was referred for more services, but the particular model of case management did not involve budget-holding so there was no way for the case manager to influence further the provision of services for people who needed them.

In New Zealand, the current practice is that people with TBI who require ongoing support have a case manager appointed by ACC (provided ACC has been notified of the need for further assistance). The case manager has a role in coordination of assessments and management throughout the lifetime of a claim. For people with severe and very severe TBI, an ACC lifetime planner may also be appointed. There may be a need, in addition to the ACC case manager role, for one of the clinicians involved in the rehabilitation and/or support of the person with TBI, to provide a specific 'key worker' role. This can only be determined on a case-by-case basis with full discussion among all the people involved.

The case coordinator should:

- be focused on the needs of the person with TBI and their carer(s)
- have specialist training in the role and in the needs of people with TBI and the services provided for them, and in the case of paediatric case coordinators, the particular needs of and services for children with TBI
- provide continuity and good communication
- be the key point of contact for the rehabilitation team with ACC and other agencies and family/whānau.

It is important that the person with TBI knows who their case coordinator is and that they, and their carer(s), are immediately advised of a change of case coordinator or ACC case manager.

4.4 Rehabilitation teams

RECOMMENDATIONS	GRADE
Common goals of the team should be consumer centred.	C
The assessment and planning of rehabilitation should be by a coordinated, multidisciplinary team taking an interdisciplinary approach.	C
Teams should have clear, skilled leadership and efficient coordination.	C
The case coordinator should be central to deciding which other disciplines need to be involved in the planning and delivery of rehabilitation.	C
All health care practitioners working with people following a traumatic brain injury need to have had specialist training in the application of their disciplines to neurological conditions.	B

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

4.4.1 Types of team

The composition of teams of professionals from different disciplines involved in the rehabilitation of a person who has had a TBI may be multidisciplinary, interdisciplinary or transdisciplinary.

In multidisciplinary teams, professionals work alongside each other, but not necessarily together. Discipline-specific interventions running in parallel rehabilitation therapy services within hospital settings often adopt a discipline-specific approach.

Interdisciplinary teams are more integrated in approach than multidisciplinary teams. The team members plan an integrated rehabilitative programme together and work towards an agreed set of common goals, with collaborative interventions and joint sessions of therapy. Most specialist brain injury rehabilitation teams work in this way in New Zealand.

In transdisciplinary teams, the boundaries between individual disciplines of team members are relaxed, and team members adopt a common problem-solving approach. This approach is often appropriate for community-based rehabilitation services, where it may not be practical for the full team to meet for every therapy session for each individual.

Whichever team approach is taken, the team will require clear, skilled leadership and efficient coordination to provide effective rehabilitation.⁷ Delivery of rehabilitation is most effective when done by a coordinated, multidisciplinary team of people from the different disciplines involved¹¹⁹ taking an interdisciplinary approach.¹²⁰

In New Zealand, most specialist brain injury rehabilitation teams meet and plan together with the person with TBI and their family/whānau and carer(s) in the rehabilitation ward. However, teams in the orthopaedic, medical and surgical wards often work in isolation and require specific measures to support interdisciplinary working.

In general, the common goals towards which the team works should be consumer centred (ie, those that the person with TBI and their family/whānau and carer(s) consider to be important and achievable).⁷ This is an ideal and there are situations, such as poor insight or suicidality, where it may not be appropriate. Teams, including case coordinators working with people after TBI, should work in partnership with the family.

4.4.2 Community access to multidisciplinary care

Currently in New Zealand, people receiving care in middle-sized or larger centres may have the rehabilitation delivery coordinated by a multidisciplinary team. In the community there are also multidisciplinary rehabilitation teams operating. People may be receiving help from a variety of agencies all at one time; many neuropsychologists, occupational therapists, speech-language therapists and physiotherapists are private providers.

There are also providers operating teams of rehabilitation clinicians in the community.

General practitioners in some centres may fulfil the role of medical rehabilitation specialists (at least for mild and moderate injuries). There may be specialist workplace assessors, or occupational medicine practitioners, and for children and young people there may be Group Special Education and specialist teachers involved.

There may be little communication or collaboration between the providers of different services, and effort is required to ensure effective coordination and communication.

4.4.3 Team composition and role

The composition of the team – that is, the different disciplines represented on the team – will depend upon the needs of the person and the stage of rehabilitation. Assessment and planning and the delivery of rehabilitation to people who have had a TBI will require expertise in participation-focused assessment and delivery of services. Along with this primary focus, expertise and understanding of the domains of potential impaired function, together with knowledge of possible non-neurological complications, will allow a comprehensive,

but client-centred, goal-planning approach to rehabilitation. Specific areas where expertise in assessment and management is required include:

- the process of social integration for an individual and their family
- the person's leisure, vocation and study needs
- the person's safety in their home or other environment
- the person's functioning in daily activities
- sharing of information in an appropriate form, time and environment
- family and social support
- motor impairments, such as weakness, altered tone and lack of coordination in the limbs
- problems with speech and swallowing
- sexuality issues
- sensory impairment, including visual problems such as reduced acuity, loss of visual field and gaze palsies, hearing loss and loss of smell and taste
- cognitive impairments, especially of memory, concentration, insight and/or orientation
- cognitive and physical fatigue
- emotional issues, mood disturbance and other psychological disturbance
- language problems, particularly cognitive-communication disorder or aphasia
- reduced control over bowels and bladder.

4.4.4 Teams for children and young people

In addition to the disciplines above, rehabilitation teams working in paediatric settings should include the injured child's family/whānau, formal and informal carer(s) and an education representative. Family therapists, play therapists and child psychotherapists should be available as needed. A paediatric case coordinator/key worker should be appointed who, where necessary, can liaise with mental health services, education and Child, Youth and Family Services.

Chapter 5:

Rehabilitation following clinically significant traumatic brain injury – assessment

Overview

- There is a substantial research gap in evaluating the impact of various service configurations, service delivery methods and specific interventions for people with TBI in New Zealand, particularly from the perspective of the individual with TBI and their family/whānau.
- A TBI can result in deficits that can be classified generally as physical, cognitive, behavioural/emotional or communicative. The identification of these deficits and any consequential impact on functioning is an important step towards helping the person with TBI, their family/whānau and carer(s).
- Diagnostic assessment within rehabilitation services aims to determine where there is a probable injury to the brain, and if so, to determine the nature and extent of the injury and the short- and long-term effects of the injury.
- Many of the symptoms of TBI overlap with other conditions; physical, psychological and psychiatric. It is important to attribute symptoms correctly to TBI or other medical conditions and to identify and treat comorbid conditions in order to develop an effective TBI rehabilitation plan.
- When TBI is sustained in childhood, neuropsychological and other assessments may need to be repeated several times as the child matures to adulthood.

RECOMMENDATIONS	GRADE
People who have had a traumatic brain injury should be assessed for functional deficits in activities of daily living and be assessed for specific impairments in: <ul style="list-style-type: none"> • control over bowels and bladder • speech and swallowing • motor control • sensory function • language production and comprehension • cognition and memory • behaviour and emotion • potential medical and psychiatric comorbidities, which have symptomatic overlap with traumatic brain injury. 	C
All people with traumatic brain injury should be considered for referral for a neuropsychological assessment to evaluate cognitive functioning.	C
Assessment should include seeking information from family/whānau and carers who knew the person before their injury and who are caring for the person post-injury.	C
Staff assessing people with traumatic brain injury should have training and expertise in the application of their disciplines to people with neurological disorders.	C
Staff assessing children and young people with traumatic brain injury should have general paediatric training and specific expertise in the application of their disciplines to children with neurological disorders.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS	
An assessment of the Glasgow Coma Scale for the purpose of estimating the severity of traumatic brain injury should be made from 30 minutes after the injury.	✓
The primary focus of assessment should be on the person's participation goals, and an assessment of activity limitation and impairments should be made within this context.	✓
A speech-language therapist should lead communicative and dysphagia assessments.	✓
A neuropsychologist should lead a cognitive and behavioural assessment.	✓
Rehabilitation teams should have access to suitable health care practitioners to provide consultative services, education and oversight, especially when particular health care practitioners are unavailable to be members of a team.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

TBI rehabilitation is a complex process. There is little robust evidence about commonly used interventions. Many of the interventions studied have tended to be delivered from a hospital-based, clinician-driven paradigm of TBI rehabilitation, which is at odds with the rehabilitation paradigm briefly described at the beginning of

Chapter 4, *Rehabilitation services*. This chapter is based on *Rehabilitation Following Acquired Brain Injury: National Clinical Guidelines* produced by the Royal College of Physicians and British Society of Rehabilitation Medicine, in 2003. It draws heavily on literature around people with stroke.⁸

In an evidence-based guideline it is necessary to draw together what evidence there is for the effectiveness of various interventions. This will not necessarily reflect the importance of those interventions or the frequency with which those interventions are used in everyday practice. There are many textbooks about TBI rehabilitation practice that offer a more cohesive, pragmatic, if not necessarily formal evidence-based approach (eg, Ponsford's 'rehabilitation for everyday adaptive living' (REAL) guide¹²¹ or Rosenthal's textbook¹²²).

There is a substantial research gap in evaluating the impact of various service configurations, service delivery methods and specific interventions currently offered in New Zealand for people with TBI, particularly from the perspective of the individual with TBI and their family/whānau. This research could inform future versions of this guideline and influence improvements in clinical practice to ensure best outcomes are achieved by people with TBI and their families/whānau and carers.

This section covers the diagnostic and assessment procedures after the acute phase of TBI for people who have been referred to rehabilitation services following a moderate to severe TBI, or people who have been referred for specialist assessment with unresolved symptoms following mild TBI. For initial diagnosis and assessment see Chapter 2, *Pre-hospital assessment, management and referral to hospital*.

A TBI can result in deficits that may generally be classified as physical, cognitive, behavioural/emotional or communicative. Identification of these deficits and any consequential impacts on functioning is an important first step towards being able to effectively help the person with the TBI, their carer(s) and family/whānau. Assessment should include seeking information from family/whānau and carers who knew the person before their injury and who are caring for the person after the injury, as they will be able to add information.^{8,123}

The diagnostic assessment within rehabilitation services is to determine whether there is a probable injury to the brain; and if so, the nature and extent of that injury and the short- and long-term effects that the injury is likely to have caused. Once determined, this assessment aids in establishing the needs for immediate and long-term medical and rehabilitative care. For example, if the person has suffered injuries which mean they are kept prone, impairments of balance and motor control may be less apparent.

The diagnosis and assessment of the severity of a brain injury may be complicated by the presence of non-brain injuries and brain injury symptoms that are masked by medical problems, particularly in the case of 'mild' TBI.⁶⁹

The assessment of people with probable TBI should always be performed by people with training and expertise in the application of their disciplines to people with neurological disorders.^{7,8,10} Likewise, the assessment of children and young people under the age of 18 with probable TBI should be performed by people with training and expertise in the application of their disciplines to children with neurological disorders.^{7,8,11}

5.1 Non-neurological medical sequelae of traumatic brain injury

Non-neurological medical complications of TBI are common and varied, and include pulmonary, metabolic, nutritional, gastrointestinal, musculoskeletal and dermatological problems.⁶⁹ It is outside the scope of this guideline to detail the best practice for the assessment of these medical issues. However, it is important that the diagnostic procedures include assessment of potential medical issues,⁸ and that where they are detected the person be referred for the appropriate treatment.

5.2 Differential diagnosis

Many of the symptoms of TBI overlap with other conditions, both physical and psychological/psychiatric, including dissociative, motivational and somatoform disorders. For example, a need to check things constantly because of memory difficulties may be misinterpreted as obsessive-compulsive disorder.¹²⁴

It is important to attribute symptoms correctly to TBI or other medical conditions, and to identify and treat comorbid conditions in order to develop an effective TBI rehabilitation plan. This may require specialist diagnosis and identification. Where progress is not as expected, and it is unclear whether a person's symptoms are due to TBI or one of these other disorders, they should be referred for a specialist neuropsychological assessment.¹²⁴

Also see Chapter 14, *Special issues* for more details of mental health disorders and other conditions, which may or may not be resulting from the TBI.

5.2.1 Differential diagnoses in children and young people

In children and young people, developmental, psychological and psychiatric conditions (including attention deficit hyperactivity disorder [ADHD], foetal alcohol effects, hearing and visual impairments, drug and alcohol use in adolescents, developmental disorders, non-TBI-related cognitive difficulties and emotional problems) may have symptomatic overlap with the effects of TBI. Where there is a lack of clarity about the aetiology of the symptoms, or where progress is less than expected, a specialist assessment should be made to identify and refer for treatment any non-TBI causes of the symptoms.

5.3 Physical assessment

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

Assessments of the physical functioning of people with TBI should include assessment for the following:

- motor deficits:
 - muscle weakness and paralysis
 - abnormal muscle tone (spasticity)
 - deficits in joint range of motion
 - ataxia/coordination
- sensory deficits:
 - visual/hearing loss
- symptoms, eg, headache, fatigue, pain
- dysphagia
- seizures
- functional mobility:
 - changing and maintaining body position
 - carrying, moving and handling objects
 - walking and moving (including, but not limited to, crawling, climbing, running, jumping and swimming)
 - mobilising with the aid of assistive technology.

There is some evidence that a specialist in physical rehabilitation medicine should lead both the physical assessment and planning of physical therapy.¹⁰

5.3.1 Dysphagia assessment

A speech-language therapist should lead both the assessment and planning of dysphagia therapy. It should include:

- a detailed diagnostic assessment to address issues of diagnosis, probable causality and disability
- a rehabilitation-focused assessment, which addresses the need for, and the potential to benefit from, rehabilitation.¹²⁵

5.4 Communicative assessment

Communicative assessments should be performed by a speech-language therapist, in conjunction with others in the team.⁸ Assessments of the communicative functioning of people with TBI should include assessment for the following:

- language deficits; expression and comprehension
- cognitive communication disorder
- dysarthria
- apraxia of speech
- acquired dyslexia
- acquired dysgraphia.

5.5 Neuropsychological assessment

All people with clinically significant TBI should have an assessment of cognitive and behavioural/emotional functioning. This will usually be undertaken by a neuropsychologist.⁸

A neuropsychological assessment includes an interview of the person with TBI and their family/whānau and carer(s), plus standard assessment measures, and focuses on assessment deficits in cognitive and behavioural/emotional functioning.

A detailed neuropsychological assessment can contribute to the evaluation of the following:

- the likely impact of cognitive impairment on the rehabilitation programme
- areas of strength on which the person may be able to build during rehabilitation (and the person's prognosis in terms of their ability to function independently in the community or to return to work, study or driving)
- help to identify the appropriate areas for effective rehabilitation input.⁸

The assessment can encompass any or all of the following:

- a detailed diagnostic assessment to address issues of diagnosis, probable causality and disability
- a rehabilitation-focused assessment, which addresses the need for, and the potential to benefit from, rehabilitation
- a vocation-focused assessment, which addresses limitations to, and suitability for, specific vocational pursuits
- a permanent functional impairment assessment, which addresses the extent of permanent disability associated with the injury
- a behavioural management assessment, which focuses on behaviour analysis and may assist in the development of behaviour modification programmes.

5.5.1 Cognitive assessment

Cognitive assessment identifies the person's functional-cognitive abilities through an occupational therapy assessment in the home, work, school or community context.

Cognitive assessment requires input from a multidisciplinary rehabilitation team along with family/whānau and carers. Face-to-face contact is essential for assessment.

Assessment of the cognitive functioning of people with TBI should include the following areas:⁸

- insight and awareness
- attention
- memory
- speed of information processing
- perception
- complex problem-solving
- self-monitoring
- social judgement.

5.5.2 Behavioural/Emotional assessment

Assessment of the behavioural and emotional functioning of people with TBI should include the following:⁸

- emotional lability
- poor initiation
- mood change
- adjustment problems
- personality changes, including:
 - aggressive outbursts
 - disinhibition
 - inappropriate sexual behaviour
- poor motivation
- drug and alcohol misuse
- mental health disorders, particularly depression, anxiety disorders and psychosis.

Chapter 14 provides more detail on special issues.

5.5.3 Tools for neuropsychological assessment

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

CAUTION – ABSENCE OF EVIDENCE

When TBI is sustained in childhood, neuropsychological assessment may need to be repeated several times as the child matures to adulthood.

There are two main types of computerised neuropsychological testing.

1. Those tests designed to detect reduced cognitive functioning compared with a baseline measure, usually intended to detect mild TBI sustained by sports players. These tests include CogSport (www.cogsport.com) and IMPACT (www.impact.com), also known as concussion screening.
2. More comprehensive computerised test batteries that are based on standardised neuropsychological testing such as Integneuro and Neuromarker.⁶

Concussion screening has the advantage that it does not require a neuropsychologist, and may be of value for the initial assessment of people with mild TBI. When there has been a pre-injury base line measurement, these tests, which may be recorded by team doctors in some sports, provide a simple binary indication of ‘yes there is/no there is not a change in cognitive function’. They are therefore appropriate for medical practitioners to use

as part of an initial assessment of mild TBI. If there are significant abnormalities on such screening assessments that do not recover rapidly to normal, referral for assessment by a neuropsychologist is indicated.¹²⁶

Computerised neuropsychological testing is not particularly useful for assessment of people with moderate to severe TBI.

Test batteries, based on standardised neuropsychological measures, are intended for use by neuropsychologists and other appropriately trained practitioners who are able to interpret the results. These tests can be used for all levels of severity of TBI.

Although there is some recent evidence of the validity and reliability of some of these tests,^{127,128} there are no good trials comparing them with the traditional (non-computerised) forms of testing. A question remains about whether the performance measured by computerised tests equates with that measured by the non-computerised tests. There is insufficient evidence to recommend them for routine use. The use of computer-based tests inevitably results in the loss of information gained from observation of the way in which the test participant performs a particular task.

Chapter 6:

Rehabilitation following clinically significant traumatic brain injury – intervention

Overview

- TBI is a complex process and currently there is little robust evidence about commonly used interventions.
- A person who has had a TBI may show physical effects of the injury, which may require physical rehabilitation for which there is strong evidence for improving functional independence.
- Recovering mobility is an important goal for people who are immobile following a TBI.
- Both urinary and faecal incontinence are common following severe TBI. This can be distressing, socially disruptive and can hinder progress in other areas of rehabilitation.
- When a person has post-TBI sensory (visual or hearing) disturbance, this may exacerbate disorientation and confusion, or impact on higher cognitive function.
- Pain is frequently under-diagnosed in people with TBI, therefore specially adapted assessment tools or the skills of a speech-language therapist and family/whānau and carers may be required to elicit symptoms accurately.
- People may have communication impairments following a TBI and may require speech-language therapy as an intervention.
- The nature of cognitive deficits resulting from TBI depends, to some extent, on the severity and location of the injury. Cognitive deficits are likely to be more difficult in terms of rehabilitation than the physical and behavioural effects of TBI, and harder for the family/whānau, carers and employers to recognise, accept and accommodate.
- Cognitive rehabilitation has been shown to be effective, although the effectiveness of specific interventions is unclear. There is very little evidence for the effectiveness of medications for the cognitive sequelae of TBI.
- A person who has suffered a TBI may show psychological/behavioural effects from the injury. Behavioural rehabilitation attempts to aid the recovery, improve function where possible, and provide strategies to minimise the negative impact of the symptoms that persist.
- Anxiety, depression and other mental health conditions are common after TBI and often increase if not identified and treated.
- People with TBI who have difficulties in activities of daily living should be assessed and an individual treatment programme should be developed and implemented.
- Sleep difficulties and fatigue are both common problems following TBI of all severities.
- Return to employment or an alternative occupation is a primary goal and a central factor in the restoration of the quality of life for people with TBI.
- There is strong evidence that vocational rehabilitation improves vocational outcomes for people with TBI in securing sustainable employment or alternative occupation, and is cost effective.
- A substantial proportion of people with TBI, particularly at the more severe end of the spectrum, may suffer effects on sexuality, such as impaired sexual functioning.
- There is little evidence on the treatment of sexual dysfunction in people with TBI; most advice for rehabilitation focuses on counselling, for which there is no evidence of effectiveness. There is no good evidence for any particular medications for the control of sexually inappropriate behaviour.
- Continuous or intermittent input from a rehabilitation team may be appropriate over long periods of time following TBI.

This chapter is based on *Rehabilitation Following Acquired Brain Injury: National Clinical Guidelines* produced by the Royal College of Physicians and British Society of Rehabilitation Medicine, in 2003. It draws heavily on literature around people with stroke.⁸

As stated in Chapter 5, in an evidence-based guideline it is necessary to draw together what evidence there is for the effectiveness of various interventions. This will not necessarily reflect the importance of those interventions or the frequency with which those interventions are used in everyday practice. There are many textbooks of TBI rehabilitation practice which offer a more cohesive, pragmatic, if not necessarily formal evidence-based approach (eg, Ponsford's REAL guide¹²¹ or Rosenthal's textbook¹²²).

There remains a substantial research gap in evaluating specific interventions currently offered in New Zealand for people with TBI, particularly from the perspective of the individual with TBI and their family/whānau.

Throughout this section and this guideline we refer the reader to the MedSafe data for details of the contraindications and adverse effects of medications. More information can be found at www.medsafe.govt.nz.

There is a very small literature of robust research evaluating rehabilitation interventions in a TBI population. In the following sections, many of the recommendations are extrapolated from findings in populations with other brain injuries (particularly stroke) or in mixed populations including some people with TBI.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

6.1 Physical rehabilitation

RECOMMENDATIONS	GRADE
A physiotherapist or occupational therapist with neurological expertise should coordinate physical therapy to improve the motor function of people with traumatic brain injury.	C
Any physical treatment approaches should take account of any associated orthopaedic or musculoskeletal injuries.	C
The physical rehabilitation programme should include a written and illustrated plan for other members of the team, including family/whānau and carers.	C
A speech-language therapist with dysphagia expertise should coordinate the dysphagia therapy.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT

Any programmes should be adapted to accommodate the person's normal environment and activities as far as possible.	✓
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This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

A person who has had a TBI may show physical effects of the injury. These effects may include:

- loss of motor control: both speed and coordination
- abnormal muscle tone and movements, including spasticity and tremors
- impaired bladder and bowel control
- seizures
- impairments of vision, hearing, smell and/or taste
- impairments in the ability to produce speech
- significant fatigue, both physical and cognitive
- impaired stamina and endurance.¹⁰

The aim of physical rehabilitation is to aid the recovery of normal functioning as far as possible, and to provide compensatory strategies to minimise the negative impact of the symptoms that persist (ie, to increase independence through the facilitation of motor control and skills). There is strong evidence that demonstrates the effectiveness of this approach in improving functional independence.⁸

Physiotherapists and occupational therapists, and in the case of children or young people, paediatric physiotherapists and occupational therapists, need to be both skilled in the physical management of neurological deficits and experienced in the recognition and handling of associated cognitive and behavioural deficits which may impact on the ability of the injured person to engage and cooperate in therapy sessions, and the functional application of motor control (ie, their ability to carry over physical gains into daily activities).⁸ Therefore, a physiotherapist or occupational therapist with neurological expertise should coordinate physical therapy to improve the motor function for all people with brain injuries.⁸

Any of the current physical treatment approaches should be practised within a neurological framework to improve the injured person's function, but should also take account of any associated orthopaedic or musculoskeletal injuries.⁸

The physical rehabilitation programme should include a written plan, with illustrations where appropriate, to guide other members of the team (including family/whānau and carers) in carrying over motor skills into other daily activities.⁸

It is the opinion of the Guideline Development Team that, where possible, and particularly when the person is in the community, any programmes should be adapted to accommodate the person's normal environment and activities, eg, gardening, walking, swimming or doing structured exercises under the supervision and/or with the assistance of family/whānau or carers.

In the case of dysphagia, speech-language therapists need to be skilled in the management of dysphagia both in providing compensatory strategies that ameliorate the swallowing dysfunction and in physical rehabilitation to aid the recovery of normal functioning as far as possible.

6.1.1 Motor control and function

RECOMMENDATIONS	GRADE
People with traumatic brain injury who are unable to maintain their own sitting balance should have timely provision of an appropriate wheelchair and suitable supportive seating package, with regular review of the seating system as their needs change.	C
Age-appropriate supportive seating and wheelchairs should be provided for children and young people.	C
People with complex postural needs should be referred to a specialist interdisciplinary team which includes expertise in specialist seating.	C
People with mobility problems should be considered for appropriate walking or standing aids.	C
Orthoses should be individually fitted.	C
The following should be considered as an adjunct to conventional therapy: <ul style="list-style-type: none"> treadmill training with partial bodyweight support strength training gait re-education exercise training. 	B
A carefully monitored and evaluated trial of botulinum toxin A (BTX-A) for the treatment of focal spasticity in adults with traumatic brain injury may be considered.	C
A carefully monitored and evaluated trial of BTX-A for the treatment of focal spasticity in children with traumatic brain injury may be considered, with awareness that a longer-term treatment may be necessary before any benefits are found.	C
A trial of intrathecal baclofen for the treatment of severe spasticity in adults or children with traumatic brain injury may be considered, but should be carefully monitored for possible complications, including pump malfunction.	C
A carefully monitored and evaluated trial of tizanidine may be considered, particularly for spasticity of the lower extremities.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT

Any rehabilitation programme should include a flexibility routine when there is any spasticity.



This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

6.1.1.1 Supportive seating and standing

Maintaining an upright posture helps to prevent osteopenia, loss of muscle bulk and normal cardiovascular and autonomic responses.⁸ Aiding sitting and standing will also promote normal postural tone, proprioceptive information and maintain range and alignment of joints.⁸

Postural re-training is an important precursor to gait re-education. In the early stages, supportive systems help to maintain the trunk and head in a good position and free the upper limbs for functional use. As truncal stability improves, systems which encourage more active movement may be introduced to achieve dynamic balance in sitting and standing.

People who have had a TBI who are unable to maintain their own sitting balance should have timely provision of an appropriate wheelchair and suitable supportive seating package. The potential need for accommodating communication devices and regular review to ensure the continued suitability of the seating system as their needs change should also be taken into account.⁸ People who are unable to stand independently should be provided with a suitable standing aid if appropriate, and this provision should be continued into the community if still required at the time of transfer.⁸ In the case of children and young people, age-appropriate supportive seating and wheelchairs should be provided.

People with complex postural needs should be referred to a specialist interdisciplinary team which includes expertise in specialist seating.⁸

6.1.1.2 Aids and orthoses

Orthoses such as ankle-foot orthoses or hand splints may help some people to maintain normal posture and stability during function. People with mobility problems should be considered for appropriate walking or standing aids to improve stability, which may include ankle-foot orthoses.⁸ Care must be taken when fitting orthoses to avoid pressure areas, especially where deformity exists or sensation is impaired. If an orthosis is supplied it should be individually fitted.⁸

6.1.1.3 Rehabilitation of motor control

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

When planning a programme to improve motor control and general fitness, the following should be considered:

- treadmill training with partial bodyweight support as an adjunct to conventional therapy
- strength training to improve motor control in targeted muscle groups
- gait re-education to improve walking ability
- exercise training to promote cardiorespiratory fitness.⁸

6.1.2 Spasticity

Spasticity is a condition that results when the nervous system has lost control of the coordination between the contraction and relaxation of muscles. Spasticity causes muscle stiffening, and flaccidity may also be present. Spasticity may be exacerbated by various stimuli (such as a full bladder, pressure areas) which need to be managed appropriately. It is the Guideline Development Team's opinion that a sound flexibility routine is necessary to counteract the effects of spasticity, and should be included in any rehabilitation programme for motor control. There should be a team approach to management, with goals set prior to considering any of the additional options outlined below.

6.1.2.1 Botulinum toxin A

A recent systematic review of the effectiveness of botulinum toxin A (BTX-A) for treating focal upper and lower limb spasticity found that in most cases BTX-A decreases muscle tone across most conditions, with an improvement in range of motion, gait and function.¹²⁹ However, the improvement does not always reach statistical significance, which may be due to both methodological issues and the wide range of conditions causing spasticity included in the review.¹²⁹

A randomised controlled trial of the use of BTX-A to treat adults (including people with TBI) presenting with focal hypertonia affecting upper or lower limbs found that the intervention group had better scores on many scales than the placebo control group, although the goal attainment scale score in both groups was similar at 12 weeks. It was concluded that selective use of BTX-A can result in improvements in range of movement and focal disability in spasticity of the lower limbs.¹³⁰

There is therefore a small body of evidence that BTX-A may be effective for the treatment of spasticity in adults with TBI, and a carefully monitored and evaluated trial of BTX-A may be considered.^{129,130}

A longitudinal study of BTX-A in children found earlier improvement in less complex motor control tasks (hand tapping) and pinch force tasks, but improvement in more complex, forward-reaching tasks occurred much later or not at all, and concluded that although BTX-A reduced tone and increased range of movement of the spastic upper extremity, the degree of motor improvement is dependent upon the complexity of the task.¹³¹ There is limited evidence for the effectiveness of BTX-A in children with lower limb spasticity from cerebral palsy.¹³² Any trial of BTX-A in children should therefore be carefully monitored for effectiveness.

For both adults and children, repeated treatments are likely to be required as BTX-A effects generally last no longer than two to three months.

See MedSafe data at www.medsafe.govt.nz for contraindications and side effects of BTX-A.

6.1.2.2 Intrathecal baclofen

A meta-analysis of studies on the effectiveness of intrathecal baclofen for severe spasticity found positive effect sizes (of between 1.12 and 10.00) for all studies in all diagnostic groups, including TBI.¹³³ The cumulative overall success rate of intrathecal baclofen was estimated to be 78.1%, and at an average of 1.8 years after implantation; the mean current dosage level was 246 mcg/day (SD:192).

However, a small controlled trial of intrathecal baclofen in children and young people aged between four and 19 at the start of the trial found that although there was a favourable outcome in all participants, with the greatest benefit being a reduction of lower limb tone and carers noting improved muscle tone, behaviour, sitting and general ease of care, significant complications were reported in some of the 12 participants, including hypotension (2), bradycardia (2), apnoea (2), sedation (1), mechanical pump complications (10 occasions in five years), cerebrospinal fluid fistula (1), local infection (3), and meningitis (2). The study lacked the power to determine whether the complications noted were due to the intrathecal baclofen.¹³⁴

See MedSafe data at www.medsafe.govt.nz for contraindications and side effects of intrathecal baclofen.

6.1.2.3 Tizanidine

A small randomised controlled trial examining the effectiveness of tizanidine for spasticity due to acquired brain injury found that the average lower extremity and spasm scores decreased significantly. The treatment was significantly better than placebo in decreasing lower and upper extremity tone. With a reduction in motor tone, there was also an increase in motor strength.¹³⁵ A non-systematic review of the antispastic effect of tizanidine in placebo-controlled trials reported that the treatment group showed a reduction in muscle tone scores of 21–37% compared with 4–9% for the placebo group and that 60–82% showed an improvement in muscle tone.¹³⁶

Therefore, there is a small body of evidence that tizanidine may be effective for the treatment of spasticity in adults with TBI, particularly for spasticity of the lower extremities, and a carefully monitored and evaluated trial of tizanidine may be considered.

See MedSafe data at www.medsafe.govt.nz for contraindications and side effects of tizanidine.

6.1.3 Continence

RECOMMENDATIONS	GRADE
People with continence problems should not be discharged from residential care until continence aids and services have been arranged at home and carer(s) have been adequately prepared.	C
A plan for the rehabilitation of urinary incontinence should include: <ul style="list-style-type: none"> • a regular monitoring programme • strategies for alerting the carer(s) to the person's need to pass urine where there are communication problems • a toileting regimen based on reinforcement in cases of cognitive impairment. 	C
Anticholinergic medication should only be prescribed after demonstration of an overactive bladder.	C
Intermittent catheterisation should be considered in adults with a postmicturition residual volume of >150 ml.	C
Long-term catheters, if necessary, should be used as part of a planned catheter management programme using an agreed protocol.	C
The impact of long-term catheters, particularly indwelling urethral catheters, on sexual function should be considered.	C
Supra-pubic catheters should be used in preference to long-term urethral catheters.	C
In the case of constipation, an active bowel management regimen should be instituted as soon as possible, which includes: <ul style="list-style-type: none"> • ensuring sufficient fluid intake • the use of natural laxatives or simple bulk laxatives • exercise and standing, where possible • avoiding medications which slow gut motility • maximum privacy and comfort during defecation • supported sitting up for defecation at the earliest safe opportunity, and at a regular time each day. 	C
Where the rectum is full but no spontaneous evacuation occurs, daily rectal stimulation may be used.	C
If the rectum is empty for three days running despite continuing oral intake, the use of an osmotic laxative or a stimulant should be considered.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

Bladder and bowel management plans should be developed with the full knowledge and support and help of the person's primary carer.



Intermittent catheterisation should be considered in children with a postmicturition residual volume of >10% of bladder capacity.



This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

Both urinary and faecal incontinence are common following severe TBI, and may occur with less severe injury. It is distressing, socially disruptive and a major burden to carers once injured people are discharged home and can seriously hinder progress in other areas of rehabilitation. Active continence management and re-training of the bladder and bowel, when needed, are therefore critical parts of a rehabilitation programme.

People with continence problems should not be discharged from residential care until adequate arrangements have been made for continence aids and services at home and the carer(s) have been adequately prepared.⁸

6.1.3.1 Bladder management

People who have continuing post-TBI urinary continence problems should be assessed by a professional trained in continence management for people who have a TBI, and where necessary, have access to specialist urologist/continence management and advice, including further investigation (eg, urodynamics or ano-rectal physiology).⁸ The rehabilitation plan should include:

- a regular monitoring programme, eg, 24-hour voided volume chart and fluid intake charts
- in cases of communication and mobility problems, effective strategies for alerting carers to the person's need to pass urine
- in cases of cognitive impairment, an established toileting regimen based on reinforcement.⁸

Anticholinergic medication should only be prescribed after demonstration of an overactive bladder (eg, by the passage of small, frequent volumes on a 24-hour voided volume chart with a postmicturition residual volume of <100 ml, or by formal urodynamic investigation).⁸

6.1.3.2 Catheters

If a person has a postmicturition residual volume of >100 ml, intermittent catheterisation should be considered.⁸ In children, an abnormal postmicturition residual volume is >10% of maximal bladder capacity¹³⁷ and with values above this it would be appropriate to consider a programme of intermittent catheterisation. Long-term catheters should only be used after full assessment and consideration of less invasive forms of bladder management. If necessary they should be used as part of a planned catheter management programme using an agreed protocol. The impact on sexual function should be considered, particularly the potential problems associated with an indwelling urethral catheter.⁸ Supra-pubic catheters should be used in preference to long-term urethral catheters.⁸

6.1.3.3 Bowel management

Following TBI, constipation is common due to immobility, use of medications with anticholinergic side effects, embarrassment from lack of privacy, and poor fluid and dietary intake. It may be further exacerbated by other coexisting neurological problems such as spinal injury. Constipation may cause discomfort and exacerbate spasticity, and it may progress to faecal impaction and overflow incontinence if not proactively managed. An active bowel management regimen should be instituted to establish the person's normal pattern as soon as possible, with the support and help of the person's primary carer where appropriate. This should include:

- ensuring sufficient fluid intake
- the use of natural laxatives such as prunes, kiwifruit or simple bulk laxatives (if fluid intake is sufficient)
- encouraging exercise and standing, where possible
- avoiding medications which slow gut motility, such as codeine and tricyclic antidepressants
- careful attention to ensure maximum privacy and comfort during defecation
- supported sitting up for defecation on a toilet or commode at the earliest safe opportunity, and at a regular time each day.⁸

Daily rectal stimulation (eg, with suppositories or a microenema) may be used where the rectum is full but no spontaneous evacuation occurs despite the conditions above.⁸

If the rectum is empty for three days running, despite continuing oral intake, the use of an osmotic laxative (eg, polyethylene glycol) or a stimulant (eg, senna) should be considered.⁸

6.1.4 Sensory impairment

RECOMMENDATIONS	GRADE
People with visual and/or hearing loss should be assessed and treated by a team with the appropriate experience or in conjunction with a specialist service.	C
People with traumatic brain injury with any visual disturbance should be assessed by a team which includes: <ul style="list-style-type: none"> • ophthalmologists • orthoptists where there are problems with eye movement/double vision • people with expertise in rehabilitation for the visually impaired. 	A
All people presenting post-traumatic brain injury with persistent visual neglect or field defects should be offered specific retraining strategies.	A
All people should be assessed for pain on a regular basis and treated actively in accordance with their wishes.	B
Practitioners should be alert to the possibility of pain in people who have difficulty communicating, and pay attention to non-verbal signs of pain.	C
Practitioners and carers should be educated about: <ul style="list-style-type: none"> • hypersensitivity and neurogenic pain • appropriate handling of the paretic upper limb during transfers. 	B
Pain management protocols should be in place, which include: <ul style="list-style-type: none"> • handling, support and pain relief appropriate to the individual needs of the injured person • regular review and adjustment to changing need. 	B C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

When a person has post-TBI sensory disturbance, including partial loss of hearing or vision, this may exacerbate disorientation and confusional states or impact on higher cognitive function.⁸ People with visual and/or hearing loss should be assessed and treated by an interdisciplinary team with the appropriate experience or in conjunction with another specialist service able to meet their special needs.

