## **ADAPTING YOUR PRACTICE**

Recommendations for the Care of Patients Who Are Homeless or Unstably Housed Living with the Effects of Traumatic Brain Injury

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#### DISCLAIMER

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#### PREFACE

Clinicians experienced in providing health care to the homeless routinely adapt their practice to foster better outcomes for their patients. This document is for health care professionals, program administrators, other staff, and students serving individuals with traumatic brain injury (TBI) who are homeless or at risk for homelessness. Its purpose is to improve patient care by enhancing understanding of recommended strategies for the successful screening, treatment, and management of traumatic brain injury in unstably housed populations. Some clinicians may be reluctant to screen for a history of traumatic brain injury, feeling that there is little they can do to help. We hope the information in this guideline will persuade clinicians that simple accommodations will not only increase access to care, but also improve patient outcomes.

Standard clinical guidelines often fail to take into consideration the unique challenges presented by homelessness that may limit access to needed services or adherence to a plan of care. To address this oversight, the Health Care for the Homeless (HCH) Council has made the development of recommended clinical practice adaptations for the care of people experiencing homelessness one of its top priorities. Since 2002, the National HCH Council has developed and revised recommendations for the management of health problems that are common among people experiencing homelessness and particularly challenging for their caregivers. These recommendations are available at <a href="https://www.nhchc.org">https://www.nhchc.org</a>.

The need for adapted practice guidelines for the care of individuals with TBI and unstable living situations stems from the fact that TBI is the leading cause of death and disability among children and young adults in the United States (Centers for Disease Control and Prevention [CDC], 2015). Associated disabilities include neuropsychological dysfunction and behavioral problems, which many times interfere with a person's ability to maintain stable housing, employment and relationships. Previous studies have found high rates of cognitive impairment among individuals who are homeless, and a study conducted in Toronto, Canada, found that 58% of men and 42% of women experiencing homelessness had a history of TBI, with the first TBI occurring before the onset of homelessness (Topolovec-Vranic et al., 2013). These novel findings suggest that TBI may play a previously unrecognized role in the onset and course of homelessness and in the use of the health care system by individuals who are homeless.

The following recommendations are for TBI generally, and where specific, we will highlight unique aspects of managing TBI for patients who are homeless. We hope these recommendations will provide helpful guidance to health care professionals and contribute to improvements in both quality of care and quality of life for people experiencing homelessness.

#### ACKNOWLEDGEMENTS

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#### INTRODUCTION

Traumatic Brain Injury (TBI) is pervasive in the United States, resulting in an estimated 2.5 million emergency department visits per year (Faul, Xu, Wald, & Coronado, 2010). The Centers for Disease Control and Prevention (CDC) estimates that between 3.2 and 5.3 million people in the United States are living with lasting disability resulting from TBI. The incidence rate of TBI easily exceeds other neurological conditions, including stroke, epilepsy, and multiple sclerosis.

TBI is caused by a bump, blow, or jolt to the head or a penetrating head injury that disrupts the normal function of the brain.

(CDC, 2015)

Fortunately, approximately 85% of TBIs are mild (CDC, 2015). The clear majority of people who sustain mild TBIs will recover completely within weeks to months; however, those with moderate to severe injuries, multiple mild TBI, or mild TBI complicated by mental health or other diagnoses often have lasting effects. TBI is often called an *invisible disability* because it is common for survivors to have significant cognitive, behavioral, and emotional difficulties without any obvious physical impairments (DePalma & Hoffman, 2018).

Recent studies have found that half of all people who were served in programs addressing homelessness report a history of TBI. As many as 70% of those reporting TBI sustained their injuries before becoming homeless (Hwang et al., 2008), suggesting that TBI creates a risk for becoming homeless. There is also evidence that being homeless increases the likelihood of sustaining a brain injury and being homeless makes it more difficult to recover fully. Having a brain injury and living without stable housing comes with a host of risks. People living with TBI are significantly more likely to sustain a second injury, become a victim of crime, be arrested, or become dependent on the emergency department for treatment (To et al., 2015). Fortunately, there is a growing awareness that the disability associated with TBI is easily overlooked or misunderstood. Once recognized, there are simple practice adaptations that can make services more accessible and interventions more successful.

Further, people experiencing homelessness are at high risk for other types of neurological insult. As shown in Table 1, the term *acquired brain injury* (ABI) is used to indicate not only TBIs but also injuries to the brain that are the result non-traumatic causes. These might include f exposure to substances such as drugs, alcohol, or environmental toxins that damage brain tissue, as well as the damaging effects of medical conditions such as stroke, infection of the central nervous system, or anoxia. The term *developmental disability* refers to congenital conditions and injuries at birth. Although this guideline focuses primarily on TBI, many of the recommendations for accommodation will also apply to those living with neurocognitive impairment that is related to other conditions (ABIs) and in some of the accommodations may be useful for people living with developmental disabilities or cognitive impairments that are the result of degenerative conditions.

#### Table 1. Different Types of Brain Injury

#### Types of Brain Injury Acquired Brain Injury (ABI)

Injury to the brain that is not hereditary, congenital, degenerative or induced by birth trauma. The injury results in a change in neuronal activity which may affect functioning

Examples of Non-	Traumatic Injury	Examples of Trau	matic Injury (TBI)
Toxic exposures (e.g. drugs, alcohol, environmental toxins)	Brain Tumor	Closed Brain Injury (e.g. external blow to the head)	Penetrating Brain (e.g. gunshot wound, stabbing)
Anoxia related (e.g. cardiac arrest, overdose)	Infection	Blasts, falls, assaults, vehicular accidents, sports accidents	Blasts, falls, assaults, vehicular accidents, sports accidents

The outcomes of brain injury vary widely as a function of both the severity and nature of the injury as well as the history and health of the person sustaining the injury. The kind of treatment and social support a person receives following injury plays a large role in how well the person recovers and adapts to lasting disability. Those with limited resources or social supports understandably have the poorest outcomes.

When providing care for people who have a history of TBI, it is important to consider the difficulties they are experiencing may be the result of an invisible disability. For example, problems reading social cues or regulating emotion and behavior can make a person appear intolerant or belligerent. Having trouble with organizing or initiating daily activities as the result of impaired executive functioning is easily misinterpreted as a lack of motivation or laziness. Failing to remember instructions or rules may be interpreted as noncompliance. To make matters more complicated, people living with brain injury may also lack insight into their disability and fail to ask for or accept the help they need. Table 2 provides an overview of the range of unrelated yet common difficulties that may result from brain injury.

