

# Clinical Practice Guidelines for the Care of People Living with Traumatic Brain Injury in the Community

## Full Report

Prepared by:  
Dr Lyndal Trevena, Associate Professor Ian Cameron and Ms Mamta Porwal



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**MOTOR ACCIDENTS  
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## About these guidelines

This more comprehensive book is designed to accompany a smaller quick reference version summarizing the best available evidence about the longer term care of patients with traumatic brain injury (TBI). Each chapter attempts to summarise the best evidence available to answer questions about frequency, diagnosis, treatment and prognosis of common problems in TBI patients. The evidence has been grouped under five broader categories:

- common health problems in TBI patients,
- mental healthcare in TBI patients,
- cognitive and behavioural problems in TBI patients,
- lifestyle issues and quality of life and
- substance abuse in TBI patients.

This book could be used if you want to read more about a specific aspect of TBI. It describes the best available evidence more fully than the quick reference version, it lists the reference sources, suggests resources for patients and carers, gives a technical report on the guideline development and provides some of the valid diagnostic checklists for use with your TBI patients.

Next to the key points in this booklet we have listed the strength of evidence using the following NHMRC criteria (descending order):

Level I = Systematic review of all randomised controlled trial
Level II = At least one properly-designed randomised controlled trial
Level III-1 = Well designed pseudo-randomised trials
Level III-2 = Comparative studies with concurrent controls and allocation not randomised (eg cohort studies, case-control studies or interrupted time series with a control group)
Level III-3 = Comparative studies with an historical control
Level IV = Case series or before and after studies.

Where checklists are available in the appendix of these guidelines, this is denoted by a (\*). The evidence for treatment in TBI patients is listed as either 'effective', 'insufficient/conflicting' or 'evidence of no effect'.

## Chapter 1: GENERAL BACKGROUND ON TRAUMATIC BRAIN INJURY

### KEY POINTS:

- 1. The incidence of traumatic brain injury (TBI) resulting in hospitalisation in NSW each year is estimated to be 126 per 100,000 population. It is most common in males aged 15-35 years. (Level IV)**
- 2. Cognitive and behavioural changes, difficulties maintaining personal relationships and coping with work are reported by survivors as more disabling than any residual physical deficits (Level IV)**
- 3. Retraining and re-skilling, behavioural management, drug therapy, rehabilitation are commonest modes of treatment adopted in patients with traumatic brain injury. (Level III-3)**
- 4. Severe TBI is not curable and medical and rehabilitation management may not ultimately be able to provide the improvement desired by the patient and his or her family. General practitioners play a central role in management of TBI patients, their carers and long-term consequences. (Consensus)**

### How common are traumatic brain injuries?

The incidence of traumatic brain injury (TBI) resulting in hospitalisation in NSW each year is estimated to be approximately 126:100,000 (Fortune 1999). TBI is most common in males aged 15-24 years with 70% of TBI hospital separations found to be in males (Fortune 1999). The male to female ratio of TBI is approximately 2:1 (Tate 1998). More than two-thirds of the moderate to severe TBIs in Australia each year are due to motor-vehicle accidents. Mild TBI is more common and probably under-estimated at around 131 per 100,000 each year. Many cases do not present to hospital and are not reported. Moderate and severe TBI incidence is 15 and 14 per 100,000 respectively.

### Does the incidence vary between States and amongst indigenous Australians?

Queensland has the highest incidence of all states in Australia -211 per 100,000 population (Fortune 1999). The ACT has the lowest incidence (71 per 100,000). Indigenous Australians had much higher standardised rates of TBI-associated hospitalisation (343 per 100,000) than non-Indigenous Australians (142 per 100,000).

### What are the likely outcomes following traumatic brain injury?

People with traumatic brain injury face major ongoing problems. While TBI can cause long-term physical disability it more commonly has complex sequelae, pre-dominantly cognitive, behavioural and personality problems. A useful schema summarizing the common sequelae of traumatic brain injury is shown in Table 1 (Khan 2003).

There is limited evidence for the effective diagnosis and management of many common problems in TBI patients. In particular, a lack of consensus about definitions and poor measurement tools for common outcomes such as functional status and behaviour provide challenges to those who care for TBI patients in the community. General practitioners play a significant role in providing ongoing support for TBI patients in the community, and are a major source of information and counselling for patients, families and carers.

The US National Institute of Health states that cognitive and behavioural changes, difficulties in maintaining personal relationships and coping with work are more disabling than any other residual physical deficits according to many TBI survivors (NIH 1998).

**Table 1: Consequences of traumatic brain injury\***

<p>Cognitive, Behaviour and Neurological issues:</p> <ul style="list-style-type: none"><li>▪ Memory impairment, concentration.</li><li>▪ Impaired problem solving</li><li>▪ Sleep disturbance-insomnia, fatigue, headache</li><li>▪ Language problems- problems finding words</li><li>▪ Impaired reading and writing skills.</li><li>▪ Impaired judgment and safety awareness</li></ul> <p>Behaviour and personality changes:</p> <ul style="list-style-type: none"><li>▪ Impaired social and coping skills</li><li>▪ Psychiatric disorder- anxiety, depression, post-traumatic stress disorder, obsessive-compulsive disorder, schizophrenia.</li><li>▪ Altered emotional control, poor-frustration tolerance, anger management.</li><li>▪ Apathy, low motivational states</li></ul> <p>Common life style consequences:</p> <ul style="list-style-type: none"><li>▪ Unemployment and financial hardships</li><li>▪ Inadequate transportation alternatives</li><li>▪ Difficulties in marital relationships, family and carers' burden, loss of independence.</li><li>▪ Substance Abuse</li><li>▪ Medical complications: Post traumatic seizures, post-concussion syndrome, medicinal side-effects.</li><li>▪ Return to driving issues.</li><li>▪ Sexual dysfunction</li></ul>
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\*Khan F, Baguley IG Cameron ID. Rehabilitation after traumatic brain injury. MJA 2003 178 (6): 290-295.

Approximately 70-75% of all traumatic brain injuries fall into the mild category. Cognitive and behavioural changes are common but usually recover within 3-6 months. However 10-15% of these patients complain of persistent post-concussion syndrome - a syndrome comprising headache, irritability, insomnia and sleeping difficulties, cervical pain, and vestibular complaints.

Moderate and severe TBI patients experience a broad range of outcomes. Assessing the extent of cognitive, behavioural and physical deficits is an important first step in setting goals for rehabilitation.

### **In patients with traumatic brain injury, what are the effective modes of treatment?**

Retraining and re-skilling, behavioural management, drug therapy and rehabilitation are the commonest treatments used in patients with traumatic brain injury. Returning to work is an important factor that contributes to satisfaction and quality of life. Options include retraining, re-skilling, on-the-job training or supported employment services. Drugs have limited use in the management of traumatic brain injury. Multidisciplinary community rehabilitation after severe traumatic brain injury yields benefits in functioning. More evidence is dealt with in the relevant sub-sections of these guidelines.

## **What is the likely prognosis of patients with traumatic brain injury?**

TBI is a heterogenous disorder of public health significance. Rehabilitation services tailored to the needs of individuals, as well as community-based non-medical services, are required to optimise outcomes over the course of recovery.

The individual with TBI and their social support networks should have access to rehabilitation services through the entire course of recovery, which will continue for many years after the injury. Survivors of severe TBI face the challenge of resuming a meaningful life for themselves and their families. However, severe TBI is not curable and medical and rehabilitation management may not ultimately be able to provide the improvement desired by the patient and his or her family. General practitioners play a major role in the management of TBI patients and their carers, providing a useful source of information, psychological support and counselling.

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## CHAPTER 2: Common health issues in TBI

### Section 1: SEIZURES

#### KEY POINTS:

1. Late seizures are more common than early (ie within 7 days of injury) following TBI (10% vs. 4%) (Level III-2).
2. Late post-traumatic seizures are more likely if there are early seizures, brain contusions, CT abnormalities, focal EEG changes or a severe level of injury (Level III-2).
3. Phenytoin reduces the chance of early post-traumatic seizures, RR= 0.34 (95%CI 0.21 – 0.54) but prophylactic phenytoin, carbamazepine and valproate have no effect on the prevention of late post-traumatic seizures. (Level I)
4. There is insufficient evidence for the effect of yoga, EEG biofeedback, relaxation, education and cognitive therapy on epilepsy in general (Level I).
5. Patients with post-traumatic epilepsy are more likely to have poor behavioural and functional outcomes (Level III-2)

#### Included studies by question category

Frequency	Diagnosis	Treatment	Prognosis
Five studies (Level III-2) <ul style="list-style-type: none"> <li>○ Englander et al (2003)</li> <li>○ Mazzini et al (2003)</li> <li>○ Annegers etc al (2000)</li> <li>○ Haltiner A et al (1996)</li> <li>○ Asikainen et al (1999)</li> </ul>	One study (Level III-2) <ul style="list-style-type: none"> <li>○ Angeleri et al (1999)</li> </ul>	Four systematic reviews of RCTs (Level I) <ul style="list-style-type: none"> <li>○ Chang BS et al (2003)</li> <li>○ Schierhout G et al (2003)</li> <li>○ Ramaratnam S et al (2004)</li> <li>○ Ramaratnam S et al (2004)</li> </ul> One additional RCT (Level II) <ul style="list-style-type: none"> <li>○ Dikmen et al (2002)</li> </ul>	Two studies (Level III-2) <ul style="list-style-type: none"> <li>○ Mazzini et al (2003)</li> </ul>

### FREQUENCY

#### How common are post-traumatic seizures in patients with traumatic brain injury compared to the general community?

Seizures after TBI are often categorized as either early (i.e. within the first seven days after injury) or late (i.e. greater than one-week post-injury). Late seizures are more common than early (10% vs. 4% - Englander 2003). Mazzini et al (2003) found that 27/143 patients developed seizures within mean time of 11.9 +/- 8.6 months from severe TBI. Sixty six out of 647 patients (10%) studied by Englander et al developed seizures. Two-thirds of these had their first seizure between 8 days and six months after injury and thus it is most common for post traumatic epilepsy to develop within the first year after brain injury.

There is some evidence that both early and late seizures are more likely in patients with CT evidence of biparietal contusions (66% chance), dural penetration with bone and metal fragments (62.5% chance), multiple intracranial operations (36.5% chance), multiple subcortical contusions (33.4% chance), subdural haematoma with evacuation (27.8% chance), midline shift greater than 5mm (25.8% chance) or multiple or bilateral cortical contusions (25% chance).

This is consistent with the findings of Annegers et al (2000) looking at 5984 episodes of TBI that the relative risk of seizures was 1.5 (95%CI 1.0 to 2.2) for mild TBI; 2.9 (95%CI 1.9 to 4.1) after moderate TBI; and 17.2 (95%CI 12.3 to 23.6) after severe TBI. Significant risk factors in this study were also brain contusion with subdural haematoma, skull fracture, loss of consciousness and amnesia for more than 1 day, and age over 65 years.

Two further studies Haltiner A et al (1996) and Asikainen et al (1999) (Level III-2 evidence) were found to be consistent with these findings.

## DIAGNOSIS

### In patients with traumatic brain injury, what symptoms and/or tests are most effective in diagnosing post-traumatic seizures?

Angeleri et al (1999) showed in a prospective evaluation of 137 consecutive patients with TBI that a history of early seizures, a single CT lesion and a focal EEG at one month were all significantly associated with an increased risk of post-traumatic epilepsy. The Glasgow Coma Score was not significantly correlated with post-traumatic epilepsy.

**Table 1: Relative Risk of Post-traumatic Epilepsy\***

Variables	Relative risk	95% Confidence interval
Early seizure	8.58	2.87-25.65
Glasgow Coma Score	0.93	0.30-2.96
Single CT lesion	3.43	1.23-9.57
Focal EEG	3.49	1.10-11.05

\* Angeleri et al (1999)

## TREATMENT

### In patients with traumatic brain injury are anti-epileptic drugs, cognitive behavioural therapy, electroencephalogram (EEG) bio-feedback and educational interventions and yoga more effective than no treatment in treating post-traumatic seizures?

Chang et al (2003) published a systematic review of four RCTs on the use of anticonvulsant therapy to prevent post-traumatic seizures. They found that patients given phenytoin prophylaxis immediately after injury were at a significantly lower risk of *early* post-traumatic seizures compared with controls RR=0.37(95%CI 0.18 to 0.74). They did not find any significant difference in the risk of *late* posttraumatic seizures between patients given anticonvulsant prophylaxis and controls RR=1.05 (95%CI 0.82 to 1.35).

Similarly Schierhout et al (2003) found 6 eligible RCTs for their Cochrane review on the effects of prophylactic antiepileptic agents after TBI and reported pooled relative risk for seizure prevention in the first week after injury was RR=0.34 (95%CI 0.21 to 0.54). They found that acute phase seizure control was not accompanied by a reduction in mortality RR=1.15 (95%CI 0.89 to 1.51), nor a reduction in neurological disability [RR=1.49 (95%CI 1.06 to 2.08) for carbamazepine and RR=0.96; (95%CI 0.72 to 1.26) for phenytoin] nor a reduction in late seizures; pooled RR=1.28 (95%CI 0.90 to 1.81).

One additional RCT (Dikmen et al 2000) measured outcomes in TBI patients on prophylactic sodium valproate and found that it had no effect on seizure or cognitive outcomes, although there was a trend toward a higher mortality in the treatment compared with the control group.

Two Cochrane reviews by Ramaratnam S et al (2004) (Level 1) were inconclusive about the effectiveness of relaxation therapy, cognitive behavioural therapy, electroencephalogram (EEG) bio-feedback, educational interventions and yoga as a treatment for epilepsy in general. These reviews were not specific to TBI study populations.

## **PROGNOSIS**

### **In patients with traumatic brain injury, what is the likely prognosis of post-traumatic seizures?**

Mazzini et al (2003), in a cohort of 143 patients with severe TBI, also reported clinical outcomes in patients with post-traumatic epilepsy. Results indicated post-traumatic epilepsy was more likely to be associated with disinhibition, irritability, aggression and agitated behaviour. TBI patients with post-traumatic epilepsy were also more likely to have a poorer functional status, social integration and rehabilitation outcomes. This may be related to behavioural problems interfering with rehabilitation programs as the study reports a similar profile of TBI severity in both groups.

Along with the significant risk factors mentioned by Annegers et al (2000) and Englander et al (2003); Mazzini et al (2003) also placed importance on degree of hydrocephalus and hypoperfusion in predicting prognosis of post-traumatic epilepsy.