6.1.4.1 Visual disturbance

Some visual disturbance or loss of vision following a TBI may resolve with time and appropriate rest, but this will require expert assessment. Where a person has any visual disturbance, the interdisciplinary team involved in the assessment of vision should include ophthalmologists, and orthoptists should also be involved where there are problems with eye movement or double vision. People with expertise in rehabilitation for the visually impaired should be involved regarding functional use of vision, mobility training and equipment. All people presenting post-TBI with persistent visual neglect or field defects should be offered specific re-training strategies.⁸

6.1.4.2 Hearing disturbance

In the case of hearing disturbance such as hypersensitivity following a TBI, the interdisciplinary team involved in assessment should include audiologists for the assessment of hearing and suitability of hearing aids. Advice should be sought from a hearing therapist for hearing-impaired people, with regard to rehabilitation and equipment provision.⁸

6.1.4.3 Pain

Pain is frequently under-diagnosed in TBI and is associated with poor outcomes.⁸ People with communication and cognitive deficits are often unable to describe their sensory symptoms. Specially adapted assessment tools⁸ or the skills of a speech-language therapist, and family/whānau and carers may be required to elicit symptoms accurately.

Painful musculoskeletal sequelae of TBI can include heterotopic ossification, contracture and deformity. Shoulder pain is particularly common in upper limb paresis, arising from spasticity in the shoulder girdle muscles, malalignment or subluxation due to muscle imbalance or weakness, or secondary damage to soft tissues (eg, rotator cuff tears or impingement).

Neurogenic pain may be associated with local hypersensitivity to touch. Pain may be exacerbated by poor handling and the uncontrolled effects of gravity. Successful management depends on an accurate assessment and intervention depending on the contributing factors, and preventive measures to support the affected limb in all positions.

All people should be assessed for pain on a regular basis and treated actively in accordance with their wishes.⁸ Health care practitioners should be alert to the possibility of pain in people who have difficulty communicating, and should pay particular attention to non-verbal signs of pain.¹³⁸ Health care practitioners and carers should be educated about hypersensitivity and neurogenic pain, and about appropriate handling of the paretic upper limb during transfers.⁸ Protocols should be in place for the management of pain, which include:

- handling, support and pain relief appropriate to the individual needs of the injured person
- review at regular intervals and adjustment in accordance with changing need.⁸

6.1.4.4 Neurodevelopmental therapy for children and young people

Neurodevelopmental therapy, originally developed for the treatment of cerebral palsy, is frequently advocated by its proponents for people with other forms of neurological impairment, including that resulting from TBI. In this therapy, therapeutic handling focuses on facilitating ‘desired’ movements while preventing ‘undesired’ movements, which are believed to produce secondary problems that reduce the functional potential of the person.

A systematic review of the evidence (which mainly involved children and young people with cerebral palsy) for neurodevelopmental therapy found it to be contradictory and inconclusive,¹³⁹ and there is no evidence to support the routine use of neurodevelopmental therapy in children and young people with TBI.

6.1.5 Communication and language rehabilitation

RECOMMENDATIONS	GRADE
A person with traumatic brain injury who has specific communication difficulties should be assessed by a speech-language therapist for suitability for speech-language therapy.	B
A person with traumatic brain injury who has specific communication difficulties where achievable goals are identified, should be offered an appropriate treatment programme, with monitoring of progress.	A
A communication rehabilitation programme should: <ul style="list-style-type: none"> • take into account the person’s premorbid communication style and any cognitive deficits • provide the opportunity to rehearse communication skills in naturalistic situations • include the family/whānau and carer(s) in developing strategies for optimum communication • include communication aids where appropriate. 	C C C B
Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.	

GOOD PRACTICE POINTS	
A communication rehabilitation programme should provide compensatory strategies.	✓
CHILDREN AND YOUNG PEOPLE	
Assessment and intervention for communication deficits in children should be appropriate to their age and development.	✓
Assessments and the development of communication rehabilitative strategies for children and young people should be done by paediatric speech-language therapists with expertise in traumatic brain injury.	✓
This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.	

TBI can affect communication in different ways.⁸ Following a TBI, people may have communication impairments, including speech production impairments, which impact on intelligibility and problems with receptive and expressive language including reading and writing, and higher-level language skills such as pragmatics and more general social interaction. Speech-language therapy intervention should therefore target as necessary:

- motor speech production and reduced intelligibility, including disorders of the voice
- receptive or expressive language skills (including reading and writing)
- ‘high level’ abstract language skills and social interaction skills, including social appropriateness.

6.1.5.1 Interventions and strategies

A person who, post-TBI, has specific communication difficulties should be assessed by a speech-language therapist to assess their suitability for intensive or regular speech-language therapy treatment. Where achievable goals can be identified, and continuing progress demonstrated, they should be offered an appropriate treatment programme, with monitoring of progress.⁸ The programme should:

- take into account the person's premorbid communication style and any underlying cognitive deficits
- give the opportunity to rehearse communication skills in situations appropriate to the context in which the person will live/work/study/socialise after discharge
- include the family/whānau and carer(s) in developing strategies for optimum communication within the immediate social circle
- consider the need for communication aids including gesture drawing, communication charts and computerised systems⁸
- provide compensatory strategies to manage communication disturbances.

6.1.5.2 Interventions and strategies for children and young people

Assessment and intervention for communication deficits in children should be appropriate to their age and development. Many interventions will be implemented through special education services (see Chapter 12, *Children and young people and traumatic brain injury*). It is important that assessments and the development of communicative and rehabilitative strategies be done by people with expertise in the management of children with TBI.

6.1.6 Cognitive rehabilitation

RECOMMENDATIONS	GRADE
Where cognitive impairment is causing management difficulties or limiting the response to rehabilitation, specialist advice should be sought.	C
People with persistent cognitive deficits following traumatic brain injury should be offered functionally oriented cognitive rehabilitation.	B
Cognitive rehabilitation should include: <ul style="list-style-type: none">• in the acute phase, management in a structured and distraction-free environment and targeted programmes for those with executive difficulties• attempts to improve attention and information-processing skills• teaching compensatory techniques• the use of external memory aids.	A B C A
Trial-and-error learning should be avoided in people with memory impairment.	B
A trial of methylphenidate may be considered for adults or children with traumatic brain injury who have deficits in the speed of mental processing or attention deficit hyperactivity disorder secondary to traumatic brain injury.	C
A trial of donepezil hydrochloride may be considered for adults with traumatic brain injury who have deficits in memory and sustained attention.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

Cognitive rehabilitation should include procedural learning information and principles.	✓
Any trial of medication for people with traumatic brain injury should be commenced at low doses, with cautious increases in dosage, and be monitored for effectiveness and adverse side effects.	✓
Any trial of medication for a person with traumatic brain injury should be preceded by a clear explanation to the person with traumatic brain injury and their carer(s), and a caution that effects of medications are less predictable in people with traumatic brain injury.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

The nature of cognitive deficits resulting from TBI depends, to some extent, on the severity and location of the injury. Cognitive deficits can include: difficulties in understanding and/or producing speech; difficulties with attention, memory and the ability to concentrate; difficulties with initiating and planning daily activities; and impairments in other cognitive tasks such as reasoning, judgement, initiation, planning, problem-solving and decision-making. Relatively minor impairments in areas such as prioritising and decision-making can have a profound effect on functioning.

Although the physical and behavioural effects of TBI often present significant challenges for rehabilitation, the cognitive deficits may be the most difficult for families/whānau, carers and employers to recognise, accept and accommodate. This difficulty may be relatively greater in the case of people with TBI who have few or no physical symptoms detectable to the observer, when the people around them may be unable to understand why, for example, they cannot remember and follow instructions, or why they sometimes act inappropriately.

Limitations of the injured person's insight and awareness of their own difficulties, in particular, may impact on their ability to engage effectively in rehabilitation, and may therefore affect the timing of intervention.

6.1.6.1 Targets and interventions

The aim of cognitive rehabilitation is both restorative and remedial. Intellectual deficits may be lessened by various repetitive exercises and compensatory or adaptive cognitive rehabilitation, where adaptive devices and strategies, together with modification of the environment, are used to try to restore functioning by minimising the negative impact of the symptoms that persist. There are four possible strategies involved:

1. attempting to restore function
2. attempting to teach skills to reduce the impact of the deficits resulting from the TBI
3. modifying tasks or the environment to aid the performance of tasks
4. using behavioural approaches such as feedback and reinforcement to support the learning of skills and strategies.¹²¹

6.1.6.2 Cognitive management

Where cognitive impairment is found to be causing management difficulties or limiting the response to rehabilitation, specialist advice should be sought.⁸

Cognitive rehabilitation has been shown to be effective, although the effectiveness of specific interventions is unclear.^{10,100,101,140,141} People with persistent cognitive deficits following TBI should be offered cognitive rehabilitation. This may include:

- management in a structured and distraction-free environment and targeted programmes for those with executive difficulties (ie, problems with planning, organisation, problem-solving and divided attention), in the acute phase¹⁴²
- attempts to improve attention and information-processing skills¹⁰⁰
- teaching compensatory techniques to overcome their everyday problems⁸
- the use of external memory aids to enhance independence in the presence of memory deficits¹⁴³
- procedural learning information and principles.

Trial-and-error learning should be avoided in people with memory impairment,⁸ as it tends to reinforce unwanted outcomes/behaviours.

6.1.6.3 Specific interventions in cognitive rehabilitation

There is good evidence that cognitive rehabilitation is beneficial for people with TBI and there is no evidence of harm. Although one Health Technology Assessment report concluded that the evidence of beneficial results was ambiguous, this report was based on a limited evidence base and only considered particular interventions.¹⁴⁰

Another recent robust and comprehensive systematic review concluded that:

- functionally oriented cognitive therapy can help adults with TBI to cope with their disabilities and may aid in the recovery of cognitive function
- there is no good evidence that restorative cognitive therapy enhances neuronal recovery or repair or that the repetitive cognitive exercises improve functional outcomes
- there is some evidence that intense, comprehensive-holistic, highly structured programmes that include compensatory cognitive therapy can be more effective than more traditional speech, occupational and behavioural therapy, although some studies provided conflicting results
- there is insufficient evidence to make specific recommendations regarding personal selection criteria for specific therapies.¹⁴¹

However, the heterogeneous nature of the population of people with TBI, the interventions used in cognitive rehabilitation, and the various measures used means that there is little evidence for individual interventions. The systematic review above found that there is insufficient evidence to draw any conclusions about which cognitive rehabilitation programmes are most effective.¹⁴¹

Many of the complementary and alternative therapies used for TBI primarily, but not exclusively, address cognitive deficits. See Chapter 7, *Complementary and alternative medicines*.

6.1.6.3.1 Medications for cognitive deficits

People with TBI may be more sensitive (ie, have a 'low threshold') to the effects (positive and negative) of medications. Any trial of medication for people with TBI should be commenced at low doses, with careful monitoring for both effectiveness and adverse side effects, and cautious increases in dosage. There also needs to be a clear explanation to the person with TBI and their carer(s) with a caution that effects of medications are less predictable in people with TBI.

There is very little evidence for the effectiveness of medications for the cognitive sequelae of TBI, and input from a neuropsychiatrist or other appropriately trained and experienced clinician is advisable before any trial of medication.

See MedSafe data (www.medsafe.govt.nz) for contraindications and side effects of medications listed in this section.

6.1.6.3.1.1 *Amantadine*

Amantadine has been proposed for the treatment of behavioural, motivational and cognitive deficits in people with TBI. However, the small trials in this population have produced conflicting results. The only randomised controlled trial in a rehabilitation population (of only 10 people) showed no improvement over placebo.^{144–146} A randomised cross-over trial of amantadine versus placebo in 35 hospitalised people with severe TBI showed more rapid improvement in the intervention group on primarily cognitive measures, but no difference between the two groups by six months.¹⁴⁷ There is insufficient evidence of the effectiveness of amantadine in people with TBI on which to base a recommendation.

6.1.6.3.1.2 *Bromocriptine*

One small uncontrolled trial of bromocriptine to treat poor motivation in people with TBI was identified. Improvements were found in anxiety and depression, and cognitive tests sensitive to motivation or frontal lobe involvement were found. However, there were some methodological issues with this study, and there is insufficient evidence from which to draw conclusions about effectiveness.¹⁴⁸

6.1.6.3.1.3 *Methylphenidate and amphetamines*

A Cochrane review of the effectiveness of methylphenidate and amphetamines used in the acute stage to promote recovery from TBI found no evidence of benefit.¹⁴⁹

A further recent systematic review of methylphenidate treatment of ADHD secondary to TBI in children, adolescents and adults found that methylphenidate showed beneficial effects on hyperactivity and impulsivity but smaller effect sizes than observed in primary ADHD, and no robust effect on cognition. A more favourable outcome was associated with the initiation of treatment soon after the injury, although this factor was not systematically studied, and with trials with relatively long durations. It was concluded that robust trials in this population were needed before any recommendation may be made for routine treatment.¹⁵⁰

A small randomised controlled trial of 23 people aged 16 to 64 years with moderate to severe TBI found that sub-acute administration of methylphenidate appeared to enhance the rate but not the ultimate level of recovery as measured by the DRS and tests of vigilance.¹⁵¹ A further randomised controlled trial of methylphenidate used in people with TBI who had been referred specifically for assessment and treatment of attentional deficits found that the participants in the treatment arm showed significant improvement in the speed of mental processing. It was concluded that methylphenidate may be a useful treatment in TBI for symptoms that can be attributed to slowed mental processing.¹⁵²

Therefore, there is insufficient evidence on which to base any recommendation for routine use of methylphenidate and amphetamines in the treatment of people with TBI. However, a trial of methylphenidate may be considered where the person has deficits in speed of mental processing.

6.1.6.3.1.4 *Donepezil hydrochloride and other cholinergic agents*

A non-systematic review reported that there is some weak evidence that cholinergic agents may be of use for the treatment of attention and memory deficits following a TBI.¹⁵³ A single uncontrolled trial of three acetylcholinesterase inhibitors (donepezil, galantamine and rivastigmine) for the treatment of fatigue, poor memory, diminished attention or diminished initiation in people with chronic, stable TBI found that 61% of participants had a marked positive response, with almost all responders reporting better vigilance and attention leading to better general function. Fifty-five percent of people wanted to continue therapy.¹⁵⁴

One small randomised controlled trial found benefits from donepezil hydrochloride on measures of memory and sustained attention in people with TBI, benefits which may have been sustained after treatment cessation, although that is difficult to ascertain from this study.¹⁵⁵ Several further uncontrolled trials of donepezil in people with TBI also reported positive effects on cognition.^{156–160}

Thus, although there is insufficient evidence on which to base a recommendation for routine treatment with cholinergic medication, a trial of donepezil hydrochloride may be considered where the person has deficits in memory and sustained attention.

6.1.6.4 Cognitive rehabilitation in children and young people

A recent systematic review concluded that there is little evidence for or against cognitive rehabilitation for children and young people with TBI.¹⁴¹ In the absence of evidence there is no reason to suspect that the benefits found for adults would not apply to children when programmes are adapted for this age group.

Cognitive rehabilitation for children and young people needs to address not only the aim of regaining lost functionality, but also the ongoing need to develop more advanced cognitive skills as the child matures. The child with TBI will require regular monitoring for the appropriateness and effectiveness of cognitive rehabilitative strategies, and the development and implementation of new programmes and compensatory techniques to match the needs of the developing child.

Cognitive rehabilitation of children and young people with TBI may be delivered by teams of people from neuropsychology, occupational therapy and speech-language therapy, or through educational interventions by Group Special Education. See also Chapter 12, *Children and young people and traumatic brain injury*.

Home-based cognitive therapy becomes increasingly appropriate as children reach an age when they would usually be expected to become more independent of their families. For example, external memory aids and compensatory techniques to assist planning, organisation and problem-solving will help children to become more independent of their caregivers.

6.1.6.4.1 Medication for cognitive deficits in children and young people

6.1.6.4.1.1 Amantadine

Only one case-controlled study of amantadine for the treatment of cognitive impairments in an adolescent population (aged 13–18 years) with TBI was identified. The treatment group had a greater improvement in functioning than the control group, but the treatment group was more impaired at the start of the trial. Subjective improvements were noted in 63% of the treatment group. Nine percent had adverse effects such as hallucinations, delusions, increased aggression and nausea/vomiting, which reduced if the dosage was decreased or the treatment stopped.¹⁶¹ There is insufficient evidence on which to base a recommendation for the routine treatment of children with TBI with amantadine.

6.1.6.4.1.2 Stimulants

There is little robust research on the use of stimulant medication in children and young people with TBI. One small (n=10) randomised controlled trial of the use of methylphenidate found no significant differences between methylphenidate and placebo on measures assessing behaviour, attention, memory and processing speed.¹⁶² A systematic review of methylphenidate treatment of ADHD secondary to TBI in children, adolescents and adults cited above concluded that there is insufficient evidence for any recommendation for routine treatment.¹⁵⁰ This echoes the evidence for use in adults above. There is therefore no evidence on which to base a recommendation for the use of methylphenidate or other stimulant medication in this population. However, treatment providers may consider a trial of medication, particularly if there is historical evidence of pre-injury ADHD symptoms. In that case, target symptoms should be clearly identified before the trial, and effects (both benefits and adverse effects) should be monitored across more than one setting. The incidence of side effects is higher in children with neurological injury, so dosages should start low.

6.1.7 Psychosocial/Behavioural rehabilitation

RECOMMENDATIONS	GRADE
People with traumatic brain injury should be provided with access to specialist psychological assessments and interventions to assist in the management of their behavioural difficulties, including substance abuse.	C
People with severe behavioural problems, especially those with a tendency to wander, should be referred to specialist behavioural management services.	C
When there is severe behavioural disturbance, supervision and behavioural management by a professional trained in behavioural management should be provided.	C
In the case of people with severe behavioural problems, especially those with a tendency to wander, the interdisciplinary team should develop an integrated approach to manage behaviour and refer to specialist behavioural management services when necessary.	C
Families/Whānau and carers should be given information and ongoing support as required to help them to understand cognitive and behavioural problems, and guidance on how to interact appropriately with the person with traumatic brain injury and how to access services.	C
Psychotropic medications used to manage agitation and aggression in people who have had a traumatic brain injury should be carefully selected for their side effect profiles, and the use and effectiveness closely monitored.	C
If no effect is observed within six weeks, the drug should be 'tailed off' and another drug trialled after a suitable wash-out period.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

Treating clinicians should ask about the use of any non-prescription medicines, supplements and complementary or alternative medicines.	✓
When necessary, an assessment by a neuropsychiatrist should be made to differentiate neurobehavioural difficulties from symptoms of a functional illness.	✓
A person with traumatic brain injury who may require medication for irritability and aggression should be referred to a neuropsychiatrist for treatment.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

A person who has suffered a TBI may show psychosocial/behavioural effects from the injury. These may include outwardly detectable changes in behaviour and personality, such as irritability, agitation, impulsivity, disinhibition and verbal and/or physical aggression. There may be changes in mood, with effects such as emotional lability, depression, anxiety and suicidality, and sexual difficulties. Changes in the person's relationships with other people may also occur, with the person being more egocentric and isolated. These behavioural changes often cause negative responses from family/whānau, friends and other people, including employers, with whom the person with the TBI has contact, and this may impede the person's recovery. Difficulties in this area of functioning were reported by families as hardest to cope with after TBI. These changes can lead to social isolation and people may need access to advocacy, and families/whānau may require ongoing support.¹⁰

One longitudinal study of people with TBI found that families may recognise more behavioural changes than practitioners. It found that families identified behaviour change in about 80% of the people with TBI, and that more behavioural problems were reported by families than by nurses at hospital. Behavioural symptoms also appeared to worsen over the three years of the follow-up, with an increase in aggressive behaviour. There was no correlation between behaviour change and age or the severity of the injury as measured by post-traumatic amnesia.¹⁶³

Specific issues relating to post-TBI mental health, including treatment, are addressed in Chapter 14, *Special issues*.

6.1.7.1 Targets and interventions

The aim of behavioural rehabilitation is to aid recovery, improve functioning where possible, and provide strategies to minimise the negative impact of the symptoms that persist.

6.1.7.1.1 Behaviour management

A variety of unwanted or antisocial behaviours may sometimes develop after brain injury, including verbal or physical aggression, sexual disinhibition and attention-seeking behaviour.⁸ Longitudinal studies suggest that planned behavioural modification programmes, consistently applied, are effective in preventing these undesired behaviours from becoming established.⁸

In the case of people with severe behavioural problems, especially those with a tendency to wander, the interdisciplinary team should develop an integrated approach to manage behaviour, and referral to specialist behavioural management services may be required.^{7,8} In the event of severe behavioural disturbance, appropriate supervision (including one-on-one supervision when required) by a professional trained in behavioural management should be provided to ensure the safety of the person and those around them, and to provide effective behavioural management.⁸

If the problems persist or worsen over more than two weeks, or if they give rise to severe concern for safety, and cannot be managed in the community, the person should be transferred to a secure residential specialist unit to provide a safe environment and specific assessment and treatment.⁸

People with TBI should be provided with access to specialist psychological assessment and interventions to assist in the management of their behavioural difficulties, including substance abuse.^{8,164,165} Families/Whānau and carers should be given specific information and ongoing support as required to help them to understand the nature of cognitive and behavioural problems, and guidance on how to interact appropriately with the brain-injured person and how to access services.⁸

6.1.7.1.2 Training for parents who have traumatic brain injury

There is some evidence that errorless compliance training, a non-coercive intervention for improving child compliance, may be an effective intervention for parents with cognitive and behavioural impairments that decrease their potential to benefit from traditional parenting approaches. A small uncontrolled trial of errorless

compliance training for parents with TBI of oppositional children (ages two to seven years) found generalised and durable increases in child compliance. Improvements were also reported in parent self-esteem.¹⁶⁶ Although the evidence in this area is not robust and insufficient on which to base a recommendation for routine application for all parents with TBI, consideration should be given to the provision of errorless compliance training for people with TBI who are having difficulties with non-compliant children.

6.1.7.1.3 Medication for behaviour management

A recent systematic review of pharmacological interventions found that there was insufficient evidence to determine whether any medications are effective in the treatment of behaviour disorders in people with TBI.¹⁶⁷ It was reported that there is some weak evidence (based on case studies) that psychostimulants may be effective in the treatment of apathy, inattention and slowness, and that high-dose beta-blockers, anticonvulsants and antidepressants, particularly selective serotonin reuptake inhibitors (SSRIs), are effective in the treatment of agitation and aggression. Some medications, particularly lithium and dopaminergic drugs, can cause adverse effects and deterioration.

BEHAVIOUR MANAGEMENT IN CHILDREN AND YOUNG PEOPLE

Children and young people may have behavioural sequelae following severe TBI. However, there is little evidence specifically on behaviour management interventions in children and young people with TBI. In New Zealand, this is often managed through Group Special Education and family interventions such as parenting initiatives. See Chapter 12, *Children and young people and traumatic brain injury* for more details.

6.1.7.2 Management of emotional and personality issues

Anxiety, depression and other mental health conditions, including substance abuse, are common after TBI and often increase if not identified and treated. For more details of management see Chapter 14, *Special issues*.

Many 'over-the-counter' products may cause symptoms of emotional and personality issues, and/or may interact with prescribed medications. It is important that the treating health care practitioner asks about the use of any supplements and complementary or alternative medicines.

6.1.7.2.1 Irritability, agitation and aggression

In a review of post-TBI irritability, agitation and aggression, it was found that, of people with mild TBI, about a third report irritability as a symptom. Thirty percent to 35% of people with mild TBI described irritability one year after injury. Furthermore, this was the most commonly reported neurobehavioural symptom. The severity of injury did not affect the prevalence of irritability, and while the frequency of most other symptoms decreased or stabilised over time, reports of irritability increased between six months and a year after insult. In people who had suffered a severe TBI, irritability (as reported by family members) was present in 67% a year post-injury, and as prevalent (64%) amongst a separate sample five years post-injury.¹⁶⁴

Acute-onset irritability is probably primarily attributable to organic dysfunction, while late-onset irritability may be secondary to a mood disorder arising from poor adjustment to physical and social impairment.¹⁶⁴ Symptoms of TBI may sometimes be mistaken for mental illness and thus lead to administration of inappropriate and ineffectual medications. In some cases, assessment by a neuropsychiatrist can aid in differential diagnosis. Also see Chapter 14, *Special issues*.

Aggression may be exhibited acutely or delayed by some time post-injury and, particularly when manifested physically, can distress and endanger carers and practitioners. It may also impact on the rehabilitation of the person with TBI, as it may result in exclusion from programmes. Risk assessments should be performed using empirically validated, actuarial risk-assessment measures, which are more accurate than clinical judgement

alone.¹⁶⁸ Family/Whānau and carers should receive support and training in how to manage this behaviour and protect their own safety. Also see Chapter 13, *Needs of carers*.

6.1.7.2.1.1 Pharmacological management of post-traumatic brain injury agitation and aggression in adults

The administration of sedating medication is an appealing option in the management of aggression, as the risks imposed by this behaviour are substantially and rapidly reduced. However, while sedation may sometimes be appropriate as an emergency measure, it is not acceptable as a long-term solution for the majority of people. In most cases, pharmacological restraint will not target the factors underlying irritability and aggression, and it will hinder adequate assessment.¹⁶⁴ A further drawback is that sedation is not specific to suppressing aggressive behaviour; all, including appropriate, behaviour will be affected.

Another unwelcome consequence will be to depress further the person's impaired cognitive functioning, thereby hindering new learning (including the acquisition of adaptive behaviours). Finally, people with TBI are very sensitive to medication, and undesirable side effects can in themselves prove debilitating. For example, while psychostimulants are used in the treatment of distractibility and impulsivity, a potential side effect is increased irritability.¹⁶⁴ Therefore, it is important that people who may require medication should be discussed with, or referred to, a neuropsychiatrist for treatment.

A Cochrane systematic review evaluated the effectiveness of various psychotropic medications used to manage agitation and aggression in people who have had a TBI. The conclusion of the reviewers was that while numerous drugs have been tried, there is little good evidence to support their effectiveness in this population. They suggest that drugs be carefully selected for their side effect profiles, and the use of and effectiveness for the individual with TBI be closely monitored. The effects of medication are generally observed within two to six weeks from starting medication. It was suggested that if no effect is observed within six weeks, the drug should be 'tailed off' and another drug trialled after a suitable wash-out period.¹⁶⁹

6.2 Optimising performance in daily living tasks

RECOMMENDATIONS	GRADE
DAILY LIVING SKILLS	
All daily living tasks should be practised in the most realistic and appropriate environment, with the opportunity to practise skills outside therapy sessions.	C
An individual treatment programme aimed at maximising independence in the areas of self-maintenance, productivity and leisure should be developed and implemented.	C
Family and carers should be involved in establishing the most appropriate routines for activities of daily living for people with traumatic brain injury, which take account of their lifestyles and choices.	C
All people with traumatic brain injury who have difficulties in activities of daily living should be assessed by an occupational therapist, nurse or other health care practitioner with expertise in brain injury and experience in this area.	C
Services should recognise that the provision of 'care' for some people with traumatic brain injury may mean the supervision and practice of community living skills, rather than hands-on physical care.	C

RECOMMENDATIONS	GRADE
EQUIPMENT AND TECHNOLOGY	
People with traumatic brain injury who have difficulties in functioning should be assessed by people with expertise in this area, to determine whether equipment or adaptations could increase their safety or independence.	C
The need for equipment should be assessed on an individual basis and in the environment in which it will be used.	C
The prescription of equipment should take account of any cognitive and behavioural deficits and their constraints on the person's ability, or their carer's ability, to use the equipment safely and appropriately. Where this is in doubt, arrangements should be in place for regular review.	C
When an item of equipment has been identified as required for a person with traumatic brain injury, it should be provided as quickly as possible and before the person is discharged to the community.	C
The person, their family/whānau or carer(s) should be trained in the safe and effective use of equipment.	C
The ongoing effectiveness of equipment should be reviewed on a regular basis and in accordance with the manufacturers' guidelines.	C
People and their families/whānau and carers should be given clear written information on who to contact for repairs, replacement or future help and advice regarding the equipment.	C
Where necessary, a specialist assessment of each individual's ability to use a personal computer should be arranged and the need for adapted hard- and software recorded.	C
Rehabilitation teams should consider computers and other technology as adaptive sources of meaningful occupation or as compensatory strategies for people with significant sequelae of brain injury.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

DAILY LIVING SKILLS

Carers and family, if willing and acceptable to the person with traumatic brain injury, should be trained and supported to help with therapy.



EQUIPMENT AND TECHNOLOGY

People with traumatic brain injury should be given information and advice about changes in technology and computer use relevant to their needs.



The assessment for, and prescription of, augmentative communication devices should be made by suitably accredited clinicians.



Careful consideration should be given to the appropriateness of technology for individuals who may be vulnerable, such as people with symptoms of disinhibition or impaired judgement. Caution and monitoring of the person's use of the technology may be necessary in some cases.



This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

6.2.1 Activities of daily living

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

People with TBI who have difficulties in activities of daily living should be assessed by an occupational therapist with expertise in brain injury, and an individual treatment programme aimed at maximising independence in areas of self-maintenance, productivity and leisure should be developed and implemented.⁸

The majority of rehabilitation interventions undertaken by the TBI rehabilitation team are aimed at minimising impairments and maximising performance in daily living tasks. These tasks include basic self-care and more extended activities of daily living (eg, shopping and meal preparation), work and leisure activities. To maximise new learning and the relearning of old skills, evidence suggests that activities should be practised in a naturalistic and realistic environment. Ideally, this should be the person's own home and local environment with the opportunity to practise skills outside therapy sessions.⁸ Independence is achieved through practice, the learning of adaptive techniques, and the provision of equipment and/or environmental adaptation. Family/Whānau and carers should be involved in establishing the most appropriate routines for activities of daily living which take account of the injured person's lifestyle and choices,⁸ and family/whānau and carers should be trained and supported to help with this. Services and funders should recognise that the provision of 'care' for some people with TBI may mean the supervision and practice of community living skills, rather than hands-on physical care.⁸

6.2.2 Provision of equipment and adaptations

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

The provision of equipment or adaptations provides a solution to the individual's unique needs within their own environment. There is strong evidence for the general benefit and cost effectiveness of equipment provision for people who need it, albeit not in the TBI population.⁸

Every person with TBI who has difficulties in functioning should be assessed to determine whether equipment or adaptations could increase their safety or independence.⁸ The need for equipment should be assessed on an individual basis and in the environment in which it will be used.⁸ The prescription of equipment should take account of any cognitive and behavioural deficits and their constraints on the person's ability to use the equipment safely and appropriately. This also applies to equipment for use solely by the person's carer(s). Where this is in doubt the equipment provider should be responsible for ensuring that arrangements are in place for regular review.⁸

Once an item of equipment has been identified as required for a person with TBI, it should be provided as quickly as possible⁸ and before the person is discharged to the community. The person, their family/whānau and/or carer(s) should be thoroughly trained in its safe and effective use. Its ongoing use and relevance should be reviewed on a regular basis and in accordance with the manufacturer's guidelines.⁸ People should be given clear written information on who to contact for repairs, replacement or future help and advice regarding the equipment.⁸

6.2.3 Computers and assistive technology

Personal computers have increasingly become routine household items. As well as providing a useful adjunct to therapy in some areas, they offer opportunities for sedentary recreation and social interaction (via e-mail).⁸ In some cases the acquisition of computer skills may also provide opportunities for employment. The increasing availability of adapted hardware and software can also offer an alternative means of writing for those who are no longer able to hand write.⁸ This can also provide augmented communication and be linked with environmental control systems.⁸

Other new technology, such as cellphones, pagers and personal digital assistants, can also be very useful. One large study found that there were significant differences in case closure status and expenditure on vocational rehabilitation for people with TBI who were provided with assistive technology compared with those who were not, although there were no significant differences in the average earnings of the two groups.¹⁷⁰

Rehabilitation teams should routinely consider computers and other technology as adaptive sources of meaningful occupation or as compensatory strategies for people with significant sequelae of brain injury.⁸

People with TBI should be given information and advice about changes in technology and computer use relevant to their needs. Where necessary, a specialist assessment of each individual's ability to use a personal computer should be arranged and the need for adapted hardware and software recorded.⁸

However, careful consideration of the appropriateness of technology for individuals with TBI is necessary. People with symptoms of disinhibition or impaired judgement may be particularly vulnerable to the risks of computer technology, such as internet 'scams' or predatory behaviour from other users. Caution and monitoring of the use of the technology may be necessary in some cases.

6.3 Sleep and fatigue

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

Sleep difficulties and fatigue are two very common problems following TBI of all severities. The two problems do not necessarily go together, although sleep disturbance can certainly contribute to fatigue. People with TBI and health care practitioners recognise two ‘types’ of fatigue:

1. ‘cognitive fatigue’, where mental effort without physical exertion leads to severe tiredness and an inability to proceed
2. ‘physical fatigue’, where smaller than expected amounts of physical exertion lead to severe tiredness and an inability to proceed.

Fatigue is one of the most frequently reported symptoms following TBI. It often also poses a barrier to return to work or other daily activities. There is virtually no good quality evidence relating to its extent, impact and effective treatment. The management of fatigue is an important goal of rehabilitation post-injury. It is also thought that fatigue may have impact on other symptoms of TBI (eg, headaches, or cognitive and behavioural symptoms) which are often reported to be exacerbated when the person is tired.