Somatosensory	Motor	Cognitive	Emotional and Behavioral
Headaches	Hemiparesis	Impaired Attention	Depression
Fatigue/Lethargy	Spasticity	Impaired concentration	Anxiety
Dizziness	Slowed performance	Impaired memory	Impaired emotional perception and regulation
Blurred or double vision	Poor coordination	Slowed information processing	Impulsivity
Visual field cuts	Dysarthria (impaired speech)	Language impairment	Aggression/irritability
Sensitivity to light/noise	Dysphagia (impaired swallowing)	Impaired visuospatial processing	Poor initiation
Anosmia (lost sense of smell)	Balance problems	Impaired executive functioning	Drowsiness
Aguesia (lost sense of taste)			Sleeping more than usual
Tinnitus (ringing in ears			Difficulty falling asleep

Cable 2. Listing of Common	Outcomes of	Moderate to	Severe Brain Inju	ry
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In an ideal world, people affected by brain injury would have access to health care professionals who understand how the impact of TBI can make it difficult to access and participate in services. These same professionals would work in interdisciplinary teams that include physicians, physician assistants, nurses, social workers, occupational therapists, speech therapists, physical therapists, and neuropsychologists and other specialists with expertise in brain injury. In reality, people living with brain injury may not understand how or when to access care or may seem unmotivated or even hostile when care is offered. Care that is offered may be less effective because of the barriers presented by impairments of memory, behavior, insight, and communication.

By virtue of the complex relationship between neurological impairment and physical and psychosocial functioning, people with a history of TBI are likely to present with a particularly diverse and challenging set of needs when they seek services in settings that address homelessness. Concerned clinicians and service providers can significantly improve their care of their patients by being aware of the high rate of TBI amongst homeless populations and appropriately adapting their practices to meet each patient's specific needs.

#### PURPOSE AND INTENDED AUDIENCE

The purpose of this document is to assist health care professionals, program administrators, and other staff members working with homeless and marginally housed people to recognize and accommodate the needs of people living with the lasting impact of brain injury. This document considers the varied levels of health and social services made available through health centers and the communities they serve. It also attempts to accommodate the needs of professionals with diverse backgrounds and experience.

Existing evidence-based guidelines for brain injury—including those referenced in this document are mainly concerned with care that occurs immediately following injury and provide recommendations for rehabilitation services delivered by brain-injury specialists in the year or two that follows. However, there are no evidence-based guidelines that specifically address the provision of long-term community-based support services to this population. In part, this is because of the heterogeneous nature of brain injury and its long-term outcomes.

In addition, some problems resulting from brain injury, such as impaired emotional regulation, persist well after formal rehabilitation services have ended, and present as social and mental health problems to be managed outside of brain-injury specific services. For example, problems with impulsivity and difficulties in managing emotions after a moderate to severe injury may be less problematic during the rehabilitation period, when the person's life is likely to be highly structured. However, when a patient returns to the community and things do not go as planned or the recovery from mild injury is prolonged and the individual develops mental health or a substance use disorder, they may only be treated by providers with mental health and addictions expertise. These providers may not specifically recognize the role that brain injury had in the development of the problems and ultimately brought the patient into treatment.

Likewise, only recent research has revealed the very high prevalence of brain injury survivors served in mental health and addictions settings (Brenner et al., 2013; Corrigan, Bogner, & Holloman, 2012; K. Dams-O'Connor et al., 2014). This is also true for programs serving the homeless, marginally housed, and justice-involved populations (Kristen Dams-O'Connor et al., 2013). For this group of brain injury survivors (defined as approximately 2-years post-acute), disabilities are lasting and may not be fully recognized by the service providers who are the primary focus of these guidelines.

#### LEVELS OF RECOMMENDATIONS

We recognize some programs may operate with limited resources and may not be able to implement all the guidelines. For this reason, the guidelines include basic recommendations, which may be an appropriate place to start for programs such as small health centers, medical respite care programs, or shelters. Specific guidelines are geared toward programs able to garner some specialized resources for individuals with special needs. Such programs might include larger health centers or multifunctioning organizations. The specialized recommendations are geared toward programs that have access to interdisciplinary teams. These might include teams with specialized funding to address the needs of people with disabilities who are homeless or marginally housed. Each level of guidance builds on the one preceding it, allowing programs to develop their service offerings based on available resources.

	<b>LEVEL I</b> <b>BASIC</b> Reduce Barriers to Care	<ul> <li>Clinic staff are trained to complete brief TBI screening on all patients</li> <li>Clinic staff are trained to provide basic accomodations for patients with TBI</li> <li>Clinic staff are aware of relevant community-based resources for people living with cognitive impairment due to TBI</li> </ul>
	<b>LEVEL II</b> <b>SPECIFIC PROGRAM</b> Specific Supports Provided	<ul> <li>Clinic programs have the capacity for structured cognitive screening</li> <li>A member of the clinic team is trained as a brain injury expert and can provide direct consultiaon regarding functional compensation</li> <li>Program provides case management support</li> <li>Clinic partners with brain injury programs and other social services partners</li> </ul>
	<b>LEVEL III</b> <b>SPECIALIZED PROGRAN</b> Interdisciplinry Care	<ul> <li>Clinic has access to professionals experienced treating brain injuries, such as: occupational therapist, social worker, speech therapist, neuropsychologist, psychiatrist, and rehabilitation nurse</li> <li>The team can complete diagnostic assessments that enables access to specialized programs and health care services</li> <li>The program develops housing options for patients with TBI</li> </ul>

#### SUMMARY OF RECOMMENDED PRACTICE ADAPTATIONS

#### **Overview**

In the body of this document, the recommendations practice are organized according to their place in the clinical processes that take place when an individual seeks services. Recommendations pertaining to screening and assessment are included in the sections related to Screening for Brain Injury, Assessing for Cognitive and Functional Impairments and Medical *Evaluation*. Adaptations to accommodate people living with brain injury concerning Care Plan, Education and Self-management are reviewed in their respective sections. The section Associated Conditions and Complications includes general information regarding common co-occurring conditions. Background information related to the longterm effects of traumatic brain injury, along with recommendations for screening for brain injury, specific information about cognitive impairment, cognitive compensation and other program recommendations are found in the

recommendations can be applied in settings with

varied levels of resources.