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## Section 2: SOMATIC COMPLAINTS<sup>1</sup>

### KEY POINTS:

1. Headaches (29-54%), dizziness (26-58%), pain (11-48%) and sleep disturbances (11-58%) are more common in people with TBI than the general population (Level III-2).
2. Self reported headaches, dizziness and sleep disturbances are the somatic complaints most attributable to TBI. Somatic complaints are also common in the general community and in people with chronic illness and disability. Self-reports of dizziness are particularly sensitive and specific to TBI patients. The Dizziness Handicap Inventory (DHI) is a useful and reliable method for evaluating the efficacy of antivertigo/dizziness drugs (Level IV).
3. There is no evidence for the effective management of headaches and sleep disturbance specific to TBI patients. Vestibular rehabilitation (including exercise therapy) is effective in early stages of dizziness (Level II). Betahistine 48mg daily for eight weeks halved the dizziness handicap scores of TBI patients at six weeks compared with flunarizine (not available in Australia) (3.6 points compared with 7.5 points) (Level II).
4. The natural history of somatic complaints in TBI patients is not well documented, although two studies indicate that they are just as common five years after injury as they are at ten years post-injury (Level III-2)

### Included studies by question category

Frequency	Diagnosis	Treatment	Prognosis
Two studies (Level III-2)	Two studies (Level IV)	Two studies (Level II)	Two studies (Level III-2)
<ul style="list-style-type: none"> <li>○ Hibbard et al (1998)</li> <li>○ Masson et al (1996)</li> </ul>	<ul style="list-style-type: none"> <li>○ TIRR: Gordon et al (2000)</li> <li>○ DHI: Jacobson et al (1990)</li> </ul>	<ul style="list-style-type: none"> <li>○ Albera et al (2003)</li> <li>○ Yardley et al (1998)</li> </ul>	<ul style="list-style-type: none"> <li>○ Masson et al (1996)</li> <li>○ Hibbard et al (1998)</li> </ul>

## FREQUENCY

### In patients with traumatic brain injury, how common are somatic complaints as compared to the general community?

Masson et al (1996) compared 176 head-injured patients with 80 patients who suffered lower limb injuries five years after their hospitalization and found that head injured patients were more likely than lower limb-injured patients to report headaches (44-54%), dizziness (26-37%), sleep disturbance (11-67%) and pain (11-48%). The frequency of these complaints did not appear to relate to the severity of the head injury.

Similarly, Hibbard et al (1998) compared 338 TBI patients with 273 people with no disability and found that headaches (29.0%), balance difficulties (58%) and sleep disturbance (58%) were more common in TBI patients than people without disability.

<sup>1</sup> 'Somatic complaints' are defined as those experienced within the body (as opposed to the mind or environment).

## **DIAGNOSIS**

### **In patients with traumatic brain injury, what symptoms and/or tests are most effective in diagnosing somatic complaints?**

Gordon et al (2000) studied 410 individuals with TBI and compared self-reported symptoms in that group with 287 people having no disability, 104 with spinal injury, 197 who were HIV-positive and 107 who had undergone liver transplantation. They found that of the 67 symptoms from the TIRR (The Institute of Rehabilitation and Research) Checklist<sup>2</sup>, dizziness was the only physical symptom that was more common in TBI patients than the other groups.

Somatic complaints are common in the general community and their accurate diagnosis is problematic.

Assessing the severity of dizziness has been accurately done in 52 TBI patients using the Dizziness Handicap Inventory (DHI), (Jacobson 1990). This scale showed a correlation between severity of head injury, reported symptoms and the total score.

Another study (Jacobsen 1998) aimed to develop a screening version of Dizziness Handicap Inventory (DHI-S). Results found DHI-S had a higher reliability ( $r=0.86$ ) than DHI, supporting DHI-S as a psychometrically robust screening measure of self perceived dizziness disability-handicap tool. (A copy of the screening version of the DHI can be found on p47)

### **Is vestibular rehabilitation or betahistine more effective for the treatment of dizziness in TBI patients compared with no treatment or other drugs?**

NB: We found no studies that looked at effective management of headache or sleep disturbance in TBI patients.

#### **Dizziness**

A randomised controlled trial in a primary care setting (Yardley 1998) tested vestibular rehabilitation (including exercise therapy) against no treatment and found an improvement in treated patients relative to untreated patients OR=3.1 (95%CI 1.4 to 6.8) at six weeks and 3.8 (95%CI 1.6 to 8.7) at six months. A double blind trial (Albera 2003) compared the effect of betahistine dihydrochloride 48mg daily for eight weeks and flunarizine (not available in Australia) on the dizziness handicap in patients with recurrent vestibular vertigo. They found that betahistine dihydrochloride halved the total Dizziness Handicap Inventory (DHI) score when compared to Flunarizine (3.6 points compared with 7.5 points on the DHI scale).

### **In patients with traumatic brain injury, what is the likely prognosis of somatic complaints?**

The natural history of somatic complaints in TBI patients is not well documented. Masson (1996) reported that somatic complaints were approximately as common five years after injury as they were in at 10 years in a different study by Hibbard (1998).

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<sup>2</sup> Lehmkuhl et al (1988) The TIRR Symptom Checklist (Houston: The Institute of Rehabilitation Research) 1988.

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### Section 3: POST CONCUSSION SYNDROME

**KEY POINTS:**

1. Post-concussional syndrome (PCS) occurs in up to 15% of TBI patients but is probably no more common in TBI patients than others with chronic pain and trauma (Level I).
2. The Rivermead Post-concussional symptoms Questionnaire (RPQ)\* is a useful tool for identifying patients with this syndrome (Level II).
3. Brief cognitive and educational interventions shortly after injury are effective strategies for reducing PCS frequency and severity (Level II).
4. There is some evidence that individualized homeopathic remedies are more effective than placebo in reducing the frequency and severity of PCS in mild TBI patients (Level II).
5. There is insufficient evidence for the effectiveness of full bed rest for the prevention of PCS in TBI patients (Level II).
6. The majority of PCS symptoms will resolve within 3 months of injury (Level I).

Early post-concussive effects following TBI are common and usually resolve spontaneously over days or weeks following injury. The Post-Concussion Syndrome (PCS) is defined by the ICD-10 Diagnostic Criteria 310.2 as:

- 1 History of head trauma with loss of consciousness preceding symptom onset by maximum of 4 weeks
- 2 Three of more symptom categories:
  - a. Headache, dizziness, malaise, fatigue, noise intolerance
  - b. Irritability, depression, anxiety, emotional lability
  - c. Subjective concentration, memory, or intellectual difficulties without neuropsychological evidence of marked impairment
  - d. Insomnia
  - e. Reduced alcohol tolerance
  - f. Preoccupation with above symptoms and fear of brain damage with hypochondriacal concern and adoption of sick role

Its existence as an entity specifically associated with brain injury (as opposed to other trauma) is often debated.

**Included studies by question category**

<b>Frequency:</b>	<b>Diagnosis :</b>	<b>Treatment</b>	<b>Prognosis</b>
One systematic review (Level I) ○ Rees et al	Two studies (Level III-2) ○ Ingebrigsten et al (1998) ○ King et al (1995)	Five studies (Level II) ○ Wade et al (1998) ○ Mittenberg et al, ○ de Kruijk (2002) ○ Chapman et al (1999) ○ Paniak et al (2000)	One systematic review (Level I) ○ Carroll et al (2004)

## **FREQUENCY**

### **How common is post-concussion syndrome in patients with traumatic brain injuries compared to the general community?**

Rees et al (2003) report on 10 observational studies that compared the incidence of PCS symptoms in TBI patients against other trauma or chronically ill patients. They concluded that the PCS symptom cluster is no more common in TBI patients than other trauma patients and that the persistence of PCS at 12 months may be less than the commonly reported figure of 15%, because this figure is based on inpatient populations.

## **DIAGNOSIS**

### **In patients with traumatic brain injury, what symptoms and/or tests are most effective in diagnosing post-concussion syndrome/ mild traumatic brain injury?**

Ingebrigtsen et al (1998) reported that the diagnosis of PCS by the Rivermead Post-concussion symptoms Questionnaire (RPQ) had predictive validity in PCS patients (mean =19.1, SD=11.9) compared to those without PCS (mean 1.2, SD=1.8,  $P<0.001$ ). The validity and reliability of RPQ was also reported by King et al (1995) but found to be less predictive at 6 months compared with 3 months and 7-10 days. In other words, its usefulness decreases over time from injury. A copy of the RPQ can be found on p48.

## **TREATMENT**

### **In patients with traumatic brain injury, are educational interventions, cognitive therapy, homeopathic treatment, or bed-rest more effective than no treatment or placebo for post-concussion syndrome/mild TBI?**

Mittenberg et al (1996) showed in a small RCT ( $n=58$ ) that TBI patients receiving a printed manual and a therapist visit with cognitive behavioural instruction prior to hospital discharge had a shorter duration of PCS symptoms (33 vs. 51 days) and significantly fewer of the 12 symptoms at follow-up (1.6 vs. 3.1). Wade et al (1998) also showed a significant reduction in RPQ scores in TBI patients who had a psychologist visit and printed information prior to hospital discharge ( $n=314$ ). Paniak et al (2000) compared a similar single session of education about common TBI problems to a more intensive multiple visit regimen including neuropsychological assessment and feedback in mild TBI patients (Level III-2). They found no difference in PCS symptomatology between the single session and the more intensive treatment program after 3 and then 12 months.

Chapman et al (1996) reported in a randomized control trial (Level II) of 60 mild TBI patients reported patients receiving an individualized homeopathic remedy based on a selection from 18 homeopathic medicines (listed on p49) were less likely to report PCS symptoms than those receiving placebo ( $P=0.027$ ).

de Kruijk J et al (2000) conducted an RCT on 107 mild TI patients comparing full bed rest against no bed rest but were unable to show any significant difference in PCS symptoms between the two groups.

## **PROGNOSIS**

### **In patients with traumatic brain injury, what is the likely prognosis of post-concussion syndrome?**

Carrol et al (2004) found seven cohort studies reporting on PCS in their systematic review. There was consistent evidence that PCS symptomatology is common especially within the first month following injury, but the symptoms are not unique to head injury. Most symptoms resolve within 3 months and there is some evidence that persistent PCS is more likely in patients who are involved in litigation and/or compensation. There was no association observed age, gender, cause of injury.

## References:

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## CHAPTER 3: Mental Healthcare in TBI patients

### Section 1: DEPRESSION

#### KEY POINTS:

1. Major depression occurs in approximately 27% of TBI patients there is a 1.5 times higher lifetime chance of depression in TBI compared with non head-injured patients (Level III-2)
2. 'Feelings of hopelessness', 'difficulty enjoying activities' and 'feeling worthless' are the most distinguishing symptoms of depression in TBI patients. Difficulty falling asleep, restlessness weakness and poor concentration are also common but not as specific. Commonly used depression scales such as the Beck Inventory may not be as valid in TBI patients (Level IV)
3. Desipramine is an effective treatment for depression in TBI patients but may have harmful side effects (Level II). Sertraline may be effective yet less harmful alternative (Level III-2)
4. There is some evidence that aerobic exercise programs have no effect on depression in TBI patients (Level II)
5. Community-based outreach rehabilitation twice weekly may be an effective treatment for depression in the first two years post-injury (Level II).
6. Depression will resolve in more than half TBI patients (Level III-2).

#### Included studies by question category

Frequency:	Diagnosis :	Treatment	Prognosis
Two studies (Level III-2)	Two studies (Level III-2)	Four studies (Level II)	Four studies (Level III-2)
<ul style="list-style-type: none"> <li>o Holsinger et al (2002)</li> <li>o Seel et al (2003)</li> </ul>	<ul style="list-style-type: none"> <li>o Seel et al (2003)</li> <li>(Level IV)</li> <li>o Sliwinski et al (1998)</li> </ul>	<ul style="list-style-type: none"> <li>o Powell et al (2002)</li> <li>o Bateman et al (2001)</li> <li>o Wroblewski et al</li> <li>o Schoenberger et al (2001)</li> </ul> One study (Level III-2) <ul style="list-style-type: none"> <li>o Fann et al</li> </ul>	<ul style="list-style-type: none"> <li>o Kaponen et al (2002)</li> <li>o Hibbard et al</li> <li>o Rapoport et al (2003)</li> <li>o Underhill et al (2003)</li> </ul>

### FREQUENCY

#### In patients with traumatic brain injury, how common is depression compared with the general community?

Seel et al (2003) estimated in their study that 27% of their large multi-center study population with traumatic brain injury had at least five DSM-IV Criteria for diagnosis of major depressive disorder. This is consistent with other studies in similar populations. Holsinger et al (2002) interviewed 520 War Veterans who suffered head injuries and compared their lifetime prevalence of depression with 1198 veterans without head injury. After controlling for age and education, the lifetime prevalence was 18.5% in the head injured group compared with 13.4% in the non-head injured group; OR=1.54 (95%CI 1.17 to 2.04). The increased risk of depression appeared to persist with age.

## **DIAGNOSIS**

### **In patients with traumatic brain injury, what symptoms and/or tests are most effective in diagnosing depression?**

Patients with neurotrauma commonly experience difficulty falling asleep, restlessness, weakness and poor concentration as a direct result of their brain injury. Such overlap in symptomatology can make standardized assessment tools for depression such as the Beck Depression Inventory (BDI) less accurate in brain-injured people than in the general population. These symptoms are still 6 to 9 times more common in depressed TBI compared with non-depressed TBI patients. More distinguishing symptoms are probably 'feelings of hopelessness', 'difficulty enjoying activities' and 'feeling worthless'. Seel et al (2003) reported that these symptoms are 10 to 19 times more common in depressed TBI patients. Sliwinski et al (1998) estimate a low sensitivity for the BDI of only 36% in discriminating depressed from non-depressed individuals with brain injury. They noted that high BDI scores in brain injured patients are more likely to reflect hyper-reactivity to post-TBI symptoms than clinical depression. Patients who are unemployed, on low income or have a minority status are more likely to become depressed after traumatic brain injury.

## **TREATMENT**

### **In patients with traumatic brain injury, are antidepressants, cognitive therapy, electrotherapy, rehabilitation or aerobic exercises more effective than no treatment for depression?**

Desipramine (a tricyclic antidepressant) is the only pharmacotherapy that has been evaluated in a placebo-controlled trial with TBI patients. Wroblewski et al (1996) found in a trial of only 10 patients, that there was a significant improvement in affect/mood scale in the treatment group compared with the untreated (placebo lead-in) group ( $P=0.001$ ). It is worth noting that two patients dropped out of this study due to adverse effects of desipramine (seizures and mania).

One non-randomised controlled study of sertraline in 16 TBI patients (Fann 2000) reported that 13 of these (87%) and a greater than 50% improvement in their Hamilton Rating Scale for Depression. One patient dropped out due to adverse effects of treatment (dizziness, nausea, tinnitus, lethargy) but most improved in psychologic distress, anger, aggression, functioning and post-concussive symptoms.