Medications sometimes used to help with fatigue following TBI have not undergone investigation in this population and should be used cautiously, if at all.

The management of fatigue is sometimes hampered by poor insight, so that while caregivers may recognise the impact of the increasing fatigue, this may not be recognised by the person themselves.

One contributing factor in the development of fatigue may be the development of sleep disorders, including difficulties in both the onset and maintenance of sleep, or changes to the sleep/wake cycle. If these difficulties persist they can then lead to the typical symptoms associated with chronic sleep deprivation.

Good management of sleep difficulties can be counter intuitive; for example, a common response to poor sleep is to try to stay awake longer during the day, the thought behind this being that the person would be really tired by the time they went to bed. However, this may generate an overtired state, with consequent sleep disturbance and exacerbated symptoms. Advice from a professional experienced in managing fatigue and/or sleep disorders can be useful in establishing a suitable treatment programme.

6.4 Vocational rehabilitation

RECOMMENDATIONS	GRADE
People with traumatic brain injury should be assessed for the need for vocational rehabilitation to assist their return to work, or for entering the workforce for those not previously employed, and vocational rehabilitation should be provided to those found to need it.	A
Standard vocational rehabilitation interventions such as cognitive training and behaviour modification should be monitored for effectiveness, and supported employment provided for those for whom the standard interventions are insufficiently effective.	A

RECOMMENDATIONS	GRADE
<p>Supported employment should include these fundamental aspects:</p> <ul style="list-style-type: none"> • job placement, including: <ul style="list-style-type: none"> – matching job needs to abilities and potential – facilitating communication between the person, the employer and carers – arranging travel/training – proactive assessment of the job environment for potential problems by someone with expertise in this area • job site training and advocacy by the job coach including: <ul style="list-style-type: none"> – training – proactive identification of problems – designing solutions in cooperation with the person with traumatic brain injury, carers and employers – ongoing assessment with continuous monitoring of key aspects of the person's performance in work • job retention and follow-up by the job coach including: <ul style="list-style-type: none"> – monitoring of progress to anticipate problems and intervene proactively when necessary. 	B

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

Return to employment or an alternative occupation is a primary goal and a critical factor in the restoration of quality of life for people with TBI. If people with TBI are unable to access, return to or remain in previous or alternative employment, there are major economic implications as well as far-reaching consequences for the individual and their family/whānau.¹²

Not everyone with a TBI will need the same degree of vocational rehabilitation. A systematic review reported that 60–85% of people with a mild TBI, 50–60% of people with a moderate TBI, and 20–30% of people with a severe TBI were re-employed by one year post-injury,¹⁰ so the need for vocational rehabilitation is likely to be greater the more severe the injury. Many children with severe TBI will have difficulty in establishing themselves in employment on leaving school¹⁷¹ and may require specialist vocational assessment, advice and support. There is also some evidence that women experience more difficulty with return to work than men.¹⁷²

Factors associated with or predictive of return to work include:

- age^{36,173–175}
- sex¹⁷²
- pre-injury level of education^{45,174–176}
- pre-injury employment status³⁶
- possession of qualifications¹⁷⁵
- pre-injury occupation¹⁷⁷
- pre-injury psychiatric history¹⁷⁶
- pre-injury drug and alcohol use¹⁷⁶
- injury severity^{176,178}
- mechanism of injury including violent mechanism¹⁷⁶ and fall⁵⁹
- duration of loss of consciousness at time of injury^{45,174}
- post-traumatic amnesia^{5,178}
- level of disability at discharge^{174,176,177}
- Glasgow Outcome Scale at six months¹⁷⁹ and at five years post-injury (in people with childhood TBI)¹⁸⁰

- cognitive functioning^{45,175,178} and specific cognitive variables, including verbal memory, verbal fluency and mapped test of planning and strategy¹⁷³
- neuropsychological assessment scores on reading comprehension, immediate and delayed verbal memory, level of depression, and dysphasic symptomatology¹⁸¹
- behavioural competence⁴⁵
- accurate self-awareness post-injury¹⁸²
- psychological distress post-injury^{36,178}
- disability post-injury^{176,183}
- community integration post-injury¹⁷⁶
- social interaction post-injury¹⁷⁷
- post-injury employment with greater decision-making latitude¹⁷⁷
- availability of vocational rehabilitation services (vocational guidance and counselling, on-the-job training)¹⁸⁴
- race (in the USA).¹⁸⁵

6.4.1 Vocational rehabilitation interventions

Those unable to return to paid employment are often not provided with the advice, opportunity and support to enable them to find an alternative occupation appropriate to their needs. However, there is consistent strong evidence that vocational rehabilitation, such as supported employment, improves vocational outcomes for people with TBI in securing sustainable employment or alternative occupations, and is cost-effective.^{10,186–188}

The return to work of people with TBI who have symptoms that may impact on their employment, whether in a previous job or a new one, such as memory problems and planning, may be more durable when any such problems are recognised, the appropriate strategies are implemented and the person and their colleagues are educated about TBI and its sequelae and impact on employment. Therefore, people with TBI should be assessed for the need for vocational rehabilitation to assist their return to work, or for entering the workforce for those not previously employed (such as people who sustained a TBI in childhood). Where need is identified, the person with TBI should be supported in their employment, or their ability to become employed, which will help their ability to participate in employment, and so their ability to earn an income, which will contribute to an appropriate quality of life.

6.4.1.1 Supported employment

Supported employment is only necessary where standard vocational rehabilitation is not sufficient to achieve the desired level of employment for a person with TBI. This may be a short-term transition stage or may be long term, especially for people with a severe TBI because regular vocational rehabilitation programmes are insufficient, and other interventions such as cognitive training and behaviour modification show limited success.¹⁸⁹

The key feature of supported employment strategies is that they are applied ‘on the job’ in the work environment. Supported employment programmes include vocational support (eg, in placement finding and monitoring, with job coaching, education of employers and colleagues and a plan for progression in the workplace that is provided by a specialist vocational rehabilitation provider).

Training and practice to prepare the person for work may be important, but the job coach always accompanies the person to the job site to help them work out on-the-spot solutions to problems as they arise and to facilitate communication between them and the employer. Problem-solving on the job is a defining principle of supported employment.

There is strong evidence for the effectiveness of supported employment in improving return to work for people with severe TBI.^{10,186} People with TBI who are not able to return to their previous work or who are having difficulties with their work should receive an assessment of their need for vocational rehabilitation and/or supported employment. People with severe TBI should receive an assessment of need for vocational rehabilitation and supported employment, even if they have returned to work.¹²

A systematic review identified that there are several models of supported employment, including apprenticeships, small businesses and work ‘enclaves’. The most common, and the one most appropriate for people with TBI, is individual placements, where training and support are provided on an individual basis in ordinary work settings. The four fundamental components of supported employment for people with TBI are identified below.¹⁰

1. Job placement, including: matching job needs to the person’s abilities and potential; facilitating communication between the person with TBI, the employer and carers; arranging travel and/or training; and proactive assessment of the job environment for potential problems.
2. Job site training and advocacy, which dictates an active role for the job coach. The job coach performs functions usually left to the employer in conventional vocational rehabilitation (such as training), and also needs to proactively identify problems and design solutions in cooperation with the person with TBI, carers, employers and anyone else involved.
3. Ongoing assessment with continuous monitoring of key aspects of the person’s performance in work. This is usually an intense intervention by the job coach at the beginning of the placement, but is expected to reduce as the person successfully adjusts to the work placement.
4. Job retention and follow-up, where the job coach monitors progress to anticipate problems and intervenes proactively when necessary to prevent crises from disrupting the person’s job placement. This may continue indefinitely, but the need is expected to diminish over time.

6.5 Sexuality

RECOMMENDATIONS	GRADE
The opportunity to discuss issues relating to sexuality should be offered early after significant traumatic brain injury, to both the person and their partner. This should be initiated by the health professionals.	C
Advice about sexuality should cover both physical aspects (eg, positioning, sensory deficits, erectile dysfunction, drugs) and psychological aspects (eg, communication, fears, altered roles and sense of attractiveness).	C
Families/Whānau and carers should be reassured that sexually inappropriate behaviour is not unusual in people who are in the early stages of recovery from a traumatic brain injury and that it should improve with time, and be provided with training in how to avoid inadvertently reinforcing the behaviour.	C
If the sexually inappropriate behaviour is severe, dangerous or persistent, it will need to be addressed as part of the rehabilitation programme for the person.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

Sexuality encompasses not only intercourse, but also intimacy, communication and psychological aspects including the sense of self-worth, attractiveness and significance of role. Sexual functioning is important and desirable for the majority of people, including those who have had a TBI.

A substantial proportion of people with TBI, particularly at the more severe end of the spectrum, may suffer effects on sexuality such as impaired sexual functioning, resulting from both the TBI and medications for conditions related to the TBI; and also sexually inappropriate behaviour resulting from behavioural and cognitive impairments from the TBI.

Information, advice and open discussion can be very beneficial in overcoming sexual problems following TBI, yet very few people receive any help. Help needs to be given early and staff need to take the initiative, thus giving permission to talk about sex.

6.5.1 Sexual dysfunction

People with TBI may suffer some sexual dysfunction including disorders of desire and an impaired ability to achieve or maintain an erection, and an impaired ability to achieve orgasm. This may occur either as a consequence of the injury or as a side effect of medication such as antidepressants. It may also occur as a psychological result of changed roles within relationships and other issues that may or may not be direct consequences of the TBI.

One study, for example, found that people with TBI, compared with a non-injured control group, reported more frequent physiological difficulties impacting on their sexual energy and drive, and their ability to initiate sex and achieve orgasm. The study also found that people with TBI had physical difficulties impacting on positioning, movement and sensation; and body-image difficulties influencing feelings of attractiveness and comfort with having a partner view one's body during sexual activity.

Men with TBI reported less frequent sexual activity and relationships, and more frequent difficulties in sustaining an erection. Women with TBI reported more frequent difficulties with arousal, pain, masturbation and lubrication. Age at injury and severity of injury were negatively related to reports of sexual difficulties in both men and women with TBI. In men with TBI but without disability, the most sensitive predictor of sexual dysfunction was level of depression. For women with TBI, an endocrine disorder and level of depression combined was the most sensitive predictor of sexual difficulties.¹⁹⁰

6.5.1.1 Management of sexual dysfunction

There is very little evidence on the treatment of sexual dysfunction in people with TBI. Most advice for rehabilitation focuses on counselling,^{190,191} but there was no evidence reporting outcomes for counselling interventions.

One small uncontrolled study of adults with TBI and SSRI-induced sexual dysfunction reported a trial of the addition of mianserin at doses of 7.5–15 mg per day. Improvement in sexual function was reported by 88% following this intervention, with 59% reporting that sexual function achieved pre-treatment (with the SSRIs) level. Twelve percent did not respond to this intervention and were instead given sildenafil citrate, which was effective.¹⁹² Another small uncontrolled trial of an assistive device also reported benefits. Thirty men with chronic neurological impotence who were offered a trial of vacuum tumescence constriction therapy were followed up for an average of 21 months, at which time more than 50% were still actively using the device and the average frequency of coitus had increased from 0.3 per week to 1.5 per week ($p < 0.0001$).¹⁹³

There is therefore insufficient evidence on which to base a recommendation for any routine intervention for sexual dysfunction following TBI.

6.5.2 Sexually inappropriate behaviour

Sexually inappropriate behaviour, also known as hypersexuality, is probably a result of TBI-induced disinhibition and can arise in a variety of forms, including frotteurism (eg, rubbing against another person), inappropriate touching and sexual comments, exhibitionism, overt sexual aggression and even rape. Surveys show it tends to be males who exhibit these behaviours.¹⁹⁴

For example, one review of 477 people admitted to a brain injury hospital in England over five years found that 6.5% of them had committed a sexual offence, defined as a specific event in which the incident resulted in a criminal charge, a complaint or intervention. Offences were mainly against staff, but also against family members, other people receiving treatment in the hospital and strangers. Nearly 10% of cases included overt sexual aggression, and nearly 12% of the incidents were against children. All the incidents were committed by males.¹⁹⁴ These behaviours can also occur in paediatric populations.¹⁹⁵

Sexually inappropriate behaviour can be emotionally demanding of families/whānau, carers and treatment staff, and it may give rise to important legal and management issues and dilemmas. One review of the topic reported previously unpublished data showing that 70% of rehabilitation professionals reported that sexual touching was a common problem at their facilities, and 20% reported that the use of sexual force by patients was common, while 97% claimed that the sexually inappropriate behaviour of such clients had at least a moderate impact on the clients' rehabilitation and community re-entry. Sixty percent of the professionals said they did not have adequate training to deal with such behaviour.¹⁹⁵

In acute care settings, people with TBI may display themselves in sexually inappropriate ways, masturbate, or make inappropriate comments; behaviours which may be best managed by means of the provision of privacy and distraction techniques. People with TBI who are in a confused state may make sexual jokes or attempt sexual touching of carers or therapists. A clear statement about what is and is not appropriate and removing the person's hand or moving away for a few seconds should be adequate.¹⁹⁵

Family/Whānau members and carers should be reassured that this behaviour is not unusual in people who are in the early stages of recovery from a TBI and that it should improve with time, and be provided with training in how to avoid inadvertently reinforcing the behaviour.¹⁹⁵ However, if the sexually inappropriate behaviour is severe, dangerous or persistent, it will need to be addressed as part of the rehabilitation programme for the person. The behaviour can be very distressing for family/whānau and carers, who will need support to cope with it.¹⁹⁶

There is little evidence of the effectiveness of specific interventions, and most research reports individual case studies. The following strategies are adapted from a recent review of the topic.¹⁹⁵ A neuropsychologist should advise which level of approach is suitable for the person with TBI.

For people with TBI at a basic level of cognitive functioning:

- establish supervision conditions and networks, limiting access to potential victims and avoiding involvement in prohibited behaviours (eg, alcohol use)
- implement behavioural strategies including role-plays, aversive conditioning or verbal satiation, and repetition and reinforcement of desired behaviours
- clearly differentiate appropriate and inappropriate boundaries and behaviours, and encourage repetition of the desired behaviours
- consider pharmacological interventions
- incarceration may be necessary in severe cases, and may act as a successful deterrent in some cases.

For people with TBI at an intermediate level of cognitive functioning:

- provide psychoeducation, including a discussion of interpersonal behaviour and the effect of a brain injury on sexuality
- assist the individual in understanding the feelings of the recipient(s) of the sexually inappropriate behaviour
- the use of videos illustrating the individual's behaviour and the feelings of others may be useful at this stage
- encourage consideration of the personal costs of an offence. This is especially important with people who have narcissistic and antisocial personality traits
- foster the practice of broad-based social skills (managing interpersonal contact) in addition to interventions specifically directed toward the sexually inappropriate behaviour
- provide a limited discussion about the emotions and thoughts that may increase the risk of an offence.

For people at a more advanced level of cognitive functioning:

- establish a relapse prevention plan that includes the relevant antecedents to the sexually inappropriate behaviour and identify means of intervening before problematic behaviour occurs
- challenge those cognitive distortions that allow the individual to minimise or justify sexually inappropriate behaviour.

6.5.2.1 Medication for sexually inappropriate behaviour

There is no good evidence for any particular medications for the control of sexually inappropriate behaviour. Case studies report successful control of this behaviour with medroxyprogesterone acetate (Depo-Provera).^{197,198} However, these studies were uncontrolled and individual cases, and therefore insufficient on which to base any recommendation.

6.6 Leisure and recreation

RECOMMENDATIONS	GRADE
Traumatic brain injury rehabilitation services should support people with clinically significant traumatic brain injury in developing alternative leisure and social activities, in liaison with local voluntary organisations.	C
Assessments of all people with traumatic brain injury should include the identification of: <ul style="list-style-type: none">• their level of participation in leisure activities• the barriers or compounding problems which inhibit their engagement in such activities.	C
People with traumatic brain injury who have difficulty undertaking leisure activities of their choice should be offered a goal-directed, community-based programme aimed at increasing participation in leisure and social activities.	C
Carers should be given advice on how to maintain their own leisure and social activities while in a caring role.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

A return to leisure activities will depend upon both the severity of the TBI and the demands of the leisure activity the person wishes to resume. The person will need medical clearance before participating in some activities, such as riding, diving and motorbike riding. For details of return to sports and physical activities see Chapter 14, *Special issues*. There is a lack of specific evidence in this area, and this section is adapted from the UK publication *Rehabilitation Following Acquired Brain Injury: National Clinical Guidelines*.⁸

Engagement in leisure activities is increasingly recognised as an important determinant of quality of life.¹⁹⁹ It is consistently highlighted in user surveys, and is now a recognised health domain in the WHO ICF.³

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

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

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

Community TBI services should guide and support people with clinically significant TBI in developing alternative leisure and social activities, in liaison with local voluntary organisations.^{8,199} Assessments of all people with TBI by a rehabilitation professional or team should include the identification of:

- their level of participation in leisure activities (including indoor and outdoor pursuits)
- the barriers or compounding problems which inhibit their engagement in such activities.⁸

People with TBI who have difficulty undertaking leisure activities of their choice should be offered a goal-directed, community-based programme aimed at increasing participation in leisure and social activities.⁸ Some targeted programmes for people with disabilities, such as riding or swimming for the disabled, may be helpful.

6.7 Evaluating progress in rehabilitation

The *TBI Tools Review for the Development of Guidelines on the Assessment, Management and Rehabilitation of Traumatic Brain Injury*, 2005, which supports this guideline (see Appendix D for a link to this resource) provides an assessment of various tools that may help in evaluating progress in rehabilitation.

6.8 Discharge from rehabilitation services

Continuous or intermittent input from a rehabilitation team may be appropriate over long periods of time following TBI (ie, years) depending on the specific goals being addressed. Withdrawal of rehabilitation team management may occur appropriately when:

- the person with TBI wishes to exit from a formal rehabilitation programme
- no new achievable goals can be identified by the person with TBI and/or their carer(s).

Chapter 7:

Complementary and alternative medicines

Overview

- Although many complementary and alternative medicines (CAMs) are advocated for use in people with traumatic TBI, there is limited evidence available on their effectiveness.
- There may be risks of harm or interactions from CAMs. Health practitioners should ask and record what people with TBI are using.
- Evidence shows **unacceptable levels of harm** from craniosacral therapy in people with TBI.
- There is no evidence that ginkgo helps cognitive and other impairments following TBI.

There are many therapies and products proposed for use in people with TBI. These are not routine treatments and can be grouped under the term ‘complementary and alternative medicine’ or CAM. CAM use in people with TBI may be targeted at a particular aspect of functioning (usually cognitive) or at the post-TBI syndrome. This chapter focuses on the CAMs more commonly advocated for use by people with TBI. The evidence is summarised in Table 7.1.

The evidence for CAM is, by nature, ‘emerging’ and this guideline has used a grading system aimed at providing plain-language interpretations of the lower levels of evidence that currently exist around CAM. The Guideline Development Team has avoided making recommendations in this chapter, so that consumers can weigh the evidence presented and in consultation with their advisors reach their own conclusions about whether or not they should use a particular treatment for a particular condition. More details of these grades can be found in Appendix B and at www.cam.org.nz.

There may be risks of harm or interactions from CAMs. It is important that there is open communication between rehabilitation practitioners, CAM practitioners and the person with TBI, their family/whānau and carer(s). It is important that the rehabilitation team ask specifically about the use of CAMs, including dietary supplements, which the person or their carer(s) may not perceive as a ‘therapy’ or ‘medication’.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

7.1 Biofeedback

Biofeedback provides feedback of information to the person about some aspect of physical behaviour or functioning. Two studies on the use of biofeedback for rehabilitation following TBI were identified. One small randomised controlled trial of a standing biofeedback training device for postural training in adults with hemiplegia after TBI or stroke found a benefit from the device.²⁰⁰ A single case study demonstrated benefits of visual feedback superior to traditional speech therapy for a child with TBI.²⁰¹

7.2 Electroencephalographic biofeedback/neurofeedback

Electroencephalographic (EEG) biofeedback, often referred to as neurofeedback, is a test in which electrodes are placed on the scalp to measure the electrical activity of the brain. This modification is manifested as changes in behaviour or perception.

The literature search found several controlled studies and systematic reviews.^{202–210} These showed positive results in terms of improved outcomes for people with mild to moderate TBI, with both self-reported symptoms and independent measures showing improvements in cognitive performance, pain and headache, in some cases achieving premorbid functioning in the short term. Studies generally showed an effect after 18 to 20 sessions of treatment. However, there is not yet enough high-level evidence to identify whether the benefits observed in these studies are sustained over time.

7.3 Homoeopathy

Homoeopathy is a system of treating people using very low-dose preparations according to the **similia** principle: 'like cures like'. In 'classical' or individualised homoeopathy, practitioners aim to identify a single homoeopathic preparation that matches the person's general 'constitution', including the symptoms for which the person is seeking treatment. Owing to differences in elements of people's constitutions, two people with identical conventional diagnoses may receive different homoeopathic prescriptions. It is therefore not appropriate to examine the effectiveness of any one remedy applied to all people with TBI.

Only one study of sufficient quality was found on the use of classical homoeopathy for TBI. This was a randomised double-blind placebo controlled trial of 60 adults with mild TBI.²¹¹ A total of 18 different remedies were used in individualised treatments. The study reported that at the four-month follow-up point, there were significant reductions in self-reported symptoms in the treatment group, although there were no improvements in standardised cognitive, linguistic or memory tests. The effect or relative benefit increased with duration from injury. Some possible adverse reactions were reported (eg, nausea and dizziness), but the study had insufficient power to detect whether these were reactions to the treatment.

7.4 Manipulative therapies

7.4.1 Craniosacral therapy

Craniosacral therapy is a form of gentle manipulation of the bones of the skull. A systematic review found that there is very little research of adequate quality on the use and effectiveness of craniosacral manipulation for people with TBI. The one study found that was of moderate quality showed unacceptable levels of harm from craniosacral therapy.²¹² Three out of 55 people in the study showed a 'very unfavourable response to therapy', including headaches, high blood pressure and spasms. Case series reports cannot definitively establish a causal relationship between craniosacral therapy and the adverse reactions described. However, these documented harmful reactions call into question the safety of craniosacral therapy in this group of people.

7.4.2 Chiropractic

Chiropractic emphasises the ability of the body to heal itself by restoring and maintaining the health of the whole person through natural means. Specifically, chiropractic aims to restore and maintain joint, muscle and nervous system function.

The Guideline Development Team was unable to find any research that met the criteria for review on the use of chiropractic in people with TBI.

7.4.3 Osteopathy

Osteopathy seeks to restore and maintain the health of a person by working on the muscles, joints and other structures that make up the neuromusculoskeletal system through gentle manipulative procedures.

The Guideline Development Team was unable to find any research that met the criteria for review on the use of osteopathy in people with TBI.

7.5 Herbal remedies

7.5.1 Ginkgo

Ginkgo (*Ginkgo biloba*) extract is one of the most studied complementary medications and one of the most commonly recommended complementary medications for people with TBI on internet sites.

Some of the potential benefits ascribed to ginkgo include effects on recognition memory, processing speed, attention, concentration, mood, tinnitus, sexual dysfunction, nephrotoxicity, glaucoma and claudication. Additional potential beneficial effects, based on analysis of the active constituents, include blockade of cell death, antiplatelet activity, free radical scavenging, changes in blood flow and protection from anoxia.^{79,213,214}

A Cochrane review²¹⁴ and a further review^{213,214} of ginkgo for cognitive impairment found ginkgo superior to placebo on a number of measures, but these did not specifically review the use of ginkgo in people with TBI. A further systematic review⁷⁹ concluded that ginkgo extract may be valuable for conditions that are commonly seen following TBI. There is evidence of effectiveness for treating: tinnitus; impaired cognitive skills including memory, concentration, attention and processing speed; and agitation, psychosis and aggression. However, the authors caution that there is no good research on the effectiveness of ginkgo extract specifically in the TBI population, and suggest that research focusing on this area may be warranted.

Both reviews caution about the side effect profile of ginkgo extract, as it may have an anticoagulant effect, reducing platelet 'stickiness'. Spontaneous bleeding related to ginkgo extract has been reported. There could also be an interaction with other anticoagulant drugs given before surgery.

7.5.2 Ginseng

Most of the research into the effects of ginseng on cognitive skills has focused on either enhancing cognition in healthy people or ameliorating the cognitive decline associated with aging and dementia. The Guideline Development Team was unable to find any research specifically examining the effectiveness of ginseng in people with TBI.

7.5.3 Ashwagandha

The use of ashwagandha, commonly known as withania, is purported to enhance mental functioning, and because of this it is sometimes used by people with cognitive impairment post-TBI. It is also claimed to have sedative effects, and should not be used concurrently with prescribed sedatives due to the risk of interaction. However, there is no data in humans to provide evidence of its effectiveness or harm for people with TBI.

7.5.4 Gotu kola

Gotu kola (*Centella asiatica*) is also known as hydrocotyle or Indian pennywort. It is frequently suggested as a treatment to enhance mental functioning. However, the research evidence on gotu kola has been on the effect it has in promoting the healing of burns and wounds. There is no evidence to support its use to treat impaired cognition in people with TBI.

7.6 Dietary supplements

7.6.1 Vitamin B₁₂

Vitamin B₁₂ is involved in the regulation of mental function, and supplementation is sometimes suggested for people with impaired cognition. A Cochrane review²¹⁵ investigated the effectiveness of Vitamin B₁₂ supplementation in improving impaired cognition, but found no evidence to support its use in people with TBI.

7.7 Acupuncture

Acupuncture is a Chinese therapeutic process where needles are used to stimulate points along meridians to enhance the healing process. Evidence on the use of acupuncture for post-TBI symptoms is scarce and inconsistent.²¹⁶ Therefore, current evidence does not support the use of acupuncture to treat people with TBI.

7.8 Distant healing

A systematic review of distant healing, which includes ‘treatments’ such as prayer, mental healing, therapeutic touch and spiritual healing, found that the methodological issues with studies of such interventions prevented drawing any firm conclusions.²¹⁷

TABLE 7.1:

SUMMARY OF THE EVIDENCE FOR COMPLEMENTARY AND ALTERNATIVE MEDICINE IN TREATING ADULTS WITH TRAUMATIC BRAIN INJURY

INTERVENTION	LEVEL OF EVIDENCE*
BIOFEEDBACK There is evidence from a small randomised trial that biofeedback may help postural training	Evidence with reliability but open to debate
EEG BIOFEEDBACK/NEUROFEEDBACK There is evidence from a systematic review of non-randomised studies that neurofeedback may improve symptom scores and measures of memory, pain and headache in the short term	Evidence with reliability but open to debate
HOMOEOPATHY There is evidence from one small randomised study that homoeopathy does not improve memory, but may significantly reduce self-reported symptom scores	Some evidence but based on studies without comparable groups
CRANIOSACRAL THERAPY There is evidence from a case series that craniosacral therapy can cause significant problems in some people	Some evidence but based on studies without comparable groups

INTERVENTION	LEVEL OF EVIDENCE*
CHIROPRACTIC OR OSTEOPATHIC THERAPY	No study evidence
GINKGO Benefits: <ul style="list-style-type: none"> there is evidence from pathophysiological studies that ginkgo may benefit non-clinical outcomes there is evidence from studies in non-TBI populations of minor improvements in cognitive skills Harms: <ul style="list-style-type: none"> there is evidence of spontaneous bleeding with ginkgo there is evidence for an interaction of ginkgo with warfarin 	Some evidence without a high degree of reliability Some evidence without a high degree of reliability
GINSENG, ASHWAGANDHA, GOTU KOLA	No study evidence
VITAMIN B₁₂ Systematic reviews have not investigated the use of vitamin B ₁₂ in people with traumatic brain injury and cognitive impairment	No study evidence
ACUPUNCTURE There is poor quality evidence of an effect on the outcomes studied	No study evidence
DISTANT HEALING There is poor quality evidence of an effect on the outcomes studied	No study evidence

* See Appendix B for definitions of the levels of evidence.

Chapter 8:

Management of persistent symptoms and activity limitations following mild traumatic brain injury

Overview

- Symptoms commonly reported following mild TBI include headache, nausea, dizziness, blurred vision, confusion, fatigue, poor concentration, memory problems, sleep difficulties, irritability and noise intolerance.
- There is some evidence that early, relevant information about common symptoms of mild TBI, emphasising high rates of recovery, can positively influence the rate of later persistent symptoms.
- The presence of persistent symptoms following mild TBI necessitates further assessment.
- A careful assessment of possible alternative causes of symptoms post-mild TBI should also be made to ensure correct treatment.

A recent systematic review of published prospective studies of mild TBI shows fairly rapid recovery occurs for the great majority of people in the first few hours, to the first month after the injury.⁶⁷ Many recover within a few hours. However, these same studies also describe a group of people who fail to recover fully during that time, and there is no predictive relationship between the apparent severity of injury (within the overall context of a mild TBI) and the persistence of symptoms.

In New Zealand, contracts for mild TBI clinics (sometimes called ‘concussion clinics’) are currently held by DHBs and other providers, with their primary role being to attempt to ‘sort out’ the issues for and possible management of people with persistent symptoms after mild TBI. These contracts usually include a specialist medical assessment, a neuropsychological assessment and a variable number of therapist (usually occupational therapy) sessions.

Feedback from clinicians involved with the mild TBI clinics suggests that they do not see exclusively people with mild TBI, but also, appropriately, a number of people who have actually suffered a moderate-severe TBI.

This chapter reviews evidence for the characterisation of people with persistent symptoms following mild TBI and effective interventions that improve outcomes for this group, alongside current practice in New Zealand.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

8.1 Symptoms of mild traumatic brain injury

Symptoms commonly reported following mild TBI include headache, nausea, dizziness, blurred vision, confusion, fatigue, poor concentration, memory problems, sleep difficulties, irritability and noise intolerance. Deficits in cognitive functions such as memory, attention and speed of processing are common in the first few

days and up to a month after the injury, and the majority of studies report recovery for most within three to 12 months.⁶⁷ However, some people will continue to experience clinically significant and disabling symptoms beyond a year after the initial injury.

8.1.1 Symptoms in children and young people

Most studies of outcomes in children and young people post-mild TBI report neither short- nor long-term cognitive problems. Headaches, dizziness and fatigue are common in the first week after the injury. One study compared younger children (aged between 2.5 and 4.5 years at the time of injury) with mild TBI with a control group of children with non-head injuries.²¹⁸ This study found that 29% of children with mild TBI, compared with 14% of those in the control group, had been referred to remedial reading, but there were possible confounding factors identified.

The same study found a slight deficit in visual closure (the ability to fill in missing parts of a visual stimulus such as a letter missing from a word) in the mild TBI group at six and 12 months post-injury, but this deficit did not relate to reading ability when the children were assessed later.²¹⁸ Studies reporting behavioural problems and academic scores found no difference pre- and post-injury, although two studies suggested there were behavioural impairments in injured children regardless of the nature of the injury.⁶⁷ An injury, even one not involving TBI, rather than mild TBI per se was shown to be associated with behavioural issues.

The overall rate of moderate to severe disability, as measured by the Glasgow Outcome Scale, ranged from 0 to 1%, although one small study reported that 2% of more severely injured children have moderate-severe disability at six months post-injury. However, most studies have methodological shortcomings that prevent certainty that the outcomes are definitely attributable to the mild TBI.⁶⁷

8.2 Characterisation of people with persistent symptoms following mild traumatic brain injury

The cause of persistent symptoms following an episode of mild TBI is highly controversial. In the past, there has been considerable disagreement between two opposing schools of thought about people with persistent symptoms. On the one hand, this was thought to be a situation with damage to the brain resulting in persistent symptoms, albeit with (usually) normal imaging of the brain, which required time and occasionally other interventions for the situation to resolve. The other school of thought characterised the problem as a psychological one, with no significant damage to the brain but a problem of pessimistic expectation around recovery, catastrophisation, illness behaviour and work intolerance. For a discussion on this, see Ruff (2005).²¹⁹

A systematic review of the literature in this area concluded that there is a probable organic basis for early symptoms (although this doesn't explain why some people with entirely trivial injuries get the same symptoms) but no evidence to support ongoing organic brain 'damage' causing persistent symptoms. It was concluded that persistent post-concussion syndrome (PCS) after mild TBI, uncomplicated by any focal injury, is biologically inseparable from other examples of the post-traumatic syndrome and counsels against use of the term PCS.¹⁴ A further systematic review by the WHO Collaborating Centre Task Force on Mild Traumatic Brain Injury found that where symptoms (and associated activity limitation) persist, compensation and/or litigation is a factor, but there is little consistent evidence for other predictors. The authors cautioned that the literature was of very mixed quality, and that causal inferences were often mistakenly drawn.⁶⁷

8.3 Prevention of persistent symptoms following mild traumatic brain injury

RECOMMENDATION	GRADE
All people with possible or definite mild traumatic brain injury should receive information about common symptoms and reassurance that recovery over a short period of time (days to a few weeks) is highly likely.	B

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

There is some evidence^{220,221} that early, relevant information about common symptoms of mild TBI, emphasising high rates of recovery, can influence the rate of later persistent symptoms. A large randomised controlled trial in the UK showed that routine follow-up of a population with predominantly mild TBI resulted in lower rates of disabling symptoms at six months.⁹⁷

8.4 Assessment of people with persistent symptoms after mild traumatic brain injury

RECOMMENDATION	GRADE
A careful assessment of possible alternative causes of the symptoms post-mild traumatic brain injury should be made to ensure correct treatment, with referral to specialists if necessary.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS	
If a person with a mild traumatic brain injury presents because they have symptoms which are causing concern late, or re-presents to health care services after being discharged with information, an initial assessment should be performed and the person referred, if appropriate.	✓
When a person, particularly a child, with mild traumatic brain injury has symptoms persisting beyond a month, a careful reassessment of possible severity should be made.	✓
All people with persisting, clinically significant symptoms of traumatic brain injury after four to six weeks should be referred for a specialist assessment, usually including a neuropsychological assessment.	✓
An appraisal of the severity and impact of symptoms of traumatic brain injury should be made, and: <ul style="list-style-type: none">• minor problems should be managed symptomatically• the person should be offered reassurance and information on symptom management strategies.	✓
If there are more severe symptoms, or suspicion that the traumatic brain injury is not ‘mild’, the person should be referred for further assessment and rehabilitation, as appropriate.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

If a person with a mild TBI presents late, or re-presents to health care services after being discharged with information because they have symptoms which are causing concern, the initial assessment should follow the process outlined in Section 2.5, *First assessment – delayed*, and the person referred, if appropriate.

As it seems probable that there is a high rate of misidentification of moderate-severe TBI as mild TBI, when a person, particularly a child, with mild TBI has symptoms persisting beyond a month, there should be a suspicion that the person's injury may have been more severe than initially thought, and a careful reassessment of possible severity should be made.

8.4.1 Assessment for other conditions

Some symptoms consistent with mild TBI may be caused by other conditions. For example, dizziness, tinnitus and vertigo can be caused by Meniere's disease, or by a perilymphatic fistula, which may also result from head trauma.²²² Dizziness and vertigo can also be post-traumatic vertigo, which needs to be correctly identified and may be amenable to treatment. Cognitive impairments can be caused by both acute and post-traumatic stress and other mood and anxiety disorders, which may or may not be connected with the mild TBI. In children and young people, ADHD is frequent following a mild TBI, but the evidence shows that it is probably because more children with ADHD have TBIs.⁶⁷

It is important that a careful assessment of possible alternative causes of the symptoms post-mild TBI is made to ensure correct treatment. Referral should be made to specialists, if necessary (eg, an ear, nose and throat [ENT] specialist for assessment for unresolved dizziness, tinnitus and vertigo).