**Screen for Brain Injury Assess Cognitive and Functional** Impairment Conduct Medical Evaluation and **Develop Specific Plan of Care to** Manage Co-Occuring Health and **Behavioral Health Conditions** Adapt Service Design and Delivery to Accomdate Cognitive and Behavioral Symptoms **Integrate with Community** Resources Appendices. Table 3 provides an overview of how

	<b>Basic</b> <b>Recommendations</b> Services are offered in a manner that reduces barriers to care.	Specific Program Recommendations Specific accommodations are provided.	Specialized Program Recommendations A team can offer specialized interventions.
Screen for Brain Injury	Ohio Valley Screening Questions	Ohio Valley Brain Injury Identification Method	Ohio Valley Brain Injury Identification Method
Recognize Cognitive and Functional Impairment Patients are assessed for cognitive and functional impairment. Assessments should touch on the following: Communication Memory Planning and problem solving Wayfinding Social interaction	Staff members complete available online training and know how to recognize the signs of cognitive impairment that may present in their patients. Staff members take time to build a working alliance with patients with signs of cognitive impairments. Staff members explore the potential for cognitive difficulties when a patient presents with difficulty in completing tasks, complying with rules, or communicating the needs and wishes.	A team member has training and experience in recognizing and evaluating cognitive and functional impairment and can perform screening using standardized measures. This team member will often be an occupational therapist. Cognitive screening is conducted by or under the supervision of a trained professional who supports the interpretation of findings and assists in the development of recommendations.	The team has access to or includes brain injury professionals, such as occupational therapists, physical therapists, social workers, speech and language therapists, neuropsychologists, psychiatrists, neurologists, psychiatric and rehabilitation nursing providers. The team has access to professionals who can provide diagnostic evaluations that enable access to diagnosis specific programs and/or disability and specialized services.
Medical Evaluation and Development of Care Plan Mental health Seizure disorder Endocrine functioning Headache Sensory functioning Sleep/Fatigue	When referring for health care, the team should provide information related to the history of brain injury as well as any cognitive and functional issues observed. The team can refer clinicians to evidence- based guidelines.	The team includes a brain injury-awareness provider to conduct a history and physical exam in consideration of the likelihood of cognitive impairment and history of trauma. Clinicians utilize evidence-based guidelines.	An integrated team consists of clinicians and includes specialty care providers and specialty services.

Table 3. How the	Levels of Recor	nmendations and	<b>Practice Ada</b>	ptations may	be A	pplied
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#### ADAPTING YOUR PRACTICE Recommendations for the care of Patients who are Homeless or Unstably Housed Living with the Effects of Traumatic Brain Injury

• Post-concussive symptoms			
Accommodate Cognitive and Behavioral Symptoms	Staff members develop a team that creates a culture welcoming to those with brain injury by following the recommendations for basic cognitive accommodation.	The team can create individualized support plans based on the recommendations of a trained professional.	The team provides specialized care. Specific programming is developed, including housing options that accommodate cognitive impairment.
Integrate with Community Resources	Members of the team contact local and state brain injury associations to establish a list of available community- based programs. The team becomes aware of resources for developmental disability and aging.	The team develops active partnerships with brain injury and other social services and may co-manage care of patients. Active case management is provided.	The team provides specialized care. Assessments and triage may be focused on obtaining specialized and support services.

#### SUMMARY OF MAJOR RECOMMENDED PRACTICE ADAPTATIONS

#### **S**creening for **B**rain Injury

- 1. During initial contacts, the clinician should be attentive to possible **signs of functional cognitive impairment**, such as trouble keeping appointments or violating rules, and accommodate accordingly. Please note, TBI screening and more detailed assessments may be affected by a person's chronic lack of sleep and y the lack of food. Assessing these factors are also important.
- 2. Practitioners should screen all patients for TBI using <u>The Ohio Valley Brain Injury</u> <u>Identification Method Training</u>. Screening methods that elicit a complete history should include questions regarding a) orientation to types of brain injuries, b) probe for the first injury, c) most serious injury, d) most recent injury, and e) a history of multiple mild injuries such as occur in sports or physical abuse.
- 3. Cognitive screening is recommended where possible if there is a positive screen for brain injury with loss of consciousness (LOC) > 30 minutes, LOC of any duration if the injury occurred within the past 6 months, and/or when there appears to be ongoing cognitive impairment as observed on interview, or if there is a complaint of physical or cognitive symptoms related to the TBI. Recommended measures include the Montreal Cognitive Assessment (MoCA) and the Brief Cognitive Status Exam (BCSE).
- 4. Assessment of functional impairment is recommended for all patients with a history of TBI with LOC > 30 minutes, LOC after a brain injury within the last 6 months, a complaint of or directly observed impairment and/ or a reported history of multiple concussions. It may also be useful for individuals with suspected or demonstrated cognitive impairment related to other diagnoses. Clinical interview and observation may provide information about areas of difficulty. Using a structured measure will facilitate collection of information. Recommended measures include World Health Organization Disability Assessment Schedule (WHODAS 2nd ed.) and Adaptive Behavior System 3rd ed. (ABAS 3<sup>rd</sup> ed.).
- 5. When a history of brain injury with LOC is reported, the likelihood of mental health and substance use disorders as well as legal difficulties are significantly increased. These factors should also be assessed.
- 6. Information should be obtained regarding the history of seizures, endocrine disorders, headache/pain, fatigue, and sleep disorders.

#### **Medical Evaluation**

1. Trauma-informed care and cultural humility should be practiced when assessing all patients seeking services in settings that serve people who are homeless or marginally housed because this patient group is understood to have a high incidence of trauma.

- 2. Assessors should be alert to the evidence of trauma in physical appearance, including scars.
- 3. Medical screening should include endocrine functioning.
- 4. Medical screening should include neurological examination.
- 5. Medical imaging is only likely to be required for newly emerging or worsening impairments or symptoms. In mild TBI, imaging is only required when there is a deterioration in functioning and/or the patient is taking anticoagulant medication or has been diagnosed with a clotting disorder.
- 6. Blood and urine testing may be used to determine medication compliance and assess for substance use.
- 7. Assessment of neurobehavioral issues following traumatic brain injury should address preinjury vulnerability factors, injury-related factors, and post-injury factors.
- 8. Occupational therapy assessment, where available, should be conducted to assess for impairments of daily functioning, and physical therapy assessment conducted for mobility impairments.
- 9. An assessment of speech and language should be conducted.
- 10. Neuropsychological assessment should be accessed to clarify diagnosis and/or to support disability claims and recommendations for service providers.