One randomised controlled trial ( $n=110$ ) (Powell 2002) showed that community-based rehabilitation via twice weekly outreach visits significantly improved depression scores in this group compared with the control group who received written information alone. (40% of outreach patients clinically improved compared with 20% of controls).

One small randomised controlled trial of 12 TBI patients showed that biofeedback using Flexyx neurotherapy system (FNS), an EEG-based biofeedback method used by some psychologists, improved depression scores compared with TBI patient in the waiting list control group after six weeks therapy, Schoenberger et al (2001).

One randomised controlled trial of aerobic exercise in 157 TBI patients showed no effect on depression compared with relaxation exercises (Bateman et al 2001).

## **PROGNOSIS**

### **In patients with traumatic brain injury, what is the likely prognosis of depression?**

Seel et al (2003) report that in over 60% of patients with depression and TBI, this will resolve. Depression and substance use disorders they found, are much more likely to resolve than anxiety disorders in the Axis I psychopathology. Koponen et al (2002) similarly reported in a 30-year follow-up of 60 TBI patients that 48.3% had an axis I psychiatric disorder. Of these the most

common was depression (26.7%) followed by alcohol abuse or dependence (11.7%), panic disorder (11.7%), specific phobia (8.3%) and psychotic disorders (6.7%).

Underhill et al (2003) found that TBI patients who suffer from depression are more likely to have decreased life satisfaction than non-depressed TBI patients after 3 years (n=324). Rapoport et al (2003) also showed in a cohort study of 170 TBI patients that those who suffered from major depression did have lower self-reported psychosocial function, greater psychological distress, more post-concussive symptoms and greater examiner-rated neurobehavioral disturbances. Major depression can therefore affect multiple domains in TBI patients.

## References:

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## Section 2: ANXIETY

### KEY POINTS:

1. Estimates of the prevalence of anxiety disorders in TBI patients are affected by variability in measurement and diagnosis. Prevalence may be of the order of 10-20% with post-traumatic stress disorder, obsessive-compulsive disorder and generalised anxiety disorder being much more likely to occur than phobias (Level III-2)
2. No TBI-specific measures for diagnosing anxiety disorders were found.
3. Cognitive therapy appears to be an effective intervention for the prevention of PTSD in TBI patients compared with repeat assessments and self-help booklets (Level II).
4. It appears that anxiety disorder may increase initially after injury but reduce gradually over time (Level III-2)
5. An extended period of unconsciousness may be somewhat protective against the development of PTSD (Level III-2)
6. A history of psychiatric illness increases your risk of TBI (OR=1.6) (Level III-3)

DSM-IV defines ten broad groups of anxiety disorders, any of which may occur in TBI patients (Agoraphobia, Panic Attack, Specific Phobia, Social Phobia, Obsessive-Compulsive Disorder, Posttraumatic Disorder, Acute Stress Disorder, Generalised Anxiety Disorder, Anxiety Disorder due to a General Medical Condition, Substance-Induced Anxiety Disorder).

### Included studies by question category

Frequency:	Diagnosis :	Treatment	Prognosis
Two studies (Level III-2) <ul style="list-style-type: none"> <li>○ Hibbard et al (1998)</li> <li>○ Deb et al (1999)</li> <li>○ Fann et al (2002)</li> </ul>	None	One study (Level II) <ul style="list-style-type: none"> <li>○ Ehlers et al (2003)</li> </ul>	<ul style="list-style-type: none"> <li>○ Fann et al (1995)</li> <li>○ Ashman et al (2004)</li> <li>○ Bryant et al (1999)</li> <li>○ Glaesser et al (2004)</li> </ul>

## FREQUENCY

### How common are anxiety disorders in patients with traumatic brain injuries as compared to the general community?

Deb et al (1999) interviewed 120 TBI patients 12 months after injury and found that 9.0% had panic disorder compared with 0.8% in the general population; 2.5% of TBI patients had generalized anxiety disorder compared with 3.1% in the general community; 0.8% of TBI patients had phobic disorder compared with 1.1% in the general community and 1.6% had obsessive compulsive disorder compared with 1.2% in the general population. They used the Clinical Interview Schedule Revised and the Psychosis Screening Questionnaire. A large population census study in the UK used these same measures to obtain the general community estimates. Panic disorder prevalence was the only anxiety disorder that was statistically different between the two groups ( $p < 0.001$ ).

Hibbard et al (1998) found a higher prevalence of anxiety disorders in 100 TBI patients. They reported 19% had post-traumatic stress disorder (compared to 8% in general population), 15% had obsessive-compulsive disorder compared with 3% in general population), 14% had panic disorder (compared to 2% in general population) and 9% had generalised anxiety disorder (compared to 4% in general population) and 10% had phobias (compared to 13% in the general population). Reported prevalence of anxiety disorders before injury were similar to those in the general population. This study used the DSM-IV structured clinical interview by a trained psychologist which may explain the difference in results compared with Deb et al.

Fann et al (2002) undertook a population based case-control study to determine whether psychiatric illness is a subsequent risk factor for TBI on 1440 TBI patients. They determined that psychiatric illness (patients who had previous diagnosis of acute stress or adjustment reaction; organic psychotic disorders or organic non-psychotic disorders and somatoform disorders) year prior to TBI had significantly increased relative risk of TBI to 1.7 (95%CI 1.4 to 2.0) compared to those without specific diagnosis)

### **What assessment scales or tools are accurate and useful in diagnosing anxiety disorders in patients with traumatic brain injury?**

We found no diagnostic tools that had been developed or specifically validated within TBI populations.

### **In patients with traumatic brain injury, is cognitive therapy or self-help booklet or other therapies more effective than no treatment in prevention or management of anxiety disorders?**

We found only one randomised trial of an intervention for preventing post-traumatic stress disorder (PTSD). This study on 85 patients compared cognitive therapy to a self-help booklet to a control group having repeated assessments. After 9 months, fewer patients in the cognitive therapy group had PTSD (11.0%) compared with those receiving the self-help booklet (61%) OR=12.9 (95%CI 3.1 to 53.1) or repeat assessments (55%) OR=10.3 (95%CI 2.5 to 41.7).

We found no controlled studies for the efficacy of any other therapies (including pharmacotherapy) in TBI patients. As discussed in the depression section, there have been some case series that suggest SSRIs may be effective for controlling agitation but side effects may be problematic.

### **In patients with traumatic brain injury, what is the likely prognosis of depression?**

Fann et al (1995) reported in 50 TBI patients that 24% had generalised anxiety disorder and that this was associated with a lower functional status as measured by the Medical Outcomes Study Health Survey.

Ashman et al followed 188 TBI patients over 6 years and found that the likelihood of Axis I pathology decreased over time, although their prevalence increased initially.

Bryant et al (1999) compared levels of acute stress disorder in 63 TBI patients with 72 non-TBI motor vehicle accident victims. He suggests that a period of loss of consciousness is protective against the development of PTSD as PTSD was more common in the non-TBI accident victims. Loss of consciousness therefore, may be an important prognostic indicator for the development of PTSD. Glaesser et al (2004) replicated these findings in 46 TBI patients. 27% of the sample who were not unconscious had PTSD compared with only 3% in those who had an extended period of unconsciousness (P<0.02).

## References:

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## Section 3: SCHIZOPHRENIA

### KEY POINTS:

1. Schizophrenia is around twice as common in TBI patients than in the general community (Level IV).
2. TBI patients with schizophrenia or a schizophrenic-like psychosis (SLP) are likely to present with paranoia and auditory hallucinations of gradual onset (Level III-3).
3. In view of a lack of evidence about treatment of schizophrenia in TBI patients, the evidence for efficacy of newer antipsychotic agents in non-TBI patients should be considered. Risperidone and carbamazepine may be effective (Level I).
4. The natural history of schizophrenia and SLP is likely to be subacute or chronic although data is very limited on this (Level III-2)

### Included studies by question category

Frequency:	Diagnosis :	Treatment	Prognosis
One study (Level III-2) ○ Fann et al (2004) One study (Level IV) ○ Silver et al (2001)	One Study (Level III-3) ○ Sachdev et al (2001)	Two systematic reviews (Level I) ○ Hunter et al (2004) ○ Leucht et al (2004)	Two studies (Level III-2) ○ Sachdev et al (2001)

### How common is psychosis in patients with traumatic brain injuries as compared to the general community?

Silver et al (2001) found in their random sample of 5034 adults in New Haven, that the prevalence of schizophrenia in patients with TBI is almost double than that in the general community - adjusted OR=1.8 (95%CI 1.0 to 3.3). The same study reported that 3.4% of patients with a history of TBI had a lifetime prevalence of schizophrenia compared with 1.9% in the general community using DSM-III criteria.

Fann et al (2004) conducted a major cohort study of 939 healthcare plan members with TBI over 3 years and found that there was an increased risk of psychotic disorder in moderate-severe TBI patients OR=5.9 (95%CI 1.6 to 22.1) at 13-24 months; OR=3.6 (95%CI 1.0 to 12.3) at 25-36 months.

### In patients with traumatic brain injury, what symptoms and/or tests are most effective in diagnosing psychosis?

Sachdev et al (2001) conducted a case-control study on 45 TBI cases with schizophrenic-like psychosis (SLP) and 45 matched TBI controls. They describe a profile of the post-traumatic SLP patient as one with predominantly paranoid hallucinatory psychosis of gradual onset and a sub-acute or chronic course. Hallucinations were usually auditory and depression was often present as well. Formal thought disorder and catatonic features were rare and the history was therefore very similar to primary paranoid schizophrenia. Unfortunately this study did not compare TBI patients to non-TBI schizophrenic patients.

It found that SLP was more common with severe injury, particularly of the left parietal (P=0.01) and/or right temporal lobes (P=0.01). A positive family history of psychosis and the duration of loss of consciousness were more likely to be associated with SLP.

### **In patients with traumatic brain injury, are antipsychotics more effective than no treatment or placebo for psychosis?**

We found no studies looking specifically at treatment of schizophrenia or SLP in TBI patients. Several Cochrane reviews have reported on the efficacy of various antipsychotic medications in the treatment of general patients with schizophrenia. Hunter et al (2004) advise that newer antipsychotic agents such as risperidone are effective and better tolerated by many schizophrenic patients compared with older antipsychotics. There is some evidence that adjunctive carbamazepine may improve global well-being but not mental state scores Leucht et al (2004) and inconclusive evidence that adjunctive valproate is helpful.

### **In patients with traumatic brain injury, what is the likely prognosis of psychosis?**

We found no longitudinal studies reporting on the prognosis or natural history of schizophrenia or SLP in TBI patients although Sachdev et al describe a chronic course for TBI patients (without comparison).

### **References:**

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## CHAPTER 4: Cognitive and behavioural problems in TBI patients.

### Section 1: COGNITIVE IMPAIRMENT

#### KEY POINTS:

1. Self-reported memory problems, difficulty writing letters and dealing with paperwork are more common in TBI patients compared with lower limb-injured controls. The prevalence amongst TBI patients 5 years post-injury increases with injury severity. Two-thirds of severe TBI patients report memory problems, 44.4% have difficulty writing a letter and 59.3% have trouble dealing with paperwork (Level III-2).
2. The cognitive subscale of the TIRR checklist has a high proportion of items that are potentially useful for screening TBI patients for cognitive dysfunction (Level III-2).
3. Memory aids and reminder devices can reduce the number of everyday memory failures in TBI patients. Cognitive rehabilitation can also reduce anxiety and improve self-concept and interpersonal relationships in TBI patients. There is no evidence that cognitive rehabilitation improves health or employment outcomes (Level I).
4. There is inconclusive evidence for the effectiveness of dopamine agonists for improvement of memory and executive functions in TBI patients (Level II).
5. Mindfulness meditation techniques have no effect on cognition in TBI patients (Level II).
6. Cognitive deficits usually resolve in mild TBI patients within one to three months of injury. Cognitive improvement may continue in moderate –severe TBI patients for up to 2 years (Level III-2).

#### Included studies by question category

Frequency:	Diagnosis :	Treatment	Prognosis
One study (Level III-2) <ul style="list-style-type: none"> <li>○ Masson et al (1996)</li> </ul>	One study (Level IV) <ul style="list-style-type: none"> <li>○ Gordon et al (2000)</li> </ul>	Three systematic reviews (Level I) <ul style="list-style-type: none"> <li>○ Carney et al (1999)</li> <li>○ Chesnut (1999)</li> <li>○ Cicerone et al (2000)</li> </ul> Three studies (Level II) <ul style="list-style-type: none"> <li>○ McDowell et al (1998)</li> <li>○ McMillan et al (2002)</li> <li>○ Hart et al (2002)</li> </ul>	One systematic review (Level I) <ul style="list-style-type: none"> <li>○ Schretlen et al (2003)</li> </ul> One study (Level III-2) <ul style="list-style-type: none"> <li>○ Sherer et al (2002)</li> </ul>

## **How common are cognitive problems in patients with traumatic brain injuries as compared to the general community?**

Masson et al (1996) studied a number of outcomes in 231 TBI patients. 182 of these patients were followed up 5 years after injury and the prevalence of a number of outcomes compared with 64/80 lower limb patients who acted as controls for the study. Self-reported memory problems were significantly more common in mild TBI patients (32.1%) compared with lower limb injured controls (15.6%) -  $P < 0.05$ . Amongst TBI patients there was a significant trend for memory problems to be more common with injury severity – Mild (32.1%), Moderate (60.0%) and Severe (66.7%) -  $P < 0.001$ . Whilst no lower limb-injured patients reported difficulties with writing a letter or dealing with paperwork this was increasingly common with TBI severity. The prevalence of difficulty writing a letter 5 years post-injury was for mild TBI (2.7%), moderate TBI (8.8%) and severe TBI (44.4%). The prevalence of difficulty dealing with paperwork 5 years post-injury was for mild TBI (1.9%), moderate TBI (8.6%) and severe TBI (59.3%).

## **In patients with traumatic brain injury, what symptoms and/or tests are most effective in diagnosing cognitive problems after injury?**

There are numerous scales and neuropsychological tests that are commonly used by specialists to measure cognitive function. Since these guidelines aim to be useful for general practitioners we have focused on clinically useful measures of cognitive function rather than the more formal psychometric and neuropsychological scales that would be administered at a tertiary referral unit.