8.4.2 Neuropsychological assessment

All people with clinically significant symptoms of TBI persisting beyond four to six weeks should be referred for a specialist assessment including a neuropsychological screening assessment (see Section 5.5, *Neuropsychological assessment*).

8.4.3 Ongoing management

If the assessment shows that the symptoms are probably symptoms resulting from mild TBI, an appraisal of the severity and impact of the symptoms should be made. Minor problems such as headache, dizziness and fatigue may be managed symptomatically, and the person offered reassurance and information on strategies to manage symptoms.

Based on the available evidence, a pragmatic approach to people with persistent symptoms is described in '6 Steps', (see Appendix D for a link to the resource).

If there are more severe symptoms, or suspicion that the TBI is not 'mild', the person should be referred for further assessment and possible rehabilitation, as appropriate (see Chapter 5, *Rehabilitation following clinically significant traumatic brain injury – assessment* and Chapter 6, *Rehabilitation following clinically significant traumatic brain injury – intervention*). For the management of symptoms of mental health problems, including drug and alcohol problems, see Chapter 14, *Special issues*.

8.5 Return to work or study

Planning for return to work or study depends on a lot of different factors, including the severity of any symptoms and/or deficits, the nature of the work or study, and opportunities for support in the workplace or study environment. There is no high quality evidence from published trials to guide management in this area. Some of the important issues are covered in one of the supplementary materials accompanying this guideline – '6 Steps' (see Appendix D). Wrightson and Gronwall²⁸ provide some useful information for health providers and consumers seeking guidance about return to work and study. (Also see Chapter 14, *Special issues*.)

Chapter 9:

Post-discharge follow-up and support for people with traumatic brain injury

Overview

- Some people who have had a mild TBI experience long-term disability following discharge from hospital, which may include headaches, dizziness and other persistent symptoms.
- All people with any degree of severity of head injury and their carers should be made aware of the possibility of longer-term symptoms and disabilities from TBI.
- People who have been discharged following a TBI, and their carers, should be provided with written information and verbal instructions on what signs or symptoms require reassessment or the need for further information, along with details of who to contact for help.
- There is good evidence that routine follow-up of people with TBI that is outside the ‘mild’ or ‘trivial’ TBI range improves outcomes.
- Any person who has had a head injury, who may or may not have received medical attention at the time of the injury, who later seeks contact with primary care or an Emergency Department with symptoms of TBI should be offered an appointment with a professional trained in assessment of the sequelae of TBI.
- Following TBI, the needs of people and their families/whānau and carers change over time, and for some, may increase significantly. Many may require long-term counselling and emotional support.
- People who have experienced TBI, and their carers, will need a variety of information upon discharge. There is evidence that the need for information is one of the most commonly unmet needs of parents of children with TBI, yet information has been identified as the single most important form of support for families.
- Information on TBI should be given in simple, easy-to-understand language.
- People who have had a TBI and are being transferred to rehabilitation services should have a management plan prepared, which should detail the care, rehabilitation and support needed, and how it is to be provided.

The post-discharge follow-up and support needs of people who have had a possible or definite TBI and their families/whānau and carers range from the need for information provided at discharge to long-term support of the person with TBI.

People with any degree of head injury or TBI should only be discharged to their homes if it is certain that there is somebody suitable there to supervise them. People with no carers at home should only be discharged if suitable supervision arrangements are organised.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

9.1 Follow-up

RECOMMENDATIONS	GRADE
Anyone with traumatic brain injury and a recorded Glasgow Coma Scale of 13 or less at any stage after the first 30 minutes OR who received a CT scan of the head as part of their initial assessment should be routinely followed up with, as a minimum, a written booklet about managing the effects of traumatic brain injury and a phone call in the first week after the injury. This follow-up needs to be undertaken by someone trained in identifying and managing common problems following traumatic brain injury.	B
Any person who has had a head injury and later seeks contact with primary care or an Emergency Department with symptoms of traumatic brain injury should be referred for assessment by a professional trained in assessment of the sequelae of brain injury.	C
Anyone with moderate or severe traumatic brain injury discharged from a residential rehabilitation setting should be considered for scheduled telephone follow-up contact using motivational and problem-solving techniques.	B

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

9.1.1 Detection of late sequelae

Some people who have had a mild TBI experience long-term disability following discharge from hospital.⁴ Symptoms such as headache, dizziness, memory deficits, slowness of thought, poor concentration, communication problems, inability to work and problems with self-care have been described. These people, if the symptoms last for three months or more, are sometimes categorised by the International Classification of Diseases (ICD-10) as having post concussion syndrome (PCS). However, there is considerable disagreement about the use of this term.¹⁴ (See Chapter 8, *Management of persistent symptoms and activity limitations following mild traumatic brain injury*.)

People who have been discharged from an Emergency Department, general practitioner or other community service with none of the indications for immediate intervention or likely need for rehabilitation (see Chapter 4, *Rehabilitation services* and Chapter 5, *Rehabilitation following clinically significant traumatic brain injury – assessment*), and their carers, should be given information and verbal instructions on what signs or symptoms warrant reassessment or need for further information, along with details of who to contact for help (see Section 9.2, *Continuing care and support*).

9.1.2 Routine follow-up of people with traumatic brain injury

There is good evidence that routine follow-up of people with TBI outside the ‘mild’ range improves outcomes.^{97,223} These studies used, as a minimum, a telephone call in the first week, supplemented where necessary by face-to-face follow-up and/or intervention.

A UK study by Wade et al (1998), especially when taken with that group’s earlier (negative) randomised controlled study, suggested that people with more significant injuries get most benefit from routine follow-up.⁹⁷

In the first UK trial by Wade and colleagues (1997),²²⁴ 1156 consecutive participants with ‘head injury’ presenting to an Emergency Department or admitted to hospital were randomised to receive routine follow-up or not to follow up. By six months there was no significant difference between the groups on various measures although sub-group analysis suggested people with more severe injuries (post-traumatic amnesia for more than one hour) benefited more than those with milder injuries.

In the 1998 trial, 314 randomised people were admitted to hospital with ‘head injury’ and 60% had post traumatic amnesia longer than one hour. In the intervention group, all participants were given written information on head injury and advice on how to cope with it. This information covered:

- managing post-concussion symptoms
- coping with reduced speed of information processing
- likely prognosis and recovery times
- how to reduce the impact of cognitive and emotional stress on post-concussion symptoms and conversely the stress associated with post-concussion symptoms
- coping with post-traumatic stress
- advice on graduated return to normal activities.

Around 25% of the participants could not be contacted by phone. Of the remainder, 10% received a telephone follow-up call only, 19% were assessed face to face, 34% were assessed face to face and received additional telephone support and 12% were assessed face to face and required further outpatient contact, which included a range of services, including neuropsychological assessment. By six months, participants in the trial group had significantly better scores for social disability and lower symptom scores on a post-concussion symptom checklist. For example, on the Rivermead Post Concussion Questionnaire, 68% of the intervention group versus 45% of the control participants scored in the lowest two categories, that is reporting with fewer symptoms.

In a randomised controlled trial of 202 adults with mild TBI²²⁵ in Australia (Glasgow Coma Scale score 13–15, post traumatic amnesia <24 hours, no focal neurological signs, did not have a CT scan) the intervention group had a neuropsychological assessment at one week from the injury (but received no feedback about the results) and received an information booklet aimed at helping them to cope with the effects of mild TBI. The control group received neither the assessment nor the booklet. By three months, the intervention group had lower scores on most items on a post-concussion checklist, significantly so for anxiety and sleeping difficulty. They also had lower scores on a ‘global severity’ score. There was no difference between the groups on formal neuropsychological assessment. There is some uncertainty about whether these benefits are simply due to the information booklet or whether having a neuropsychological assessment could also have affected the results. A high rate of loss to follow-up (38%) means some caution needs to be applied to the findings in general.

In a USA trial of 171 people following moderate and severe TBI discharged from inpatient rehabilitation,²²³ intervention group participants received seven scheduled telephone follow-up calls from a ‘care manager’ over one year. This person was specifically trained in this role and used motivational interviewing principles in carrying out goal-setting, reassurance and problem-solving. Eighty-four percent of the calls involved information provision and/or counselling alone, with 15% involving specific referrals. The control group received no contact from the research team. At 12 months follow-up, participants in the intervention group had significantly better scores on the primary composite outcome index and on specific composites such as functional status and quality of well-being. There were no significant differences on vocational status or community integration.

9.1.3 Self-referrals

Any person who has had a head injury, who may or may not have received medical attention at the time of injury, and later seeks contact with primary care or an Emergency Department with symptoms of TBI should be offered an appointment with a professional trained in assessment of the sequelae of brain injury.⁸ This assessment should follow the process detailed in Section 2.5 *First assessment – delayed* and should include assessment for the prognostic factors to meet ACC’s funding/planning needs.

9.2 Continuing care and support

RECOMMENDATIONS	GRADE
The aim of long-term services should be to enable and sustain optimal societal participation for both the person with traumatic brain injury and their family/whānau and carer(s), while supporting personal choice and helping them to adjust to the new situation.	C
Information should be given in both written and verbal formats.	C
Written information should be concise and clear, use simple, easy-to-understand language and be illustrated with graphics, if appropriate.	C
People who have had a traumatic brain injury and their carers should receive information including: <ul style="list-style-type: none"> • symptoms and signs which may indicate what to do about them and the need for further investigation • reassurance about symptoms and signs which are not unexpected • advice about safety and self-care measures • advice on alcohol or drug misuse for people who initially presented with drug or alcohol intoxication • details of community resources • information for carers on the difficulties of an injury that cannot be detected by those who do not know about the injury. 	C
A letter or e-mail detailing the clinical history, examination and any imaging should be sent to the general practitioners of all people who have attended an Emergency Department with a head injury and been discharged. A copy of this letter should be given to the person or their carer(s).	C
All people with any degree of severity of head injury and their carers should be made aware of the possibility of long-term problems from a traumatic brain injury and of services they could contact should they experience long-term problems.	C
People who have had a traumatic brain injury and are being transferred to rehabilitation services should have a written management plan (of which they are given a copy) that details: <ul style="list-style-type: none"> • current needs • key contacts • responsible services/professionals • sources of continued information, support and advice. 	C
Management plans should be agreed jointly between the person, their carer(s) and health and social care professionals from the services involved in the transition prior to transition and a time-frame for review agreed.	C
Upon transfer or discharge, there should be a written discharge report which includes: <ul style="list-style-type: none"> • the results of all recent assessments • a summary of progress made and/or reasons for case closure • recommendations for future intervention. 	C

RECOMMENDATIONS	GRADE
Copies of the management plan and the discharge report should be provided to the person and their family/whānau and carer(s), and to all professionals relevant to the person's current stage of rehabilitation.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT	
Information about possible long-term effects should be given in a practical and reassuring manner, and efforts should be made to alleviate the concerns of people with traumatic brain injury and their carers.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

CHILDREN AND YOUNG PEOPLE

There is no adequate evidence in this area specifically for children and young people with TBI that can be used to guide decision-making. The information and recommendations for adults should be used with caution in these groups.

The needs of people who have sustained a TBI, and their families/whānau and carers, change over time and for some may increase significantly. Many people who have had a TBI require long-term counselling and emotional support to assist understanding and adjustment to altered family roles and circumstances.

Families and carers also report the need for information, practical support, continued education and easy access to health and social care systems to combat isolation, emotional distress, stress and practical overload. Ongoing support is required in the community in order to maximise independence and quality of life for what may be, in younger people, the next 50 years or more of their lives.

The aim of long-term services should be to enable and sustain optimal societal participation for both the person with TBI and their family/whānau and carer(s), with personal choice, and will involve helping them to adjust to the new situation.^{8,113} Services will need to be delivered in a whole range of settings and, importantly, will involve adapting and developing a range of specialised professional skills and attitudes to working with people with TBI and their carers. A social/educational model of care is appropriate, and effective services will emphasise on collaboration between rehabilitation specialists and people involved in the everyday life of the person with TBI.

9.2.1 Information

People who have been in receipt of medical and rehabilitative care will need a variety of information upon discharge, depending upon the severity of their injury, the time since the injury and at what point the information is being given. The people who are caring for them at home, after discharge, will also need information. There is evidence that the need for information is one of the most commonly unmet needs of parents of children with a TBI,²²⁶ while information has been identified as the single most important form of support for families.^{11,227}

People who are being discharged early after an injury may require observation at home by their carers. A systematic review identified one observational study in which carers were given specific, explicit written information. The study reported high levels of compliance with written instructions for home observation after Emergency Department discharge.²²⁸ Compliance was better when the injured person had experienced some loss of consciousness, or was younger, and where the observer was the person's mother.

One qualitative study examined effective formats for information to be provided to people with acute and chronic disorders who regularly attended an outpatient clinic.²²⁹ They found that people are frequently likely to seek further information following (rather than during) an encounter with their care provider; and that they want a permanent record of personal health data and relevant educational information.

Information needs to be concise, clear and illustrated with graphics, if appropriate. Receiving information of this sort favourably affected the participants' trust in, relationship with and confidence in their physicians, and when, during therapy, they were given printouts of graphic trends depicting their responses to therapy, people were more motivated to adhere to their treatment plans and more satisfied with their care.²²⁹ There is no reason why this information should not apply equally to carers as well as people with TBI.

Information should be proactively offered, and it should not be assumed that carers will ask for information they require. There is evidence that many carers will not seek information even when needed, particularly for less severely injured people.^{11,230} Results of a UK study stated that information should be provided to all people with possible TBI regardless of severity of injury or functional impairment.²³⁰ A Cochrane systematic review concluded that both verbal and written health information should be given to people and their carers on discharge to home.²³¹

The combination of verbal and written health information enables the provision of standardised care information to people and their carers, which appears to improve knowledge and satisfaction. Information should be given in simple, easy-to-understand language.^{232,233}

People who have had a possible or definite TBI and their carers will need clear information in the following categories:

- symptoms and signs which may indicate a need for further investigation, including what action the person or their carer(s) should take if they experience any of these (such as, go to a general practitioner or Emergency Department) and an indication of urgency
- reassurance about symptoms and signs which are not unexpected and about which they need have no concerns, specifically including the expected progress and resolution of the after-effects of the TBI, together with details of what to do if the signs and symptoms do not resolve in the expected time-frame
- advice about safety and self-care measures, including minimising the risk of re-injury and caution with use of drugs and alcohol
- information and advice on alcohol or drug misuse for people who initially presented with drug or alcohol intoxication
- information about community resources
- information for carers on the difficulties of an injury that cannot be detected by those who do not know about the injury.⁷

9.2.1.1 Communication with community services

There is also a need for information to be supplied to the person's general practitioner about the nature of the injury and expected outcomes, so that the general practitioner is prepared if the person or their carer(s) seek further help at a later date.⁷

A communication (letter or e-mail) should be generated for all people who have attended an Emergency Department with a head injury, and sent to their general practitioners when they are discharged. This letter should include details of the clinical history, examination and any imaging. This letter should be open to the person or their carer(s), or a copy should be given to them.⁷

9.2.1.2 Advice about long-term problems and support services

There is no evidence that enables both sensitive and specific identification of people who will have longer-term sequelae from TBI.^{7,67} Even a proportion of people with mild TBI may have long-term disabling sequelae.^{51,234–239}

Therefore, all people with any degree of severity of head injury and their carers should be made aware of the possibility of long-term symptoms and disabilities from a TBI and should be made aware of the existence of services that they could contact should they experience long-term problems. Details of support services should be included on discharge advice cards. People should also be advised to contact their doctors about these problems.⁸

Information about possible long-term effects should be given in a practical and reassuring manner, and efforts should be made to alleviate the concerns of people with TBI or their carers. This is particularly important for people who appear more anxious and who may, for example, attribute unrelated symptoms to the TBI, after the TBI sequelae have resolved.

9.2.1.3 Information for people with mild traumatic brain injury on discharge from Emergency Department or community services

People with a possible or definite TBI who have been assessed in an Emergency Department, by a general practitioner, or by another service in the community as having no risk factors indicating immediate need for further monitoring or intervention, should receive verbal advice and a written advice card.²³¹ The details of the card should be discussed with the person and their carer(s). If necessary (such as for people with literacy or language difficulties, or with visual impairment), other formats (such as pictures, tapes or videos) should be used to communicate this information. Communication in languages other than English should also be facilitated.⁷

The risk factors outlined in the information card should be the same as those used in the initial community setting to advise people on Emergency Department attendance (see Chapter 4, *Rehabilitation services*). People and carers should also be alerted to the possibility that a few people may make a quick recovery but could go on to experience delayed complications. Instructions should be included on contacting community services in the event of delayed complications.

The person being discharged will need to have someone who can look after them for the first few days, and sometimes longer, after discharge. The information on the card given to the injured person should be explained to the carer as well as to the person being discharged.⁷ When being given the information, people should be given the opportunity to ask questions and express concerns, and the practitioner should provide reassurance and advice.

9.2.1.4 Information on discharge from hospital to community rehabilitation services

People who have had a TBI and are being transferred to rehabilitation services should have a management plan prepared. The person with TBI and their carer(s) should be given information about, and offered contact with, the appropriate voluntary services and self-help groups that may be useful to them.^{8,11,226,229,230,240,241} The management plan should detail the care, rehabilitation and support needed, and how it is to be provided.

Transfer to the community should include a written management plan⁸ outlining:

- current needs
- key contacts
- responsible services/professionals
- sources of continued information, support and advice.

Management plans should be agreed jointly between the person, their carer(s) and health and social care professionals from the services involved in the transition. The management plan should be accepted by all parties **prior to transition** and a time-frame for review agreed (usually three to six months post-discharge), although earlier review should be available if requested by the injured person or their carer(s).⁸

Upon transfer or discharge, there should be a written discharge report that includes:

- the results of all recent assessments
- a summary of progress made and/or reasons for case closure
- recommendations for future intervention.⁸

Copies of both the management plan and the discharge report should be provided to the person and their family/whānau and carer(s) where appropriate and to all professionals relevant to the person's current stage of rehabilitation, especially the general practitioner.⁸

9.2.1.5 Information for people with traumatic brain injury and their carers on discharge from rehabilitation services

People who have had a TBI and are being discharged from rehabilitation services, and their carers, should be appropriately prepared for the discharge. They should be given information that details:

- management of ongoing problems for which further rehabilitation is not appropriate
- sources of continued information, support and advice.

Chapter 10:

Māori and traumatic brain injury

Overview

- In New Zealand, there are significant ethnic disparities in the prevalence of TBI.
- Māori have high incidence rates of TBI and evidence suggests that TBI is under-reported in Māori.
- Māori are at risk of poorer outcomes following TBI.
- Māori traditionally have a holistic view of health and this should be considered in rehabilitation of Māori with TBI.
- An increase in the Māori health workforce may improve access and improve overall outcomes for Māori with TBI.
- Communication is increasingly regarded as central to the practice of primary health care, directly and indirectly determining the outcome of the interaction.
- Māori with TBI have specific and unique rehabilitation needs.

RECOMMENDATIONS	GRADE
At the service level <ul style="list-style-type: none">• Practitioners working with Māori with traumatic brain injury should receive training and support in culturally safe practice.	C
At the individual level <ul style="list-style-type: none">• Rehabilitation of Māori with traumatic brain injury should include the diagnosis and management of traumatic brain injury-related syndromes, including mental illness and substance abuse.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

<p>Nationally</p> <ul style="list-style-type: none"> • A national action plan aimed at improving outcomes for Māori with TBI should be developed. • Accurate ethnicity data for TBI incidence should be collected. 	<p>✓</p> <p>✓</p>
<p>At the service level</p> <ul style="list-style-type: none"> • Accurate ethnicity data for people with TBI managed by a service should be collected. • Where possible, the case coordinator/key worker for Māori with TBI should be Māori, or where this is not possible, the case coordinator should have support from a Māori cultural advisor. • Māori community health workers and other Māori health workers fluent in te reo Māori should be considered as part of the rehabilitation team for Māori with TBI. • Neuropsychological and other assessment measures that have been standardised for Māori populations should be used, where possible. 	<p>✓</p>
<p>At the individual level</p> <ul style="list-style-type: none"> • Rehabilitation practitioners assessing Māori with TBI should consider the validity of the questions within neuropsychological and other assessment measures that have not been standardised for Māori. • All decisions should be made in consultation with the individual with TBI, and if they wish, their whānau. • Effective methods of delivery of quality information should be employed. Information should be provided in appropriate formats, both verbal and written. • The whānau of the person with TBI should be supported during the rehabilitation process. 	<p>✓</p>

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

This chapter presents information about the epidemiology of TBI and TBI risk factors in Māori. This chapter also includes discussion of potential improvements to service delivery that aim to provide Māori with more appropriate and effective care. Information from the rest of this guideline applies equally to Māori, and this chapter supplements the general guideline with information specific to Māori with TBI.

10.1 Epidemiology of traumatic brain injury in Māori

There are significant ethnic disparities in the incidence and prevalence of TBI in the New Zealand population. TBI is a major health issue for Māori, as they have a high incidence rate with relatively poor outcomes. It is important to note that any analysis is somewhat limited due to ongoing difficulties in the accurate collection of ethnicity data,²⁴² as well as inaccuracy in the coding of admission and discharge diagnoses of TBI.⁸⁵ With these limitations in mind, it is likely that the incidence of mild TBI (14%) is under-reported in Māori and that moderate or severe TBI is more common (at 21.5%)²⁴³ than would be expected on demographic grounds. ACC's *Summary Guidelines on Māori Cultural Competencies for Providers* highlights the need for the collection of accurate ethnicity data.²⁴⁴

The major causes of TBI for Māori are road accidents, sports injuries and assaults.²⁴³ The high-risk groups for these injuries include children, young adults and older people, with statistics from ACC indicating that males aged 15 to 30 years make up the largest group, followed by children under 15 years.

Some research shows that ethnic disparities are even more evident amongst children. A retrospective review of all children and young people under 15 years of age, who were admitted to Auckland's Starship Children's Hospital over a 45-month period to October 2001, highlighted that head and thoracic injuries predominated and were typically associated with lower limb injuries. Māori and Pacific children represented 74% of all these cases.²⁴⁵

An overview of injuries in New Zealand²⁴⁶ discussed the need for further research aimed at identifying modifiable environmental factors and the initiation of preventive action. It is estimated that the risk of injury (including TBI) for Māori is 1.5 to 2.5 times greater than the risk for non-Māori.

Predominantly anecdotal evidence suggests that Māori are at risk of poorer outcomes following TBI. One study showed that prison populations appeared to have disproportionately high rates of TBI and recurrent TBI compared with the general population, with the majority of those in prison with TBI being Māori.²⁴⁷ Dual diagnosis of TBI and substance abuse or TBI and mental illness is also more common in Māori than non-Māori.⁸⁴ See also Chapter 14, *Special issues*.

10.1.1 Māori traumatic brain injury action plan

The disproportion in incidence and outcomes of TBI for Māori compared with non-Māori is such that the Guideline Development Team considers the development of an action plan, targeted at improving outcomes, necessary.

The Guideline Development Team considers that a TBI action plan could be adapted from the Māori Cardiovascular Action Plan.²⁴⁸ The Cardiovascular Action Plan was developed to provide a guide for cardiovascular policy development and implementation for health services in New Zealand. Within the Plan, several areas for health service action aimed at improving outcomes for Māori were proposed. For more details, see the guideline for *The Assessment and Management of Cardiovascular Risk*, available at www.nzgg.org.nz.

An action plan for improving outcomes for Māori with TBI should focus on the following:

- policy – Treaty of Waitangi-based policy and decision-making
- information systems – complete and consistent collection of ethnicity data, service provider funding
- access, delivery and standards development – TBI rehabilitation health needs assessments, kaupapa Māori health services
- audit, evaluation and quality standards improvement – measurement of key performance indicators to monitor service responsiveness to Māori TBI rehabilitation needs
- Māori TBI workforce and health service development
- kaupapa Māori research.²⁴⁸

10.2 Health perspective of Māori

Māori currently make up 15% of the New Zealand population.³³ However, Māori are not a homogeneous group. Although there are many cultural norms and similarities amongst Māori, it is important to recognise that there are also differences. Health care practitioners should ascertain whether the person wishes to receive Māori culture-specific service delivery. Simply asking the person directly may not be sufficient, as people may sometimes decline for fear of 'being a nuisance' or because they wish to please a non-Māori practitioner, so the option should be offered to the person by a Māori practitioner or cultural advisor.

Māori with a head injury and possible TBI, or their carers and whānau, may not be proactive in seeking help because they are not aware of the risks. In particular, less serious injuries may be managed within the whānau without seeking medical help. To Māori, the head is tapu and some iwi do not like the head being touched at all. For providers there needs to be an awareness and cultural sensitivity, particularly in regards to imaging processes and surgical procedures on the head following a head injury so that Māori with TBI and their whānau

can make fully informed decisions. Information explaining head injury and the need for procedures such as CT scans, MRI and surgical interventions in a culturally acceptable way should be developed for Māori in order to facilitate the provision of ‘best practice’ care and achieve quality outcomes.

Traditionally, Māori have a more holistic view of health than the general population. When providing health and rehabilitation care and support for Māori with TBI, it is important to remember that the person and their needs are not to be considered in isolation, but in the context of their environment, both physical and social (that is, their physical circumstances and their whānau). Under a Māori culture-specific approach, the well-being of the whānau should be considered alongside the well-being of the person with TBI. Consultation with Māori, hapū and iwi resources should be sought when assessing the need for any interventions for the person with TBI. All decisions, where possible, should be made collectively with the person’s whānau, with permission from the person with TBI.

10.3 Service delivery for Māori

Māori have historically had low rates of access to and utilisation of health services and, more specifically, disability support services.²⁴⁹ Data about the health care sector’s workforce indicates that 5.4% of the regulated health care workforce is Māori, far below the desired level.²⁵⁰ It has been suggested that a contributing factor to low service utilisation could be the low proportion of Māori service providers. To improve access for Māori to services, and to improve overall Māori TBI outcomes, steps are needed to increase the Māori health care sector’s workforce and strengthen the capacity of Māori service providers.

Communication is increasingly regarded as central to the practice of primary health care, directly and indirectly determining the outcome of the interaction. International research²⁵¹ has identified the impact and importance of communication between the general practitioner and the person seeking care for that person’s health, and the links this communication can have with perceived discrimination.²⁵²

However, a qualitative study in New Zealand has shown that when non-Māori general practitioners talk about Māori health, they often use language that can imply or attribute ‘blame’ on Māori for their health status, or use language that justifies existing service provision.²⁵³ This may negatively impact on the effectiveness of interactions between Māori and their general practitioners. Practitioners working with Māori with TBI should receive training and support in culturally safe practice. Where possible, the case coordinator/key worker for Māori with TBI should be Māori, and preferably of the same sex as the person with TBI. Where a Māori case coordinator is not possible, the case coordinator should have support from a Māori cultural advisor.

A study exploring TBI rehabilitation processes and outcomes in Māori, Pacific peoples and European New Zealanders in New Zealand showed both similarities and differences,²⁵⁴ and highlighted where TBI rehabilitation service delivery needs for Māori may differ from those of non-Māori. Suggestions arising from this research were:

- to involve and support the family, extended family and/or partners
- to promote the ‘Whatever It Takes’ model
- to endorse and implement cultural practices
- to recruit more Māori rehabilitation professionals
- to involve rehabilitation staff at a management level
- to appoint a cultural advisor as part of the rehabilitation team
- that spending more time with Māori may be necessary in order to ensure accurate information is provided, and to allow them to ask questions (see also Section 9.2.1, *Information*, on provision of information)
- that continual clarification of understanding and probing for feedback may also be of benefit
- that managed care does not allow for ‘extra’ time in some practices, but this important aspect of culturally appropriate services may need to be factored into policy
- that the provision of culturally, aesthetically appropriate surroundings is important to the level of comfort for Māori, which may include physical, cultural or spiritual aspects of care
- to obtain input from tangata and/or mana whenua.

Many of these suggestions will not be able to be implemented immediately. Where these measures are not currently achievable, the minimum provision for Māori with TBI should be the availability of advice and support from a Māori cultural advisor.

10.4 Assessment of Māori with traumatic brain injury

Neuropsychologists also need to take into account formal education levels and language abilities when assessing Māori with TBI. Most neuropsychological assessment tools have not been standardised for Māori populations and therefore there is uncertainty about the applicability of the measures and the interpretation of the results of neuropsychological assessments for Māori. Neuropsychological measures often have culturally determined elements which may be inappropriate for New Zealand; correction for these may improve applicability within New Zealand.²⁵⁵ The same issues will apply to some measures used by other disciplines and all rehabilitation practitioners assessing Māori with TBI should consider the validity of assessment tools.

10.5 Whānau support

The whānau of the person with TBI will also need support. Regular whānau meetings could be considered during rehabilitation, and advice on financial issues and support groups should be included in discharge information. See also Section 9.2.1, *Information*, for details of information.

Where whānau members are carers of the person with TBI, and particularly where they are involved in the provision of rehabilitation interventions, training and support should be provided (see Chapter 13, *Needs of carers*).

Chapter II: Pacific peoples and traumatic brain injury

'I am not an individual,
I am an integral part of the cosmos.
I share divinity with my ancestors, the land, the seas and the skies.
I am not an individual because
I share a tofi with my family, my village, my nation.
I belong to my family and my family belongs to me.
I belong to my village and my village belongs to me.
I belong to my nation and my nation belongs to me.
This is the essence of my sense of belonging.'

Tui Atua Tupua Tamasese, 1997

Overview

- In New Zealand, 5% of ACC's 'concussion' claimants identified as Pacific peoples in 2003. It is likely that Pacific peoples are under-represented in TBI-related claims for a number of reasons.
- It is important to acknowledge the traditional beliefs and culture of Pacific peoples and to be cognisant of the stigma that surrounds illness and disability. Cultural diversity between and within Pacific cultures should also be recognised and acknowledged.
- Health care practitioners should be aware of the barriers to access for Pacific peoples (eg, cost and language) and be proactive in offering services.
- Currently, there is a lack of high-level evidence to guide recommendations when planning TBI rehabilitation for Pacific peoples. However, guidance on providing culturally appropriate service and improving outcomes for Pacific peoples is summarised in this chapter.
- At present, there is a lack of research on outcomes of TBI for Pacific peoples in New Zealand.

RECOMMENDATIONS	GRADE
Socioeconomic circumstances, such as access to transport or a telephone, should be considered when planning traumatic brain injury rehabilitation.	C
Language interpreters should be offered regardless of perceived proficiency in English.	C
There should be a Pacific team or at least one Pacific health care practitioner available as part of the multidisciplinary rehabilitation team for Pacific peoples with traumatic brain injury.	C
A Pacific cultural advisor and/or matua should be available to traumatic brain injury rehabilitation staff for consultation.	C
All information should be produced in Pacific languages and in oral form (eg, videos), where possible.	C
The need for culturally aesthetically appropriate physical surroundings and environments for Pacific peoples should be taken into account.	C
Caution should be used with assessment tools that have not been developed or standardised for Pacific peoples. Decisions regarding assessment, rehabilitation and coordination should be based on contextual information from a variety of sources and should include Pacific input.	C
Traumatic brain injury assessment and rehabilitation processes for Pacific peoples should be structured so that they involve family, extended family and an interpreter and/or matua, and include cultural protocols, where required.	C
Traumatic brain injury rehabilitation staff should be aware that there is much diversity between Pacific cultures, and that detailed concepts of rehabilitation will also vary between and within cultures.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS	
Traumatic brain injury rehabilitation staff should be aware of traditional Pacific beliefs and the stigma surrounding illness and disability in order to minimise the potential for giving offence.	✓
Services should be offered to Pacific peoples with traumatic brain injury, rather than expecting them to initiate contact and ask for it.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

11.1 Pacific peoples in New Zealand

The term ‘Pacific peoples’ describes the diverse range of people living in New Zealand who have migrated from nations of the South Pacific, and/or who identify with one or more of the Pacific islands because of ancestry or heritage. Due to migration, 6.5% of New Zealand’s current total population is of Pacific ethnicity.²⁵⁶ New Zealand’s 2001 Census reports that almost half, or 115,017 of the Pacific population are Samoan, followed by Cook Island Māori (52,569), Tongan (40,716), Niuean (20,148), Fijian (7,041), Tokelauan (6,204) and

Tuvaluan (1,965). The majority (60%) of this population were born in New Zealand with about two-thirds of this population located in the Auckland region.²⁵⁶

This section provides a broad overview of issues utilising a pan-Pacific approach. However, it is important to recognise and acknowledge the cultural diversity between and within Pacific cultures. Each nation has its own specific set of cultural beliefs, customs, values and traditions. The status, authority, tradition, obligations and power structures are different for each group.²⁵⁷ Moreover, the level of familiarity a Pacific individual has with New Zealand culture (aculturation) will determine the extent to which the content of this section applies.

In 2003, 5% of ACC's 'concussion' claimants identified as Pacific peoples.²⁵⁸ However, Pacific peoples may be under-represented in TBI-related claims, given that the Pacific population is comparatively younger than the general population in New Zealand, and that younger people make the most claims. Faleafa (2004) has also concluded that there is a relationship between Pacific peoples' over-representation in certain social indicators and characteristics associated with the increased likelihood of sustaining TBI, such as high involvement in motor vehicle accidents, assaults, sports-related injuries, higher unemployment, lower educational levels, higher crime involvement and lower socioeconomic status.²⁵⁹

11.2 Perception of health for Pacific peoples

Perceptions of health are governed by cultural norms and values. Traditionally, Pacific cultures are more sociocentric (ie, their orientation is towards the social group) than non-Māori and non-Pacific New Zealanders, who tend towards being more individualistic (where orientation is towards the individual).²⁶⁰ There are many values common to Pacific nations, such as respect, reciprocity, communalism, collective responsibility, gerontocracy, humility, love, service and spirituality.²⁶¹

Pan-Pacific concepts of family encompass the immediate and extended family, as well as the wider community. Traditionally, people in need of care through illness, disability or age have been cared for by their families and within the extended family structure. Caring for people is seen as the responsibility of the family, as only family, it is felt, will provide care with the necessary kindness. While this may be a tremendous support and strength of Pacific families, it could act as a barrier to obtaining services outside the family.²⁶²

Traditional Pacific concepts of health are holistic, where well-being is defined by the equilibrium of mind, body, spirituality, family and environment. The **Fonofale** model²⁶³ is one example that captures this concept from a Samoan perspective, portraying six dimensions of health:

- familial
- spiritual
- physical
- mental
- other (encompassing demographic and situational variables)
- cultural (the philosophical drive, attitudes and beliefs of Pacific islands' culture).

These dimensions are interdependent with the environment, context and time relevant to the individual. As with Māori models of health, the dimensions are considered to be interwoven and interdependent, with altered states of wellness occurring when one or more of the dimensions is out of balance.