#### Plan of Care

- 1. Clinicians should work collaboratively with the patient (and any significant others) to develop realistic, short-term goals.
- 2. When cognitive and functional impairment are observed or suspected, the care plan should include practice and environmental supports, such as:
  - a. Written information using a simplified format;
  - b. Use teach-back (repetition of information by the patient) to ensure information has been understood;
  - c. Prompts and reminders provided with the patient's permission;
  - d. Direct support to follow through with required tasks; and
  - e. Appointments that are scheduled on a routine basis, at the same place and time, and with familiar providers.
- 3. Where available, patients should be connected to targeted intensive case management designed for those living with disability. Case management services may include a focus on

completion of functional activities and medical compliance as well as promoting engagement in meaningful activity.

- 4. Supportive housing, which includes ongoing access to functional supports and case management services, will be required to ensure housing stability.
- 5. On-going training and guidance is needed for staff caring for homeless populations regarding the different local housing options (emergency, transitional and supportive housing); how to interact with law enforcement and local jail staff to improve communication and coordination between the health and justice systems.
- 6. The use of small incentives such as coffee or food may be useful to encourage attendance and support engagement.
- 7. Programming offered on a routine basis and in a single location will improve patient engagement.
- 8. Functional cognitive assessment completed by or under the supervision of an occupational therapist and/or neuropsychologist is recommended where available.
- 9. An interdisciplinary team that includes neuropsychology, occupational therapy, social workers, and rehabilitation support workers is recommended to ensure holistic care.

#### **Medication Management**

- 1. When medication is indicated for people living with brain injury, it should be introduced at the lowest possible dose and titrated slowly upward.
- 2. When prescribing any medical treatment, the provider should consider the patient's willingness and ability to comply with care and the potential for medications to be lost or stolen.
- 3. The health provider should simplify dosing instructions and schedules as much as possible. Patients with TBI may have difficulty following complex medication instructions or remember to take medications at multiple times per day.
- 4. Drug selection and monitoring are required to minimize the potential adverse effects on arousal, cognition, motivation, and motor coordination following TBI. The use of medications that target more than one brain injury-related symptom/syndrome is recommended if possible (e.g., one agent for both mood and insomnia or for both headache and insomnia).
- 5. If seizure medications are required, consideration should be given to choosing medication that minimizes the negative impact on neuropsychological functioning.

- 6. Individuals with brain injury who report difficulty with sleep and fatigue should be assessed. The use of melatonin and trazadone should be considered.
- 7. Benzodiazepines (lorazepam) and other non-benzodiazepine hypnotic (zopiclone) medications may cause side effects such as: amnesia/memory loss, increased daytime fatigue, decreased alertness, decreased concentration; that may confound and even delay recovery after brain injury. Therefore, benzodiazepines should be considered as a last resort treatment for sleep disorders and used for periods no longer than 7 days.
- 8. Because Selective Serotonin Reuptake Inhibitors (SSRIs) have a better side effect profile, they are recommended as a first-line treatment for depression after brain injury. Sertraline and citalopram have been found to be effective for some individuals. If SSRIs have been trailed and are found to be ineffective or there have been unwanted side effects, referral to a psychiatrist with experience in brain injury is recommended.

#### **Education and Self-management**

- 1. Cognitive assessment results should be shared with the patient.
- 2. Patients should be introduced to available compensatory strategies, such as smart phones, notepads, and calendars. Training and support will generally be required to ensure their effectiveness. The process of developing cognitive compensations should be collaborative, addressing specific functional needs the individual identifies.
- 3. Education about the particularly damaging effects of substance use after brain injury should be provided. Simplified materials are available at <u>Ohio Valley.org</u>.
- 4. Patients should be offered information about managing problems including headache, fatigue, and sleep.
- 5. Patients should be encouraged to take advantage of any available support groups or educational materials provided by local brain injury support services.
- 6. Accompanying patients to introduce them to new settings and programs may be required to accommodate problems in initiation and planning. Programs designed for people living with cognitive impairment (e.g. programs for people living specifically with brain injury or other disabilities) may be required to encourage participation in meaningful activity.

#### Service Delivery Design

- 1. Service providers should evaluate existing resources for individuals living with brain injury to identify gaps in services.
- 2. Service providers should consider the development of partnerships with state and local brain injury societies or providers to fill identified gaps.
- 3. Service providers should be aware of the programs and benefits designed for people living with disability.
  - a. Adult survivors of childhood injuries may qualify for benefits for people with developmental disability, where available.
  - b. Programs that screen for and document disability may support access to services and benefits.
- 4. The design of intake and intervention should allow adequate time to build a working alliance and engagement. Patients with cognitive impairment will usually require additional time in individual appointments and may require longer periods of time to engage in intervention or treatment.
- 5. Workers providing outreach services to individuals with brain injury may need smaller caseloads that allow for greater intensity of care, which includes accompanying patients to appointments and providing direct support in the community.

#### Follow-up

Because of difficulties with initiation and memory as well as problem solving, people with brain injury are likely to require an assertive approach to follow-up. Frequent brief visits may encourage better follow-up and enable development of a positive routine.

### Practice Adaptations for the Care of Patients Who Are Homeless or Unstably Housed Living with the Effects of TBI

#### SCREENING FOR BRAIN INJURY

#### History

Screening for brain injury should be included in history taking for all patients experiencing homelessness. This section will present an overview of how to screen for brain injury, as well as information regarding how to recognize and assess for cognitive and behavioral impairment during the initial interview.

Structured interviews are the standard method for screening of a history of traumatic brain injury. Medical records may not be readily available for vulnerable populations. Even when medical records are available, they may not capture all the injuries that have taken place because so many occur without medical attention.

Taking an accurate history requires that the patient is able to understand the clinician and the clinician is able to understand the patient. Starting out with a few casual, open-ended questions can begin the process of evaluating what will be needed to establish good communication. The common practice of asking a question such as "What brings you here today?" is a good start. Beginning with broad questions will allow you to observe the patient's ability to organize and express their thoughts. If a patient happens to be using a communication device, simply asking the patient to demonstrate its use is the best way to get started.