As discussed in the section on Post-Concussion Syndrome, the TIRR Checklist is a potentially useful screening tool. Unlike the physical symptoms subscale, however, Gordon et al (2000) found that a large proportion, 23 out of the 35 cognitive symptoms, were sensitive and specific for TBI patients compared with controls (individuals without disability, individuals with spinal cord injury, individuals with HIV and liver transplant recipients). Relevant cognitive items include: Reading, writing or doing maths; Solving problems; Speech; Getting lost easily in unfamiliar places; Performing your job or school work; Becoming confused in familiar places; Planning future events; Learning new information; Handling your own personal affairs or finances; Making quick decisions without thinking of the consequences; Being easily distracted; Forgetting or missing appointments; Forgetting phone numbers; Forgetting to do chores or work; Forgetting what you read; Learning slowly; Thinking slowly; Trouble following instructions; Losing your train of thought; Forgetting things you have done; Forgetting to turn off appliances; Making conversation; Talking too fast or slow

## **In patients with traumatic brain injury, are some forms of cognitive rehabilitation more effective than others, are dopamine agonists more effective than placebo and is meditation an effective therapy for attention problems?**

We found only one small trial ( $n=24$ ) that considered pharmacological therapy for cognitive impairment in TBI patients. McDowell et al (1998) found a significant improvement in executive control working memory 90 minutes after ingestion of 2.5mg bromocriptine compared with placebo in a cross-over trial.

Cognitive rehabilitation, on the other hand, is a more commonly employed therapy for TBI patients with cognitive impairment. Definitions of cognitive rehabilitation vary but a traditional definition is that it consists of a set of therapies used to help improve damaged intellectual, perceptual, psychomotor and behavioural skills. Cognition itself includes memory, attention, learning, thinking or mental organization, affect and expression and executive functions.

McMillan et al (2002) evaluated brief mindfulness meditation techniques (Attentional Control training and Physical Exercise fitness sessions) on 145 patients with TBI for 12 months and found no effect of these techniques in improving cognition symptomatology of TBI group compared to

the controls receiving no treatment.[Please refer to Chapter 7 for more details on brief meditation mindfulness technique practice]

Three systematic reviews (Cicerone 2000, Chestnut 1999 & Carney 1999) and one subsequent RCT (Hart 2002) support the effectiveness of memory aids such as portable voice organizers, wristwatch alarms, memory notebooks and programmed reminder devices in reducing everyday memory failures. There is also evidence that cognitive rehabilitation reduces anxiety and improves self-concept and interpersonal relationships but there is little evidence of any effect on health and/or employment. There is also some evidence that Computer-Assisted Cognitive Rehabilitation can improve information recall but this effect has only been demonstrated for immediate recall (Chestnut 1999)

### **In patients with traumatic brain injury, what is the likely prognosis of cognitive impairment?**

Schretlen et al (2003) conducted a meta-analysis on 39 studies of the outcomes of head injury. They found that for the majority of *mild* head injury, cognitive recovery is most rapid in the first few weeks after injury and usually returns to baseline within 1-3 months. In moderate or severe TBI patients, however, cognitive improvement may continue for up to two years and persists in some patients.

Sherer et al (2002) demonstrated in 388 TBI adults that early cognitive status is strongly predictive of productivity level 12 months post-injury. Less impaired patients (75<sup>th</sup> percentile) were 1.61 times more likely (95%CI 1.07-2.41) to be productive than those who were more impaired (25<sup>th</sup> percentile). [NB: This effect was adjusted for other predictors].

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## Section 2: PERSONALITY AND BEHAVIOUR CHANGES

### KEY POINTS:

1. Behavioural problems may occur in more than half (61.6%) patients 12 months after injury. They may be more than twice as common in TBI patients as patients with lower limb trauma and are more likely to have a depressive temper. Irritability, impatience and socialisation problems are the more common behavioural issues following TBI. They are more frequent in severe TBI (Level III-2).
2. The Neurobehavioural Functioning Inventory NFI (carer-rated), Neurobehavioural Rating Scale-Revised NRS-R (clinician-administered) and the TIRR (self-report) are all potentially useful tools for assessing and monitoring behavioural outcomes of TBI. Bias in these measures however, is likely and it may be useful to use more than one in practice (Level III-2).
3. There is no definitive evidence for the effectiveness of drug therapy for behavioural problems in TBI patients. There is weak evidence, mainly based on case studies, that psychostimulants are effective in the treatment of apathy, inattention and slowness; high dose beta-blockers for agitation and aggression; anticonvulsants and antidepressants (particularly SSRIs) in the treatment of agitation and aggression (especially in the presence of an affective disorder). Lithium and dopaminergic drugs may have adverse effects in some patients. (Level I)
4. There is limited evidence that anger management is an effective treatment for TBI patients with anger problems (Level II).
5. Behavioural problems appear likely to be chronic. It is possible that 63.0% severe BI patients suffer from irritability and 40.7% with depressive temper five years post-injury (Level III-2).

### Included studies by question category

Frequency	Diagnosis	Treatment	Prognosis
One study (Level III-2) <ul style="list-style-type: none"> <li>○ Masson et al (1996)</li> <li>○ Deb et al (1999)</li> </ul>	Five studies (Level III-2) <ul style="list-style-type: none"> <li>○ Kreutzer et al (1996)</li> <li>○ Rapoport et al (2002)</li> <li>○ Vanier et al (2000)</li> <li>○ McCauley et al (2001)</li> <li>○ Golden et al (2003)</li> <li>○ Gordon et al (2000)</li> </ul>	One systematic review (Level I) <ul style="list-style-type: none"> <li>○ Shoumitro et al (2004)</li> </ul> One study (Level II) <ul style="list-style-type: none"> <li>○ Medd et al (2000)</li> </ul>	One study (Level III-2) <ul style="list-style-type: none"> <li>○ Masson et al (1996)</li> </ul>

## **How common are personality and behavioural problems compared to the general community?**

Masson et al (1996) compared 231 TBI patients with 80 lower limb-injured (LLI) control patients five years after injury, and reported that mild TBI patients were significantly more likely to have a depressive temper (38.6% in TBI compared with 14.1% in LLI) and were more likely to report irritability (37.7% in TBI compared with 14.1% in LLI). There was a significant trend in prevalence with TBI severity for irritability but not for depressive temper.

Deb et al (1999) found that in a cohort of 196 TBI patients, 61.6% had neurobehavioural symptoms and about 40% had three or more behavioural symptoms one year after injury. The most common were irritability (35%), impatience (30.5%), mood swings (28%), slowness in thinking (18%), sleep problems (31.6%), socialization problems (24.8%), fatigue (33.8%), lack of initiative (15%), poor memory (31.7%), difficulty in planning (22%), socially disinhibited behaviour (3%), depressed mood (19.4%) and verbal outbursts (15%). Deb et al did not use a validated instrument to measure these symptoms but did use carer interviews to try to validate patient responses (see below).

## **What assessment scales or tools are most effective in diagnosing behaviour and personality problems in people with traumatic brain injury?**

Clinically useful and reliable diagnostic tools for behavioural and personality disorders are difficult to find. Clinician, family-member and self report of TBI patient behaviour often differ from each other.

DSM-IV defines a personality disorder as a lasting pattern of behaviour and inner experience that markedly deviates from norms of the patient's culture. The pattern should manifest in at least 2 of these areas:

- Affect (appropriateness, intensity, lability and range of emotions)
- Cognition (how the patient perceives and interprets self, others and events)
- Impulse control
- Interpersonal functioning

Cognitive, affective and functional issues for TBI patients are dealt with in other sections of this guideline, so this section will focus mainly on behavioural symptoms associated with TBI.

One of the most widely used and validated measures for personality is the Minnesota Multiphasic Personality Inventory – 2 (MMPI-2) but this scale was not developed specifically for brain-injured patients, is 180 items long and not practical for the general practice context. Earlier work on this scale suggests that five of the ten MMPI clinical scales have diagnostic utility for TBI patients (Hypochondriasis, Depression, Hysteria, Psychasthenia and Schizophrenia).

Kreutzer et al (1996) developed a clinically relevant and valid measure for adult TBI patients, the Neurobehavioural Functioning Inventory (NFI). It was given to an identified primary caregiver or someone who knew the patient well and found to be well-correlated with clinician-administered psychometric and formalised testing. The frequency of each problem is rated on a 4-point scale of *never* (1), *sometimes* (2), *often* (3) or *always* (4). Items relevant to the measurement of behavioural problems lie within the 'Aggression' domain and include: Hits or pushes others; Inappropriate comments or behaviour; Screams or yells; Threatens to hurt others; Breaks or throws things; Curses at others; Curses at self; Argues; Rude to others

Rapaport et al (1996), Vanier et al (2000) and McCauley et al (2001) have used and validated another scale, the Neurobehavioural Rating Scale-Revised (NRS-R). Not unlike the NFI, this scale has five domains F-1 Intentional behaviour, F-2 Emotional state, F-3 Survival oriented behaviour/emotional state, F-4 Arousal state and F-5 Language. The NRS-R involves the clinician administering a brief structured interview that includes questions and observations about cognitive, behavioural and emotional sequelae common to TBI patients. It also includes

performance on some cognitive tasks (e.g. orientation, four-item object recall and verbal problem solving). The NFI (carer version), and NRS-R (clinician) are reproduced at the back of these guidelines for use with patients.

Problems with the validity of all of these scales are highlighted by Gordon et al (2000) using the TIRR patient self-assessment and by Golden et al (2003) using the MMPI. Both highlight that severe TBI patients often lack insight and awareness of their problems, creating difficulties in using and interpreting behavioural measurement tools.

Further research is required to ascertain the correlation between patient, clinician and carer assessments of behavioural problems in TBI patients, particularly those with severe injury.

### **In patients with traumatic brain injury, are social support, vocational or computer assisted rehabilitation, psychotherapy or behaviour modification and more effective than no treatment for behaviour and personality problems?**

Deb et al (2004) conducted a systematic review of sixty three studies on the effectiveness of pharmacological treatment options for behavioural disorders in TBI patients. They found that there was no strong evidence either way for the effectiveness of drug treatments for behavioural problems in TBI patients. However, there was weak evidence, mainly based on case studies, that psychostimulants are effective in the treatment of apathy, inattention and slowness; high dose beta-blockers for agitation and aggression; anticonvulsants and antidepressants (particularly SSRIs) in the treatment of agitation and aggression (especially in the presence of an affective disorder). Lithium and dopaminergic drugs may have adverse effects in some patients.

Medd et al (2000) conducted a small randomized trial on 28 patients with TBI who had been identified as having problems with anger. The treatment group received six one-hour individual sessions on anger management and had a statistically significant improvement on the State-Trait Anger Expression Inventory (STAXI) after two months compared with those who were on the waiting list.

### **In patients with traumatic brain injury, what is the likely prognosis of behaviour and personality problems?**

Masson et al (1996) report that five years after injury 37.7% mild TBI patients reported irritability compared with 14.1% lower-limb injured controls ( $P < 0.01$ ). There was a significant trend for irritability to increase with injury severity with 63.0% severely brain injured subjects suffering from irritability after 5 years. Depressive temper was also more likely in mild TBI patients (47.4%) compared with controls (14.1%;  $P < 0.01$ ). 40.7% of severe TBI subjects suffered with depressive temper five years after injury.

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# CHAPTER 5: Lifestyle issues and Quality of Life in TBI patients

## Section 1: QUALITY OF LIFE (QoL)

<p><b>KEY POINTS:</b></p> <ol style="list-style-type: none"> <li><b>1. Lack of consensus about a definition for Quality of Life in TBI patients has resulted in an absence of validated TBI-specific assessment tools (Level I).</b></li> <li><b>2. People with severe TBI are likely to perceive their quality of life as normal whereas those with mild TBI will rate QoL as worse (Level III-2).</b></li> <li><b>3. Work, socializing, close friends and significant others are important unmet needs for TBI patients (Level IV).</b></li> <li><b>4. SF-36 is an internally consistent and reliable tool for identifying problems in relation to quality of life in individuals TBI. The Community Integration Questionnaire (CIQ) is another reliable and valid measure in TBI patients (Level IV).</b></li> <li><b>5. Employment, particularly part-time work is an important prognostic indicator for QoL after TBI (Level III-2).</b></li> <li><b>6. Caregiver perceptions of patient fitness to drive strongly influence driving levels but do not accurately predict driver safety. Medical assessment is a more accurate method of determining road safety (Level III-2).</b></li> </ol>
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Definitions of Quality of Life (QoL) for TBI patients vary considerably. The WHO defines <sup>1</sup>'Quality of life' as *"an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concern"*. This lack of consensus about definition contributes to the difficulty of accurately measuring QoL in TBI patients. Generally, QoL measurement includes physical, psychological, social and cognitive domains. QoL in this chapter is discussed in relation to common issues like employment, social and community reintegration after TBI, importance of education, marital status in comparison to others in the community.

### Included studies by question category

Frequency	Diagnosis	Treatment	Prognosis
<ul style="list-style-type: none"> <li>a. Brown et al (1998)</li> </ul>	<ul style="list-style-type: none"> <li>o Findler et al (2000)</li> <li>o Berger et al (1999)</li> <li>o Sander et al (1999)</li> </ul>		<ul style="list-style-type: none"> <li>o Ruffolo et al (1999)</li> <li>o Wagner (2002)</li> <li>o O'Neill et al (1998)</li> <li>o Cifu et al (1997)</li> <li>o Coleman et al (2002)</li> <li>o Fleming et al (1999)</li> </ul>

## **How does quality of life in people with traumatic brain injury compare with the general community?**

Brown et al (1998) compared QoL scores in 430 TBI patients with 101 people with spinal cord injury and 187 people with no disability. They interviewed participants and collected data about their perceived quality of life and unmet needs. They found that people with more severe TBI were more likely to have QoL scores similar to the no disability group. On the other hand, mild TBI patients perceived their QoL as worse than controls.

Brown also found that the unmet important needs were relatively large in TBI patients and were particularly strong in the areas of work, socializing, close friends and significant other. Factors that were highly correlated with QoL also included material comforts, parenting, close friends, learning, understanding and expressing self and active recreation.

## **What clinically useful scales or tools are most effective in assessing quality of life in patients with traumatic brain injury?**

As discussed earlier in this section, an accepted definition and a well-validated measurement tool for QoL is not really available for brain-injured patients. Berger et al (1999) undertook a systematic review of the literature on QoL assessment in TBI patients and concluded that no one scale could be considered best for QoL because there is no homogeneity in definition of QoL amongst the literature.

We found one study that tested a well-validated clinically useful scale on TBI patients. Findler et al (2001) found that Medical Outcomes 36-Item Short Form Health Survey or SF-36 was reliable and valid as a measure of health-related QoL in TBI patients. They assessed health-related QoL in 271 patients without disability, 98 with mild TBI and 228 with moderate-severe TBI. After controlling for age, income, gender and depression SF-36 scores they reported similar results to Brown et al. TBI patients had lower SF-36 scores than controls on all subscales (general health, physical functioning, physical role, bodily pain, vitality, emotional role, mental health, social functioning). Like Brown, they found that mild TBI patients had lower health-related QoL scores than moderate-severe TBI patients.

Another widely accepted measure that relates to QoL is the Community Integration Questionnaire (CIQ). This includes questions about Home Competency, Social Integration, and Productive Activity and has been revised and well validated by Sander et al (1999) in 312 TBI patients. A copy of the CIQ is available at the back of this book.