11.3 Access to and utilisation of health and disability services

Pacific peoples have historically had low access and utilisation rates of disability support services in general. One contributing factor is thought to be the high degree of stigma attached to disability in Pacific cultures, so that the presence of disability is shaming for the family and may carry with it a fear of 'gossip'.²⁶² This has been related to traditional spiritual explanations of disability (eg, as a punishment from God or a curse due to a family

wrong). Although there is no evidence that this attitude extends to TBI-related disabilities in people who have had no pre-existing disability, it is important to acknowledge traditional Pacific beliefs and to bear in mind the stigma surrounding illness and disability in order to minimise the potential for giving offence.²⁶²

Pacific peoples tend to see health care professionals less for many reasons. This includes seeing health care professionals for ACC matters. There may be a perception amongst Pacific employees that they will not be believed if they report an injury, especially if it happened at work. Cost can also be a reason for not seeking medical care. People may not be able to afford the ACC co-payment that is charged, and may be anxious about paying for the prescription of medications.

Language difficulties are a further barrier to accessing services. Trying to explain how an injury happened and describing their symptoms can be very challenging for a Pacific person with limited English. There may be no (similar) words in Pacific languages to describe certain symptoms, so the health care professional may become frustrated at being unable to get a 'good history'.

The use of therapies and medicines traditional to their culture may also be preferred by many Pacific peoples, and lead to non-utilisation of ACC-funded providers and lack of reporting of an injury.

11.4 Rehabilitation planning for Pacific peoples with traumatic brain injury

There is a lack of high-level evidence on which to base recommendations when planning TBI rehabilitation for Pacific peoples. However, the needs of Pacific peoples must still be addressed in order to provide a culturally appropriate service and endeavour effectively to improve outcomes for Pacific peoples. The following guidelines have been suggested:

- **Service accessibility:** In some situations, asking for help (which can extend to seeking services) for Pacific peoples is seen as rude because help is usually offered rather than requested.²⁶² Therefore, in order for rehabilitation to be effective, the service will need to be offered to people with TBI, rather than expecting them to initiate contact and ask for it. Socioeconomic circumstances must also be considered (eg, access to transport or a telephone).
- **Communication:** Many Pacific peoples for whom English is a second language describe the considerable disadvantages in not being able to communicate clearly and confidently, and the consequent reluctance to consult outside their own small communities. Shyness resulting from this difficulty in communicating, together with the cultural reluctance to attract attention to one's self, exacerbates the problem so that it becomes a significant barrier to accessing care and services.²⁶² Language interpreters should be offered regardless of perceived proficiency in English.
- **By Pacific for Pacific:** Ideally, there should be a Pacific team or at least one Pacific health care practitioner available as part of the multidisciplinary rehabilitation team. It is also advisable to have a Pacific cultural advisor and/or matua available to staff for consultation. For mainstream services, establishing partnerships and consulting with Pacific health providers is essential.
- **Pacific-appropriate resources:** Much of the health and disability service information, as well as TBI rehabilitation-specific information, comes in written form. Although it is important for consumers to have written information available due to the potential deficits in memory that can occur following TBI, this is not culturally appropriate for Pacific peoples with their oral tradition, and may require too high a proficiency in written English.²⁶² All written material should be produced in Pacific languages and in oral form (eg, videos) where possible.
- **Holistic approach:** The role in rehabilitation of the family, extended family and community should be acknowledged and empowered. Individual attitudes and beliefs surrounding TBI and TBI rehabilitation (eg, spiritual beliefs) should be identified and incorporated into the rehabilitation plan. Culturally aesthetically appropriate physical surroundings and environments are important for level of comfort for Pacific peoples and should be taken into account.

- **Caution with assessment tools:** There is no formal research investigating the reliability and validity of the use of any commonly used standardised tests and tools with Pacific peoples. Consequently, an invalid assessment may give rise to recommendations for a rehabilitation programme that may have minimal effectiveness for a Pacific person. Health care practitioners are advised to be cautious with assessment tools. For example, neuropsychologists need to take into account formal education levels and language abilities when assessing Pacific peoples.²⁵⁹ Any decision-making regarding assessment, rehabilitation and coordination should be based on contextual information from a variety of sources and should include Pacific input.
- **Cultural protocol:** One of the practicalities of working in an ethical and culturally safe manner with Pacific peoples is that more time may be needed to ensure accurate and reliable information is gathered.²⁵⁹ Involving family and extended family, as well as an interpreter and/or matua, and then including cultural protocols where required (such as a prayer and/or blessing), may all play a role in the assessment and rehabilitation process.
- **Cultural diversity:** While commonalities across Pacific cultures do exist and can be applied to rehabilitation, detailed concepts of rehabilitation will also vary between and within Pacific cultures.

11.5 Research issues

There is a lack of research on outcomes of TBI for Pacific peoples in New Zealand. Therefore this chapter is largely based on expert opinion, and provides a starting point for health care practitioners working with the Pacific TBI-rehabilitation community.

Rigorous and culturally appropriate epidemiological and outcomes-focused research investigating TBI in the Pacific population could inform both the development of evidence-based best practice and resource allocation. Any research conducted in New Zealand should routinely specify the ethnic composition of the population sample.

Chapter 12:

Children and young people and traumatic brain injury

Overview

- There is a lack of robust evidence on care and support for children and young people with TBI.
- The impact of TBI on potential development is likely to be greater the younger the person is. The precise outcomes of TBI in children are hard to establish because TBI impairments emerge over many years as function matures.
- TBI in early childhood may have lasting effects; more specifically, there may be an impact on the child's attainment of developmental milestones.
- Rehabilitation of children and young people does not differ greatly from rehabilitation of adults, although there are some aspects that differ for children, which are summarised in this chapter.
- Children who have been admitted to hospital with a TBI should be assessed for functional limitations and referred appropriately before discharge.
- Careful management of the transition from stage to stage (ie, acute care to rehabilitation) is required for children and young people who have experienced TBI.
- Long-term continued monitoring and follow-up of children and young people with TBI is necessary to ensure the benefits for the individual.
- Education and training of those working in special education are recommended to minimise any misconceptions about TBI in children and young people.

The acute management and rehabilitation of children and young people with TBI is addressed throughout this guideline. When management for children differs from that for adults, this is highlighted; otherwise, recommendations apply equally to adults and paediatric populations. This chapter addresses aspects of the acute care and management which are specific to children and young people. Issues for the families and carers of children and young people are addressed in Chapter 13, *Needs of carers*.

12.1 Definitions

Defining the upper age limit of 'children and young people' presents its own difficulties, as there are various approaches taken to the upper limit in the literature. Many studies have taken an inclusive developmental approach and included young adults in their early 20s because they may, functionally, still be in late adolescence and in transition to independent adult life. Others, however, have used arbitrary upper age delineators, varying between the ages of 12 and 21 years.

This guideline has adopted a flexible and pragmatic approach generally, where it is detailed if the management and care differ due to younger age. Generally, this chapter is referring to people under the age of 18 years. However, practitioners should use their professional experience to apply this information, and may consider some of the information in this chapter appropriate to a physically and emotionally immature young adult, providing that it is within the context of their normal social role.

There are differences in the way that rehabilitation may be delivered to children and young people with TBI, particularly in the longer term. For example, some cognitive rehabilitation and behavioural management

interventions may be delivered under the auspices of special education services (Group Special Education), often within school, and this is covered in this chapter.

There is a lack of robust evidence on many aspects of care and support for children and young people with TBI and more research is required.

12.2 Effects of traumatic brain injury in children and young people

Following a TBI, there are three classes of sequelae that may be experienced by people of all ages with TBI:

1. immediate effects
2. longer-term and late-emerging effects
3. impairments of development as it would have occurred without the injury.

The impact of TBI on potential development is likely to be greater the younger the person is. Childhood and adolescence are times of rapid changes physically, cognitively, socially and in capacity, and therefore the impact on the pre-injury potential development of a child with TBI may be considerable. Impairments may continue to emerge over many years as function matures.

This impact on potential development makes it particularly difficult to establish, from the research base, the precise outcomes of TBI for children. It is rare that data sufficient to predict future development has been recorded for children who later have a TBI, prior to their injury. More frequently, performance post-injury is compared with inaccurate and incomplete pre-injury data, or post-hoc estimates of pre-injury functioning. However, a systematic review reported the following longer-term effects of TBI in children:

- a predictable pattern of delays and deficits in language acquisition for children up to the age of three, when compared with uninjured children
- subtle, hidden cognitive deficits in cases of apparently normal performance in children with focal TBI, where the children were using compensatory strategies
- non-linear changes in growth related to injury variables.¹¹

There is also good evidence that a TBI in early childhood may have lasting effects. One controlled study in Auckland reported that children who had a mild TBI when aged between 2.5 and 4.5 years exhibited impaired visual closure (the ability to fill in missing parts of a visual stimulus, such as a letter missing from a word) at a year after the injury, and that this was related to impaired reading scores at age six years.²¹⁸ However, although these children's injuries had been classified as 'mild TBI', the clinical histories included high proportions of risk factors indicative of more serious injury by the criteria being used in this guideline.

In addition, there may be an impact on the child's attainment of developmental milestones. A child's disability may increase with increasing age, both due to difficulty with learning and acquiring new skills as a result of the brain injury and due to types of brain injury which have their first noticeable consequences at a later developmental stage. Development may be delayed or disrupted by a TBI (eg, puberty may be precipitated by a TBI)¹⁹⁵ and by the loss of socialisation that may occur as a result of the TBI, such as the impact of an extended hospitalisation, absence from school and other activities. This loss of socialisation, and other impacts on development, may have age-inappropriate impacts on behaviour that persist into adulthood.

12.3 Rehabilitation of children and young people with traumatic brain injury

Rehabilitation of children and young people with TBI does not fundamentally differ greatly from rehabilitation of adults. Most information about rehabilitation strategies and interventions is covered in Chapter 6, *Rehabilitation following clinically significant traumatic brain injury – intervention*. However, there are some aspects of rehabilitation that differ for children. One difference in the management of TBI in children is that most children with TBI are, or will be, at school, and that many rehabilitative interventions will be implemented within

and focused on the demands of the school environment. The child will also have two major environmental influences: home and school, with different rules and values, which create additional demands on the child.

An analysis of data for 24,021 children aged 0 to 19 years (77.8% between 1 and 14 years of age) admitted to hospital in the USA with at least one head injury found that 63.6% also had other injuries, 16.6% of which were severe.²⁶⁴ The level of severity of TBI as assessed by the Glasgow Coma Scale was mild in 67.7%, moderate in 7.8% and severe in more than 11.5%. When discharged from hospital, 16% of these children and young people with TBI had one to three functional limitations – about half of these were limitations in bathing, dressing and walking – and 6.2% had four or more limitations (90% in bathing, dressing and walking, 75% in self-feeding, cognition and behaviour, 67% in speech, 29% in vision and 16% in hearing). Ninety percent of the children with one to three limitations and 37.7% of those with four or more were discharged to home. Despite these limitations, referral for physiotherapy (24%), occupational therapy (13%) and speech-language therapy (10%) was low.

It was noted that nearly all of the discharged children were scheduled for a later follow-up hospital visit and further referrals for rehabilitative care may have been made at that time. However, rehabilitation should start as soon as possible after the injury and be continuous, and the delay in initiating rehabilitation was seen as undesirable in terms of the likely possible effects on outcomes for the children and their families.²⁶⁴

It is important that all children who have been admitted to hospital with a TBI be assessed for functional limitations and referred appropriately before discharge.

12.3.1 Transitions

RECOMMENDATION	GRADE
The management of transitions for children and young people with traumatic brain injury should include:	
• case coordination	C
• planning for re-integration starting soon after the acute injury	C
• a full assessment of the needs of the young person with traumatic brain injury in an education environment.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

The management of transitions for children and young people with traumatic brain injury should include:

- coordinated transition plans prepared with the family/whānau and carer(s), the child/young person with traumatic brain injury, educators, and rehabilitation specialists
- information provided to schools about traumatic brain injury and possible long-term impairments
- the provision of updates and orientation to school peers
- clear and effective communication
- the provision of training/education on an ongoing basis to all staff involved in the child's education
- alternative options for learning
- supplementary therapy services
- planning for transition to adulthood with formal transition programmes
- preparation for transitions including:
 - the student being prepared for new situations, environments, people and challenges
 - staff who will be involved in the child's education being advised of their strengths, problems, needs and appropriate resources and strategies
 - preparation of carers
- the adaptability and modification of the curriculum to meet the student's needs
- monitoring during transitions for support for emergent needs.



This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Transitions – such as from acute care to rehabilitation, from inpatient care to home, return to school and from school to adult life – can be particularly stressful for children and young people and their carers, and require careful management.

Transitions are likely to require support, particularly if the child or young person has functional limitations resulting from the TBI.⁸ There is little robust evidence about specific aspects of transition planning and support specifically in this population. However, the evidence is consistent that the management of transitions should include the following:

- case coordination²⁶⁵
- planning for re-integration that starts as soon after the acute injury as possible²⁶⁶
- a full assessment of the needs of the student^{265–267}
- coordinated transition plans prepared with input from a multidisciplinary team consisting of the family/whānau and carer(s), the student with TBI, educators, and rehabilitation specialists^{265–268}
- at hospital discharge, health professionals should provide schools with information about TBI and possible long-term impairments, so that children returning to school receive appropriate support^{265,266,269}
- the provision of updates and orientation to school peers²⁶⁵
- clear and effective communication between all parties^{266,268}
- the provision of training/education in the particular needs of the student with TBI to all staff who will be involved directly or indirectly in the child's education^{266,267} on an ongoing basis, ie, with new staff each year²⁶⁵
- alternative options for learning, such as within the regular classroom, special classes or home instruction,²⁶⁷ but with home-bound instruction as short as possible²⁶⁵
- supplementary and therapy services available in conjunction with class placement²⁶⁷
- planning for transition to adulthood that starts no later than age 16 years and preferably at age 14 years²⁶⁷ with formal transition programmes²⁷⁰

- preparation for transitions including:²⁶⁷
 - the student being prepared for new situations, environments, people and challenges
 - staff who will be involved directly or indirectly in the child's education being advised of their strengths, problems, needs and appropriate resources and strategies
 - preparation of carers
- adaptability of the curriculum to meet the student's needs, including modification, where necessary, of pace, tutoring, assignments, materials and environment²⁶⁷
- careful and frequent monitoring during transitions for support for emergent needs.²⁶⁵

12.3.2 Provision of rehabilitation

RECOMMENDATIONS	GRADE
Children with clinically significant traumatic brain injury should receive long-term continued monitoring and follow-up.	C
Teachers and other educational staff involved in the teaching and rehabilitation of children and young people with TBI should receive education tailored to the specific needs of the school and the particular characteristics of the child with traumatic brain injury about: <ul style="list-style-type: none"> • typical impairments in memory and learning • common problems with behavioural and emotional self-regulation • the high risk of academic failure in children with moderate to severe traumatic brain injury • factors influencing the rate of recovery • the ability of the rehabilitation team to help address learning problems as they arise. 	C
Parents and other carers of children and young people with TBI should be provided with training in direct intervention and advocacy skills, including how to recognise when to seek specialist help and advice.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS	
The parents and carer(s) of a child with traumatic brain injury should be closely involved in the provision of information to educational staff working with the child.	✓
All teachers, particularly special education staff and resource teachers for learning and behaviour should be routinely trained to recognise patterns of impairment resulting from traumatic brain injury and to seek specialist advice, where appropriate.	✓
The need of siblings for support, assessment and education should be considered.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Rehabilitative interventions will be delivered by paediatric rehabilitation teams, by parents and carers, and by special education services, sometimes through the child's school.

There is evidence that the beneficial effects of some interventions may be lost when the intervention is discontinued, and that long-term continued monitoring and follow-up is necessary to maintain, reinforce and generalise the benefits for the individual.²⁷¹

12.3.2.1 Education

School-based interventions for children and young people with TBI require an understanding of the neuropsychological sequelae of TBI.²⁷² However, there is evidence that large proportions of special education staff may have misconceptions about TBI and its sequelae that, if not corrected, could negatively impact on the success of rehabilitation for the child or young person with TBI, and have adverse effects on their general well-being. One study testing knowledge of TBI and its sequelae in children in education professionals attending a special education conference found that the educationalists had misconceptions about recovery from severe TBI, the need for other than purely physical rehabilitation, memory loss, and about common issues such as anger, irritability and learning new things.²⁷²

A small study of Australian students with brain injury and their parents found similarly that all the parents and six of the seven students reported incidents of feeling misunderstood or disliked by teachers and peers.²⁷⁰ Lack of awareness of brain injury sequelae resulted in reduced understanding by teachers of the students' specific school needs. For example, poor memory and organisation were not recognised by teachers as contributing factors to non-completion of work. Many students experienced anguish and humiliation, leading to social isolation, low self-esteem, and school avoidance, while all parents reported high levels of stress in relation to their children's schooling.²⁷⁰

One study found that educational psychologists were well aware of the need of younger children with TBI for additional support, for longer, than adolescents. The authors looked at whether a now-outdated, but once widely held theory was still adhered to: the **Kennard Principle**: that brain damage sustained in childhood has less serious consequences due to the plasticity of the brain, and found that the educational psychologists were aware that this was not the case.²⁷³

Although there is no evidence to show that education staff in New Zealand have the same extent of misconceptions about TBI in children and young people, the need for education and training of educationalists involved with children with TBI is well supported in the literature^{267,272} and will apply equally well to New Zealand. There is evidence that the education of teachers and other educational staff involved in the teaching and rehabilitation of children and young people with TBI should address the following areas:

- typical impairments in memory and learning
- common problems with behavioural and emotional self-regulation
- the high risk of academic failure in children with moderate to severe TBI
- factors influencing the rate of recovery
- the ability of the rehabilitation team to help address learning problems as they arise.²⁷²

It is also suggested that information be tailored to the specific needs of the school and the particular characteristics of the child with TBI. The parents and carer(s) of the child should be closely involved in this process.

More generally, it is important that all teachers, but particularly special education staff and resource teachers for learning and behaviour be aware of the potential for sequelae from TBI, even from mild TBI, for possibly extended periods of time. TBI in early childhood may be overlooked until it manifests as behavioural issues in later years.

12.3.2.1.1 Educational implications of common consequences of traumatic brain injury in children

This section is adapted with permission from: Ylvisaker M, Todis B, Glang A, et al. Educating students with TBI: themes and recommendations. *J Head Trauma Rehabil* 2001;16(1):76–93.²⁶⁵

12.3.2.1.1.1 Neurological recovery

Often, children experience prolonged and unpredictable improvement, based on several dynamics of neurological recovery.

Implications

- Educational systems need to be flexible and programmes highly individualised.
- Frequent review and modification of the student's placement and programme may be required, a practice not consistent with the tradition of annual review.

12.3.2.1.1.2 Evolving ability profiles

In some cases, the student's disability increases over time, possibly related to a type of brain injury that has its first noticeable consequences at a later developmental stage or to the dynamics of the student's adjustment.

Implications

- Long-term monitoring systems must be implemented, even if the student is not receiving special education services.
- School staff need to be alert to the possibility that the disability may gradually increase over time, so that intervention can be implemented as promptly as possible.

12.3.2.1.1.3 Disability related to vulnerable parts of the brain

Theoretically, any part of the brain can be involved in TBI. However, closed head injury is frequently associated with damage to the frontal lobe and anterior and medial temporal lobes, resulting in relatively weak control over cognitive processes such as: attention; disorganised thinking and acting; relatively weak planning in relation to peers, problem-solving and strategic behaviour; relatively weak learning from consequences; relatively weak effortful learning and retrieval; difficulty holding several thoughts in mind at one time; inflexibility; perseveration; inconsistent behaviour and academic performance; concrete thinking and difficulty generalising; relatively weak social perception; and awkward social behaviour.

Implications

- Impairments may be difficult to assess. Many of these impairments are consistent with good performance on psychological, neuropsychological and psychoeducational testing. Therefore, necessary services and supports may not appear to be justified on testing alone.
- Disability may be misinterpreted (eg, neurological disinhibition as a psychiatric disorder), with inappropriate services a possible consequence.
- Traditional teaching and behaviour management that emphasise the manipulation of consequences may be ineffective.
- Long-term, contextualised coaching in 'executive functions' may be necessary.

Needs related to temporal lobe (including limbic system) injury may include weak learning (new learning) relative to the knowledge base acquired before the injury and weak emotional/behavioural regulation.

Implications

- The student may need much more repetition than would seem necessary.
- The student may need substantial antecedent support for behavioural self-regulation.

Needs related to widespread microscopic damage include relatively slowed processing.

Implications

- The student may need reduced assignments, evaluation of work based on quality not quantity, and time accommodations, particularly in examination settings.

Strengths related to relative sparing of posterior parts of the brain may include the retention of much pre-injury knowledge and skills and basic motor and sensory functions.

Implications

- Assessments must go far beyond testing academic knowledge and skill (acquired before the injury) and sensorimotor functions.

12.3.2.1.1.4 Psychoreactive phenomena

The evolution of emotional consequences after a life-threatening injury is unpredictable but may include reactions that profoundly influence educational performance. At one stage or another after the injury, some children become depressed and withdrawn, others angry and defiant, and others overtly desirous of pleasing, resulting in social vulnerability.

Implications

- Schools should monitor students' mental health and social relationships after an injury, and provide counselling and support when indicated.

Chapter 13:

Needs of carers

Overview

- The effects on the family/whānau and carer(s) of a child with TBI can be considerable.
- Continuity of support for people with TBI should also include support for their families/whānau and carers. Carers should be assessed on an individual basis for their needs for support. Carers should also be provided with relevant information and be fully involved in the development of a management plan. Carers should be provided with specific opportunities for training and emotional support and counselling, where appropriate.
- There is good support for interventions targeted at increasing social support for families/whānau and carers of children and young people, but little outcomes-focused research detailing the effectiveness of specific interventions.

RECOMMENDATIONS	GRADE
Carers should be individually assessed when assuming the carer role and at regular intervals thereafter, including for: <ul style="list-style-type: none">• the care provided• the need for support, including respite care• the need for training• their stress and mental health issues.	C
Support should be provided for carers, including: <ul style="list-style-type: none">• information• professional and social support• emotional support, including family therapy and relationship/marital counselling, as required.	B
A guide to traumatic brain injury rehabilitation services and resources should be provided to carers.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

A holistic view should be taken of the person with traumatic brain injury and their carer(s) within the context of their wider family/whānau and social networks.	✓
Health care practitioners working with people with traumatic brain injury should be aware of who the primary carers are, including both paid, formal carers and unpaid, informal carers who are usually family/whānau members.	✓
Family members, including carers, of people with traumatic brain injury should be able to maintain their previous social roles as far as possible and it should not be assumed that family members will automatically accept the carer role.	✓
Moderating factors of the ability to cope should be used to inform decisions about the interventions to provide for carers of people with traumatic brain injury.	✓
Additional support should be provided for carers, including: <ul style="list-style-type: none"> • crisis support • training and education for the carer role • training in behavioural management techniques when the person with traumatic brain injury has behavioural and personality changes resulting from the traumatic brain injury • respite care. 	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

In this section, ‘carers’ refers to people, usually members of the person’s family, who provide care for the person with TBI as a result of their relationship with that person, rather than because they are professional caregivers. This may include both paid, formal carers and unpaid, informal carers (who are usually family/whānau). Many carers do not receive any financial recognition for their input, yet their carer role can have a serious impact on their earning ability, as many families suffer considerable loss of income following a family member having a TBI.^{10,11}

13.1 Interventions for people with traumatic brain injury and their families/whānau and carers

It is important that a holistic view of the person with TBI and their carer(s), within the context of their wider family/whānau and social networks, is taken, as most interventions and support will need to address interactions between more than one individual. It should not be assumed that a person will take on the role of primary carer simply because of their relationship to the person with TBI. Therefore, it is important for the well-being of the family of the person with TBI that the family members, including carer(s), be able to maintain their previous social roles as far as possible. Practitioners working with people with TBI should be aware who the primary carers might be.

The research in this area is extremely heterogeneous, with little consistency in the outcomes examined, which makes comparison of findings particularly difficult. Furthermore, there is very little outcomes-focused research addressing the effectiveness of interventions for these issues. However, there are considerable effects on the families/whānau and carers of people with longer-term sequelae of TBI, which consistently include:

- loss of or difficulty in maintaining their normal (pre-injury) social and professional roles^{71–73,240,241,274–277}
- a reduction in the family’s social and financial status^{11,73,276}
- high levels of health problems, including high stress levels and clinical anxiety and depression in up to two-thirds of carers^{11,70–72,240,274,278–280}

(These problems are related to the level of unmet need for support,⁷⁰ being the primary carer,²⁸⁰ and cognitive, behavioural, emotional and personality changes in the person with TBI;^{280,281} while the degree of depression is related to the number of adverse events following the injury.²⁷⁸ One study found that the most distressing factor for carers was the impact that caregiving had on their personal health and free time)²⁷⁴

- a reduction in family functioning and an increase in family relationship problems^{11,73,277,280}
- an increase in marital breakdown^{73,277}
- an increase in loneliness and social isolation for carers^{73,276} and the person with the TBI.^{274,276}

Moderating factors for the ability of families and carers of people with TBI to cope with the demands of caring for the injured people include:

- coping style, including flexibility in adjusting life goals and motivation,²⁷⁵ and the carer's own satisfaction with their ability to cope with the demands²⁴⁰
- a positive attitude towards seeking social support²⁸²
- good pre-injury family functioning¹¹
- adaptation by carers, including learning ways to manage particular problems⁷¹
- the availability of social support.

Although some of these are intrinsic to the person with TBI and their family/whānau, these factors can be used to inform decisions about the interventions to provide for carers of people with TBI.

There are reports of high levels of burden, distress and health problems for carers of people with TBI. Therefore, it is important that continuing support for people with TBI include support for their families/whānau and carers upon whom the TBI has also impacted, and who will, in most cases, be providing much of the day-to-day care and support for the person with TBI. There is evidence that although friends and wider family/whānau provide help and support in the time immediately after the injury, this support usually tails off and the burden of care falls more and more on the immediate family as time passes.²⁷⁶ This makes it more difficult for the carers to maintain their social networks.

13.1.1 Carer assessment

Carers may have needs themselves resulting from their carer role, and they should be assessed on an individual basis for their needs for support, on assuming the carer role and at regular intervals thereafter.⁷⁰ Carer assessment should include assessment of:

- the care provided
- the need for support, including respite care
- the need for training in their carer role
- their stress and mental health issues.

Carers' needs for support include:

- the provision of adequate information^{11,73,227,240,241,283}
- adequate professional and social support^{73,227,241,278,279}
- the provision of emotional support including family/whānau therapy and relationship/marital counselling^{73,196,227}
- crisis support (eg, for suicidality)
- training and education for the carer role, particularly a need for training in behavioural management techniques when the person with TBI has behavioural and personality changes resulting from the TBI
- respite care.

Siblings of people with TBI can be significantly affected.¹²¹ They may become direct carers themselves when parents are absent and they may suffer from a lack of attention because of the focus on the person with TBI.

13.1.2 Information

The provision of information following discharge to the community is discussed in Chapter 9, *Post-discharge follow-up and support for people with traumatic brain injury*. Additional information should include contact details for carers' support groups and other local resources. Information should be provided in both written and verbal forms.²³¹

Families/Whānau and carers also often express a need for a 'map' of TBI rehabilitation providers and resources.²⁴¹ A guide to TBI rehabilitation should be provided to carers, which details:

- the skills, roles and responsibilities of the practitioners involved in rehabilitation, such as clinical psychologists, counsellors, psychiatrists, paediatricians, ACC case coordinators and therapists of different disciplines
- who is responsible for the provision of what service
- who to contact for help
- entitlements to support.

The case coordinator will be able to help people with TBI and their carers to navigate the system, and should be the first point of contact, and this should be emphasised in the guide.

13.1.3 Social support

Carers should be fully involved in the development of management plans and be involved in decisions about ongoing care and support for people with TBI. They should also be assisted to develop the social supports necessary for their role. Social supports that have been shown to be effective for carers of people with TBI include:⁷³

- friends
- family/whānau
- religion
- TBI support groups.

For people without easy access to support groups, such as those not living in the major urban centres, telephone support groups have been shown to be effective.²⁸⁴ Carers of people with TBI should be encouraged and supported in developing and maintaining social support networks, including friends and wider family/whānau, and support groups. In New Zealand, there is also the Brain Injury Association Liaison Service, which can provide help and support to people with TBI and their families/whānau and carers.

13.1.4 Emotional support and counselling

People with TBI and their families/whānau and carers may need counselling and support in a number of areas. Some people may find that the changes in roles when a family/whānau member has a TBI prove difficult to adapt to and they may benefit from counselling to assist with their adjustment to the new situation.⁷¹

Personality, behavioural and mood changes in the person with TBI can put strain on spousal and parental family relationships, and marital and/or family counselling may be necessary.^{73,277,280} There may also be some indirect effects of the TBI for which counselling is helpful. For example, a person with sexual dysfunction caused by psychological difficulties with body image as a result of the primary physical sequelae of a TBI, and their partner, may benefit from relationship counselling and/or counselling on sexuality.

13.1.5 Empowerment

There is some evidence from a small intervention study that the empowerment of families/whānau and carers of people with TBI can improve outcomes.²⁸⁵ Factors which were found to lead to better adjustment by carers in Hong Kong to a family member having a TBI included:

- clear personal expectations
- a desire to master the situation

- strong motivations
- the flexibility to adjust life goals
- an awareness of one's own powerless state.

Empowerment, defined in terms of psychological well-being, self-efficacy, subjective experience of the burdens in caregiving and support systems, was effectively taught through an eight-week community-based empowerment programme aimed at these factors. Some improvement in the empowerment of the families was reported. Although this was a small study with no control group and, therefore, insufficient evidence on which to base a recommendation for routine application, staff working with families and carers of people with TBI should be mindful of the potential benefits of supporting them in a way that is empowering.

13.1.6 Stress management

A small study of parents caring for children with TBI compared the outcomes for the provision of information alone with the provision of information plus coaching in stress management techniques.²⁸⁶ They found that the group who received information plus stress management showed a significantly greater reduction in depression and anxiety levels. Stress management techniques taught as part of the intervention included:

- self-monitoring
- progressive muscle relaxation and visualisation
- cognitive coping
- suggestions for social support
- suggestions for dealing with grief.

Although this was a small study and not strong evidence, parental stress has such a substantial effect on outcomes for children with TBI that the Guideline Development Team views it is reasonable to consider some form of stress management training for parents and/or siblings who are showing signs of stress, anxiety and/or depression.

13.1.7 Training

All families/whānau and carers need to be provided with specific opportunities for training in the residential rehabilitation environment and after discharge. The responsibility for residential rehabilitation training should be with residential providers, whereas the responsibility for after-discharge training should be that of the funder of community rehabilitation services for people with TBI.

Carer support groups in general and specific community groups dealing with people and families/whānau with TBI are good points of contact and sources of information for families and carers. Practitioners working with people with TBI are encouraged to provide contact details (phone numbers and/or web addresses) for such groups.

13.1.8 Respite care

Any plan for the long-term rehabilitation of someone in the community after severe TBI needs to include a provision for respite care for family/whānau and carers. This need for respite may change over time and need periodic re-evaluation.

13.2 Parents/Carers of children and young people with traumatic brain injury

RECOMMENDATIONS	GRADE
Families/Whānau of children with traumatic brain injury need provision of support aimed at enhancing the following: <ul style="list-style-type: none"> • social support • family relationships and functioning • stress management • help with adjusting to the new situation. 	C
There should be an assessment of the individual needs of the family, and interventions individualised to the family's needs and comprising some or all of the following should be provided as needed: <ul style="list-style-type: none"> • education and information • coping strategies, including problem-solving • specialist marital counselling • specialist family therapy • specialist psychotherapy for the primary carer(s) • support for building and maintaining social support networks • the development of sources of emotional support • financial advice and support. 	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT	
Formal support programmes should be developed and provided for the families/whānau, carers and siblings of children with traumatic brain injury.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Parents and carers of children and young people with TBI may be providing much of the rehabilitative care and support. In addition to support in their role, parents and other carers need training in direct intervention and advocacy skills, including how to recognise when to seek specialist help and advice.²⁷¹

Siblings are also inevitably involved as carers and in the delivery of rehabilitation, so their need for support, assessment and education should also be considered.

There was little research evidence on the impacts on a family caring for a child with TBI. Members of the Guideline Development Team provided the following best practice advice:

1. Immediate impacts: emotional

The impact of the initial injury is great on all members of a family, particularly when there are severe consequences, including the need for hospital (sometimes intensive care unit) care and concerns about the immediate survival of the child. Clinicians need to understand these effects on parents and siblings. Families/Whānau can respond with perhaps unexpected reactions, such as anger, fear and other emotional problems. Appropriate referral to counselling services and support networks may be necessary. Much anxiety may revolve around a lack of information about the future of the child, the future of the family/whānau, and rehabilitation and education possibilities for children with significant TBI.

2. Immediate impacts: practical

Issues such as who cares for siblings when the mother/father is with the child with TBI, maintenance of work, study and other social relationships for parents and siblings and a need to cope with day-to-day activities

such as laundry and house cleaning and transport of other children to school need consideration at an early stage, with appropriate support provided. Alterations to the home environment may be needed both to better facilitate day-to-day activities and to promote safety. Respite care in the short term may be critical for family members providing 24-hour supervision for a child with TBI.

3. Long-term impacts

These depend on the long-term consequences of the TBI, while the child is growing up and at important transitional developmental stages for the child, siblings and parents. There are inevitably continuing emotional impacts and continuing anxieties over the rehabilitation and educational needs of the child and their future prospects in the community.

Within this general framework, research shows that the effects on the family/whānau and carer(s) of a child having a TBI can be considerable. Effects on parents have been shown to include:

- parental injury-related stress^{287–289} that is often long term²⁹⁰
- parental mental health issues^{287,288}
- deterioration in family finances^{291,292}
- an increased financial burden on the family, related to the degree of functional impairment²⁸⁸
- the inability of parents to maintain pre-injury employment demands^{291,292}
- deterioration in parents' marital relationship²⁹¹
- changes in family functioning²⁹³
- a need for modification of housing or new housing, in the case of children with severe functional impairment.²⁹¹

Siblings of the injured child are likely to be negatively affected by impaired parental relationships and family financial stresses. Siblings may be unaware of the nature of the injured child's condition and prognosis, which may be due to clinical staff and parents attempting to protect them. However, the uncertainty and confusion that not knowing can cause may result in siblings becoming particularly anxious.¹²¹

Siblings have been shown to be affected in the following ways:

- negative impact on behaviour,²⁹¹ particularly in siblings of children with poorer functional outcomes²⁹⁴
- depression.²⁹⁴

People outside the family may also be affected by the sequelae of the TBI. Particularly in the case of more severe TBI, or where there are cognitive and/or physical deficits, the child or young person may not be able to return to pre-injury levels of participation and achievement in academic, sporting and social activities. This may lead to changes in relationships with their peers.²⁹⁵

13.2.1 Factors mediating the psychosocial effects on children and young people with traumatic brain injury and their families/whānau and carers

There is some evidence that outcomes for a child with TBI and their family are affected by a number of different factors. These include factors related to the child and family prior to the injury and factors related to the TBI and demands of care.