Screenings that only use one or two questions to determine if a brain injury has occurred have been found to miss milder and more remote histories (McKinlay et al., 2016). The Ohio Valley Brain Injury Identification method (Corrigan & Bogner, 2007) uses a series of cues to elicit a lifetime history of brain injury that is as complete as possible. This tool is recommended because it has been shown to be a reliable way to elicit TBI history and includes guidelines for clinical interpretation of the findings. It is understood that self-reporting does not represent a perfect history. Rather, the intention of this method is to estimate an individual's exposure to brain injury over the course of their lifetime.

Using the tool, an experienced interviewer may be able to complete an interview in 10 to 15 minutes. Training to administer the <u>Ohio Valley TBI Identification Method</u> is available online and may be located on the <u>Ohio Valley Center for Brain Injury and Prevention and Rehabilitation</u> website. Completion of the self-paced training will also enable a clinician to learn how to appropriately use the brief screening questions.

When a history of brain injury with loss of consciousness is reported, brain injury in childhood, or multiple mild brain injuries have been revealed; the likelihood of mental health and substance use disorders as well as legal difficulties is significantly increased. These factors should also be assessed, in addition to a history of seizures, endocrine disorders, headache /pain, fatigue, and sleep disorders.

The Advisory Committee of this document recommends additional clinical attention be provided when certain screening results as shown in Table 4 have been identified.

Table 4. Screening Results That Require Additional Clinical Attention

- WORST- History reveals there have been one moderate or severe TBI (i.e., any TBI with 30 minutes or more loss of consciousness).
- FIRST TBI History reveals any loss of consciousness before age 15.
- MULTIPLE History reveals two or more TBIs close together, including a period when patient experienced multiple blows to the head, even if apparently without effect.
- RECENT- History reveals a mild TBI in recent weeks or a more severe TBI in recent months
- OTHER SOURCES History reveals any TBI combined with another incident when patient's brain was injured.

#### Difficulty in Comprehending Questions

When the clinician suspects that the patient is having difficulty comprehending questions, the following adjustments should be made to support better communication.

- Conduct the interview in a quiet place, with minimal distraction.
- Allow enough time for the interview to be conducted at a relaxed pace.
- Separate the assessments into several sessions to accommodate fatigue, attention, or emotional lability.
- Listen for problems with speech and language: Although everyone is different, most people prefer to be asked to repeat themselves or clarify their remarks rather than glossing over them or ignoring their responses. The clinician should make it clear that what the patient is saying is important to the clinician. This results in most people willing to make an extra effort to communicate. Even when speech is fairly distorted, it is usually possible to develop an ear for an individual's speech—particularly if the clinician has the opportunity for multiple conversations. If the clinician needs to get the help of others to "translate" remarks, it is important to communicate directly with the patient and verify what they have stated was understood. When there are significant difficulties, inviting the use of gestures, nods, and the use of yes/no questions may be helpful. Likewise, when a patient seems to be struggling to find words, using words in an unusual way, or demonstrating slow or labored speech, further assessment may be needed.
- Check comprehension: It is a good practice to ask patients to repeat or demonstrate their understanding of information. Letting a patient know the clinician is interested in ensuring they are able to express themselves clearly, will often make the request for repetition less awkward.

- For patients who defer to others: People who have lived with cognitive impairment for a long time often will suggest that the interviewer ask others for information. It may be that they are feeling overwhelmed by the questions or simply do not remember. It may be wise to negotiate who might be the best source of factual information as a way of supporting the patient; however, it is also important to let them know their opinions and points of view regarding what has been learned are still very important.
- Ask patients about their cognitive and functional difficulties: Start with general questions and follow up with more specific ones. When patients can respond to a general question with details about their impairments and what they do to compensate, they probably have more self-awareness than patients who require specific questioning to elicit information about their day-to-day functioning. Examples of interview questions to assess cognitive and functional impairments may be found in Appendices C and D respectively.
- Remember that patients may use different language to describe their problems: For example, it is common for patients to say they do not really have a memory problem because they know they can remember events before their injury. However, if asked whether they remember appointments, they may readily acknowledge they have a problem.
- Use collateral informants when they are available to evaluate a patient's insight and awareness: It is also important to evaluate the difference between the patient's reports and reports from family or others. It may be necessary to confirm a patient's needs and abilities with someone who has regular contact with them.
- When a problem is discovered, ask the patient what they do about them. For example, if a patient reports frequent headaches, ask them what they do to alleviate their headache pain.
- While it is important to screen, it is also important to mitigate the potential impact of stigma related to TBI. It is common for people who have brain injury to feel they are regarded as "dumb" or to feel marginalized once a brain injury becomes known. For that reason, the clinician should be affirming as possible of the individual's strengths and abilities, emphasizing that the need for screening is to have a full understanding of the patient's medical history. All assessments should be conducted in a manner that is culturally appropriate and trauma-informed, given the high likelihood of trauma in this population.

	SCREENING FOR BRAIN INJURY
Basic Recommendation	Use brief screening questions
Specific Recommendation	The Ohio Valley Brain Injury Identification Method (Corrigan and Bogner, 2007). In the public domain. Online training is available.
Specialized Recommendation	The Ohio Valley Brain Injury Identification Method (Corrigan and Bogner, 2007). In the public domain. Online training is available.
Resources	See Appendix B for brief screening questions for brain injury.
	<u>Ohio Valley Brain Injury Identification Method</u> <u>Traumatic Brain Injury Screening: An Introduction (HRSA, 2006)</u>

 Table 5. Levels of Recommendations and Practice Adaptations to Screen for Brain Injury

**Rationale:** It is quite likely that clinicians will not be aware of a history of brain injury before the first visit. Patients may be unaware of how their history of injury might affect their current functioning or health. For this reason, they may not consider it relevant to inform the clinician. Because of the potential impact of brain injury on the patient's health and the high prevalence of brain injury among people who are homeless or marginally housed, screening all patients is recommended. The use of a validated screening instrument is recommended to elicit an individual's history as accurately as possible.

There is ample evidence that simply asking about a history of brain injury fails to produce an accurate picture of brain injury history (Corrigan and Bogner, 2007). Rather, at a minimum, it is necessary to ask about various sources of TBI that may have occurred, such as injuries to the head and neck, injuries or illnesses that required hospitalization, and circumstances, such as serving in the armed forces. When data are being collected for measuring population health or for research, the full Ohio Valley Brain Injury Identification Method is recommended.

Corrigan and Bogner (personal communication, March 2018) have also fashioned a brief screener that may be suitable for use when the full screen is not practical, and the only use for the information is for clinical care (e.g. to plan health care services for an individual). The screening questions may be found in Appendix A with an appropriate introduction to types of injuries.