## **In patients with traumatic brain injury, are rehabilitation programs, psychosocial, family, and social supports more effective than no treatment in improving quality of life?**

We found no studies that directly attempted to improve quality of life although elements of QoL may be improved by interventions for cognition, behaviour and physical health.

## **In patients with traumatic brain injury, what is the probably long-term trend in quality of life?**

Employment, social or community integration, education, and marital status, were reported by number of studies (Level III-2) to significantly influence quality of life in traumatic brain injured patients.

O'Neill et al (1998) showed in 337 TBI patients that employment had a consistent and strong relationship with perceived QoL, social integration within the community and home and leisure activities. Part-time workers had fewer unmet needs, were more socially engaged and participated in more home activities than full-time workers ( $p < .03$ ).

Ruffolo et al (1999) found that 42% of their cohort of 50 motor vehicle accident victims with mild TBI returned to work, 12% returned to pre-morbid employment levels and 30% returned to modified duties. Wagner et al (2002) found that 72% of their cohort of 105 consecutively admitted TBI patients had returned to productive activity 12 months post-injury. Cifu et al (1997) found that severity of injury and poor scores on the Disability Rating Scale and Glasgow Coma Scales during admission were related to a reduced likelihood of return to work.

Coleman et al (2002) conducted an interesting study on 71 pairs of adults who had sustained a TBI and their significant others. They found that the caregiver's perception of the patient's fitness was the strongest determinant of how much patients drive. However, unlike medical assessment, caregiver perception was not correlated with the number of driving incidents that occurred.

Fleming et al (1999) surveyed 209 TBI patients and their carers 2-5 years following their injury and found that age, injury severity and cognition were important prognostic indicators of return to work. A total of 46.5% patients had returned to work with 74.5% of these in the same or similar jobs.

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## Section 2: FUNCTIONAL STATUS

### KEY POINTS:

1. Functional difficulties are more common in patients with severe TBI than in mild-moderate groups or controls with lower limb injuries. Functional difficulties are less common than cognitive difficulties in most TBI patients (Level III-2).
2. Most tools for measuring functional status have been designed for use in the acute and post-acute hospital setting. The Neurobehavioural Functioning Inventory (NFI) and Patient Competency Rating Scale (PCRS) appear to be the most clinically useful in the community setting (Level III-2).
3. Concurrent administration of the PCRS to TBI patients and significant others in severely injured patients may be a useful tool for identifying self-awareness problems (Level III-2).
4. There is limited evidence for the effectiveness of individual placement and/or apprenticeship models of supported employment for TBI patients (Level I).
5. There is limited and conflicting evidence about the effectiveness of coordinated care and case management models for TBI patients (Level I)
6. Functional status is dynamic but generally improves over the first two years following TBI. Predictors of final functional status are uncertain (Level III-2).

### Included studies by question category

Frequency	Diagnosis	Treatment	Prognosis
One study (Level III-2)	Two studies (Level III-2)	One systematic review (Level I)	Three studies (Level III-2)
<ul style="list-style-type: none"> <li>b. Masson et al (1996)</li> </ul>	<ul style="list-style-type: none"> <li>o Hall et al (2001)</li> <li>o Leatham et al (1998)</li> </ul>	<ul style="list-style-type: none"> <li>o Carney et al (1999)</li> </ul>	<ul style="list-style-type: none"> <li>o Corrigan et al (1998)</li> <li>o Novack et al (2001)</li> </ul>

### In patients with traumatic brain injury, how common are functional difficulties, compared to others with disability?

Masson et al (1996) in their cohort study of 231 TBI adult patients found that 5 years post-injury, functional difficulties were more common in severe TBI patients and relatively uncommon in mild-moderate TBI patients. Thirty seven per cent of severe TBI patients reported difficulty with washing, 22.2% difficulty with dressing, 44.4% difficulty with walking, 25.9% difficulty going outside and 29.6% difficulty using public transport. These are likely to be underestimates given the tendency for severe TBI patients to under-rate disabilities (see below).

Functional difficulties were less common than cognitive difficulties in most TBI patients. Lower-limb injured control patients had less functional difficulty than severe TBI patients but more than the mild and moderate TBI patients.

### In patients with traumatic brain injury, what symptoms and/or tests are in diagnosing issues of functional status, return to work and daily living?

As was the case with the measurement of cognitive, behavioural and quality of life outcomes, we have limited our discussion to assessment tools that are clinically useful in the general practice context. Most measures of functional status have been developed for hospital use (eg observing skills over a week or more as an inpatient).

Hall et al (2001) assessed some of the commonly used scales for functional status in TBI patients but considered whether they were applicable in the community setting. These included the Community Integration Questionnaire (CIQ), Neurobehavioural Functioning Inventory (NFI), Patient Competency Rating Scale (PCRS), Level of Cognitive Functioning Scale (LCFS), FIM<sup>TM</sup> instrument, Functional Assessment Measure (FIM + FAM), Supervision Rating Scale (SRS), Disability Rating Scale (DRS), Revised Craig Handicap Assessment and Reporting Technique (R-CHART) and Glasgow Outcomes Scale (GOS). Forty eight individuals with a history of moderate-severe TBI 2-9 years post-injury were assessed with all instruments. Although there are some methodological limitations, this was the only study we found that considered the applicability of functional status measurement in a community setting.

Hall discusses the fact that many of the functional status measurement tools have been developed for use in the acute and post-acute setting and found that a 'ceiling effect' (or near maximum score) was common with many of the instruments. It was suggested from this analysis that the PCRS or NFI would be the most useful in a community setting. [NB: The NFI is discussed in the behaviour section of this document].

The PCRS has been further tested by Leathem et al (1998) amongst 53 TBI patients with a range of injury severity, their significant others and 131 controls. TBI patients tended to overrate their pre-accident competency compared with controls. As was the case with self-assessment of QoL, severe TBI patients tended to overestimate their competence compared with the ratings their significant others gave them, whilst the mild and moderate TBI patient-ratings were generally consistent with their carers. In the general practice setting it may be a useful screening tool for assessing self-awareness, particularly in patients with a history of severe TBI who are the most likely to have functional difficulties in the longer term.

### **In patients with traumatic brain injury, does supported employment or long-term care coordination enhance functional status compared with no therapy?**

A systematic review by Carney et al (1999) found limited evidence that supported employment can improve vocational outcomes in TBI patients. Carney describes at least five models of supported employment: (1) individual placements, (2) work enclaves, (3) apprenticeships, (4) small businesses, and (5) mobile work crews. The most commonly used and researched model is individual placement with training and ongoing individual support in an environments which has less than 5% workers disabled. Ideally the job placement should be matched for the client, job site training and advocacy should occur, there should be ongoing assessment of performance and early intervention and monitoring of potential problems. There is also limited evidence for the effectiveness of an apprenticeship model with TBI patients. Several studies have shown such a model to be associated with improved vocational outcomes in TBI patients but its feasibility and cost-effectiveness is not well evaluated.

There is limited and conflicting evidence about the effectiveness of case management and care coordination models on functional and other outcomes.

### **In patients with traumatic brain injury, what is the likely long-term functional status?**

Novack et al (2001) studied 107 patients with severe TBI resulting from road accidents and reported that premorbid factors (particularly employment), injury severity and cognitive status influenced functional status 12 months after injury. Corrigan et al found in 95 TBI patients that functional status varied greatly over the period 6 months to 5 years post-injury. Mostly they observed an improvement over the first 2 years, In contrast to Novack; they found that premorbid characteristics, injury severity and initial functional status were not predictive of final outcome.

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### Section 3:

#### ISSUES FOR CARERS, FRIENDS AND FAMILY OF TBI PATIENTS:

##### KEY POINTS:

1. Estimates of primary caregiver stress and family dysfunction vary considerably. They may be as low as 10% or as high as 68% (Level IV).
2. Primary carers (particularly wives) are at greatest risk of poor psychological outcomes. Male relatives (most of whom are secondary or tertiary carers) are likely to express their distress as anger or fatigue rather than depression or anxiety. This should be considered in assessing caregiver and family stress (Level IV).
3. Behavior management programs and provision of written material had no significant effect on reducing caregiver burden. There was inconclusive evidence about the effect of perceived level of social support on reducing caregiver distress (Level III-2).
4. The Family Needs Questionnaire (FNQ) and the Caregivers Appraisal Scales (CAS) have both been validated in TBO caregivers and found to be reliable and clinically useful (Level IV)
5. There is insufficient evidence for the effectiveness of education and case management programs on caregiver stress and burden in families of TBI patients (Level I & II).
6. Caregiver stress is greater if the TBI sufferer has a psychosocial history and in those who have financial barriers to accessing services. Social support structures appear to play an important role in the prognosis for caregiver burden (Level III-2).

In TBI literature carers/caregivers are defined as relatives or family members consisting of primary, secondary or tertiary carers. There is no consistent definition of carer's burden, stress or distress although carer's common problems are measured in terms of psychosocial disability/distress; family satisfaction/dysfunction, caregiver's perception of self-reported level of burden/stress (subjective or objective) attributable to changes in the person with brain injury (Perlesz et al).

##### Included studies by question category

Frequency	Diagnosis	Treatment	Prognosis
c. Perlesz et al (2000)	o Struchen M (2002)	o Carnevale G et al (2002)	o Douglas et al (1996)
d. Ergh et al (2002)	o Serio et al (1997)	o Sinnakaruppan et al (2001)	o Hall et al (1994)
e. Kolakowsky-Hayner et al (2001)			o Marsh et al (1998)
f. Sinnakaruppan et al (2001)			o Lanham et al (2000)

#### How common and what issues affect carers, friends, and family of individuals with traumatic brain injury?

Perlesz et al (2000) surveyed 79 families of individuals with TBI and reported that psychological distress was more common in the head-injured family member than their carers. 60% of TBI patients had depression 37.7% of primary carers on the Beck Depression Inventory. 50% TBI

patients had anxiety on the State Anxiety Scale and 44.1% primary carers; 24.4% TBI patients reported family dissatisfaction whereas 10.5% primary carers reported family dissatisfaction.

Ergo et al (2002) assessed 60 pairs of TBI-caregiver adults and found that family dysfunction was reported in 60-68%. This study also suggested that a lower level of family dysfunction is associated with a higher perceived level of social support.

Kolakowsky-Hayner et al (2001) surveyed 57 US caregivers of persons with TBI and found that Health information (51%) and Involvement in Care (47.93%) were the needs most often met. On the other hand, Instrumental Support such as help with housework and getting a break from responsibilities (31.52%) and Professional Support such as legal, financial, nursing, respite care (28.38%) were the needs most often rated as unmet.

Sinnakaruppan et al (2001) undertook a systematic review on the need so TBI caregivers and reviewed 13 studies. They reported that the carer identified needs identified as being most important related to information. Most unmet needs related to emotional support. Unmet needs appeared to relate to behavioural problems in the TBI relative. Spousal needs appear to be greater than parental, possibly due to the role change incurred by the spouse.

### **In families with individuals who have TBI, what assessment tools are available for diagnosing problems for carers, friends, and family?**

We found that many studies either used scales that had not been developed or tested with TBI caregivers and/or they had not been validated.

One study, Struchen et al (2002), investigated the factor structure and concurrent validity of the Caregiver Appraisal scale (CAS) in a sample of 241 caregivers of people with TBI. It yielded four factors across a 35-item questionnaire – perceived burden (PB), caregiver relationship satisfaction (CRS), caregiver ideology (CI) and caregiving mastery (CM). It appears to be both a valid and clinically useful scale for assessing the caregiver experience in TBI families.

The Family Needs Questionnaire (FNQ) of 37 items has also been validated in TBI patients. It has six domains 1) Need for Health Information 2) Need for Emotional Support 3) Need for Instrumental Support 4) Need for Professional Support 5) Need for Support network and 6) Need for Involvement with care. It was found to be valid and reliable when tested with 178 TBI primary caregivers.

### **In families of a person with traumatic brain injury, are case management programs or education programs effective in reducing caregiver stress and burden compared with no program?**

We found one small randomised trial and a systematic review of interventions to reduce caregiver stress and burden. Carnevale G et al randomised 27 patients and their caregivers to receive either a weekly 2-hour education session for four weeks, education extended to 8 weeks or no education. They showed no difference between groups but this study was very underpowered and therefore inconclusive.

Sinnakaruppan et al (2001) reviewed seven studies of case management programs to reduce caregiver burden in the community. Due to the poor quality of the identified studies they were unable to conclude any effect on caregiver burden.

### **In families of patients with traumatic brain injury, what is the likely prognosis for caregiver stress and burden?**

An inception cohort study of 69 TBI families by Marsh et al (1998) showed that the TBI person's emotional difficulties, particularly anger, apathy and dependency caused the greatest distress for caregivers. Carers were most distressed by their own loss of personal free time one year after

injury. Lanham et al (2000) noted that concordance between 55 carer and patient ratings on the Katz Adjustment Scale improved between 6 and 12 months after injury. They postulate that with time, carers gain awareness and patient outcomes often improve. Douglas et al (1996) describe that after 3.5 years social support, caregiver depression, coping and perceptions of patient competency are predictive of long-term family functioning.

Hall et al (1994) studied 55 TBI families over 3.5 years and found that although caregiver perceived stress did not significantly change over time, carers reported an increase in medication use, a change in employment and an increase in financial stress. 47% of caregivers had altered or given up their jobs at one year and 33% at two years post-injury. Spouses reported a higher and increasing number of behavioural problems compared to parents. Stress was higher in caregivers of TBI patients with a psychosocial history and in those who had financial barriers to accessing services.

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## CHAPTER 6: SUBSTANCE USE DISORDER:

### KEY POINTS:

1. Alcohol use is frequently related to TBI with high pre-injury alcohol use in most populations studied (Level III-2).
2. Younger TBI patients and those who had high pre-injury consumption levels are most at risk of post-injury alcohol abuse. There is conflicting evidence about the post-injury patterns of alcohol use although one study over a longer time period suggests that use increases with duration since injury (Level III-2).
3. 42% head injured with varying severity were legally intoxicated (above 100mg/dL) blood alcohol level on presentation in emergency department.
4. The CAGE questionnaire for alcohol abuse has 86% specificity and 91% sensitivity following TBI. The SASSI-3 was an effective tool in screening for drug abuse in individuals with TBI.
5. TBI patient self-reports of alcohol use may be fairly reliable (Level IV).
6. Once problem drinking is identified it may be best to use more detailed multidimensional and composite measures (Level III-2).
7. There is limited evidence that comprehensive case management in TBI patients with alcohol problems increases employment, community integration and physical well-being compared with no case management. There is also limited evidence that Systematic Motivational Counselling improves motivational structure and possibly reduces substance use (Level II and Level III-2)
8. There is some evidence that alcohol use declines in the first year following TBI but may increase gradually over subsequent years. (Level III-2)

### **How common are substance abuse disorders in traumatic brain injured as compared to the general community?**

Kreutzer et al (1996) found in 322 TBI patients that alcohol use patterns were dynamic during the 4 years post-injury. The TBI patients generally had a higher alcohol consumption rate prior to injury and certainly many injuries were alcohol-related. Higher post-injury consumption levels were more likely in younger patients and in those who had high blood alcohol levels on admission. Injury severity was also correlated with consumption levels but they found that in general post-injury alcohol consumption rates were no higher than the general community.