- **The pre-injury psychosocial adjustment of the child.** Children with premorbid psychosocial problems are more likely to suffer psychosocial adjustment issues subsequent to the injury.²⁹⁶
- **Pre-injury family functioning.** Families with poorer functioning prior to a child's injury are more likely to have a greater degree of dysfunction post-injury.^{293,297,298} Children and young people with TBI whose families have pre-injury dysfunction are also more likely to have psychiatric disorders post-TBI,^{299,300} and to have poorer adaptive functioning.³⁰¹
- **The response of the primary carer(s) to the child's injury.** Behavioural outcomes for the injured child over the first two years have been shown to be related to the emotional reaction of the primary carer acutely after the injury.³⁰²
- **Partner support available to the primary carers.** Behavioural outcomes for the injured child over the first two years have been shown to be related to whether the primary carer (usually the mother) of the child has

a partner, although this association did not persist beyond two years post-injury.³⁰² A good relationship between the child's parents, with consensus on roles and responsibilities is also related to better psychosocial outcomes for the child and family, as is the amount of paternal time spent with the injured child.³⁰³

- **Family functioning.** Children and young people with TBI are more likely to develop novel ADHD and conduct disorders if their families are dysfunctional post-injury.³⁰⁴
- **The degree of functional impairment of the child with TBI.** This has been shown to be related to family functioning.³⁰⁵
- **Stress levels.** Families of children with TBI where the parents/carers have high stress levels are more likely to have poorer psychosocial outcomes.³⁰⁶ One study comparing parents of young people aged 15–24 years with and without TBI found that parents of people with TBI experienced higher levels of marital stress, and that this was related to global psychological distress levels in the mothers.³⁰⁷
- **Time since the injury.** The proportion of parents/carers with high levels of distress reduces over time as they adjust to the new situation. However, a substantial proportion continue to have high levels of stress.^{288,290}
- **Social support.** This has been shown to enhance the coping of families of children with TBI,³⁰⁸ and adequacy of social support for carers has been shown to be a significant indicator of family functioning.³⁰⁵ The availability of social support has also been shown to impact on the carer's reaction to functional deficits caused by the TBI. Only among carers with low social support were cognitive dysfunction and personal unawareness of deficit adversely related to life satisfaction. In contrast, these characteristics were unrelated to life satisfaction among caregivers with adequate social support.^{309,310} However, a systematic review identified that most unmet needs of carers were related to the provision of emotional support.²²⁷
- **Coping.** This has been shown to be improved by the empowerment of carers of people with TBI²⁷⁵ (see section 13.1.5, *Empowerment*); seeking social and spiritual support;^{303,311} strong family relationships;³¹² and acceptance and the use of humour.³¹³

From this, it can be inferred that families of children with TBI need provision of support aimed particularly at enhancing the following:

- social support
- family/whānau relationships and functioning
- stress management
- adjusting to the new situation.

Although there is some research on the provision of such support through various interventions, it is largely descriptive and infers probable effectiveness from documented need. There is good support for interventions targeted at increasing social support^{8,10,11,240,276,305,309–311,314,315} but little outcomes-focused research detailing the effectiveness of specific interventions. One Hong Kong-based pilot study described a family empowerment programme which was found to be effective and which targeted each of the four aspects described above.²⁸⁵

Suggested interventions are generally individualised to the families' needs⁷⁰ and comprise some or all of the following as required:^{70,196,241,285,308,316}

- an assessment of the individual needs of the family/whānau and carer(s)
- education and information
- coping strategies including problem-solving
- specialist marital counselling
- specialist family therapy
- specialist psychotherapy for the primary carer(s)
- support for building and maintaining social support networks
- the development of sources of emotional support
- financial advice and support.

In addition, formal support programmes should be developed and provided for families, carers and siblings as they deliver much of the rehabilitation, have a high rate of stress as a result, and family/whānau functioning is a major factor mediating psychosocial effects on children.

Chapter 14:

Special issues

Overview

- Informed consent, as defined by the Health and Disability Commissioner, needs to be considered as a special issue in the management of TBI. People who have had a TBI sometimes have cognitive and communicative difficulties, which may limit their capacity to make informed decisions about their treatment.
- Some people with TBI may not be able to return to driving due to prohibiting conditions, such as seizures or cognitive impairments that affect judgement, attention, reaction times and emotional/behavioural control. However, many people with milder forms of TBI may be able to return to driving or acquire driving skills following appropriate assessment.
- People presenting with TBI have a high premorbid rate of drug and alcohol misuse, and the highest incidence of TBI is among young adult males who also have the highest incidence of substance misuse.
- People with TBI with a history of drug and/or alcohol misuse show higher mortality rates, poorer neuropsychological outcomes and a greater likelihood of repeated injuries and late deterioration following TBI.
- People with TBI who have substance misuse problems require careful assessment and management due to the cognitive and emotional problems arising from the TBI. However, there is very little robust research examining the effectiveness of interventions for drug and alcohol use for people with TBI.
- People who have had a TBI frequently experience mental health problems. However, there is considerable debate about the extent to which these result from TBI and how these disorders are best addressed in this population.
- Depression and anxiety disorders are common following TBI, particularly depression. Psychosis following TBI is also well recognised.
- There is a high rate of mental health disorders in children and young people following TBI.
- There is some evidence of the influence of pre-existing psychological conditions on post-TBI mental health in children and young people. ADHD and depressive disorders have been identified as the most common mental health disorders following a TBI.
- In the diagnosis of post-TBI depression, there are key issues to consider, which include assessing the severity of depression.
- A number of depression scales have been developed to quantify depression using a graded method.
- Interventions for post-TBI mental health disorders are frequently part of a broad neuropsychological rehabilitation programme. However, there is little evidence about specific interventions for this population.
- There is some evidence that multiple TBIs can have cumulative effects, leading to poorer outcomes.
- The term 'concussion' is widely used and this chapter provides some clarity on the definition of concussion.
- Signs and symptoms associated with a suspected TBI are listed in this chapter.
- There is little evidence, variability in practice and little expert consensus on how repeated TBIs should be managed for children.
- After controlling for demographics, pre-existing conditions and head injury severity, there is no difference in outcomes between people with TBI from violent causes and those whose injury is from other causes.

14.1 Capacity and consent

RECOMMENDATIONS	GRADE
Health care practitioners should make every effort to ascertain injured people's wishes with regard to each individual intervention, and where this cannot be determined, to discover what their attitude to treatment might have been but for the traumatic brain injury.	C
A clinical neuropsychologist and/or a speech-language therapist should be consulted with regard to assessing an individual's cognitive abilities or enhancing communication.	C
Where a person lacks, or may lack, capacity, and treatment is considered which appears to be against their wishes, the advice of a psychiatrist should be sought with regard to determining capacity and any possible application of the Mental Health Act 1992.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS	
Family and carers, particularly the next of kin, should be consulted about the likely wishes of the individual in light of their premorbid values and beliefs.	✓
Specialist assistance from a neuropsychologist or neuropsychiatrist should be sought to maximise the capacity of the person to consent to treatment.	✓
When the person with traumatic brain injury is Māori, a Māori facilitator should also be involved in the process of gaining consent.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Informed consent is a process requiring: effective communication between all concerned; the provision of all necessary information about options, risks and benefits to the consumer; and the consumer's freely given and competent consent.³¹⁷ New Zealand legislation governing informed consent is covered by the Code of Health and Disability Services Consumers' Rights,¹¹⁴ and more information can be obtained on the Code and its application from the Health and Disability Commissioner's website at www.hdc.org.nz.

The capacity to consent to treatment requires the injured person to be able to:

1. understand and retain information about the treatment proposed and any alternative options that may be available
2. weigh up the benefits and risks associated with treatment, including any possible consequences of declining treatment.

People who have a TBI sometimes have cognitive and communicative difficulties that limit their capacity to make informed decisions about their treatment and to give consent. Alternatively, they may be able to understand, but their judgement can be clouded by related symptoms such as depression, especially where hopelessness is a prominent feature.

In the above situations assessment may be complex. The treating health care practitioner is required to provide management in the best interests of the person who lacks capacity, but those 'best interests' must be carefully established,¹³ as outlined below.

- Health care practitioners have a duty of care to make every effort to ascertain injured people's wishes with regard to each individual intervention and, where this cannot be determined, to discover what their attitude to treatment might have been but for the TBI.
- Family and carers can play an important role in indicating the likely wishes of the individual in light of their premorbid values and beliefs, but cannot give consent for them. It is, however, important that family and carers be involved, particularly next of kin.
- A clinical neuropsychologist and/or occupational therapist and/or speech-language therapist may be helpful in assessing the individual's cognitive abilities or in enhancing communication to ascertain their level of capacity for consent and their wishes with regard to treatment.
- In complex situations where the person with TBI lacks, or may lack, capacity, and treatment is considered which appears to be against their wishes, the advice of a psychiatrist should be sought with regard to determining capacity and any possible application of the Mental Health Act.³¹⁸

The capacity to consent can fluctuate in people with TBI and efforts should be made, with specialist assistance from a neuropsychologist or neuropsychiatrist, to maximise the capacity to consent of the person. When the person with TBI is Māori, a Māori facilitator should also be involved. Also see Chapter 10, *Māori and traumatic brain injury*.

14.2 Driving

GOOD PRACTICE POINTS

The rehabilitation team should:

- inform the person and their family/whānau and carer(s) about the law and driving after brain injury
- provide clear guidance for the general practitioner and family, as well as the person, about any concerns about driving.



Land Transport New Zealand should undertake discussions with relevant agencies to formulate new recommendations regarding people driving following a traumatic brain injury.



This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

There are a number of reasons why some people with TBI may not be able to return to driving. Prohibiting conditions include seizures, visual field defects or cognitive impairments that affect judgement, attention, reaction times and emotional/behavioural control. However, many people with milder forms of brain injury may be able to return to driving or acquire driving skills following appropriate assessment. Driving is a complex activity which requires intact cognitive abilities as well as a certain level of physical ability. Determining when someone is unfit to drive following a TBI can be very difficult, especially when such a decision may have very significant ramifications for the individual, eg, work loss, financial disadvantage.

The rehabilitation team should inform the person and their family/whānau and carer(s) about legal requirements regarding fitness to drive following TBI. They should also provide clear guidance for the general practitioner and family, as well as the person, about any concerns regarding driving. They also need to reinforce the need for disclosure and assessment in the event that return to driving or, in young people, learning to drive, is sought post-injury.⁸

14.2.1 New Zealand legislation

The responsibilities of registered medical practitioners under the Transport Act (Vehicle and Driver Registration and Licensing) 1998 are detailed in *Medical aspects of fitness to drive: a guide for medical practitioners* (www.landtransport.govt.nz/licensing/docs/ltsa-medical-aspects.pdf).

New Zealand law requires medical practitioners to:

- *advise the Director of Land Transport New Zealand (LTNZ), via the Chief Medical Advisor's office, of any individual who poses a danger to public safety by continuing to drive when advised not to*
- *consider the guidelines in Medical aspects of fitness to drive when conducting a medical examination to determine whether an individual is fit to drive.*

14.2.1.1 Specific information

'The medical examination' is detailed in *Medical aspects of fitness to drive: a guide for medical practitioners* (page 14). Details specific to driving following a TBI are also included (page 44).

Enable New Zealand (phone toll free on 0800-171-981) can provide current information on where to get driving assessments in New Zealand.

14.2.1.2 Driving licence revocation procedures

In New Zealand, the guidelines for action to be taken when a medical practitioner considers that a person is medically unfit to drive are summarised as follows:

- voluntary surrender of the licence and discontinuation of driving with no questions asked
- compulsory review by the Director of LTNZ, which may lead to the revocation of any class(es) or all classes of licence held, limitations on the use of any class(es) held and the right to have any revocation or limitation reviewed by the District Court.

The general practitioner's role is to:

- advise the person with regard to the above options, if necessary in writing
- advise the person that a second opinion may be obtained, if required
- advise the Director of LTNZ, in the event that the doctor's advice to cease or limit driving is not accepted by the person, that in the opinion of the general practitioner, the person is likely to continue driving.

For full details see *Medical aspects of fitness to drive: a guide for medical practitioners* (pages 9 and 17–20).

14.2.2 Beyond the legislation

The LTNZ *Medical aspects of fitness to drive: a guide for medical practitioners* (page 24) describes two categories of people with 'head injuries'.

1. 'Minor' head injury.

- *'An individual who sustains a minor head injury without loss of consciousness or any other complication should not drive for 3 hours'*
- *'An individual who sustains a minor head injury but does lose consciousness should not drive for 24 hours and should have a medical assessment before returning to driving'*
- *'An extension of the recommended periods' is advised with complications, specified as 'loss of good judgement, decreased intellectual capacity, post-traumatic seizures, visual impairment or loss of motor skills'. Clearance by a medical practitioner required before allowed to drive.*

2. 'Serious or significant' head injuries

These are defined as 'acute intracerebral haematoma requiring surgery or compound depressed fracture or dural tear or with more than 24 hours' post-traumatic amnesia'. The LTSA [LTNZ] requires that 'all cases are fully and properly assessed' prior to 'any suggestion of a return to driving'.

- *'Most individuals with severe head injuries, including those with post concussion syndrome, should not drive within six months of the event, and a return to driving should be subject to a medical practitioner assessment.'*

The Guideline Development Team considers these categories are insufficient to describe the variety of situations that exist after TBI. The Guideline Development Team recommends that LTNZ undertake discussions with relevant agencies to formulate new recommendations regarding driving following TBI.

14.2.3 Alcohol and other drugs in association with driving

Alcohol and other prescribed, over-the-counter or recreational drugs can significantly impair cognitive functioning. Many people with TBI report increased sensitivity, particularly to the effects of alcohol. Therefore, a zero-tolerance rule should apply for alcohol and recreational drugs prior to driving for a period equal to twice the minimum standdown period for the severity of TBI. The central nervous system and psychotropic effects of prescribed or other medications and supplements should be considered when advising about driving for people with TBI who require these medications.

14.3 Drug and alcohol use and misuse

RECOMMENDATIONS	GRADE
Any comorbid issues should be identified and addressed in people with traumatic brain injury and drug and alcohol problems.	C
Family/Whānau members and other carers need to be educated on how to identify high-risk situations, and how to identify and respond to warning signs and relapses relating to drug and alcohol misuse in people with traumatic brain injury.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

People with traumatic brain injury should be advised that the effects of psychoactive drugs and alcohol may be increased, and that they should abstain from use for twice as long as the time taken for all symptoms to resolve.	✓
Rehabilitation professionals should refer people with traumatic brain injury and substance misuse problems to specialist drug and alcohol services.	✓
Families/Whānau should be involved early to aid in determining drug and alcohol issues in people with traumatic brain injury.	✓
Management strategies for drug and alcohol issues in people with traumatic brain injury should be developed in collaboration with specialist traumatic brain injury staff. Formal systems of collaboration between specialist traumatic brain injury staff and drug and alcohol service staff should be developed.	✓
Drug and alcohol service staff working with people with traumatic brain injury should receive training in traumatic brain injury sequelae and their effects on drug and alcohol use.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

People presenting with TBI have a high premorbid rate of drug and alcohol misuse. In addition, the highest incidence of TBI is among young adult males, who also have the highest incidence of substance misuse. Post-injury, people with TBI with a history of drug and alcohol misuse have an extremely low rate of employment.³¹⁹ Corrigan found that alcohol intoxication was present in one-third to half of people admitted to hospital with TBI and that nearly two-thirds of people receiving rehabilitation after TBI may have had a history of substance misuse that preceded their injuries.^{320,321}

There is also a high rate of post-injury drug and alcohol misuse in people who have had a TBI. This rate, however, at least for alcohol, appears to be similar to that in the general (non-injured) population.³²²

People with more severe disability post-TBI have lower alcohol consumption rates. Younger people and people with higher blood-alcohol levels on original presentation with TBI are more likely to show an increasing consumption of alcohol longer term following the TBI.³²² People with TBI also report a reduced tolerance of alcohol and drugs.

In the Guideline Development Team's opinion, people with TBI should be advised that the effects of psychoactive drugs and alcohol may be increased, and that they should abstain from use for double the time taken for all symptoms to resolve.

A recent literature review on drug and alcohol use in people with TBI found that rehabilitation professionals often lack comprehensive training and skills in the treatment of substance misuse.¹⁶⁵ It suggested that rehabilitation professionals need to refer people with TBI and substance misuse problems to relevant agencies, including treatment outside the rehabilitation facility. It also suggested that they should recommend whether inpatient or outpatient intervention is required.¹⁶⁵

The converse may also be true: that drug and alcohol professionals have little understanding of the:

- way drugs and alcohol are metabolised post-TBI
- impact of impulse control and overall poor decision-making
- social isolation
- other sequelae of TBI that impact on drug and alcohol consumption (such as the difference between addiction issues and the management of drug and alcohol issues related to executive dysfunction).

Standard interventions may need modification for people with TBI. However, there is some difficulty in working out the relative effects of TBI and drugs and alcohol. Therefore, the management of drug and alcohol issues in people with TBI should be developed in collaboration with specialist TBI staff, along with formal systems of collaboration. It is also important to involve families early to aid in determining issues. All staff working with people with TBI should receive training in TBI sequelae and their effects on drug and alcohol use.

14.3.1 The influence of pre-injury drug and alcohol use on outcomes

People with TBI with a history of drug and/or alcohol misuse show higher mortality rates, poorer neuropsychological outcomes and a greater likelihood of repeat injuries and late deterioration following TBI.³²⁰ This is particularly the case for people with a history of more severe substance misuse problems.

There is a considerable body of evidence identifying a strong relationship between post-TBI mental health problems, such as depression and anxiety, and pre-injury psychiatric history. However, an analysis of the research indicates that pre-injury substance use is the significant factor, and when this factor is accounted for, other psychiatric conditions are no longer significant as predictors of post-TBI mental health issues (see Section 14.4, *Mental health in adults with traumatic brain injury*). Determining pre-injury drug and alcohol use may therefore be of use in predicting an increased likelihood of post-injury mental health problems.

14.3.2 Assessment and diagnosis and interventions for drug and alcohol misuse

A review of the literature on drug and alcohol use in people with TBI concluded that there should be routine quantitative assessment, records review and long-term monitoring to identify and follow up drug and alcohol misuse in people with TBI.¹⁶⁵ Assessment should use standardised tools and measures to allow for the comparison and collection of data.^{323,324}

It is also important that comorbid issues are identified and addressed to maximise the effectiveness of rehabilitation and treatment for drug and alcohol misuse. For example, many women with alcohol misuse issues have a history of sexual misuse which will impact on the success of the rehabilitation.³²⁵

People with TBI who have substance misuse problems require special treatment due to the cognitive and emotional problems arising from the TBI.³²⁶ Although there is research describing the problem of drug and alcohol misuse in people with TBI, there is very little robust research examining the effectiveness of interventions aimed at this specific population.

Research has identified four 'types' of people who have had a recent TBI based on pre-injury alcohol consumption, alcohol problems and alcohol dependence. These 'types' corresponded to people with a history of:

1. alcohol misuse
2. alcohol dependence
3. alcohol dependence in remission
4. normal or non-drinkers.

It is suggested that if health care practitioners match people's types to specific interventions, such as educational and motivational interventions, as well as treatment for substance misuse, this may result in more effective care.³²⁷

A small study of 50 adults, looking at how motivated people with recent TBI are to change their alcohol drinking habits and what factors affect their motivation, found that after a TBI, drinkers frequently contemplate changing their alcohol use, and that a history of alcoholism, higher daily consumption and alcohol being a factor in the injury were all associated with greater readiness to change.³²⁸ Comparison with a separate medical sample also supported a TBI being associated with greater action to change alcohol use. It was concluded that the use of motivational interviewing techniques may facilitate change during this period.

A comprehensive review of the TBI and substance misuse literature found that people with TBI and a history of pre-injury substance misuse are at risk of resuming the substance misuse on discharge to the community.¹⁶⁵ Family/Whānau members and other carers need to be educated on how to identify high-risk situations and how to identify and respond to warning signs and relapses in people with TBI.

14.4 Mental health in adults with traumatic brain injury

RECOMMENDATIONS	GRADE
If a person with TBI has significant neuropsychiatric problems, local mental health teams should be involved in the development of a management plan, including inpatient management, discharge management and follow-up.	C
Specialist neuropsychiatry support should be available to local mental health teams in the management of people with complex neuropsychiatric problems following TBI.	C
If a person with TBI is unwilling to stay in hospital yet needs to do so because it would not be safe for them to go home, consideration should be given to the need for treatment under the Mental Health Act 1992.	C
Staff should be aware of their duty of care to ensure the safety of people who are putting themselves or others at risk, including ensuring carer safety and immediately accessible assistance and support.	C
Services for people with traumatic brain injury, including: <ul style="list-style-type: none"> • local acute care and rehabilitation services contracted to manage people with traumatic brain injury • local mental health services • ACC personnel, should collaboratively specify and document policies for dealing with people with traumatic brain injury who have mental health issues, whether they pre-date or follow the traumatic brain injury.	C
Where traumatic brain injury is a result of deliberate self-injury, or where people with traumatic brain injury exhibit suicidality, they should have a psychiatric assessment including a risk assessment and consideration of the need for further intervention from the mental health team.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT	
Staff of mental health services should receive training in recognition of the particular issues they may encounter in people with traumatic brain injury.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

People who have had a TBI frequently experience mental health problems, and there is considerable debate around the extent to which these result from the TBI and how these disorders are best addressed in this population. Post-injury depression and other mood disorders, anxiety disorders, and other mental health disorders can negatively impact on the success of rehabilitation and the functioning and quality of life in both people with TBI and their carers.³²⁹

Formalised close and collaborative liaison is essential between TBI rehabilitation services and mental health services, and mental health staff should receive training in recognition of the particular issues they may encounter in people post-TBI. If a person has significant neuropsychiatric problems, local mental health teams should be involved in after-care planning.⁸

Specialist neuropsychiatry support should be available to support local mental health teams in the management of people with complex neuropsychiatric problems following TBI.⁸

People who have had a severe TBI sometimes lack insight into their difficulties, so if a person is unwilling to stay in hospital yet needs to do so because it would not be safe for them to go home, consideration should be given to the need for treatment under the Mental Health Act 1992.^{8,318} However, even if people cannot be admitted under the Mental Health Act, staff should be aware of their duty of care to ensure the safety of people who are putting themselves or others at risk. This should include ensuring carer safety and immediately accessible assistance and support.

The Guideline Development Team has found that a recurring message from health care practitioners working with people with TBI is the difficulty of adequate cohesion between mental health services, rehabilitation services and ACC. This is thought to partly reflect historical service divisions, different funding streams and uncertainty about what services are able and willing to offer.

In the Guideline Development Team's opinion, local acute care and rehabilitation services contracted to manage people with TBI, along with local mental health services, need to work together to specify and document policies for dealing with people with TBI who have mental health issues, whether they pre-date or follow the TBI. ACC personnel need to be involved in these discussions and 'sign off' any local policies so that they can be included in existing and future contracts.

14.4.1 Mood disorders

Depression is particularly common post-TBI. For example, a recent large cross-sectional study found that 42% of adult outpatients with TBI referred for assessment at a trauma centre had diagnosable depression.³³⁰ An earlier study found that about 25% of people with a TBI met diagnostic criteria for a major depressive episode and more for a minor depressive episode.³³¹ A large study of World War II veterans compared the lifetime incidence of depression for those with and without TBI, and found that the lifetime prevalence of major depression in the TBI group was 18.5% compared with 13.4% in those with no TBI (OR 1.54, 95% CI 1.17–2.04). This increase in depression was not explained by a history of myocardial infarction, stroke or alcohol misuse, but the risk of depression increased with severity of the head injury.³³²

Several studies of depression in the non-TBI community have found that depression inhibits cognitive functioning, particularly executive functioning, and motivation – a reduction in 'goal-directed' behaviour. In depressed people with TBI, depression-caused impairments in cognition and motivation will be additive to the impairments caused by the TBI, increasing the level of disability and reducing the effectiveness of rehabilitation.³²⁹ It is therefore important that depression is identified and treated in people with TBI.

There is less research on the incidence of mania secondary to TBI. One study of 66 adults with TBI found that 9% met the criteria for mania at some point during follow-up, a frequency significantly greater than that seen in other brain-injured populations such as people who have had a stroke. Mania post-TBI was not found to be associated with the severity of the injury, extent of physical or cognitive impairment, level of social functioning, or previous family/personal history of psychiatric disorder.³³³

14.4.2 Anxiety

Anxiety disorders are also common following a TBI. One study found that the reported incidence of anxiety disorders in people post-TBI was as follows: generalised anxiety disorder 3% to 28%, panic disorders 4% to 17%, phobic disorders 1% to 10%, obsessive compulsive disorder 2% to 15% and post-traumatic stress disorder (PTSD) 3% to 27%.³³⁴

14.4.3 Psychosis

Psychosis following TBI is well recognised, and has a higher prevalence in the post TBI population than in the general population, with an increased risk (RR 0.2–16.3) having been reported in various studies.³³⁵

14.4.4 Post-traumatic stress disorder

Historically, there has been some controversy about the possibility of the coexistence of TBI and PTSD. It was argued that the amnesia and loss of consciousness associated with TBI prevented memories of the trauma, and thus there would be no memory of trauma to trigger PTSD. However, more recently the research has demonstrated that PTSD resulting from the TBI can and does occur in people with TBI.^{336–338} For example, one study of 96 people admitted to a brain injury unit following severe TBI found that, at a six-month follow-up, 27% had clinical PTSD.³³⁹ Another study of 66 people who had suffered a severe TBI found that at an average of nearly six years (range 1–26 years) post-injury, 18% had moderate-to-severe symptoms of PTSD which were unrelated to the severity of the injury, educational background, premorbid or current measured intelligence quotient, or memory impairment.³⁴⁰

One small study suggested that there may be a relationship between the duration of unconsciousness and the development of PTSD. In this study, 46 people who were receiving post-TBI rehabilitation were divided into two groups according to whether they had experienced a prolonged period of unconsciousness (>12 hours) at the time of injury. It found that 27% of the people who were not unconscious for an extended period, but only 3% of those who were unconscious for more than 12 hours as a result of the accident, were diagnosed as having current PTSD.³⁴¹ (See Section 14.4.10.1, *Diagnosis and management of post-traumatic stress disorder for people with traumatic brain injury*.)

14.4.5 Suicidality

TBI sometimes results from self-harm or an attempted suicide. People with TBI may also become suicidal following their injury. Where TBI is a result of deliberate self-injury, or where people with TBI exhibit suicidality, they should have a psychiatric assessment including a risk assessment and consideration of the need for further intervention from the mental health team.⁸

For more details of the management of people after a suicide attempt, see the guideline for *Assessment and Management of People at Risk of Suicide* available at www.nzgg.org.nz.

14.4.6 Post-traumatic brain injury mental health disorders in children and young people

It is known that there is a high rate of mental health disorders in children and young people following a TBI. One study of children and adolescents (aged 6–15 years), a year post-TBI, found a high rate of novel psychiatric disorders, and that 78% of these disorders persisted in 48% of the children studied.³⁴²

Another study found that 19% of children had ADHD post-TBI, and this was novel (ie, secondary to the TBI in nearly half).³⁴³

Another study of children and young people (aged 5–22 years) found that 30.4% had one or more psychiatric hospitalisations following the TBI prior to admission to rehabilitation.³⁴⁴ A large matched-controls study of children aged 14 years or less, three years after they had sustained a mild TBI, found that the incidence of any psychiatric illness was 30% in the children who had a mild TBI, significantly higher than the 20% in those with no TBI.³⁴⁵

One prospective cohort study of children found that PTSD developed in 13% of children with severe TBI that was accompanied by traumatic amnesia. Predictors of PTSD included female gender and early post-injury anxiety symptoms, which are consistent with predictors of PTSD that develop after non-head-injury trauma.³⁴⁶ Another study comparing children with and without TBI who had been involved in vehicle accidents found that, 13 weeks after their accidents, 38% of children with TBI and 46% of those without TBI had PTSD.³⁴⁷

One small prospective cohort study examined the incidence of mania in children hospitalised following TBI. They found that 8% developed mania or hypomania, and suggested that the severity of injury, location of lesion(s) and family history of major mood disorder may be associated with the development of mania post-TBI in children.³⁴⁸ This incidence is similar to that found in adults post-TBI.³³³

14.4.7 The influence of pre-injury mental health disorders on outcomes

One aspect of the debate is how the effects of a TBI are confounded by a pre-injury history of mental health disorders and related personality factors. One concern is that premorbid characteristics and issues may be misinterpreted as symptoms resulting from the TBI, and thereby reduce the accuracy of diagnosis. More seriously, a mistaken belief that post-injury symptoms are **not** attributable to the injury could lead to misdiagnosis, and under the ACC system in New Zealand, could be a barrier to appropriate and adequate care and management. The influence of pre-existing substance misuse is addressed in Section 14.3, *Drug and alcohol use and misuse*. This Section addresses the influence of mental health conditions other than substance misuse.

There is a large body of literature detailing the theoretical influence of pre-injury psychological functioning on the development of post-TBI psychological disorders.³⁴⁹ However, there are fewer papers testing this theoretical approach by actually measuring the relationship. The literature search identified a number of studies examining the prevalence of pre-injury mental health issues and comparing outcomes for adult and paediatric TBI survivors with and without such history.

However, it is important to remember that an 'association' between pre-injury factors and post-injury outcomes is merely an association. Causality in any individual case cannot be inferred from a statistical association, nor does a lack of a statistical association mean that in individual cases there is no influence on outcomes from pre-injury factors. Nonetheless, pre-existent mental health difficulties may be conceptualised as vulnerability factors for post-injury psychological problems.

14.4.8 Post-traumatic brain injury mental health disorders

There is very little research which excludes or separately analyses drug and/or alcohol misuse in the pre-existing mental health conditions examined. However, when pre-existing drug and alcohol misuse is excluded, the evidence is consistent that there is no relationship between pre-existing mental health disorders and those occurring after the TBI.

One paper, reporting on two Australian studies, examined the possible relationship between pre-injury morbidity and post-injury outcomes as a function of severity of injury. The study found that in both a matched control study of people six years after a severe TBI and a second study of people with a mild TBI, there was no effect of pre-injury characteristics on any of the outcomes measured.³⁵⁰

Another small case-controlled study of people with mild TBI and with or without a pre-injury history of depression found no differences on self-reported post-concussive symptoms, Minnesota Multiphasic Personality Inventory scales, or neuropsychological measures between the case-matched groups. It was concluded that health care practitioners need to be cautious in attributing post-concussive symptoms or neuropsychological deficits to a pre-existing affective disorder.³⁵¹ A further study found that people with depression post-TBI had a higher frequency of previous psychiatric disorders than people post-TBI with no depression, but that when drug and alcohol misuse was excluded from the analysis, the difference between the groups was no longer significant.³³¹

14.4.8.1 Post-traumatic brain injury psychosis

A recent systematic review of the literature about psychosis post-TBI has identified considerable methodological issues with the previous research and the analyses of the data.³³⁵ It was concluded that while there was a strong association between pre-existing psychotic disorders and TBI (ie, people with psychotic disorders were more likely to have a TBI), there was little, if any evidence of sufficient quality to support a causal link between TBI and psychosis. However, this paper used schizophrenia as a synonym for psychosis, which is incorrect – people with post-TBI psychosis may have many psychotic symptoms without presenting clinically as having schizophrenia. An addendum to the review described a recently published paper, which the review authors said provided ‘weak’ evidence for head injury as a cause of psychosis.³³⁵

Although the body of literature on this topic has some methodological shortcomings, it is largely consistent in reporting post-TBI psychosis. Attributing psychosis to a TBI should only be done after much careful discussion and investigation of pre-injury signs and symptoms. (See Section 14.4.10.2, *Diagnosis and management of post-traumatic brain injury psychosis*.)

14.4.8.2 Mental health in children and young people with traumatic brain injury

There is a reasonable body of evidence around the influence of pre-existing psychological conditions in children and young people post-TBI. However, the variation in and the width of the age groups included in the research makes it impossible to analyse for specific age groups.

ADHD and depressive disorders have been identified as the most common new mental health diagnoses following a TBI.³⁴² One study showed that while pre-injury ADHD is about five times more common (ie, about 20% of the sample studied) in children and young people who have moderate-severe TBI than those who have no TBI, about 19% of children without pre-injury ADHD develop ADHD secondary to the injury.³⁴³ Another study found that children with mild TBI but no psychiatric history were at higher risk for hyperactivity in the first year after injury (incidence 3%; first year relative risk 7.59; 95% CI 2.7–21.6).³⁴⁵

One study found a clear relationship between TBI and novel mood and anxiety disorders, and that post-injury stress levels and the severity of the TBI were the most robust predictors of the development of a newly diagnosed psychiatric disorder post-TBI.³⁵² Another study comparing outcomes for children with mild or moderate-severe TBI and those with orthopaedic injuries reported that the three groups did not differ on pre-injury depressive symptoms, but parents of children with TBI reported more depressive symptoms at six- and 12-month follow-ups. It was suggested that TBI increases the risk of depressive symptoms, especially among more socially disadvantaged children.³⁵³

Another study found that, in children, psychosocial adjustment deteriorated significantly after a TBI, and that post-injury psychosocial impairments are common in children with moderate to severe TBI and are related to injury severity.²⁹⁶ The study concluded that in most cases, the problems cannot be attributed exclusively to pre-injury dysfunction.

A series of studies examining psychiatric outcomes for a cohort of children aged 6–14 years when hospitalised for a TBI, found that at three months post-injury, a pre-injury psychiatric condition was a predictive factor for a psychiatric disorder. However, this was not the case at either the six-month or one-year follow-up. Constant predictors of psychiatric disorder were severity of injury (when classified as mild or severe), socioeconomic class, intellectual functioning, behaviour/adaptive function, pre-injury family functioning and family psychiatric history. Newly diagnosed psychiatric disorders at the two-year follow-up were again also related to pre-injury psychiatric history.^{299,300,354,355}

The research in this area consistently finds an increase in the risk of novel psychiatric disorders, particularly ADHD, depression and anxiety disorders, following a TBI, which may be related to the severity of the TBI. A proportion of these disorders may be attributable to the influence of pre-injury psychiatric history, but there are a number of both injury-related and other factors which are equally or more important.

14.4.9 Diagnosis and management of mental health disorders post-traumatic brain injury

This section is adapted for New Zealand from the recent evidence-based *UK Concise Guidance for the Use of Anti-depressant Medication in Adults Undergoing Recovery or Rehabilitation Following Acquired Brain Injury*, produced in 2005 by the British Society of Rehabilitation Medicine, the British Geriatrics Society and the Royal College of Physicians' Clinical Effectiveness and Evaluation Unit.¹³

14.4.9.1 Diagnosis of post-traumatic brain injury depression

GOOD PRACTICE POINTS

The main issues to be considered are:

- whether the depression is severe enough to affect health or impede recovery
- whether the depression is likely to respond better to antidepressant medication or other interventions
- whether the antidepressant medication for the individual is safe and acceptable
- how to monitor the effectiveness of treatment
- how long to continue treatment.

✓

Using an appropriate depression screening tool, for adults or children, should be a part of routine practice.

✓

Depression screening tools should not be used as the sole indication for initiation of treatment. Diagnosis should always involve clinical judgement by a specialist experienced in managing people with TBI.

✓

The person with TBI should be referred to a psychiatrist with expertise in treating people with TBI if:

- the risk of suicide is judged significant
- the initial treatment is not effective within two months
- the presentation is complex
- pharmacotherapy is indicated and the familiar medication strategies are contraindicated.

✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

In the diagnosis of post-TBI depression there are some key issues to consider, as outlined below.