**Evidence:** Recommendations are based on expert consensus of practitioners experienced in both brain injury and homelessness.

Sources: (Corrigan & Bogner, 2007; Hwang et al., 2008; McKinlay, Horwood, & Fergusson, 2016)

#### ASSESSING COGNITIVE IMPAIRMENT

In most cases, the reason a patient may come for a health visit will not be the direct result of a history of TBI. While addressing the patient's presenting concerns, the clinician should be alert to the high likelihood of cognitive impairment and know how to accommodate for any difficulties they observe.

Cognitive screening is recommended if there are any of the following:

- A positive screen for brain injury with loss of consciousness (LOC) > 30 minutes.
- LOC of any duration if the injury occurred within the past 6 months.
- When there appears to be ongoing, cognitive impairment observed during the interview.
- A complaint of physical or cognitive symptoms related to the TBI.

#### Recommendations for Completing Cognitive Screening

- Cognitive screening should be conducted under the supervision of a trained health professional. Some clinics use mental status examinations and cognitive screening as a part of their assessments. These examinations are typically done by physicians, nurses, occupational therapists, and psychologists. Like all assessments, the findings need to be taken in context with other relevant information.
- **Performance on cognitive screening measures is influenced by many factors.** The tests administered are only as good as the effort an examinee is willing and able to put into their performance. If the patient feels the examination is not respectful, they may not give it their all. If the patient is anxious, in pain, or depressed, they may not perform at their best. Education, age, and culture also affects how a person approaches testing. Testing that is offered in a calm and quiet environment may elicit a patient's best–but not their usual performance.
- Patients may do well doing cognitive tasks. Not all problems caused by brain injury will be picked up by cognitive screening. Many people living with brain injury may perform well on cognitive tasks but still have a disordered response to emotions, rewards and punishments that is the result of brain injury. They may experience significant difficulty when they need to control their own behavior but when the examiner is providing one task at a time they do fine.

For the above reasons, mental status examinations or brief screening measures may be helpful in ruling out some simple types of cognitive problems and raising suspicion of functional impairment, but they should not be considered diagnostic. Recommended measures include <u>Montreal Cognitive</u> <u>Assessment</u> (MoCA), and <u>Brief Cognitive Status Exam</u> (BCSE).

#### **Cognitive Evaluation Guidelines**

For health centers able to perform cognitive evaluations, here are few guidelines to consider:

- Ensure the patient has fully consented to completing an assessment of their cognition and has indicated they are interested in participating.
- Ensure the assessment being used is current and has normative information for the age and educational status of the person being examined. Common measures are listed in Table 6.
- Consider the individual's physical and emotional state on the date of testing. For example, is the person rested or under the influence of a substance or prescribed medications? Is their mood stable?
- Be sure to follow the standardized test instructions (without variation).
- The examiner will need to give some feedback about the results of the examination to the examinee, and be comfortable giving truthful information in a format that the patient will comprehend.

During the assessment of a person with TBI, clinicians should consider the possibility that other factors may be contributing to cognitive performance impairments and functional limitations, including personal factors, pre-injury medical conditions, and injury-related factors and conditions.

Personal factors include:

- Cultural background
- Fluency and literacy in language of assessment
- Level of education/academic history/premorbid learning difficulties
- Premorbid intellectual level of functioning
- Occupational/vocational history
- Recreational, hobby history

Pre-injury medical conditions include:

- Substance use/abuse
- Mental health issues
- Psychosocial trauma or abuse
- Neurological disorders (e.g., dementia, seizures)
- Hearing or vision impairment
- Nutritional status

Injury-related factors and conditions include:

- Medical conditions
- Psychiatric conditions, especially mood disorders
- Fatigue
- Sleep/wake disorders

- Medications (pre- and post-injury), including over-the-counter remedies, herbs, or supplements
- Seizures
- Sensorimotor changes
- Endocrine dysfunction (e.g., growth hormone deficiency)
- Pain
- Acquired language changes (e.g., aphasia, dysgraphia)
- Injury-related vision or hearing deficits
- Manual limb or oral-motor dysfunction (e.g., weakness, incoordination)
- Consider the possibility of other comorbid factors

# Table 6. Levels of Recommendations and Practice Adaptations to Assess Cognitive Impairment ASSESSING COGNITIVE IMPAIRMENT

Basic Recommendations	When a person reports a history of brain injury and/or difficulties with behavior and follow-through, these should be regarded as risk factors for cognitive impairment. At a minimum, staff members should use the resources referenced in this guideline to become familiar with how cognitive impairment may present in the patients they serve.
	<ul> <li>Staff members should anticipate many patients will have difficulties with</li> <li>Communication</li> <li>Cognitive slowing</li> <li>Impaired attention</li> <li>Impaired new learning and recent memory</li> <li>Staff members should follow general recommendations for accommodating cognitive impairment.</li> <li>If there is a known history of brain injury, ask about previous</li> </ul>
	neuropsychological assessments.
Specific Recommendation	A team member should have training and experience in recognizing and evaluating cognitive impairment using recommended screening measures.
Specialized Recommendation	The team has access to consultation by or includes brain injury professionals who can provide specialized assessments (e.g., functional safety assessments, neuropsychological assessments, speech and language assessments) that are suitable to enable diagnosis and/or access to benefit programs.
Resources	See Appendix C for suggested cognitive impairment assessment tools. Online training resources: <a href="http://ohiovalley.org/informationeducation/tbi101/www.brainline.org">http://ohiovalley.org/informationeducation/tbi101/</a> <a href="www.brainline.org">www.brainline.org</a> <a href="mailto:Clinical Practice Guidelines">Clinical Practice Guidelines</a> for the rehabilitation of adults with moderate to severe TBI <a href="mailto:Clinical Practice Guidelines">Clinical Practice Guidelines</a> – cognitive functions for the rehabilitation of adults with moderate to severe TBI

**Rationale:** Cognitive impairment is common after brain injury, particularly in those who are chronically homeless and are living with the impact of serious mental illness and substance use disorders—conditions that are highly correlated with a history of TBI. Understanding the nature and severity of an individual's cognitive impairment should inform care planning. Documentation of an individual's impairments may also support applications for disability benefits.

**Evidence:** Recommendations are based on expert consensus of practitioners experienced in both brain injury and homelessness.