Similarly, Corrigan et al (1995) found that more than 60% of TBI's were alcohol-related, including 71% of assaults and 66% of moving vehicle accidents. More than half of the 95 TBI patients involved in the US study reported prior use of marijuana. Like Kreutzer they also found that prior to injury the study sample consumed higher than average amounts of alcohol. However, unlike Corrigan, they found that approximately 10% of TBI patients appear to increase their consumption following injury. In fact, they found that 20% who were abstinent or light drinkers before injury, increased their consumption to moderate-heavy levels following injury. They also observed a gradual increase in consumption over time since injury in their sample. Twenty-eight per cent of people 2 years or less from injury reported medium-high alcohol use compared with 38% in the 2-5 year range and 48% in the greater than 5 year group.

Bombardier et al (2002) concur with the findings of high alcohol related injury rates on admission. In their survey of 146 TBI patients they found that 59% were at-risk drinkers. Thirty four per cent

reported recent illicit drug use and 37% had toxicology results that were positive for illicit substances.

Dikmen S et al (1995) in a cohort study (n=197) of broad spectrum head injured reported 42% were legally intoxicated (above 100mg/dL) blood alcohol level on presentation in emergency department.

### **What assessment tools are most accurate and clinically useful for substance abuse problems in people with traumatic brain injury?**

A number of clinically useful assessment tools have been tested and validated in TBI populations. Ashman et al (2004) tested CAGE, the Brief Michigan Alcohol Screening test (BMAST) and the Substance Abuse Subtle Screening Inventory (SASSI-3) with 100 TBI patients and reported that the specificity of CAGE pre and post TBI was high, 96% and 86% respectively. The SASSI face valid drug scale had 95% sensitivity for drug abuse post-injury and CAGE and 91% sensitivity for alcohol abuse post-injury. Both instruments are valid, reliable and clinically useful.

Arenth et al (2001) found limitations in the SASSI-3 amongst 78 TBI subjects. It appeared to have lower sensitivity and specificity as a screening tool in TBI patients than the general population. However once substance abuse was identified the sensitivity and specificity increased.

Cherner et al (2001) developed a more detailed composite measure to detect problematic drinking in TBI patients. This instrument may be useful as a secondary assessment tool for those already identified as a problem drinker. It captures multiple dimensions of alcohol abuse and appears to be closely related to pre-injury problematic psychosocial histories.

Sander et al (1997) showed a strong correlation between patient and carer reports of alcohol use using both the B-MAST and the Quantity-Frequency-Variability Index (QFVI). This suggests that TBI patient self-reports of alcohol use may be quite reliable.

### **Is comprehensive case management, systematic motivational counselling, or vocational rehabilitation more effective than no treatment in alcohol or drug abuse related disorders in traumatic brain injured?**

Heinemann et al (2004) evaluated a community-based case management program for substance abuse treatment and prevention compared with no case management (n=309). They found that case management was associated with employment, greater community integration and physical well-being than those not receiving case management.

Cox et al (2003) compared Systematic Motivational Counselling (SMC) in 40 TBI patients with 54 TBI patients who received no motivational or substance-abuse treatment. The SMC consisted of 12 individual counselling sessions that focused on personal goals and concerns. The SMC group showed significant improvements in motivational structure, reduction in negative affect and in the use of substances.

### **In patients with traumatic brain injury, what is the likely prognosis of alcohol or drug abuse related disorders?**

As stated earlier, there is conflicting evidence about the post-injury patterns of alcohol use in TBI patients. Bombardier et al (2003) found that drinking and alcohol-related problems decreased during the first 12 months following injury in their cohort of 197 adults with TBI.

Dikmen et al (1995) reported that alcohol use initially decreased following injury but gradually increased over the first year, not quite reaching pre-injury levels. As discussed earlier, Corrigan et al (1995) demonstrated a trend for alcohol use to increase over time since injury.

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## Chapter 7: Useful resources for general practitioners: Diagnostic tools and checklists

The following pages contain some of the diagnostic checklists that have been referred to in these guidelines as valid and useful in TBI patients. We have obtained permission from the original authors to reproduce these so that they can be used in clinical practice.

### Dizziness Handicap Inventory:<sup>3</sup> (from Chapter 2 Section 2 Somatic Complaints p11)

The screening version of the Dizziness Handicap Inventory has been shown to be reliable in TBI patients both for the diagnosis of dizziness and also for monitoring the effect of treatment

#### **Scoring**

“Yes” is scored 4 points.

“Sometimes” is scored 2 points.

“No” is scored 0 points.

There are three subscales:

P = Physical

E = Emotional

F = Functional

Maximum possible score in 100

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<sup>3</sup> Jacobson, GP & Newman, CW 1990, 'The development of the Dizziness Handicap Inventory', *Archives of Otolaryngology -- Head & Neck Surgery*, vol. 116, no. 4, pp. 424-7.

NAME:

DATE:

**DIZZINESS HANDICAP INVENTORY (DHI)**

Instructions: The purpose of this questionnaire is to identify difficulties that you may be experiencing because of your dizziness or unsteadiness. Please answer “yes”, “no”, or “sometimes” to each question. **Answer each question as it pertains to your dizziness problem only.**

Question	Yes (4)	Sometimes (2)	No (0)
P1. Does looking up increase your problem?			
E2. Because of your problem do you feel frustrated?			
F3. Because of your problem do you restrict your travel for business or recreation ?			
F4. Does walking down the aisle of a supermarket increase your problem?			
F5. Because of your problem do you have difficulty getting into or out of bed.			
F6. Does your problem significantly restrict your participation in social activities such as going out to dinner, going to the movies, dancing, or to parties?			
F7. Because of your problem do you have difficulty reading?			
P8. Does performing more ambitious activities like sports, dancing, household chores, such as sweeping or putting dishes away, increase your problem?			
E9. Because of your problem are you afraid to leave your home without having someone accompany you?			
E10. Because of your problem have you been embarrassed in front of others?			
P11. Do quick movements of your head increase your problem?			
F12. Because of your problem do you avoid heights?			
P13. Does turning over in bed increase your problem?			
F14. Because of your problem is it difficult for you to do strenuous housework or yardwork?			
E15. Because of your problem are you afraid people may think that you are intoxicated?			
F16. Because of your problem is it difficult for you to go for a walk by yourself?			
17. Does walking down a sidewalk increase your problem?			
18. Because of your problem is it difficult for you to concentrate?			
19. Because of your problem is it difficult for you to walk around your house in the dark?			
20. Because of your problem are you afraid to stay home alone?			
21. Because of your problem do you feel handicapped?			
22. Has your problem placed stress on your relationships with members of your family and friends?			
23. Because of your problem are you depressed?			
24. Does your problem interfere with your job or household responsibilities?			
25. Does bending over increase your problem?			
<b>FUNCTIONAL</b>	<b>EMOTIONAL</b>	<b>PHYSICAL</b>	<b>TOTAL SCORE</b>

## Rivermead Post-concussion Questionnaire: (from Chapter 2 Section 3 Post-concussion syndrome p11)

After a head injury or accident some people experience symptoms which can cause worry or nuisance. We would like to know if you now suffer any of the symptoms given below. As many of these symptoms occur normally, we would like you to compare yourself now with before the accident. For each one please circle the number closest to your answer.

- 0= Not experienced at all
- 1= no more of a problem
- 2= a mild problem
- 3= a moderate problem
- 4= a severe problem

Compared with before the accident, do you now (i.e. over the last 24 hours suffer from):

Headaches	0	1	2	3	4
Feelings of dizziness	0	1	2	3	4
Nausea and/or vomiting	0	1	2	3	
Noise sensitivity, Easily upset by loud noise	0	1	2	3	4
Sleep disturbance	0	1	2	3	4
Fatigue, tiring more easily	0	1	2	3	4
Being irritable, easily angered	0	1	2	3	4
Feeling depressed or tearful	0	1	2	3	4
Feeling frustrated or impatient	0	1	2	3	4
Forgetfulness, poor memory	0	1	2	3	4
Poor concentration	0	1	2	3	4
Taking longer to think	0	1	2	3	4
Blurred vision	0	1	2	3	4
Light sensitivity, Easily upset by bright light	0	1	2	3	4
Double vision	0	1	2	3	4
Restlessness	0	1	2	3	4

Are you experiencing any other difficulties?  
Please specify, and rate as above:

1. \_\_\_\_\_
2. \_\_\_\_\_

## Homeopathic medicines found to be effective in post-concussion syndrome (Chapter 2 Section 3 p11)<sup>4</sup>

**Homeopathic Medicines: The 18 study medicines are presented with their common or chemical names, as well as their indications**

**Argentum nitricum** (Silver nitrate, AgNO<sub>3</sub>) - Anticipation, impulsiveness, agoraphobia, claustrophobia, vertigo, and photophobia  
**Arnica montana** (Leopards Bane)- Tenderness, bruised sensations, denial of illness, hopeless indifference, vertigo, sensations of heat or pressure in the head, and diplopia.  
**Aurum metallicum** (Gold, Au)- Suicidal depression, feeling of neglecting ones duty, violent headaches often with heaviness in the chest and photophobia  
**Baryta carbonica** (Barium carbonate, BaCO<sub>2</sub>) – Slowed mental function, irresolution, lack of confidence, paranoia, and parathesiae.  
**Calcarea carbonica** (Calcium carbonate, CaCO<sub>2</sub>) - paranoia, chills, perspiration, symptoms worse on exertion, and insomnia due to anxiety.  
**Cicuta virosa** (Water hemlock) – Convulsions, cramps, strabismus, visual disturbance, tinnitus, childish behaviour, estrangement, and want of confidence in mankind  
**Cocculus indica** (Indian cockle)- Insomnia, reaction time slowed, nausea from sight or smell of food, motion sickness, weakness, numbness trembling, empty and hollow sensation.  
**Helleborus niger** (Snow-rose)- Stupor, staring/thoughtless, slow forgetful, feels doomed, what the patient sees, hears or tastes makes no impression on mind, and worse 4-8 p.m.  
**Hyoscyamus niger** (Henbane)- Suspicion, violent outbursts, loquacity or silent disposition, shamelessness, playing with fingers, twitchings, jerks and cramps.  
**Hypericum perforatum** (St. Johns Wort)- Mistakes in writing, omitting letters, headache, vertigo, convulsions, neuralgic pains worse with change of weather.  
**Lachesis muta** (Bushmaster snake venom)- Overactivity, loquacity, vivid imagination, passionate and intense, better discharges, especially menses, left-sided complaints and worse after sleep.  
**Natrum muriaticum** (NaCl) - Defensive, closed, cautious, dwells on past, disagreeable occurrences, silent grief, averse to consolation, headaches, desire for salt, worse with heat, sun and at the seaside.  
**Natrum sulphuricum** (NaSO<sub>4</sub>) – Objective, realistic, no delusions, sadness, and suicidal tendency, headaches, photophobia, vertigo, worse dampness, aggravated, in the morning after rising, and at 4-5 a.m.  
**Nux moschata** (Nutmeg) - Dreamy, confused, slowness of response, overpowering sleepiness, sensation of extreme dryness of mouth and throat, yet no thirst.  
**Nux Vomica** (Poison-nut) – Ineffectual urging [work, stool micturation], fastidious, ambitious, unrefreshed, irritable, depressed, chilly after over medication, use of stimulants and cramps.  
**Papaver somniferum** (Opium) - Disassociation after fright, flashbacks, unaffected by external impressions or boldness and fearlessness, somnolence, snoring respiration and constipation.  
**Silica** (SiO<sub>2</sub>) - Obstinate, fixed ideas, lack of confidence, fastidious, occipital headaches, sensitive to noise, drafts and slowness  
**Sulphur** (S) - Self-centered, theorizing, no depth or focus; lazy, messy, warm-blooded, burning pains and sensations, offensive, excoriating discharges, desire for sweets and spicy food, and itching.

<sup>4</sup> Chapman, EH, Weintraub, RJ, Milburn, MA, Pirozzi, TO & Woo, E 1999, 'Homeopathic treatment of mild traumatic brain injury: A randomized, double-blind, placebo-controlled clinical trial', *Journal of Head Trauma Rehabilitation*, vol. 14, no. 6, pp. 521-42.

## TIRR Symptom Checklist (Chapter 4 Section 1 & 2)

The following is a list of 67 symptoms. If you experience a symptom 'daily' or 'almost daily' tick the 'Yes' box. If you do **not** experience the symptom or you have it only on some days then tick the 'no' box.