1. Does the person have depression which is severe enough to affect their health or to impede their recovery?¹³
It is normal (ie, not clinical depression) to have 'low' mood post-TBI, as the person may go through a period of grief and adjustment to their new situation, which is not depression. Standardised diagnostic criteria should be used in the diagnosis, drawing from the criteria in the fourth edition of the Diagnostic and Statistical Manual – Text Revision (DSM-IV-TR).³⁵⁶ The person with TBI with grief and other common (non-depression) reactions to TBI will need support and treatment if depression is diagnosed.
2. Is the depression likely to respond to anti-depressant medication or are other interventions more appropriate?¹³
3. If antidepressant medication is considered likely to be helpful, is it safe and acceptable for that particular individual?¹³
4. How do you determine if treatment has been effective, and if so, how long do you continue treatment?¹³

Basic history-taking should include a routine general health enquiry with open questions such as 'How do you feel in yourself?'. However, this may not always be sufficient to identify depression in people with TBI, and it is therefore appropriate to employ a screening method as part of routine practice. More detailed assessment is then required for those in whom depression is suspected, to identify symptoms of actual depression or lowered

mood from the general effects of TBI, and to quantify the severity of mood disturbance prior to considering treatment.

The simple 'Yale question' ('Do you often feel sad or depressed?') has been proposed as providing a good screening assessment of depression.³⁵⁷ The advantages of this single question are its apparent simplicity and timeliness. However, a dichotomous answer of 'Yes' or 'No' may in itself be problematic. Firstly, the answer requires intact comprehension and at least a reliable 'yes/no' response, which may not be present in some people following TBI. Secondly, the question, in fact, contains two different components, to which the responses may be different. For example, it is not uncommon for people to feel sad about their loss, but not depressed. Therefore, there needs to be some comparison with their normal mood state.

As with all screening tests, a dichotomous response does not provide a sensitive measure against which to assess the benefits of treatment, particularly in cases where there may have been some partial improvement in mood. Also, some people may not report low mood. Some people report emotional blunting and loss of enjoyment for everyday activities (anhedonia). People from some cultures may need different phrasing. For example, people from a Chinese culture may respond more informatively to a question on whether their energy levels are lower than usual.

14.4.9.1.1 Assessing severity

A number of scales have been developed to quantify depression in a more graded manner.

These exist in several different formats which may be chosen to suit the person's capabilities.

- **Non-verbal rating scales** – such as visual analogue scales in different forms. These may be useful where verbal communication is limited but visuo-spatial skills are adequate, although facilitation will often be required.
- **Questionnaire-based tools** – may be completed at interview or by self-report where the individual has sufficient verbal skills.
- **Scales based on observation of behaviour** such as crying, withdrawal and apathy may be useful where the individual is unable to respond to either non-verbal rating scales or questionnaire-based tools.

Some of the scales require special training and experience to administer; others are more intuitive. Some, including the Hospital Anxiety and Depression Scale, and the Beck Depression Inventory (BDI-II), are restricted by copyright, and it is necessary to purchase a licence for their use.

Short forms have been developed for some instruments, such as the Geriatric Depression Scale (GDS-15) and the Beck Depression Inventory (BDI FastScreen), but these have been developed in general populations rather than for people with TBI, so their usefulness in this context is still uncertain. Preliminary work with the BDI-II suggests that a rather different sub-set of the cognitive and affective items may be more appropriate in a TBI population in general. However, the BDI-II has been reported to give false positives on measurement of somatisation in some people with TBI.

It is perhaps useful for generalist clinical settings to have available a very simple set of screening tools for quick assessment in cases of suspected depression. Of the current freely available tools, a reasonable selection for use in general practice and rehabilitation settings for people with TBI might include:

- the Depression Intensity Scale Circles – a simplified visual analogue scale specifically designed for people with communication or cognitive difficulties, but who have adequately preserved visuo-spatial skills
- Short-Form GDS-15 – a simple questionnaire-based tool for people with adequate verbal and language skills
- Signs of Depression Screening Scale – a simple tool based on observation of behaviour such as crying, withdrawal and apathy, which may be useful where the individual is unable to respond to either of the previous tools.

Tools for use with children and young people could include:

- the Child Depression Inventory (CDI)
- the Reynolds Child Depression Scale
- the BDI.

Depression scales may be useful for screening, for determining the extent of low mood and in monitoring responses to intervention. However, tools do not provide a diagnosis, merely an indication, and may be insufficient, particularly in the TBI population. They should not be used as the sole indication for initiation of treatment, and diagnosis should always involve clinical judgement by a specialist experienced in people with TBI.

There is no one tool which may be applied universally, but it is appropriate for rehabilitation teams to familiarise themselves with a chosen selection, so that they reach a shared understanding of the meaning of a particular score. Further to this, more detailed assessment may be undertaken through interview and/or observation. Figure 14.1 presents a proposed schema for screening and assessment of depression at different levels, and the extent of clinical expertise which may be required.

FIGURE 14.1:
ASSESSMENT OF DEPRESSION IN TRAUMATIC BRAIN INJURY

Which people?

All

Any person with TBI in whom depression is suspected or for whom treatment is being considered

People with TBI with complex presentation or in whom the diagnosis is in doubt (see Level 1)

Severe/Resistant depression or suicide risk

LEVEL I: SCREENING AT EACH CLINICAL REVIEW

Yale question

'Do you often feel sad or depressed?'

Or ask nursing staff/carers/ family

'Do you think he/she feels sad or depressed?' or
'Is their mood different from the normal state?'

LEVEL II: SIMPLE ASSESSMENT OF SEVERITY

Visual analogue scales, eg,

- Depression Intensity Scale Circles
- Numeric Graphic Rating Scale

Verbal scales, eg,

- Geriatric Depression Scale – Short Form (GDS-15)
- Hospital Anxiety and Depression Scale (HADS)*
- Beck Depression Inventory FastScreen (BDI-IIFast)*

Behavioural scales

- Signs of Depression Screening Scale
- Stroke Aphasic Depression Scale

LEVEL III: MORE COMPLEX ASSESSMENT BY STRUCTURED INTERVIEW (REQUIRES TRAINING)

- Present State Examination to complete DSM-IV-TR
- Or based on standard assessment tool, eg, BDI-II*

LEVEL IV: FORMAL PSYCHIATRIC ASSESSMENT

Administered by

Medical staff or other member of the multidisciplinary team (MDT)

Members of the MDT

Clinical psychologist or MDT member with appropriate training

Psychiatrist or neuropsychiatrist

* Use of the HADS and the BDI scales is restricted by copyright. It is necessary to purchase a licence to use these tools.

Adapted from the UK's *Concise Guidance for the Use of Anti-depressant Medication*.¹³

14.4.9.1.2 Continued monitoring

Screening and assessment of depression carries no benefit if it is not followed with appropriate treatment, planning and continued monitoring to ensure response. Whatever the assessment process used, it must be timely and practical to allow for repetition on subsequent occasions for comparison.

The person with TBI should be referred to a psychiatrist with expertise in treating people with TBI if:

- the risk of suicide is judged significant
- the initial treatment is not effective within two months
- the presentation is complex
- pharmacotherapy is indicated and contraindicated.

14.4.10 Interventions for mental health disorders in people with traumatic brain injury

Interventions for post-TBI mental health disorders are frequently part of a broad neuropsychological rehabilitation programme. There is very little evidence about specific interventions for this population. It is known that mental health disorders negatively impact on the success of rehabilitation, and that early diagnosis and treatment of psychiatric disturbances can improve rehabilitation outcomes.^{323,329,352,358} An interdisciplinary, ‘multi-pronged’ approach is necessary, with participation of the person with TBI, family members and health care practitioners and therapists.³²³

14.4.10.1 Diagnosis and management of post-traumatic stress disorder for people with traumatic brain injury

GOOD PRACTICE POINT

Assessment for differential diagnosis should consider the overlap in symptoms between mild traumatic brain injury and post-traumatic stress disorder. If there is doubt, the person should be referred for a specialist neuropsychological assessment.



This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

PTSD is an anxiety disorder. The DSM-IV-TR lists the following criteria for diagnosis:

1. exposure to or witnessing of an event that is threatening to one’s well-being
2. symptoms of re-experiencing, such as intrusive memories, nightmares, a sense of reliving the trauma, or psychological and physiological distress when reminded of the trauma
3. avoidance of thoughts, feelings or reminders of the trauma, and inability to recall parts of the trauma, withdrawal, and emotional numbing
4. arousal, as manifested in sleep disturbance, irritability, difficulty concentrating, hypervigilance or heightened startle response.³⁵⁶

PTSD is frequently comorbid with other mental health problems, and is associated with impairment in social and occupational functioning.³⁵⁹ PTSD may be overlooked in people with TBI due to symptomatic overlap, particularly in someone who presents with mood or behavioural difficulties. As there is also some overlap in symptoms between mild TBI and PTSD,^{360,361} it is important that assessment for differential diagnosis be done with this in mind, and if there is doubt the person may need to be referred for a specialist neuropsychological assessment.

People often experience a range of PTSD symptoms following trauma, but the majority of these reactions will remit in the following months to one year.³⁵⁹ Cognitive-behavioural therapy is widely used for the treatment of PTSD and may be of particular value to people with cognitive disability.^{359,362}

14.4.10.2 Diagnosis and management of post-traumatic brain injury psychosis

GOOD PRACTICE POINT

People who have possible psychotic symptoms post-traumatic brain injury should be referred to a psychiatrist with expertise and experience in the management of people with traumatic brain injury.

✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

The DSM-IV-TR includes a diagnostic category – psychotic disorder due to traumatic brain injury (PDTBI) – the criteria for which are:

1. the presence of hallucinations or delusions
2. evidence that the psychosis is a direct consequence of TBI
3. the psychosis is not better accounted for by another mental disorder
4. the psychosis does not occur exclusively during a state of delirium.³⁵⁶

There may be some differences, compared with the non-TBI population, in presentation with post-TBI psychosis. One study found that only 14% of people with post-TBI psychosis experienced negative symptoms of schizophrenia (such as apathy and withdrawal) whereas between 25% and 84% of people with schizophrenia but no TBI had such symptoms.³⁶³

The diagnosis and management of post-TBI psychosis and psychotic symptoms require specialist assessment and management. People who, post-TBI, have possible psychotic symptoms should be referred to a psychiatrist with expertise and experience in the management of people with TBI.

14.4.10.3 Pharmacotherapy

RECOMMENDATION

GRADE

There should be careful consideration of the sensitivity of people with traumatic brain injury to psychotropic medication before trial use. The use of psychotropic medication should be avoided where possible, and used with caution where indicated.

C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINTS

In any trial of psychotropic medication, the ‘start low and go slow’ approach should be adopted.

✓

Medications that have an adverse effect on central nervous system functioning, particularly antipsychotics such as barbiturates, benzodiazepines, phenytoin and haloperidol, should be avoided.

✓

Serum drug levels should be monitored as necessary.

✓

The risks, benefits and harms should be discussed with the injured person and their carer(s), and it should be explained that response to medication after traumatic brain injury is less predictable than in standard practice.

✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

There are very few well constructed trials of medication for mental health disorders in the TBI population. A Cochrane review evaluating pharmacological treatments of psychosis, depression, anxiety and agitation in neurological conditions concluded that few sufficiently rigorous trials had been conducted. There was also no evidence to support any particular pharmacological approach to treatment in people with neurological conditions, including TBI.³⁶⁴

The Guideline Development Team endorses a proposed management approach for pharmacotherapy for post-TBI psychiatric conditions, with observation of the following rules:

- people with TBI are frequently very sensitive to, and may have an unpredictable response to, psychotropic medications, so there should be careful consideration before trial use. In any trial of a medication, the ‘start low and go slow’ approach should be adopted
- as a general rule, the use of psychotropic medication should be avoided where possible, and used with caution where indicated
- avoid, if possible, medications that have an adverse effect on central nervous system functioning, particularly antipsychotics such as barbiturates, benzodiazepines, phenytoin and haloperidol
- monitor serum drug levels as necessary
- always discuss the risks, benefits and harms with the injured person and their carer(s), and explain that response to medication after TBI is less predictable than in standard practice.^{323,324}

14.4.10.3.1 Pharmacotherapy for post-traumatic brain injury depression

RECOMMENDATIONS	GRADE
A specific selective serotonin reuptake inhibitor should be the first choice for treatment of post-traumatic brain injury depression unless the anticholinergic effects of a tricyclic are considered desirable.	C
The person with traumatic brain injury should be kept under direct clinical monitoring while the drug dose is increased to an effective dose to ensure that the drug is tolerated and producing the required improvement in mood.	C
People with traumatic brain injury should be asked about any over-the-counter remedies, herbs or supplements they are taking to check for potential interactions and adverse effects.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT	
If selective serotonin reuptake inhibitors have been trialled and are not effective, or have produced unwanted side effects or drug interactions, the person should be referred for review to a psychiatrist with expertise in treating people with traumatic brain injury.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

The UK guideline for the use of antidepressant medication in people with acquired brain injury¹³ found that a systematic literature search was unable to identify any formal research on which to base recommendations. Therefore, the UK guideline used the criteria from the British Royal College of Physicians: *The Psychological Care of Medical Patients: A Practical Guide*³⁶⁵ from which the following text is adapted.

The aetiology of post-TBI depression is often multifactorial. It is important to understand the reasons why it occurs in order to determine the circumstances in which antidepressants may or may not help (see Figure 14.2).

Antidepressants may be helpful for depression and possibly other mood disorders, such as emotional lability, but are unlikely to be helpful where clinical features of the TBI itself mimic depression.

FIGURE 14.2:
REASONS FOR DEPRESSION FOLLOWING TRAUMATIC BRAIN INJURY

Reasons why depression may occur following traumatic brain injury

- An emotional response to the sudden onset of disability and its associated life changes which may include physical, financial, vocational, and/or relationship losses.
- A direct result of the brain injury leading to altered biochemical balance within the brain and resulting change in the background level of mood.
- A preceding vulnerability to depression.

Reasons why symptoms which mimic depression may occur following traumatic brain injury

- Other emotional disorders associated with brain injury, such as apathy or emotional lability, may give the appearance of depression, even in the absence of a depressive disorder.
- Somatic symptoms which characterise depression in the normal population may occur as a result of hospitalisation or from the brain injury itself. This may lead to over-estimation of the degree of depression on standard tests. These symptoms may include:
 - loss of energy, appetite and libido
 - altered sleeping habits
 - poor concentration and inability to make decisions.
- Abnormal physical expression of emotional status may give the appearance of depression, eg:
 - disorders of facial expression
 - flat speech patterns
 - general physical slowness.

Adapted from: British Royal College of Physicians: *The Psychological Care of Medical Patients: A Practical Guide*.³⁶⁵

SSRIs have generally replaced tricyclic antidepressants as the drugs of first choice in depression because of their better side effect profile. This may be particularly important in people with TBI who may have poor tolerance of side effects such as sedation. A specific SSRI, such as citalopram or sertraline, represents a reasonable first choice of agent unless the anticholinergic effects of a tricyclic agent are positively desirable (for example sedation or suppression of hyper-salivation or if the tricyclic is also treating other post-TBI disorders, such as headache).

Six SSRIs are currently available – fluoxetine, fluvoxamine, paroxetine, sertraline, citalopram and escitalopram. There are important pharmacokinetic differences between them, notably in their ability to inhibit hepatic cytochrome P450 iso-enzymes, which are responsible for the metabolism of many drugs. *In vitro* studies suggest that citalopram and sertraline are least likely to inhibit these iso-enzymes and therefore least likely to cause interactions with other drugs. A survey of rehabilitation consultants and geriatricians in the UK has demonstrated these two agents to be the most common first choice for the management of depression following acquired brain injury at the current time. However, both fluvoxamine and sertraline have limited availability in New Zealand, and are not currently subsidised by PHARMAC.

Escitalopram is a newer agent, which appears also to be highly selective with minimal inhibition of cytochrome P450 iso-enzymes. Trials suggest that it is at least as effective as citalopram in the management of severe depression, but it has yet to be evaluated in people with TBI (www.biopsychiatry.com/escitalopram.html).

Other more recently introduced antidepressants include venlafaxine, mirtazapine and reboxetine. These have different pharmacological properties and are claimed to have greater specificity, equivalent or better efficacy and fewer side effects than the earlier classes of antidepressants.³⁶⁵ As yet, however, they have not been tested for people with TBI, and may also be significantly more expensive as they are not currently subsidised by PHARMAC. At present they should be used as second line drugs when SSRIs have not been effective or have produced unwanted side effects or drug interactions. If this is the case, the person should be referred for review to a psychiatrist with expertise in treating people with TBI.

The person with TBI should be kept under direct clinical monitoring whilst the drug dose is increased to an effective dose to ensure that it is tolerated and producing the required improvement in mood. Some people in the community may already be taking complementary and alternative medicines and supplements, such as St John's Wort, which may sometimes interact with prescribed medications causing serotonin syndrome and hypomania. It is important that people be asked about any over-the-counter remedies, herbs or supplements they are taking.

14.4.10.3.2 Psychotherapeutic approaches

RECOMMENDATION		GRADE
Cognitive-behaviour therapy tailored for any cognitive impairment should be used for people with post-traumatic brain injury, depression and anxiety.		C
Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.		
GOOD PRACTICE POINTS		
Cognitive-behaviour therapy should be adapted and administered for people with traumatic brain injury by clinical psychologists familiar with traumatic brain injury as well as cognitive-behaviour therapy.		✓
Simple problem-solving measures should be used to address factors contributing to low mood or anxiety.		✓
This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.		

There are a number of psychotherapeutic approaches commonly used for psychological conditions such as mood and anxiety disorders.³⁶⁵ However, there is very little evidence from trials specifically in the TBI population.

Psychotherapeutic interventions are widely considered to be potentially helpful for people who have the cognitive and communicative abilities to engage successfully (see following sections). However, at the current time, these programmes are rarely available within general medical settings, and tend to be a longer-term intervention.

14.4.10.3.2.1 Cognitive-behavioural therapy

Cognitive-behavioural therapy focuses on changing an individual's dysfunctional thoughts (cognitive patterns) in order to change their behaviour and emotional state. For children and adolescents in the general population (ie, non-TBI), cognitive-behavioural therapy is currently the treatment with the best evidential support for anxiety and depressive disorders.^{366,367} In adults in the general population (ie, non-TBI), there is good evidence to support cognitive-behavioural therapy for people with mild to moderate depression or anxiety disorders.³⁶⁸ However, the Guideline Development Team was unable to identify any well constructed trials of cognitive-behavioural therapy in the TBI population. The one recent randomised controlled trial of cognitive-behavioural therapy in people with post-stroke depression found no improvement in the group receiving the therapy for any of the outcomes measured.³⁶⁹

There is caution expressed by some authors that cognitive-behavioural therapy may not be appropriate or would need to be tailored for people with some types of cognitive impairment.^{13,329} However, some research suggests that it may be of particular value to people with cognitive disability when suitably adapted.^{359,362} Psychologists familiar with TBI, as well as cognitive-behavioural therapy, should administer the cognitive-behavioural therapy, with modifications as appropriate.

14.4.10.3.2.2 Behavioural therapy

In behavioural therapy, the person is encouraged to increase activity levels, particularly pleasant events and activities, which are assumed to be rewarding and to lead to improved mood. The Guideline Development Team was unable to identify any robust research showing the effectiveness of behavioural therapy in treatment of depression for people with TBI, although it has been demonstrated as effective in other populations.³⁷⁰ However, there is some evidence that behavioural approaches may be ineffective in depression post-TBI. Furthermore, some people with TBI may have the normal responses to reward disrupted by the brain damage.³²⁹

14.4.10.3.2.3 Life review therapy

Life review therapy is a form of psychotherapy in which people are aided to review their lives and place their conditions in the context of their lives, and has been suggested as beneficial for people with depression following TBI. Although there is no evidence for life review therapy use in the TBI population, a small randomised controlled trial in people who were depressed following a stroke found that after only three sessions, the intervention group showed significant improvements in depression and life satisfaction scores compared with the control group.³⁷¹

14.4.10.3.2.4 Practical help/problem-solving

Simple problem-solving measures to address environmental or other factors which contribute to low mood or anxiety (such as missing home and family, or worries about life outside hospital) may be beneficial.¹³

14.5 Repeated traumatic brain injury and traumatic brain injury in sports

Repeated TBI is where a person has suffered a TBI whether diagnosed and treated or not, on more than one occasion. There is some evidence that multiple TBIs can have cumulative effects, leading to poorer outcomes.

A USA review of sports-related recurrent brain injuries concluded that people who have had at least one previous TBI have an increased risk for subsequent TBI.⁴⁹ Where mild TBIs occur over an extended period of months or years, they can sometimes result in cumulative neurological and cognitive deficits, but where the repeated mild TBIs occur within a period of hours, days or weeks, the outcomes may (rarely) be 'catastrophic or fatal'.

One study of college athletes compared the effects of a concussion in those who had experienced three previous concussions with the effects in matched controls with no previous TBI.⁵⁰ They found that when tested two days post-injury, athletes with multiple concussions scored significantly lower on memory testing than athletes with a single concussion. Athletes with multiple concussions were 7.7 times more likely to demonstrate a major drop in memory performance than athletes with no previous concussions.

Repeated or multiple TBIs are of particular concern in sports, where players may be at greater risk of a repeated head injury. 'Second-impact syndrome' (SIS) occurs when an athlete sustains a second TBI before the symptoms from the first TBI have resolved. The person's status may rapidly worsen, and coma and death may eventually result. Although SIS may not be as common as some have proposed,³⁷² the identification of the initial concussion, which may have been only mild, and appropriate immediate and longer-term management, including return to play, is essential.

Owing to the lack of robust evidence on which to base recommendations for the management of sporting injuries, the Second International Conference on Concussion in Sport in Prague in 2004 produced a 'Summary and agreement statement',³⁷³ from which this section is adapted.

14.5.1 Concussion or traumatic brain injury?

The term 'concussion' is widely used, particularly in sports, to refer to the full range of severity of injury, from 'injury to the head without TBI' through to 'severe TBI'. For example, READ codes use the term 'concussion' even when there are extended periods of loss of consciousness. While the Guideline Development Team does not believe it is possible to stop the use of the term 'concussion' because it is used so widely, it is important to have some clarity about the term to ensure that people who have suffered 'concussion' receive appropriate care.

For the purposes of this guideline, the definition of the term concussion as given in the 'Prague guidelines' (see Section 14.5.1.1, *Definition of concussion*)³⁷³ is being adopted.

14.5.1.1 Definition of concussion

Sports concussion is defined as a complex pathophysiological process affecting the brain, induced by traumatic biomechanical forces. Several common features that incorporate clinical, pathologic and biomechanical injury constructs may be used in defining the nature of a concussive head injury. These include:

- concussion may be caused by a direct blow to the head, face, neck or elsewhere on the body with an 'impulsive' force transmitted to the head
- concussion typically results in the rapid onset of short-lived impairment of neurological function that resolves spontaneously
- concussion may result in neuropathological changes but the acute clinical symptoms largely reflect a functional disturbance rather than structural injury
- concussion results in a graded set of clinical syndromes that may or may not involve loss of consciousness. Resolution of the clinical and cognitive symptoms typically follows a sequential course
- concussion is typically associated with grossly normal structural neuroimaging studies
- in some cases, post-concussion symptoms may be prolonged or persistent.

Therefore, it can be seen that there is some overlap between the labels of 'concussion' and 'injury to the head but no TBI', and 'mild TBI'.

Concussion can be further described as 'simple' and 'complex' concussion. In 'simple' concussion, symptoms resolve progressively over seven to 10 days after the injury, and no intervention is necessary other than limiting play/training while symptomatic. 'Complex' concussion, on the other hand, gives rise to persistent symptoms and symptom recurrence with exertion and more severe symptoms indicative of TBI, such as seizures, loss of consciousness and prolonged cognitive impairment. Complex concussion may also result from multiple concussions over time, or where repeated concussions occur with progressively less impact force.³⁷³ People suffering complex concussion should always be referred for specialist assessment and management.

14.5.2 Immediate management of and return to play after sporting injuries

RECOMMENDATIONS	GRADE
<p>If there is any one of the following, traumatic brain injury should be suspected and appropriate management instituted:</p> <ul style="list-style-type: none"> • loss of/impaired consciousness • any seizure • amnesia: <ul style="list-style-type: none"> – unaware of period, opposition, score of game – unaware of time, date, place • headache • nausea/vomiting • unsteadiness/loss of balance and/or poor coordination • dizziness • feeling stunned or ‘dazed’ • seeing stars or flashing lights • ringing in the ears • double vision • vacant stare/glassy eyed • slurred speech • inappropriate playing behaviour – for example, running in the wrong direction • appreciably decreased playing ability • confusion, such as being slow to answer questions or follow directions • easily distracted, poor concentration • other symptoms, such as sleepiness, sleep disturbance and a subjective feeling of slowness and fatigue in the setting of an impact • displaying unusual or inappropriate emotions, such as laughing or crying • personality changes. 	C
<p>When a player shows any symptoms or signs of a concussion:</p> <ul style="list-style-type: none"> • the player should not be allowed to return to play in the current game or practice • the player should not be left alone and should be regularly monitored for deterioration • the player should be medically evaluated after the injury • return to play must follow a medically supervised stepwise process • a player should never return to play while symptomatic. 	C
<p>Return to play after a concussion should follow a stepwise process, proceeding to the next level only if asymptomatic. If any symptoms occur after concussion, the person should revert to the previous asymptomatic level and try to progress again after 24 hours.</p> <ol style="list-style-type: none"> 1. No activity. When asymptomatic, proceed to level 2. 2. Light aerobic exercise. 3. Sport-specific training. 4. Non-contact training drills. 5. Full contact training after medical clearance. 6. Game play. 	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

Taking a detailed clinical history is essential. The health care practitioner should bear in mind that:

- many athletes will not recognise all the concussions that they may have suffered in the past
- there should be specific questions about previous symptoms of a concussion, not just the perceived number of past concussions
- the recall of concussion injuries by team-mates or coaches has been shown to be unreliable
- there is an increased risk of subsequent concussion injuries after a first concussion is documented
- questioning should also request information about all previous head or neck injuries
- when there are faciomaxillary injuries, concussive injuries may be missed unless specifically assessed.³⁷³

If any one of the following symptoms or problems is present, a TBI should be suspected, and appropriate management instituted. A player does not need to have lost consciousness to suffer a TBI.

1. Cognitive features:

- unaware of period, opposition, score of game
- confusion
- amnesia (memory loss)
- loss of consciousness
- unaware of time, date, place.

2. Typical symptoms:

- headache
- dizziness
- nausea
- unsteadiness/loss of balance
- feeling stunned or ‘dazed’
- seeing stars or flashing lights
- ringing in the ears
- double vision
- other symptoms, such as sleepiness, sleep disturbance and a subjective feeling of slowness and fatigue in the setting of an impact may indicate that a concussion has occurred or has not resolved.

3. Physical signs:

- loss of or impaired consciousness
- poor coordination or balance
- concussive convulsion/impact seizure
- gait unsteadiness/loss of balance
- slow to answer questions or follow directions
- easily distracted, poor concentration
- displaying unusual or inappropriate emotions, such as laughing or crying
- nausea/vomiting
- vacant stare/glassy eyed
- slurred speech
- personality changes
- inappropriate playing behaviour – for example, running in the wrong direction
- appreciably decreased playing ability.

Neuropsychological testing is particularly important in evaluation and should be used as and where appropriate, with baseline testing where possible.

The consensus of the Second International Conference on Concussion in Sport on immediate treatment was that when a player shows **any** symptoms or signs of a concussion:

- the player should not be allowed to return to play in the current game or practice
- the player should not be left alone

- regular monitoring for deterioration is essential
- the player should be medically evaluated after the injury
- return to play must follow a medically supervised stepwise process
- a player should never return to play while symptomatic. 'When in doubt, sit them out!'³⁷³

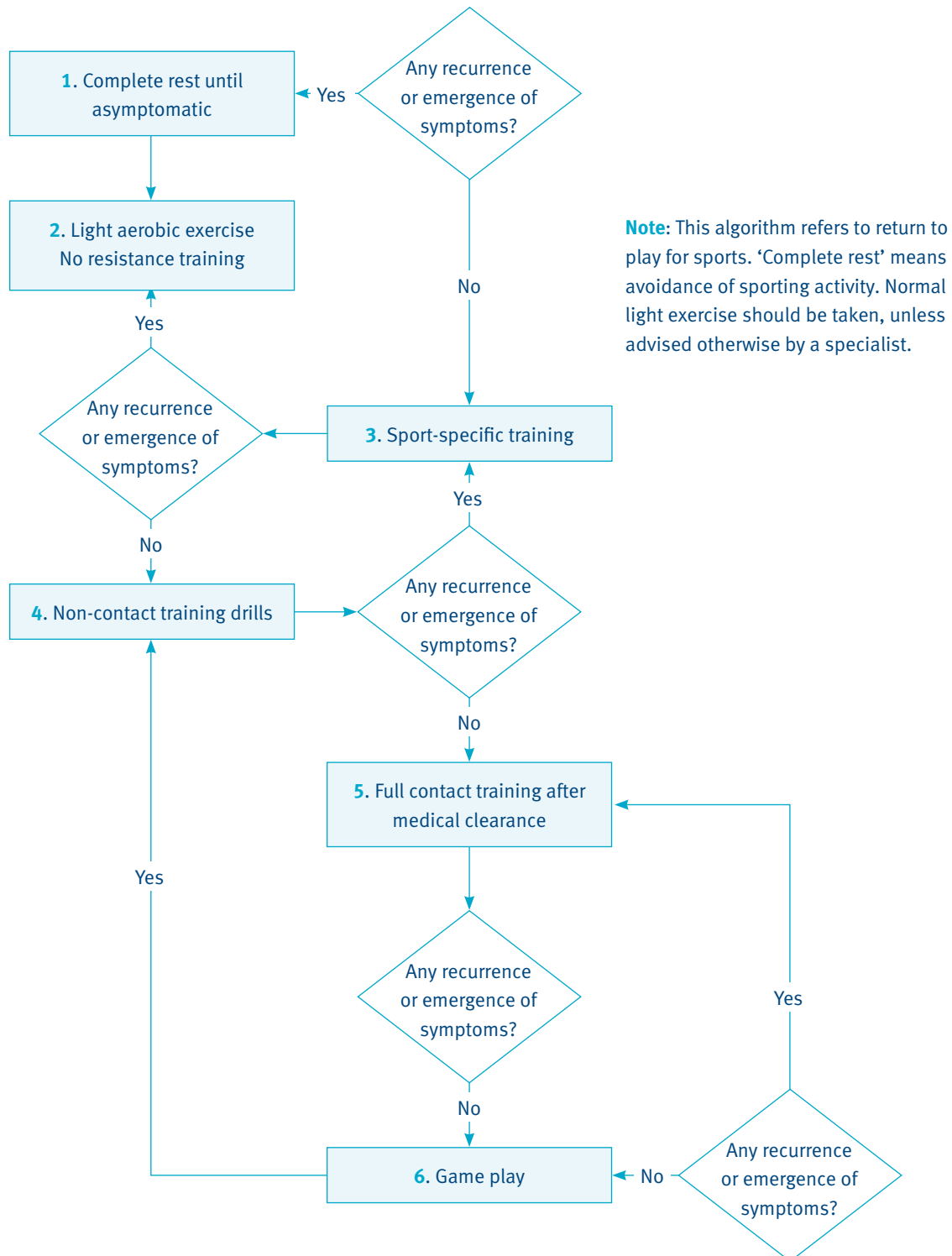
14.5.2.1 Return to play

Return to play after a concussion should follow a stepwise process (see Figure 14.3).

1. No activity, complete rest. Once asymptomatic, proceed to level 2.
2. Light aerobic exercise such as walking or stationary cycling.
3. Sport-specific training – for example, skating in hockey, running in soccer.
4. Non-contact training drills.
5. Full contact training after medical clearance.
6. Game play.

With this stepwise progression, the athlete should proceed to the next level if asymptomatic at the current level. If any symptoms occur after concussion, the person should revert to the previous asymptomatic level and try to progress again after 24 hours.

FIGURE 14.3:
ALGORITHM: SAFE STEPS TO RETURN TO PLAY AFTER A POSSIBLE TRAUMATIC BRAIN INJURY



Adapted from the British Royal College of Physicians: *The Psychological Care of Medical Patients: A Practical Guide*.³⁶⁵

14.5.3 Repeated traumatic brain injury in children

GOOD PRACTICE POINTS

Children and adolescents should not resume sports or training until all of the physical symptoms of concussion have fully resolved, following the 'return-to-play' guide.

✓

Return to school should be carefully managed following concussion, with the child monitored for recurring or emergent symptoms.

✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

Most of the evidence on repeated TBI comes from the literature on sports injuries, presumably because sports are activities where people are more at risk of injuries than in other pastimes. This literature usually focuses on adolescents and young adults. However, there is a lack of research on repeated TBIs specifically in children.³⁷⁴ A child who is symptomatic following a head injury may have sustained a far greater impact force compared with an adult with the same post-concussive symptoms. There may also be persistent effects on school performance and behaviour long after the clinical symptoms and measurable neuropsychological impairments have resolved.

A recent review of the topic reported that there is little evidence (no evidence-based guidelines), variability in practice and little expert consensus on how repeated TBIs should be managed in children. It was concluded that people over 15 years of age can be managed conservatively following adult guidelines, with an awareness that TBI symptoms may take longer to resolve than in adults. It is critical that children and adolescents not resume sports or training until all of the physical symptoms have fully resolved, following the guide in Section 14.5.2.1, *Return to play*.³⁷⁴

Return to school should be carefully managed, with the child monitored for recurring or emergent symptoms (also see Chapter 12, *Children and young people and traumatic brain injury*).

14.6 Violence and traumatic brain injury

RECOMMENDATION

GRADE

All personnel involved in the triage and assessment of people with head injuries/traumatic brain injury should have training in the detection of violence and non-accidental injury.

C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

People with violence-related injuries often present rehabilitation challenges. After controlling for demographics, pre-existing conditions and head injury severity, there is no difference in outcomes between people with TBI from violent causes and those whose injury is from other causes.³⁷⁵ However, people with TBI resulting from a violent injury are more likely to be young, male, members of minority groups and single, and to be pre-morbid drug and/or alcohol misusers than other people with TBI. Post-injury, this group reports less community integration and more headaches, confusion and sensory and attention disturbances than people whose TBI results from non-violence-related causes.^{375–378}

One study of women who presented at two Emergency Departments in Auckland with injuries found that 260 (9%) were identified as victims of assault.³⁷⁹ Assault-related injuries most commonly involved the head (OR 12.8; 95% CI 9.33–17.68). Women who presented with assault-related injuries and had known assailants were most likely to have been injured by a partner or former partner, and more likely than women with unintentional injuries to be younger and of Māori or Pacific islands origin. They were also more likely to be discharged from the Emergency Department without referral for follow-up treatment, and were more likely to leave the Department without completing treatment.

14.6.1 Non-accidental injury in children

A significant proportion of head injuries in children are non-accidental and these may result in a different pattern of morbidity from that seen in adults.⁷ One study, for example, of children admitted to hospital with non-accidental head injury found that 68% of these children were neurologically abnormal at an average follow-up of 59 months.⁴³ There was a wide range of abnormalities and outcomes including speech and language difficulties (including autistic spectrum disorder) in 64%, cranial nerve abnormalities in 20%, and visual deficits and epilepsy compounding learning difficulties in 25%. It was concluded that these children require the support of a multidisciplinary team in the community.