Sources: (Center for Disease Control and Prevention, 2015; Corrigan, Adams, & Larson, 2013; K. Dams-O'Connor et al., 2014; Gould, Ponsford, Johnston, & Schonberger, 2011; Hwang et al., 2008; Mackelprang, Harpin, Grubenhoff, & Rivara, 2014; Oddy, Moir, Fortescue, & Chadwick, 2012; Stergiopoulos et al., 2015; Topolovec-Vranic et al., 2013).

#### ASSESSING FUNCTIONAL IMPAIRMENT

Assessing functional impairment is recommended for all patients with a history of TBI with LOC or multiple concussions. The assessment may also be useful for individuals with suspected or demonstrated cognitive impairment related to other diagnoses. A clinical interview and observation may provide information about areas of difficulty. The use of a structured measurement tool will facilitate collection of the information.

AS	SSESSING FUNCTIONAL IMPAIRMENT
Basic Recommendations	Staff members should be aware some signs of functional impairment are easily mistaken for a lack of cooperation and motivation. At a minimum, staff members should use the resources referenced in this guideline to become familiar with how functional impairment may present in the patients they serve. WHODAS 2nd ed. may be used. The WHODAS is recommended as a brief screening measure to support assessment of functional impairment.
<u>En esté e</u>	Adaptive Behavior System 3rd ed. (ABAS)
Recommendation	evaluating functional impairment using recommended screening measures in Appendix D.
Specialized Recommendation	The team has access to consultation by or includes brain injury professionals who can provide specialized assessments (e.g., functional safety assessments, neuropsychological assessments, speech and language assessments) that are suitable to enable diagnosis and/or access to benefit programs.
Resources	See Appendix D for suggested tools to assess functional impairment.
	Online training resources: <u>http://ohiovalley.org/informationeducation/tbi101/</u> <u>www.brainline.org</u> <u>World Health Organization Disability Assessment Schedule</u> (WHODAS
	2nd ed.)
	Adaptive Behavior System 3rd ed. (ABAS)
	<u>Clinical Practice Guidelines</u> for the rehabilitation of adults with moderate to severe TBI

Table 7. Levels of Recommendations and Practice Adaptations to Assess Functional	
Impairment	

**Rationale:** Over half of all people who are served in programs addressing homelessness report a history of TBI. Many TBI survivors may have one or more of a wide range of lasting impairments

that affect their ability to engage productively in services and to maintain housing once they find it. The functional difficulties caused by cognitive impairments, such as trouble keeping appointments or violating rules, are easily misunderstood as noncompliance or a lack of motivation. TBI survivors themselves may be unaware of how their injury affects their current functioning or health and thus fail to inform clinicians of their history of TBI. Screening for TBI and assessing for functional impairments and comorbid conditions can greatly increase access to care and improve patient outcomes. Functional assessment can directly inform care planning

**Evidence:** Recommendations are based on expert consensus of practitioners experienced in both brain injury and homelessness.

Sources: Andersen et al., 2014; Corrigan & Bogner, 2007; Hwang et al., 2008; Topolovec-Vranic et al., 2013.

#### SUMMARY OF MAJOR RECOMMENDATIONS FOR BRAIN INJURY SCREENING, COGNITIVE AND FUNCTIONS ASSESSMENTS

- 1. Practitioners should screen all patients for TBI using screening questions that elicit a complete history. Screening methods should include orientation to types of brain injuries, and probe for the first injury, most serious injury, most recent injuries as well as a history of multiple mild injury such as occurs in sports or physical abuse. <u>The Ohio Valley Brain Injury</u> <u>Identification Method</u> training may be used to gather the needed information.
- 2. During initial contacts, the clinician should be attentive to possible signs of functional and cognitive impairments and accommodate accordingly.
  - a. The clinician should ensure good communication has been established. This usually requires a quiet, private environment and slowed, simplified messages adapted to the patient's communication style.
  - b. The clinician should be alert to the fact that a person with TBI may appear to be functioning well based on their ability to participate in the assessment, but they may have much greater difficulty with day-to-day functioning.
- 3. Cognitive screening is recommended if there is a positive screen for brain injury with loss of consciousness (LOC) > 30 minutes, LOC of any duration if the injury occurred within the past 6 months, and/or when there appears to be ongoing cognitive impairment as observed during the interview, or if there is a complaint of physical or cognitive symptoms related to the TBI. Recommended measures include <u>MoCA</u> and <u>BCSE</u>.
- 4. Assessment of functional impairment is recommended for all patients with a history of TBI with LOC > 30 minutes, LOC after a brain injury within the last 6 months, a complaint of or directly observed impairment and/ or a reported history of multiple concussions. It may also be useful for individuals with suspected or demonstrated cognitive impairment related to other diagnoses. Clinical interview and observation may provide information about areas of difficulty. Using a structured measure will facilitate collection of that information. Recommended measures include <u>WHODAS</u> 2nd ed. and the ABAS 3<sup>rd</sup> ed.
- 5. When a history of brain injury with LOC is reported, the likelihood of mental health and substance use disorders as well as legal difficulties are significantly increased. These factors should also be assessed.
- 6. History of seizures, endocrine disorders, headache/pain, fatigue, and sleep disorders should be elicited.
- 7. Many people who are homeless or marginally housed may have had negative experiences with medical providers and requires the interpersonal stance of cultural humility, and a trauma-informed approach to care provision. Those who are also living with cognitive impairment may experience an additional disadvantage when it comes to understanding the possible benefits of services and interpreting the intentions of the care providers.

- 8. When treating people living with a history of both brain injury and homelessness, clinicians may find it takes additional time and effort to build trusting relationships with patients.
- 9. It is common for people who have brain injury to feel they are regarded as "dumb" or to feel marginalized once a brain injury becomes known. For that reason, the clinician should be as affirming as possible of the individual's strengths and abilities, emphasizing the need for screening is based on having a full understanding of the patient's medical history.

#### MEDICAL EVALUATION

#### **Physical Examination**

Unless an individual is complaining of a new concussion or brain injury, the physical examination will likely be completed in the context of some other medical issue. The clinician should be aware of incidental findings that may be associated with brain injury. These may include scars on the head related to trauma or surgery, scars on the neck related to a previous tracheostomy, or other neurological signs, including asymmetries of gait, strength, eye gaze, or facial musculature. Patients should be informed of the findings and asked about their origin.