<b>Cognitive Symptoms</b>	<b>Yes</b>	<b>No</b>
<b>Do you have current difficulty with</b>		
Remembering names	<input type="checkbox"/>	<input type="checkbox"/>
Reading, writing, or doing maths	<input type="checkbox"/>	<input type="checkbox"/>
Solving problems	<input type="checkbox"/>	<input type="checkbox"/>
Speech	<input type="checkbox"/>	<input type="checkbox"/>
Getting lost easily in unfamiliar places	<input type="checkbox"/>	<input type="checkbox"/>
Performing your job or school work	<input type="checkbox"/>	<input type="checkbox"/>
Seeing another person's point of view	<input type="checkbox"/>	<input type="checkbox"/>
Remembering recent events, appointments, schedules	<input type="checkbox"/>	<input type="checkbox"/>
Becoming confused in familiar places	<input type="checkbox"/>	<input type="checkbox"/>
Caring for others for whom you are responsible (child/parent)	<input type="checkbox"/>	<input type="checkbox"/>
Getting fired from job or put on probation at school	<input type="checkbox"/>	<input type="checkbox"/>
Planning future events	<input type="checkbox"/>	<input type="checkbox"/>
Learning new information	<input type="checkbox"/>	<input type="checkbox"/>
Handling your personal affairs or finances	<input type="checkbox"/>	<input type="checkbox"/>
Making quick decisions without thinking about consequences	<input type="checkbox"/>	<input type="checkbox"/>
Concentrating	<input type="checkbox"/>	<input type="checkbox"/>
Being easily distracted	<input type="checkbox"/>	<input type="checkbox"/>
Forgetting or missing appointments	<input type="checkbox"/>	<input type="checkbox"/>
Forgetting phone numbers	<input type="checkbox"/>	<input type="checkbox"/>
Forgetting to do chores or work	<input type="checkbox"/>	<input type="checkbox"/>
Forgetting to eat	<input type="checkbox"/>	<input type="checkbox"/>
Forgetting to take medication	<input type="checkbox"/>	<input type="checkbox"/>
Forgetting what you read	<input type="checkbox"/>	<input type="checkbox"/>
Arriving late for appointments	<input type="checkbox"/>	<input type="checkbox"/>
Learning slowly	<input type="checkbox"/>	<input type="checkbox"/>
Thinking slowly	<input type="checkbox"/>	<input type="checkbox"/>
Trouble following instructions	<input type="checkbox"/>	<input type="checkbox"/>
Losing your train of thought	<input type="checkbox"/>	<input type="checkbox"/>
Forgetting things you have done	<input type="checkbox"/>	<input type="checkbox"/>
Forgetting to turn off appliances	<input type="checkbox"/>	<input type="checkbox"/>
Being disorganised	<input type="checkbox"/>	<input type="checkbox"/>
Finding it hard to get started on things	<input type="checkbox"/>	<input type="checkbox"/>
Not being able to think of the right word	<input type="checkbox"/>	<input type="checkbox"/>
Making conversation	<input type="checkbox"/>	<input type="checkbox"/>
Talking too fast or slow	<input type="checkbox"/>	<input type="checkbox"/>

## TIRR Checklist (cont'd)

### Behavioural/Affective Symptoms

Yes

No

#### Do you have current difficulty with

Arrests	<input type="checkbox"/>	<input type="checkbox"/>
Loneliness	<input type="checkbox"/>	<input type="checkbox"/>
Dealing with people	<input type="checkbox"/>	<input type="checkbox"/>
An increased number of arguments or fights	<input type="checkbox"/>	<input type="checkbox"/>
Loss of former relationships	<input type="checkbox"/>	<input type="checkbox"/>
Feeling nervous, irritable, anxious	<input type="checkbox"/>	<input type="checkbox"/>
Feeling bored	<input type="checkbox"/>	<input type="checkbox"/>
Breaking or throwing things	<input type="checkbox"/>	<input type="checkbox"/>
Complaining	<input type="checkbox"/>	<input type="checkbox"/>
Cursing at others	<input type="checkbox"/>	<input type="checkbox"/>
Cursing at yourself	<input type="checkbox"/>	<input type="checkbox"/>
Hitting or pushing others	<input type="checkbox"/>	<input type="checkbox"/>
Feeling impatient	<input type="checkbox"/>	<input type="checkbox"/>
Screaming or yelling	<input type="checkbox"/>	<input type="checkbox"/>
Threatening to hurt others	<input type="checkbox"/>	<input type="checkbox"/>
Threatening to hurt yourself	<input type="checkbox"/>	<input type="checkbox"/>

### Physical Symptoms

Yes

No

#### Do you have current difficulty with

Headaches	<input type="checkbox"/>	<input type="checkbox"/>
Handling your personal care (hygiene, cooking etc)	<input type="checkbox"/>	<input type="checkbox"/>
Changes in the ability to feel hot, cold, pain, or touch	<input type="checkbox"/>	<input type="checkbox"/>
Dizziness	<input type="checkbox"/>	<input type="checkbox"/>
Changes in the sense of taste or smell	<input type="checkbox"/>	<input type="checkbox"/>
Loss of use of any body part	<input type="checkbox"/>	<input type="checkbox"/>
Vision problems	<input type="checkbox"/>	<input type="checkbox"/>
Clumsiness	<input type="checkbox"/>	<input type="checkbox"/>
Weakness of any body part	<input type="checkbox"/>	<input type="checkbox"/>
Hearing problems	<input type="checkbox"/>	<input type="checkbox"/>
Balance problems	<input type="checkbox"/>	<input type="checkbox"/>
Double vision	<input type="checkbox"/>	<input type="checkbox"/>
Moving slowly	<input type="checkbox"/>	<input type="checkbox"/>
Staying awake	<input type="checkbox"/>	<input type="checkbox"/>
Waking up	<input type="checkbox"/>	<input type="checkbox"/>
Blurred vision	<input type="checkbox"/>	<input type="checkbox"/>

# Neurobehavioural Functioning Inventory (NFI) – (Chapter 4 Section 2 Behaviour)

## Carer Competency Rating Scale (NFI)

Patients Name: \_\_\_\_\_

Patients Age: \_\_\_\_\_

Date: \_\_\_\_\_

Informants relationship to patient (circle one):

- |                  |                    |
|------------------|--------------------|
| 1. Mother        | 8. Niece or nephew |
| 2. Father        | 9. Cousin          |
| 3. Spouse        | 10. Friend         |
| 4. Child         | 11. In-law         |
| 5. Sibling       | 12. War attendant  |
| 6. Grandparent   | 13. Other _____    |
| 7. Aunt or Uncle |                    |

Sex of informant:

Male \_\_\_\_\_

Female \_\_\_\_\_

How well is informant acquainted with patients behavior?

- |                  |                |
|------------------|----------------|
| 1. Hardly at all | 4. Pretty well |
| 2. Not so well   | 5. Very well   |
| 3. Fairly well   |                |

Instructions:

The following is a questionnaire that asks you to judge your ability to do a variety of very practical skills. Some of the questions may not apply directly to things you often do, but you are asked to complete each question as if it were something you "had to do". On each question, you should judge how easy or difficult a particular activity is for you and mark the appropriate space.

<b>Competency Rating (carer version)</b>	Can do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease
1. How much of a problem do they have in preparing my own meals?	—	—	—	—	—
2. How much of a problem do they have in dressing myself?	—	—	—	—	—
3. How much of a problem do they have in taking care of my personal hygiene?	—	—	—	—	—
4. How much of a problem do they have in washing the dishes?	—	—	—	—	—
5. How much of a problem do they have in doing the laundry?	—	—	—	—	—
6. How much of a problem do they have in taking care of my finances?	—	—	—	—	—
7. How much of a problem do they have in keeping appointments in time?	—	—	—	—	—
8. How much of a problem do they have in starting conversation in a group?	—	—	—	—	—
9. How much of a problem do they have in staying involved in work activities even when bored or tired?	—	—	—	—	—
10. How much of a problem do they have in remembering what they had for dinner last night?	—	—	—	—	—
11. How much of a problem do I have in remembering names of people I see often?	—	—	—	—	—
12. How much of a problem do they have in remembering their daily schedule?	—	—	—	—	—
13. How much of a problem do they have in remembering important things they must do?	—	—	—	—	—
14. How much of a problem do they have driving a car if they had to?	—	—	—	—	—

- |   |   |   |   |   |   |
|---|---|---|---|---|---|
| 15. How much of a problem do they have in getting help when they are confused?  | — | — | — | — | — |
| 16. How much of a problem do they have in adjusting to unexpected changes?  | — | — | — | — | — |
| 17. How much of a problem do they have in handling arguments with people they know well?                                | — | — | — | — | — |
| 18. How much of a problem do they have in accepting criticism from other people?  | — | — | — | — | — |
| 19. How much of a problem do they have in controlling crying?   | — | — | — | — | — |
| 20. How much of a problem do they have in acting appropriately when they are around friends?                            | — | — | — | — | — |
| 21. How much of a problem do they have in showing affection to people?  | — | — | — | — | — |
| 22. How much of a problem do they have in participating in group activities?  | — | — | — | — | — |
| 23. How much of a problem do they have in recognizing when something they say or do has upset someone else?             | — | — | — | — | — |
| 24. How much of a problem do they have in scheduling their daily activities?  | — | — | — | — | — |
| 25. How much of a problem do they have in understanding new instructions?   | — | — | — | — | — |
| 26. How much of a problem do they have in consistently meeting their daily responsibilities?                            | — | — | — | — | — |
| 27. How much of a problem do they have in controlling my temper when something upsets them?                             | — | — | — | — | — |
| 28. How much of a problem do they have in keeping from being depressed?   | — | — | — | — | — |
| 29. How much of a problem do they have in keeping my emotions from affecting their ability to go about days activities? | — | — | — | — | — |
| 30. How much of a problem do they have in controlling their laughter?   | — | — | — | — | — |

# Patient Competency Rating Scale (Clinician version of PCRS)

Patients Name: \_\_\_\_\_

Clinicians Name: \_\_\_\_\_

Date: \_\_\_\_\_

How well is clinician acquainted with patient's behaviour?

- 1. Hardly at all
- 2. Not so well
- 3. Fairly well
- 4. Pretty well
- 5. Very well

## Instructions

The following is a questionnaire that asks you to judge this persons ability to do a variety of very practical skills. Some of the questions may not apply directly to things they often do, but you are asked to complete each question as if it were something they "had to do". On each question, you should judge how easy or difficult a particular activity is for them and mark the appropriate space.

## Competency Rating

1	2	3	4	5
Can do	Very difficult to do	Can do with some difficulty	Fairly easy to do	Can do with ease

- \_\_\_\_\_ 1. How much of a problem do I have in preparing my own meals?
- \_\_\_\_\_ 2. How much of a problem do they have in dressing themselves?
- \_\_\_\_\_ 3. How much of a problem do they have in taking care of their personal hygiene?
- \_\_\_\_\_ 4. How much of a problem do they have in washing the dishes?
- \_\_\_\_\_ 5. How much of a problem do they have in doing the laundry?
- \_\_\_\_\_ 6. How much of a problem do they have in taking care of their finances?
- \_\_\_\_\_ 7. How much of a problem do they have in keeping appointments on time?
- \_\_\_\_\_ 9. How much of a problem do they have in starting conversation in a group?
- \_\_\_\_\_ 10. How much of a problem do they have in staying involved in work activities even bored tired?
- \_\_\_\_\_ 11. How much of a problem do they have in remembering what they had for dinner last night?

- 12. How much of a problem do they have in remembering names of people they see often?
- 13. How much of a problem do they have in remembering their daily schedule?
- 14. How much of a problem do they have in remembering important things they must do?
- 15. How much of a problem would they have driving a car if they had to?
- 16. How much of a problem do they have in getting help when they are confused?
- 17. How much of a problem do they have in adjusting to unexpected changes?
- 18. How much of a problem do they have in handling arguments with people they know well?
- 19. How much of a problem do they have in accepting criticism from other people
- 20. How much of a problem do they have in controlling crying?
- 21. How much of a problem do they have in acting appropriately when they are around friends?
- 22. How much of a problem do they have in showing affection to people?
- 23. How much of a problem do they have in participating in group activities?
- 24. How much of a problem do they have in recognizing when something they say or do has upset someone else?
- 25. How much of a problem do they have in scheduling daily activities?
- 26. How much of a problem do they have in understanding new instructions?
- 30. How much of a problem do they have in controlling their laughter?
- 30. How much of a problem do they have in controlling their laughter?
- 30. How much of a problem do they have in controlling their laughter?
- 30. How much of a problem do they have in controlling their laughter?

## Neurobehavioural Rating Scale – Revised (NRS-R) – for clinicians

Patient name: \_\_\_\_\_

Gender: F\_\_\_\_ M\_\_\_\_

Date of accident : \_\_\_\_\_

Date of evaluation: \_\_\_\_\_

Date of birth: \_\_\_\_\_

Address: \_\_\_\_\_

Evaluator's name: \_\_\_\_\_

	<b>Absent</b>	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Symptom</b>
1.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Reduced alertness
2.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hyperactivity and Agitation
3.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Disorientation
4.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Attentional difficulties
5.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Difficulties in Articulation
6.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Difficulties in Oral Expression
7.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Difficulties in Oral Comprehension.
8.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Memory difficulties
9.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Motor Slowing
10.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Exaggerated Somatic Concern
11.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Self-Appraisal Difficulties
12.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hallucinations
13.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Unusual Thought Content
14.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Anxiety
15.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Depressive mood
16.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Guilt
17.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Lability of Mood
18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Blunted Affect
19.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Irritability
20.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Disinhibition
21.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Excitement
22.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Hostility
23.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Suspiciousness
24.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Emotional Withdrawal
25.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Conceptual Disorganisation
26.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Difficulty in Mental Flexibility
27.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Difficulty in Planning
28.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Decreased Initiative or Motivation
29.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Mental Fatigability

\*Vanier, M, Mazaux, JM, Lambert, J, Dassa, C & Levin, HS 2000, 'Assessment of neuropsychological impairments after head injury: inter-rater reliability and factorial and criterion validity of the Neurobehavioral Rating Scale-Revised', *Archives of Physical Medicine & Rehabilitation*, no. 81(6), pp. 796-806.

## Community Integration Questionnaire (Chapter 5 Section 1 Quality of Life)

1 Who usually does the shopping for groceries or other necessities in your household?	<input type="radio"/> Yourself alone <input type="radio"/> Yourself and someone else <input type="radio"/> Someone else
2. Who usually prepares meals in your household?	<input type="radio"/> Yourself alone <input type="radio"/> Yourself and someone else <input type="radio"/> Someone else
3. In your home who usually does the everyday housework?	<input type="radio"/> Yourself alone <input type="radio"/> Yourself and someone else <input type="radio"/> Someone else
4. Who usually cares for the children in your home?	<input type="radio"/> Yourself alone <input type="radio"/> Yourself and someone else <input type="radio"/> Someone else <input type="radio"/> Not applicable No children under 17 in the home
5. Who usually plans social arrangements such as get-togethers with family and friends?	<input type="radio"/> Yourself alone <input type="radio"/> Yourself and someone else <input type="radio"/> Someone else
6. Who usually looks after your personal finances, such as banking or paying bills?	<input type="radio"/> Yourself alone <input type="radio"/> Yourself and someone else <input type="radio"/> Someone else
7. Approximately how many times a month do you usually participate in shopping <i>outside</i> your home	<input type="radio"/> Never <input type="radio"/> 1-4 times <input type="radio"/> 5 or more
8. Approximately how many times a month do you usually participate in leisure activities such as movies, sports, restaurants, etc?	<input type="radio"/> Never <input type="radio"/> 1-4 times <input type="radio"/> 5 or more
9. Approximately how many times a month do you usually visit your friends or relatives?	<input type="radio"/> Never <input type="radio"/> 1-4 times <input type="radio"/> 5 or more
10. When you participate in leisure activities do you usually do this alone or with others?	<input type="radio"/> Mostly alone <input type="radio"/> Mostly with friends who have head injuries <input type="radio"/> Mostly with family members <input type="radio"/> Mostly with friends who do not have head injuries <input type="radio"/> With a combination of family and friends
11. Do you have a best friend with whom you confide?	<input type="radio"/> Yes <input type="radio"/> No