14.6.2 Management of traumatic brain injury from non-accidental causes

The management of violence and assault issues are outside the scope of this guideline. However, all personnel involved in the triage and assessment of people with head injuries should have training in the detection of non-accidental injury.^{7,8}

Rehabilitation is often hindered or rendered impossible when the person with TBI is threatened with further violence. Staff assessing people with TBI should include assessment for violent cause of injury or exposure to violence, and where it is identified, refer as appropriate.

For more information see *Family Violence Intervention Guidelines: Child and Partner Abuse* (www.nzgg.org.nz).

Also see Chapter 5, *Rehabilitation following clinically significant traumatic brain injury – Assessment*, on assessment.

Chapter 15:

Implementation

The aim of this guideline is to improve outcomes for people in New Zealand who have a TBI. To achieve this goal the promotion and dissemination strategy for this TBI guideline can be implemented on four levels:

1. increasing knowledge, making practitioners aware of the guideline (education influence)
2. changing attitudes, such that practitioners agree with and accept recommendations as a better standard of care (personal factors)
3. changing behaviour, such that practitioners change their clinical practice to conform with the guideline
4. changing outcomes by improving health and quality of care for consumers.

There is an imperfect evidence base to support decisions about which guideline dissemination and implementation strategies are likely to be efficient under different circumstances.³⁸⁰ The principal findings of a 2004 systematic review show that the following approaches have had some effect:

- dissemination of the guideline information
- reminders of the most effective treatments
- educational outreach
- educational material, audit and feedback.³⁸⁰

15.1 Implementation activities

15.1.1 Increasing knowledge

Dissemination

- The full guideline and supporting documents will be published.
- Electronic formats of the guideline and supporting documents, such as pro forma discharge letters, would be useful as they can be easily downloaded and utilised.
- Summaries of the guideline should be developed for specific groups.
- Guideline recommendations could be summarised in relevant publications.
- Consumer information that is developed might be offered in Pacific languages in written and oral forms (eg, tapes and videos).
- The guideline will be presented at relevant conferences by members of the Guideline Development Team and other experts.
- General practitioner peer review groups offer an ideal forum for the introduction and discussion of the guideline. Local Guideline Development Team members could be involved in these meetings.

Targeted resources

In order to facilitate the dissemination of information to the appropriate groups and individuals, tailored information about the TBI guideline recommendations could be developed for a variety of audiences, including:

- the health care practitioners who first assess and treat people with TBI (particularly accident and emergency service personnel and primary care practitioners)
- rehabilitation service personnel
- those working with children and young people in settings such as paediatric wards, children's rehabilitation facilities and Emergency Departments
- consumers and their families, whānau and carers.

15.1.2 Changing attitudes

ACC, DHBs and related agencies should initiate discussions to consider:

- how TBI services should be structured, ie, centralised TBI specialist unit(s) versus distributed services
- how to meet the recommendations for the skill set within multidisciplinary assessment teams for people with TBI
- a plan for maximising the coordination of trauma services
- how to develop an alerting call system, with appropriate protocols
- how to develop family/local supports and coordination for people with TBI
- how to develop a Māori TBI action plan
- how to develop the case coordinator/key worker role
- how to set up and collect evaluation data
- how to set up and collect the recommended performance indicators
- how to develop educational outreach programmes aimed at reinforcing the main guideline messages to a variety of audiences such as general practitioners, emergency services, rehabilitation providers and DHBs
- how to encourage collaboration between education services, ACC, DHB mental health services, disability support services, Work and Income New Zealand, housing services and other organisations to assess whether services provided by these agencies meet the guideline recommendations.

ACC could also discuss the driving rules for people who have had a brain injury with Land Transport New Zealand.

15.1.3 Changing behaviour

Collaboration

At a local level, regional ACC offices and local DHBs could:

- review the ways local acute care and rehabilitation services contracted to manage people with TBI, plus local mental health services, work together to specify and document policies for dealing with people with TBI who have mental health issues (whether they pre-date or follow the TBI)
- initiate collaboration between agencies (eg, adult education schemes, employment schemes, charities) to obtain adapted hard- and software and training to enable people with TBI to develop appropriate computer skills.

Services for Māori

ACC and DHBs should consider developing a TBI action plan for Māori that will address ways of:

- increasing the Māori health care workforce in TBI through recruitment and retention programmes
- liaising with local Māori providers. Scholarships and other support could be developed to encourage the Māori health care workforce into the TBI field
- seeking input from local Māori providers, tangata or mana whenua to assist with service delivery for Māori with TBI.

Services for children and young people

- ACC could consider the development of the case coordinator/key worker role.
- An action plan for the management of TBI rehabilitation for children and young people should be developed.

Carers

Appropriate agencies should implement processes for:

- the assessment of carers' needs
- the allocation of respite care
- the assessment of support needs of carers of those with TBI (including financial support).

Access to services

As a result of the Current Practice Review⁵ and discussions on the guideline, it appears that there is a need to ensure that people who have had a TBI are able, when appropriate, to access the following services easily:

- specialist rehabilitation units for:
 - children and young people
 - adults
- imaging services, particularly in rural areas
- specialist clinics for managing persistent symptoms
- training for carers
- age-appropriate residential support.

15.1.4 Changing outcomes

Model discharge letters, posters for Emergency Departments and other tools should be developed to provide ongoing reminders for staff of the guideline's best practice recommendations.

In order to assess whether the guideline has been operationalised throughout New Zealand and whether there have been corresponding improvements in care and outcomes for people with TBI, evaluation of the implementation activities should be undertaken. This evaluation should occur before the guideline is due to be revised.

Evaluation at the programme level depends on a number of factors, including funder requirements, provider goals and service structure. There are several key questions for a programme-level evaluation:

1. Are the overall results of the programme consistent with the expectations of:
 - the service's consumers (individuals, families/whānau and carers)?
 - the providers?
 - the funders?
2. Was the programme carried out as specified in the guideline?
3. How do the results of this programme compare with those of similar programmes (or similar clients in a different type of programme) both locally and overseas?
4. Do the results justify the costs (for consumers, providers, funders)?
5. Can we improve our service to better meet the needs of consumers and funders? How?
6. Can we improve the efficiency with which we provide the service without compromising results?
7. What is the service's case-mix?
8. What are the benefits or limitations of the programme for enhancing interdependence?

Some programmes may have poor evaluation results because people with severe TBI generally have poorer outcomes than other individuals, whatever the rehabilitation. So the outcomes of a programme with a relatively large percentage of people with severe TBI are likely to be generally poorer than those for a programme dealing mainly with individuals with mild or moderate TBI, independent of programme content or quality.

There are some additional questions to be considered:

- How does the service measure resource use? This will vary with the type of service, eg, length of stay, hours of contact time, numbers of visits in the community.
- How does the service measure consumer and funder satisfaction?
- How does the service measure programme implementation?
- How does the service control outcome measures for factors that affect outcomes, eg, premorbid status, drug abuse, other medical/surgical or psychiatric conditions, family/whānau circumstances? As a minimum, this information needs to be collected (see Section 8.4, *Assessment of people with persistent symptoms after mild traumatic brain injury*), although it is acknowledged that gathering such information can be difficult.

15.2 Performance indicators

Owing to the complexity and scope of the guideline, a comprehensive set of performance indicators for this guideline could be developed at a later date.

In the interim, the NICE guideline⁷ has identified the following performance indicators relating to the criteria used to order imaging of the head.

To audit adherence to these NICE criteria, prospective data collection on all people with suspected TBI assessed in Emergency Departments should be undertaken.

For each of these people, data on a variety of risk factors should be collected. The following broad categories of risk factor should be addressed:

- loss of consciousness since injury
- Glasgow Coma Scale scores since injury
- age
- mechanism of injury
- signs of open or depressed skull fracture
- signs of basal skull fracture
- results of imaging
- post traumatic seizure
- focal neurological deficit
- vomiting
- amnesia (retrograde and anterograde)
- coagulopathy
- headache
- drug or alcohol intoxication
- irritability or altered behaviour
- paraesthesia in the extremities
- neck pain or tenderness.

Collecting this data will highlight areas where people seem to be receiving imaging for inappropriate criteria, or conversely are not being imaged despite meeting the criteria laid out in this guideline.

15.3 Potential impact of the guideline

The Guideline Development Team expects an evolutionary, rather than revolutionary, response in service delivery for TBI following the publication of this guideline. Given the lack of existing New Zealand incidence and outcome data, it would be unreasonable to expect major changes in a short time period. Rather it is hoped that this guideline will provide an overall framework within which to consider service provision for people with TBI and their families, and a basis for the development of policy, contracts for services, audit, research and initiatives led by community groups.

In some specific areas, particularly in the criteria for diagnosis and classification of injury severity and the assessment processes for people with suspected TBI, implementation of the guideline recommendations will lead to better practice and less variation around New Zealand.

The Guideline Development Team hopes that the implementation of this guideline and subsequent development of TBI services in New Zealand will lead to the following situation:

Nationally

1. Definitions of TBI (and 'not TBI'), along with severity grading for definite TBI, will be applied consistently.

2. People with possible TBI will be assessed in a consistent fashion using adequate tools by people trained in those assessments.
3. All people with suspected or confirmed TBI will receive information in a form that they can understand about common symptoms and likely outcomes, emphasising rapid and full recovery for the great majority of people with TBI at the less severe end of the spectrum.
4. Over time in New Zealand, the development of a limited number of highly specialised facilities for adult severe TBI rehabilitation providing outreach services will complement the current residential and community rehabilitation services operating around the country.
5. A range of options for caregiver relief will be available to families and carers.
6. Children with severe TBI will continue to have access to follow-up from highly specialised rehabilitation services.
7. TBI research will be developed (see Appendix A).

At a service level

1. All people assessing and/or managing children and young people with possible or definite TBI will understand the particular issues that make the assessment and management of TBI in children and young people different from that in adults. In general the following statements, unless qualified, apply equally to children, young people and adults.
2. People at risk of acute complications from TBI will have appropriate investigations instituted in a timely fashion. Conversely, people at low risk of acute complications will not undergo unnecessary investigation.
3. All people with moderate and severe TBI and those people with mild TBI meeting the criteria for, or actually having, a CT scan in the acute phase will have some form of follow-up organised, with the details of that follow-up being developed by local services and funders.
4. People with persistent symptoms following mild TBI who have significant activity limitation or participation restriction after four to six weeks will be considered for referral to a specialist clinic staffed by professionals experienced in the management of this situation and with the ability to perform neuropsychological assessments. Such clinics will be available and have the capacity to see clients in a timely fashion following referral.
5. People with TBI requiring admission to hospital will be managed by staff trained in the observation and management of people with TBI.
6. People at significant risk of acute complications of TBI who are not in a tertiary referral centre will have their case discussed with a member of the neurosurgical team at the tertiary referral centre with regard to whether transfer to that centre is appropriate.
7. People with severe TBI requiring intensive care management will be managed according to best practice guidelines for that situation (not covered in this guideline).
8. Rehabilitation for people following clinically significant TBI will start as early as possible and rehabilitation services will work closely with acute care teams.
9. Rehabilitation services for people with clinically significant TBI will include, or have access to, staff skilled in the management of the full range of issues that arise for this client group. These services will operate with a client-centred approach and include a designated 'case coordinator/key worker' as described in this guideline.
10. Residential rehabilitation services for people with clinically significant TBI will be skilled in the management of such clients and acknowledge the special and challenging nature of this work.
11. Community rehabilitation services will provide contextualised rehabilitation to deliver meaningful outcomes for people with TBI.
12. Vocational rehabilitation services will provide a full range of services, including job coaches where appropriate. Funders will acknowledge the need for substantial workplace support over extended periods of time for people with clinically significant TBI returning to the workforce.

13. There will be a clear strategy at both national and service levels for upskilling and accrediting TBI specialist rehabilitation staff.
14. The needs of families and carers of people with TBI will be a high priority of rehabilitation services and funders over the continuum of those people's period of activity limitation and participation restriction and, if necessary, for the whole of their lives.
15. Rehabilitation services will fully meet the needs of people with TBI from particular groups within our society, including Māori, Pacific peoples and people from other ethnic minorities, people with alcohol and drug dependence problems and people with mental health disorders.
16. Liaison between different health services will be improved to ensure that the needs of clients with TBI and other health problems (particularly alcohol and drug abuse and/or mental health disorders) are met.

Appendices

- A. Objectives for future research on traumatic brain injury in New Zealand
- B. Guideline grading systems
- C. Glasgow Coma Scale (adult and paediatric versions)
- D. Additional resources and supporting documents

Appendix A

Objectives for future research on traumatic brain injury in New Zealand

In the process of developing this guideline, the Guideline Development Team identified a number of research gaps where there was insufficient research. For future guideline updates the Guideline Development Team recommends that the following research areas be considered. These are necessarily broad. The order does not reflect a priority ranking.

1. Quantifying the incidence of TBI in New Zealand (ie, new cases)

Currently there is insufficient information to establish the incidence of TBI in New Zealand, particularly at the mild end of the spectrum, ie, being able to distinguish between cases that are initially 'suspected TBI' but don't meet the criteria for 'definite TBI' as described in this guideline. Within this problem, there are sub-problems around populations at high risk on the basis of age, gender, ethnicity, geography and comorbidities (such as mental health disorders, drug and alcohol misuse). The proportions of people with severe, moderate and mild TBI need to be accurately established for efficient service delivery.

2. Burden of TBI in New Zealand

What is the impact of TBI for individuals (and their families and carers) with TBI of different severity and demographic and other characteristics in New Zealand? This will require comprehensive case ascertainment and follow-up over long enough periods to measure important outcomes. One question that needs to be specifically addressed is whether outcomes are as bad as those measured in the 2000 Thornhill study⁴ (rates of disablement of around 45% at one year even for people with mild TBI).

3. The effectiveness of specific interventions for people with TBI

There are very many of these that are not adequately tested. The systematic design of appropriate studies and testing of interventions would be of international significance.

4. The effectiveness, timing and content of assessments for people with TBI

One specific issue is around assessments of people with mild TBI. Is a policy of early, simple assessment (eg, using computerised cognitive screening assessments) followed, where necessary, by more comprehensive assessment, more efficient and/or more effective, than the current policy of delayed, moderately comprehensive assessment using mild TBI clinics?

5. The experience of TBI for people and their carers

There is remarkably little known about how people cope with the effects of TBI. The same applies to carers. Qualitative research could help to clarify some of these issues and make a difference to the way services are delivered.

6. Children and young people with TBI

It is clear from the TBI guideline that there are many areas where there is simply no information specific to children and young people with TBI. This absence of good information applies to all of the points above and specific research in this group needs to be considered.

7. Appropriate tools and measures for use with people with TBI in New Zealand

Although there may need to be specific work on the psychometric properties of some tools, utility needs considerable attention. Which tools, when and for what purpose?

8. Measurement of performance of TBI services in New Zealand

The ability to identify services that are delivering good outcomes and those that are struggling should allow for a process of quality improvement over time. This would allow a move away from reliance on measures of process as a proxy for performance.

Appendix B

Guideline grading systems

1. Evidence and recommendation grading system (excluding complementary and alternative medicine)

Studies were graded using a two-tier system that is detailed in the *Handbook for the Preparation of Explicit Evidence-Based Clinical Practice Guidelines*, published in November 2001 by NZGG.³⁷⁰ This system has been adapted from other grading systems currently in use, in particular the SIGN system.⁸¹

The searches for this guideline concentrated on finding high grade evidence to answer the identified clinical questions, such as systematic reviews, randomised controlled trials and, where these were not available, observational studies such as well designed cohort and case control studies. Only these types of study design were graded. Where these types of study were not available, less rigorous study designs such as cross-sectional studies and case studies were considered but were not formally graded.

The two-tier system follows this process.

1. Critical appraisal of individual relevant studies (identified from the searching) and assigning of **a level of evidence** for the first section of the GATEFRAME checklist that is incorporated into the evidence tables. A random sample of appraisals in the guideline were performed independently by two assessors and the results compared.
2. Joint consensus by the Guideline Development Team on the issues of volume, consistency, clinical relevance and applicability of the body of evidence in the evidence table (filling out the NZGG Considered Judgement form for each clinical question) and the development of **graded recommendations** that attempt to answer the clinical questions posed.

Levels of evidence

There are three levels of evidence that can be assigned to the Validity section of the GATEFRAME (Section 1):

- + strong study where all or most of the validity criteria are met
- ~ fair study where not all the validity criteria are met, but the results of the study are not likely to be influenced by bias
- x weak study where very few of the validity criteria are met and there is a high risk of bias.

Developing recommendations

Recommendations were formulated by joint meetings of the multidisciplinary Guideline Development Team. The group considered the entire body of evidence (summarised in the evidence tables) and filled out Considered Judgement forms for each clinical question that was identified as being relevant to the guideline (see www.nzgg.org.nz). The following aspects were discussed: volume of evidence, applicability to the New Zealand setting, consistency and clinical impact, with the aim of achieving consensus. Consensus was sought and achieved over the wording of the recommendation and grading. In this guideline, where a recommendation is based on the clinical experience of members of the Guideline Development Team, this is referred to as a good practice point.

Grading of recommendations

The NZGG grades of recommendation are as follows:

RECOMMENDATIONS	GRADE
The recommendation is supported by good evidence (where there are a number of studies that are valid, consistent, applicable and clinically relevant).	A
The recommendation is supported by fair evidence (based on studies that are valid, but there are some concerns about the volume, consistency, applicability and clinical relevance of the evidence that may cause some uncertainty but are not likely to be overturned by other evidence).	B
The recommendation is supported by international expert opinion.	C

Grades indicate the strength of the supporting evidence, rather than the importance of the recommendations – refer to Appendix B for grading details.

GOOD PRACTICE POINT	
Where no evidence is available, best practice recommendations are made based on the experience of the Guideline Development Team, or feedback from consultation within New Zealand.	✓

This is the opinion of the Guideline Development Team, or feedback from consultation within New Zealand where no evidence is available.

2. Complementary and alternative medicines grading system

A grading system has been developed by NZGG to assess both study design and quality for complementary and alternative medicines (CAMs). This is described in Table 1. This system is compatible with the other grading systems used by NZGG and also maps to other international systems (see Table 2).

Due to the emerging nature of the evidence for CAMs, many studies are non-randomised or uncontrolled. Often no Level 1 or Level 2 evidence is available. Sometimes Level 1 or Level 2 studies cannot be carried out because it would involve a safety risk for participants. Sometimes it would be too difficult to carry out a Level 1 or Level 2 study large enough to measure rare effects. In these instances evidence is based on lower level studies.

Lower level evidence is subdivided into Level 3 and Level 4. This serves to illustrate a progression that may occur when investigating CAMs from Level 4 through Level 3 and Level 2 to Level 1 evidence.

Although possible harms and adverse events are important aspects of any CAM, they are frequently only reported from lower level studies. Higher level evidence is not often available for the reasons stated above.

A range of expert opinion also exists. In other grading systems, this is usually included in a fifth level. This level of evidence has not been reviewed for the CAM chapter in this guideline. Note also that the numbers are omitted from the level of evidence in the chapter, and that only the words are used.

TABLE 1: LEVELS OF EVIDENCE USED IN THE TBI GUIDELINE

LEVEL OF EVIDENCE	WHERE THE EVIDENCE COMES FROM
1 Evidence with a high degree of reliability	<p>Studies that use well tested methods to make comparisons in a fair way and where the results leave very little room for uncertainty.</p> <p>Trial design: usually Level 1 studies are systematic reviews or large, high-quality randomised controlled studies.</p>
2 Evidence with reliability but open to debate	<p>Studies that use well tested methods to make comparisons in a fair way but where the results leave room for uncertainty (for example, due to the size of the study, losses to follow-up or the method used for selecting groups for comparison).</p> <p>Trial design: usually Level 2 studies are systematic reviews without consistent findings, small randomised controlled trials, randomised controlled trials in which large numbers of participants are lost to follow-up, or cohort studies.</p>
3 Some evidence without a high degree of reliability	<p>Studies where the results are doubtful because the study design does not guarantee that fair comparisons can be made.</p> <p>Trial design: usually Level 3 studies are systematic reviews of case-control studies or individual case-control studies.</p>
4 Some evidence but based on studies without comparable groups	<p>Studies where there is a high probability that results are due to chance (for example because there is no comparison group or because the groups compared were different at the outset of the study).</p> <p>Trial design: usually cohort or case-control studies where the groups were not really comparable, or case-series studies.</p>

TABLE 2: SYSTEMS FOR GRADING THE QUALITY OF INDIVIDUAL STUDIES

NZGG* CAM	NZGG/ GATE†	SIGN‡	GRADE§	USPTF**	OXFORD CEBM††	NHMRC 2000‡‡	CCS 2000 CONSENSUS§§
Level 1	Good / +	++	High	Good	Level 1 abc	Level I	Level I
Level 2	Fair / ~	+	Moderate	Fair	Level 2 abc	Level II	Level II
Levels 3 and 4	Poor / –	–	Low (very low)	Poor	Level 3 ab, and 4	Level III (1, 2, 3) and IV	Level III, IV and V

* New Zealand Guidelines Group

† Graphic Appraisal Tool for Epidemiology

‡ Scottish Intercollegiate Guidelines Network

§ Grading of Recommendations Assessment
Development and Evaluation

** US Preventable Services Task Force

†† Oxford Centre for Evidence-based Medicine

‡‡ National Health and Medical Research Council 2000

§§ Canadian Cardiovascular Society 2000 Consensus

There are methods for considering the evidence from multiple studies that address a specific question, incorporating trial designs and for weighing competing factors in forming a recommendation. For more information on study design and for guidance on balancing the benefits and harms of an intervention the reader is referred to the following websites:

- www.nzgg.org.nz
- www.health.auckland.ac.nz/population-health/epidemiology-biostats/epiq/
- www.cebm.net/levels_of_evidence.asp
- www.ahrq.gov/clinic/ajpmsuppl/harris3.htm#table7
- www.gradeworkinggroup.org/links.htm
- www.sign.ac.uk/methodology/index.html
- <http://gacguidelines.ca/article.pl?sid=03/01/29/1642226&mode=thread>

Appendix C

Glasgow Coma Scale

Adults

The Glasgow Coma Scale is scored between 3 and 15, 3 being the worst and 15 the best.

It is composed of three parameters: Best Eye Response, Best Verbal Response and Best Motor Response. The definition of these parameters is given below.

BEST EYE RESPONSE (4)	BEST VERBAL RESPONSE (5)	BEST MOTOR RESPONSE (6)
1. No eye opening 2. Eye opening to pain 3. Eye opening to verbal command 4. Eyes open spontaneously	1. No verbal response 2. Incomprehensible sounds 3. Inappropriate words 4. Confused 5. Orientated	1. No motor response 2. Extension to pain 3. Flexion to pain 4. Withdrawal from pain 5. Localising pain 6. Obeys commands

Paediatric version

The paediatric version of the Glasgow Coma Scale is scored between 3 and 15, 3 being the worst and 15 the best. It is composed of three parameters: Best Eye Response, Best Verbal Response or Best Grimace Response, and Best Motor Response. The definition of these parameters is given below.

BEST EYE RESPONSE (4)	BEST VERBAL RESPONSE (5)	BEST GRIMACE RESPONSE (5)	BEST MOTOR RESPONSE (6)
1. No eye opening 2. Eye opening to pain 3. Eye opening to verbal command 4. Eyes open spontaneously	1. No vocal response 2. Occasionally whimpers and/or moans 3. Cries inappropriately 4. Less than usual ability and/or spontaneous irritable cry 5. Alert, babbles, coos, words or sentences to usual ability Communication with the infant's or child's caregivers is required to establish the best usual verbal response	A 'grimace' alternative to verbal responses should be used in those infants or children who are pre-verbal or intubated. 1. No response to pain 2. Mild grimace to pain 3. Vigorous grimace to pain 4. Less than usual spontaneous ability or only responds to touch stimuli 5. Spontaneous normal facial/oro-motor activity	1. No motor response to pain 2. Abnormal extension to pain (decerebrate) 3. Abnormal flexion to pain (decorticate) 4. Withdrawal to painful stimuli 5. Localises to painful stimuli or withdraws to touch 6. Obeys commands or performs normal spontaneous movements

Note: This appendix is included in the full guideline and online at www.nzgg.org. It may be reproduced for clinical use.

Appendix D

Additional resources and supporting documents

A list of additional resources and supporting documents available for downloading at www.nzgg.org.nz:

- *TBI Tools Review for the Development of Guidelines on the Assessment, Management and Rehabilitation of Traumatic Brain Injury*, 2005
- Supplement to the Tools Review (above): *The Use of Neuropsychological Tests in the Assessment and Rehabilitation of Traumatic Brain Injury in Aotearoa/New Zealand*
- *Traumatic Brain Injury in New Zealand: Current Practice Review*. A Report for the Accident Compensation Corporation, Medical Research Institute of New Zealand, 2004.
- Medical Radiation
- '6 Steps'.

Glossary*

Aphasia	Partial or total loss of the ability to articulate ideas or comprehend spoken or written language, resulting from damage to the brain.
Apnoea	Temporary absence or cessation of breathing.
Arrhythmia	An irregularity in the rhythm of the heartbeat.
Aspiration	Food or fluid entering the trachea and/or lungs.
Ataxia	Loss of the ability to coordinate muscular movement.
Biofeedback	The technique of using monitoring devices to furnish information regarding an autonomic bodily function, such as heart rate or blood pressure, in an attempt to gain some voluntary control over that function.
Bradycardia	Slowness of the heart rate, usually fewer than 60 beats per minute in an adult human.
Chiropractic	A system of therapy in which disease is considered the result of abnormal function of the nervous system. The method of treatment usually involves manipulation of the spinal column and other body structures.
Claudication	Pain in the legs due to restriction in blood flow or sometimes nerve compression ('spinal claudication').
Clavicles	Either of two slender bones in humans that extend from the manubrium of the sternum to the acromion of the scapula. Also called collarbone .
Coagulopathy	A defect in the blood-clotting mechanism.
Cognition	A term encompassing all the 'thinking' modalities of the brain, including alertness, registration of new ideas, memory, problem-solving.
Cognitive	Of, characterised by, involving, or relating to cognition.
Concussion	<p>A term that is widely used, particularly in sports, to refer to the full range of severity of injury, from 'injury to the head without TBI' through to 'severe TBI'. For the purposes of this guideline, the definition of the term concussion is as given in the 'Prague guidelines'.¹⁴¹</p> <p>The Prague definition of concussion is as follows:</p> <p>Sports concussion is defined as a complex pathophysiological process affecting the brain, induced by traumatic biomechanical forces. Several common features that incorporate clinical, pathological and biomechanical injury constructs that may be utilised in defining the nature of a concussive head injury include:</p> <ol style="list-style-type: none"> 1. concussion may be caused by a direct blow to the head, face, neck or elsewhere on the body with an 'impulsive' force transmitted to the head 2. concussion typically results in the rapid onset of short-lived impairment of neurological function that resolves spontaneously 3. concussion may result in neuropathological changes but the acute clinical symptoms largely reflect a functional disturbance rather than structural injury 4. concussion results in a graded set of clinical syndromes that may or may not involve loss of consciousness. Resolution of the clinical and cognitive symptoms typically follows a sequential course 5. concussion is typically associated with grossly normal structural neuroimaging studies .

* For methodology terms, go to the glossary at www.nzgg.org.nz

Consumer	Where the term ‘consumer’ is used in this guideline, it denotes people receiving or needing health care and rehabilitation services. This includes people who have suffered a TBI and their families/whānau and informal carers.
Contractures	An abnormal, often permanent shortening, as of muscle or scar tissue, that results in distortion or deformity, especially of a joint of the body.
Contusion	An injury in which the skin is not broken; a bruise.
Cranial	Of or relating to the skull or cranium.
Craniocerebral	Of or relating to both the cranium and the cerebrum.
Craniosacral	Of or associated with both the cranium and the sacrum.
Dementia	Deterioration of intellectual faculties, such as memory, concentration and judgement, resulting from an organic disease or a disorder of the brain.
Dissociative	To remove from association; separate.
Dural tear	A tear in the dura – the external lining covering the brain.
Dysarthria	Difficulty in articulating words, caused by impairment of the muscles used in speech.
Dysgraphia	Impairment of the ability to write, usually caused by brain dysfunction or disease.
Dyslexia	A learning disorder marked by impairment of the ability to recognise and comprehend written words.
Dysphagia	Difficulty in swallowing.
Electroencephalograph	An instrument that measures electrical potentials on the scalp and generates a record of the electrical activity of the brain. Also called encephalograph .
Emotional lability	Difficulty with control of emotions and emotional responses (such as crying).
Endocrine disorders	Disorders which involve the over-production or under-production of hormone substances from an endocrine gland. Examples include diabetes, hypothyroidism, hyperthyroidism, hyperparathyroidism, Cushing’s syndrome and acromegaly.
Epilepsy	Any of various neurological disorders characterised by sudden recurring attacks of motor, sensory or psychic malfunction with or without loss of consciousness or convulsive seizures.
Extracerebral	Located outside the cerebral hemispheres and inside the skull.
Extradural haematoma	A localised collection of blood, usually clotted, located outside the dura mater but inside the skull.
Focal neurological signs	Neurological signs (such as weakness or double vision) that suggest abnormal function in one part of the brain.
Gait	A particular way or manner of moving on foot.
Gaze palsies	When one or both eyes does not move normally under voluntary control.
Gerontocracy	A governing group of elders.

Glaucoma	Any of a group of eye diseases characterised by abnormally high intraocular fluid pressure, damaged optic disc, hardening of the eyeball, and partial to complete loss of vision.
Haematoma	A localised collection of blood, usually clotted, in an organ, space or tissue, due to a break in the wall of a blood vessel.
Haemotympanum	A collection of blood in the middle ear space. May occur secondary to severe barotitis media, basal skull fracture or ear trauma.
Hapū	Groups of whānau with common ancestral links; sub-tribe.
Heterotopic ossification	The development of bony substances in normally soft structures.
Holistic	Emphasising the importance of the whole and the interdependence of its parts.
Hydrocephalus	Excess fluid and/or pressure within the ventricular system of the brain.
Hypercarbia	Also called hypercapnia. An excess of carbon dioxide in the blood.
Hypertonia	Pathologically increased tone in muscles.
Hypoglycaemia	An abnormally low level of glucose in the blood.
Hypomania	A mild state of mania, especially as a phase of a manic-depressive cycle.
Hypotension	Abnormally low blood pressure.
Hypoxaemia	Reduced oxygen in the blood.
Hypoxia	Reduced oxygen in the body tissues.
Intracerebral	Occurring or situated within the brain.
Intracranial	A wound or injury occurring within the cranium.
Intrathecal baclofen	A drug administered into the cerebrospinal fluid bathing the spinal cord and brain. It is used in the treatment of spasticity, especially that due to spinal cord damage.
Iwi	A social and political unit made up of several hapu sharing common descent; Māori tribe or nation.
Mana whenua	People of authority. Mana – authority. Whenua – people.
Meniere's disease	A name applied to recurrent vertigo accompanied by ringing in the ears (tinnitus) and deafness. A dysfunction of the semi-circular canals (endolymphatic sac) in the inner ear.
Meningism	The symptoms and signs of meningeal irritation associated with acute febrile illness or dehydration without actual infection of the meninges.
Morbidity	Illness; disease.
Myocardial infarction	A term used to describe irreversible injury to heart muscle.
Nephrotoxicity	The quality or state of being toxic to kidney cells.
Neuron	Nerve cell.
Neuropsychiatrist	A medical specialist for disorders with both neurological and psychiatric features.

Neuropsychologist

A psychologist who specialises in ailments of the mind and mental processes caused by diseases of the nervous system.

Orthopaedic

The branch of medicine that deals with the prevention or correction of injuries or disorders of the skeletal system and associated muscles, joints and ligaments.

Orthoptist

One skilled in the investigation, diagnosis and treatment of defects of binocular vision and abnormalities of eye movement.

Osteopathy

A system of medicine based on the theory that disturbances in the musculoskeletal system affect other bodily parts, causing many disorders that can be corrected by various manipulative techniques in conjunction with conventional medical, surgical, pharmacological, and other therapeutic procedures.

Orthosis

Device or aid to prevent, correct or control deformities.

Otorrhoea

A discharge from the ear, especially a purulent one.

Pacific peoples

The diverse range of people living in New Zealand who have migrated from nations of the South Pacific, and/or who identify with one or more of the Pacific islands because of ancestry or heritage.

Paresis

Slight or partial paralysis.

Pathology

The scientific study of the nature of disease and its causes, processes, development and consequences.

Perilymphatic fistula

A tear or defect of the thin membranes between the air filled middle ear and the fluid filled inner ear.

Periorbital

Situated around the orbit or eye socket.

Post-traumatic amnesia

Loss of memory after trauma.

Premorbid

Preceding the occurrence of disease.

Proprioceptive

A sensory receptor, found chiefly in muscles, tendons, joints and the inner ear, that detects the motion or position of the body or a limb by responding to stimuli arising within the organism.

Psychosis

A severe mental disorder, with or without organic damage, characterised by derangement of personality and loss of contact with reality and causing deterioration of normal social functioning.

Psychosocial

Involving aspects of social and psychological behaviour.

READ codes

Diagnostic codes used by primary care providers on ACC claim forms.

Retrograde amnesia

Loss of memory before the trauma/event.

Risk factor

An aspect of personal behaviour or lifestyle, an environmental exposure, or an inherited characteristic that is associated with an increased risk of a person developing a disease.

Schizophrenia	Any of a group of psychotic disorders usually characterised by withdrawal from reality, illogical patterns of thinking, delusions and hallucinations, and accompanied in varying degrees by other emotional, behavioural or intellectual disturbances. Schizophrenia is associated with dopamine imbalances in the brain and defects of the frontal lobe and is caused by genetic, other biological and psychosocial factors.
Seizure	A sudden attack, spasm or convulsion, as in epilepsy or another disorder.
Somatosensory evoked potentials	A series of waves that reflect sequential activation of neural structures along the somatosensory pathways following electrical stimulation of peripheral nerves.
Spasticity	A condition in which certain muscles are continuously contracted. This contraction causes stiffness or tightness of the muscles and may interfere with movement, speech and manner of walking.
Stroke	Sudden decrease in or loss of consciousness, sensation and movement caused by rupture or obstruction (as by a blood clot) of a blood vessel of the brain. Stroke is characterised by rapidly developing symptoms and signs of a focal brain lesion, with symptoms lasting for more than 24 hours or leading to death, with no apparent cause other than of vascular origin.
Subdural haematoma	Bleeding into the space between the dura and the brain itself.
Tapu	In Māori tradition, something that is tapu is considered inviolable or sacrosanct due to its sacredness. Things or places which are tapu must be left alone, and may not be approached or interfered with. In some cases, they should not even be spoken of.
Tinnitus	A sound in one ear or both ears, such as buzzing, ringing or whistling, occurring without an external stimulus and usually caused by a specific condition, such as an ear infection, the use of certain drugs, a blocked auditory tube or canal or a head injury.
Vertigo	An illusory sensation of movement or spinning.
Whānau	Extended family: relationships that descend from a common ancestor.

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