<p>12. How often do you travel outside the home?</p>	<ul style="list-style-type: none"> <li><input type="radio"/> Almost every day</li> <li><input type="radio"/> Almost every week</li> <li><input type="radio"/> Seldom/never (less than once per week)</li> </ul>
<p>13. Please choose the answer that best corresponds to your current (during the past month) work situation:</p>	<ul style="list-style-type: none"> <li><input type="radio"/> Full-time (more than 20 hours/week)</li> <li><input type="radio"/> Part-time (less than or equal to 20 hrs/week)</li> <li><input type="radio"/> Not working but actively looking for work</li> <li><input type="radio"/> Not applicable retired due to age</li> </ul>
<p>14. Please choose the answer that best corresponds to your current (during the past month) school or training program situation</p>	<ul style="list-style-type: none"> <li><input type="radio"/> Full-time</li> <li><input type="radio"/> Part-time</li> <li><input type="radio"/> Not attending school or training program</li> <li><input type="radio"/> Not applicable retired due to age</li> </ul>
<p>15. In the past month, how often did you engage in volunteer activities?</p>	<ul style="list-style-type: none"> <li><input type="radio"/> Never</li> <li><input type="radio"/> 1-4 times</li> <li><input type="radio"/> 5 or more</li> </ul>

**Comments:**

**Useful website resources:**

National Health and Medical Research Council:  
<http://www.health.gov.au/nhmrc/publicat/contents.htm>

National Guideline Clearing House: [www.guideline.gov](http://www.guideline.gov)

Agency for Health Care Policy Research: <http://www.ahcpr.gov>

CPG (Clinical Practice Guideline) Infobase: <http://www.cma.ca/cpgs/>

Cochrane Collaboration [www.cochrane.org](http://www.cochrane.org)

Database of Abstracts of Reviews of Effectiveness: <http://nhscrd.york.ac.uk/dare.htm>

## CHAPTER 8: Resources and contacts for patients and carers

### Financial assistance for travel and accommodation

Patients travelling to city for treatment may be eligible for a government scheme for provision of financial and accommodation services. However this scheme has differs in its name and eligibility criteria in each state and territory:

NSW Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)  
Albury IPTAAS  
Greater Murray Area Health Service  
PO Box 326  
Albury NSW 2640  
Phone: 02 6058 4455/4498  
Website: <http://www.health.nsw.gov.au/policy/hsp/iptaas/broch.pdf>

### IPTAAS in other states:

ACT: Interstate Patient Travel Assistance Scheme (IPTAAS), NT: Patient Assistance Travel Scheme (PATS), QLD: Patient Travel Subsidy Scheme (PTSC), SA: Patient Assistance Transport Scheme (PATS), TAS: Patient Travel Assistance Program (PTAP), VAS: Victorian Patient Transport Assistance Scheme, WA: Patient Assisted Travel Scheme (PATS)

### Some useful web sites for patients and carers:

Brain Injury Association of Queensland  
PO Box 1519  
Milton  
QLD 4064  
Telephone: Within Brisbane 07 3367 1049  
Regional Qld 1800 673 074  
Fax: 07 3367 1053  
Email: [biaq@biaq.com.au](mailto:biaq@biaq.com.au)  
Website: [www.biaq.com.au](http://www.biaq.com.au)

South West Brain Injury Rehabilitation Service  
PO Box 326  
Albury  
NSW 2640  
Australia  
Phone: 02 60419902  
Fax: 02 60419928  
Email: [swbirs@swsahs.nsw.gov.au](mailto:swbirs@swsahs.nsw.gov.au)  
[www.swbirs.nsw.gov.au/resources.htm](http://www.swbirs.nsw.gov.au/resources.htm)

Headway Victoria  
Acquired Brain Injury Association Inc.  
Address: 86 - 88 Herbert Street,  
Northcote  
Victoria 3070  
Australia  
Phone: (03) 9482 2955  
Facsimile: (03) 9482 5855  
FreeCall: 1800 817 964  
Website: <http://www.headwayvictoria.org.au/>

Commonwealth Rehabilitation Services (CRS) Australia  
Unit Address  
Suite 5, 32A Oxford Street  
Darlinghurst  
NSW 2010  
Telephone: (02) 8255 9800  
Fax: (02) 8255 9833  
Website: <http://www.crsrehab.gov.au>

Brain Injury Association of New South Wales  
Brain Injury Association of NSW  
17 Macquarie Rd Auburn NSW 2144  
PO BOX 480 Auburn NSW 1835  
Freecall: 1800 802 840  
Phone: 02 9749 5366  
Fax: 02 9749 5608  
Web site: <http://biansw.org.au/>

Brain Injury Rehabilitation Unit  
Liverpool Hospital  
Locked Bag 7103  
Liverpool BC NSW 1871  
Australia  
Phone: +61 2 9828 5495  
Fax: +61 2 9828 5497  
Website: <http://www.swsahs.nsw.gov.au/biru>

## Chapter 9 – Technical Report

This chapter outlines the process of developing evidence based guidelines for health care planning of people with traumatic brain injury. Funding for the project was received from Motor Accident Authority. The guidelines were developed following the standards outlined in the National Health and Medical Research Council (NHMRC) toolkit series (1999, 2000) and will be submitted to be considered for endorsement as externally developed clinical practice guidelines.

**Existing guidelines:** A search for existing guidelines in health care planning for people hospitalized with traumatic brain injury following a motor vehicle accident was conducted. Databases searched, National Guideline Clearing House, SUM Search and Health Star were searched. We found seventeen guidelines related to traumatic brain injury however all of them were either related to acute hospital care management of traumatic brain injured, sports concussion related traumatic brain injury or rehabilitation [American Association of Neurological Sciences-Brain Trauma Foundation (2000), Eastern Association for Surgery of Trauma (2000), Brain Injury Association of America (1997), Brain Injury Association, Bullock R et al (1996), Cappa et al (2003), Brain Trauma Foundation America (2000), Sylvain et al (2001), Cushaman et al (2001), Hillary FG et al (2002), Berger et al (1999), Mass et al (2002), Cicerone et al (2000), Erlanger et al (2003), Hesdorffer et al (2002), Thomas et al (2002), TBI Guideline National Health Committee New Zealand Guideline group (2000) .There were no guidelines found for clinicians or general practitioners management of people with traumatic brain injured in the community. List of guidelines results are included in reference list.

### Target Audiences:

The proposed population groups for whom the guidelines are developed include:

- Australian general practitioners.
- Patients presenting to a general practitioner for care who have been hospitalised for a traumatic brain injury as a result of a road traffic accident.

### Review Process:

A review protocol was developed based on National Health and Medical Research Council (NHMRC) toolkit series (1999, 2000). Multi-disciplinary group involved Dr Lyndal Trevena (General Practitioner/Epidemiologist), representative from respective Division of General Practice, Dr Clayton King (Brain Injury Rehabilitation Unit), Associate Professor Ian Cameron, (Rehabilitation Specialist) and Suzanne Lulham representation from the Motor Accidents Authority (funder) and Brain Injury Association (consumer group).

The process consisted of:

- The medical literature was searched to identify relevant studies and reviews. Searches were conducted in the following databases until 2004. MEDLINE Health Star, PsycInfo, CINAHL, EMBASE, SPORTS discuss, All EBM Reviews: CDSR (Cochrane Database of Systematic Reviews), American College of Physicians Journal Club (ACP) , Database of Reviews and Abstracts of Effectiveness (DARE), Cochrane Control Trail Register (CTR).
- Appraisal was based on NHMRC “Checklist for appraising the quality of studies of diagnostic/prognostic/intervention/ etiology or risk factors” according to the level of evidence for ideal study type for each clinical question.
- Critical appraisal of articles according to selection criteria was carried out with application of NHMRC designated quality checklist; by two people working independently in order to determine studies met exclusion or inclusion criteria.

- Appraisal and analysis process included discussion on results of included studies in the text and formulation of key-points to highlight the importance of main points in each chapter.
- Formulation of Clinical Practice Guidelines for Care of People living with Traumatic Brain Injury in the Community
- Expert and consumer review by stakeholders

### Search for evidence and study types:

Search was divided in P I C O search format. Where P was Population (Traumatic brain injured, adults male/female), I was Interventions or issues (pharmacotherapy or rehabilitation) Comparator (For e.g. Is drug therapy or cognitive therapy more effective in management of depression following traumatic brain injury ,Outcome (e.g. Improved quality of life after determining the effectiveness of cognitive therapy on depression or accurate diagnosis following the effectiveness of trauma severity indices. However in effect to keep our search strategy broad comparators or outcomes were included in our literature search only at a later stage. After defining the basic P I C O for issues concerned issues search strategy was divided in question type on Etiology/Diagnosis/Therapy, and Prognosis followed by application of specific evidence based search filters (sensitive and specific) to retrieve best results followed by application of limiting search to best evidence as per NHMRC toolkit. (2000) as shown below:

Adapted from NHMRC table of ideal study types for clinical questions (2000)

Question	Study type	Level of Evidence
Intervention	Systematic Review	I
	Randomised controlled trial	II
	Cohort study	III-2
	Case-control study	III-2
Diagnostic test/ performance	Systematic Review	I
	Cross-sectional study	III-3
	Case series	IV
Prognosis	Systematic Review	I
	Cohort/ Survival study	III-2

Designation of Levels of Evidence:

Levels of Evidence	Study type
I	Evidence obtained from systematic review of all relevant randomized controlled trials.
II	Evidence obtained from at least one properly designed randomized controlled trial.
III-1	Evidence obtained from well designed pseudo randomized controlled trial (alternate allocation or other method).
III-2	Evidence obtained from comparative studies with concurrent controls and allocation not randomized (cohort studies), case-control studies or interrupted time series with a control group.
III-3	Evidence obtained from comparative studies with historical control, two or more single arm-studies or interrupted time series without a parallel control group.
IV	Evidence obtained from case-series, either post-test or pre-test and post-test.

Source: NHMRC National Health and Medical Research Council, A guide to the development, implementation and evaluation of clinical practice guidelines. Canberra: NHMRC, 1999.

**Other search methods:****Snowballing:**

The bibliographies of articles were scanned and relevant papers were tracked from library database, electronic resources, and were critically appraised.

**Hand searching:**

Some of the search results were limited to journal articles, conference papers, reports not available electronic resources were hand searched/ordered using the library resources.

**Personal contact and communication with authors:**

Authors looking at specific issues in traumatic brain injured were consulted for their expertise in the area.

**Eligibility criteria for studies:****List of Inclusion criteria:**

1. Adults with traumatic brain injury (at any duration in time/setting)
2. Studies on TBI patients with mild, moderate or severe traumatic brain injury.
3. Papers from 1970-2004 as relevant
4. Evidence based interventions or therapies applicable in management of traumatic brain injury (e.g. brief mindfulness meditation methods)

**List of Exclusion criteria:**

1. Studies conducted on patients with acquired brain injury (ABI)
2. Studies involving children
3. Animal studies e.g. traumatic brain injury in rats.
4. Papers/guidelines in foreign languages.
5. Papers prior to year 1970
6. Studies on hospital-based and post-acute TBI patients i.e. not relevant to general practice
7. Studies not meeting the quality criteria
8. Care of patients still undergoing active rehabilitation within a brain injury unit and those being treated within insurance claimant processes are not under the management of their general practitioner for TBI.

**Critical Appraisal Process:**

Critical appraisal was carried out by two individual reviewers, on full text of the articles selected from the search results. The standard NHMRC Checklists (2000) were followed to appraise the papers independently (E.g. Quality Appraisal sheet as below). In case of conflict between reviewer's results, papers were discussed and disagreement resolved or opinion of third reviewer was considered.

The results from the appraisal sheets were considered along with the full-text of the articles for included studies in guideline formulation.

**Economic issues:**

Cost interventions and evaluation were not considered for this project.

**Legal Implications:** Useful resources for general practitioners and carers are reproduced following copyright law and obtaining permission from authors/ publishers as applicable.

### **Other guidelines on traumatic brain injury:**

- American Association of Neurological Surgeons - Medical Specialty Society, Brain Trauma Foundation - Disease Specific Society. 2000.
- Practice management guidelines for the management of mild traumatic brain injury. Eastern Association for the Surgery of Trauma - Professional Association. 2000.
- Management of concussion in sports [practice parameter]. American Academy of Neurology. Brain Injury Association of America. Neurology, 1997; 48: 581-585.
- A guide to selecting and monitoring brain injury rehabilitation services. Brain injury association and the defence and Veterans head injury program.
- Bullock R et al. 1996.'Guidelines for management of severe head injury'. European Journal of American Medicine, vol 3 (2):109-217.
- S. F. Cappa, T. Benke, S. Clarke, B. Rossi, B. Stemmer and C. M. van Heugten
- EFNS Guidelines on cognitive rehabilitation: report of an EFNS Task Force. European Journal of Neurology 2003, 10: 11–23.
- Management and prognosis of severe traumatic brain injury. 2000. Brain Trauma foundation, American Association of Neurological surgeons.
- Sylvain Palmer, MD, FACS, Mary Kay Bader, et al (2001). The Impact on Outcomes in a Community Hospital Setting of Using the AANS Traumatic Brain Injury Guidelines
- The Journal of Trauma, Injury, Infection, and Critical Care.
- James G. Cushman, MD, Nikhilesh Agarwal, MD, Timothy C. Fabian, MD, Victor Garcia, et al. Practice Management Guidelines for the Management of
- Mild Traumatic Brain Injury: The EAST Practice Management Guidelines Work Group. The Journal of Trauma, Injury, Infection, and Critical Care, 2001; 51:1016 –1026.
- Hillary FG, et al. Functional magnetic resonance imaging technology and traumatic brain injury rehabilitation: guidelines for methodological and conceptual pitfalls. 2002, Journal of Head Trauma Rehabilitation, 17(5):411-30.
- Berger E, et al. 1999. Quality of Life after traumatic brain injury: A systematic review of the literature. Restorative Neurological Neuroscience; 14(2-3):93-102.
- Maas AI. . 2002 Guidelines for head injury: their use and limitations. Neurol Res Jan;24(1):19-23.
- Cicerone KD, et al. 2000. Evidence-based cognitive rehabilitation: recommendations for clinical practice. Arch Phys Med Rehabilitation. 81(12):1596-615.
- Erlanger D, et al. 2003. Symptom-based assessment of the severity of a concussion. J Neurosurgery. 2003 Mar;98(3):477-84.
- Hesdorffer DC, et al. 2002 Predictors of compliance with the evidence-based guidelines for traumatic brain injury care: a survey of United States trauma centres. J Trauma. 2(6):1202-9.
- Thomas SH, et al 2002 Hyperventilation in traumatic brain injury patients: inconsistency between consensus guidelines and clinical practice..J Trauma. 52(1):47-52; discussion 52-3.
- Traumatic Brain Injury Rehabilitation Guidelines, National Health Committee (NHC) PO Box 5013133 Molesworth Street Wellington New Zealand Guideline group.