Because a history of trauma is common in people who are experiencing homelessness, it is important to practice cultural humility <sup>1</sup>trauma-informed care<sup>2</sup> during all patient visits.

#### Diagnostic Testing and Neurological Examination

A neurological examination will provide information regarding the patient's current functioning and provide a basis for prioritizing intervention. In general, management of a patient's current neurological difficulties will be based on the relief of symptoms that are troubling. Clinicians should be aware that some positive signs on neurological examination might represent long-standing problems to which the patient has adapted. Collaborating with the patient to set priorities for care is essential. There may be some issues of which the patient is unaware. Most commonly, patients will have more difficulty in recognizing changes in behavior or emotional regulation and cognition than they do physical or sensory problems. Where possible, getting a report from someone who knows the individual well can help determine the onset of a given problem and assess its severity.

Issues that require assessment include sensory perception, including sense of smell, visual fields, and tactile perception. Visual field cuts (visual field loss) and neglect are common after TBI. While they tend to persist, patients often adapt well and experience little functional impairment. However, they continue to be vulnerable to missing information on the affected side of the brain while in busy or distracting environments, making a functional assessment desirable. When sensory impairments are observed, the clinician should ask about and observe how well the patient has adapted. When there is suspicion of neglect or loss of sensation, it is important to monitor for the presence of repeated injury without the patient's awareness. Neglect most commonly occurs on the left side of the body. For this reason, neglect should be suspected if there is evidence of repeated injury on the left side of the body.

<sup>&</sup>lt;sup>1</sup> Cultural humility is "a process of self-reflection and discovery to understand oneself and then others to build honest and trustworthy relationships. Cultural humility is a humble and respectful attitude toward individuals of other cultures that pushes one to challenge their own cultural biases, realize they cannot possibly know everything about other cultures, and approach learning about other cultures as a lifelong goal and process" Tervalon, Murray-Garcia, 1998).

 $<sup>^2</sup>$  Trauma-informed care is "a strengths-based framework that is grounded in an understanding of and responsiveness to the impact of trauma that emphasizes physical, psychological, and emotional safety for both providers and survivors, and that creates opportunities for survivors to rebuild a sense of control and empowerment" (Hopper, Bassuk, & Olivet, 2010), p. 82).

Anosmia, a loss of sense of smell, is also somewhat common after TBI. Because of a reduced sense of taste, patients may show a strong preference for sweet and salty foods—flavors that are sensed on the tongue. In addition to poor nutrition, patients may show less motivation to participate in hygiene and are at risk for ingesting spoiled food and failing to respond to the odorant used in natural gas. While most people are aware of the change in their sense of smell, some patients may not be aware.

In general, specific diagnostic testing, such as medical imaging, should be focused on newly emerging or worsening conditions. For example, changes in cognition, balance, and gait and incontinence, when they occur together, may signal a change in intracranial pressure, and with a positive examination, imaging may be required for diagnosis and treatment. Other examinations such as for hearing or vision are indicated if there is a functional impairment that can be addressed directly.

#### Screening for Endocrine Dysfunction

Hypothalamic pituitary axis dysfunction is common post-TBI and may vary in the acute, subacute, or chronic phase. This dysfunction may affect the anterior pituitary system, the posterior pituitary, or both. Individuals with severe TBI commonly develop disorders of the anterior pituitary during the acute, subacute, or chronic phase post-injury, which results in neurohormonal disturbances.

Screening of the hypothalamic pituitary axis should occur at 3–6 months post-TBI or when symptoms are suggestive of a hormonal imbalance or deficiency. Screening should include a.m. cortisol, serum glucose, thyroid hormone (Free T4), thyroid-stimulating hormone (TSH), prolactin, estrogen or a.m. testosterone (T), follicle-stimulating hormone (FSH), luteinizing hormone (LH) and insulin-like growth factor-1 (IGF-1). Clinicians should be aware that a low or normal TSH does not rule out pituitary insufficiency with thyroid hormone deficiency.

#### Blood and Urine Testing

When the clinician is concerned about a patient's ability to maintain a drug regimen or to provide a clear history, blood and urine testing may be useful.

#### Neuropsychological Assessment

An important source of information about the patient's cognitive, behavioral, and emotional status is the neuropsychological assessment. For patients who have had a moderate to severe injury, and who have participated in rehabilitation, a neuropsychological examination may be available in the medical record. Those who did not have access to health care following their injury or sustained a mild injury are less likely to have completed an assessment.

When reviewing the report, it is important to consider when it was completed in relation to the injury and how long ago each occurred. If the examination was completed at least 1-year post-injury and was within several years of the current assessment, the information is likely to be more accurate than if it was conducted before the patient stabilized or many years ago. In any case, given the high
occurrence of re-injury and the potential for other conditions to affect cognitive functioning, such as substance use, re-assessment may be considered if there are questions regarding cognitive functioning, and the most recent examination was more than a year or two ago.

Patients may not be aware of the difficulties they have with cognition. Findings of cognitive assessments should be provided to the patient in terms they can understand. Generally, this means describing how a given cognitive impairment might interfere with day-to-day functioning. For example, when memory or attention seem to be impaired on examination, the clinician might suggest that it may be helpful for the patient to have a reminder for appointments or to take medications. These observations should include ways of supporting the patient to address the observed difficulty, such as providing written instructions or problem solving with the patient on how they might remember some specific information. More specific recommendations are provided in Appendix E.

Where available, assessments may be useful for individuals where there is a question about whether and how cognitive impairments may be interfering with functional abilities. Priority should be given to those individuals where the assessment may inform how to accommodate an individual's cognitive impairment, the level of care needed, and/or to qualify for appropriate disability benefits or programs.

- In complex and marginalized populations, neuropsychological examination may be less useful for diagnostic purposes. Many patients will have several potential causes for cognitive impairment, including substance use; psychiatric conditions; infectious disease, including HIV; and neurodegenerative disease. When the patient's condition includes mild to moderate TBI along with psychiatric disease and substance use, differential diagnosis of the source of the cognitive impairment is unlikely. However, an overview of the patient's functional cognitive status is possible.
- **Providing a clear referral question will maximize the impact of the assessment.** When an opinion regarding functional ability or capacity is needed, the referral should include detailed information about the specific concerns related to decision-making and/or self-care, and access to collateral informants should be facilitated. Questions such as the existence of cognitive impairment that could interfere with participation in a vocational program are appropriate.

## Neurobehavioral Assessment

People living with brain injury present with varied behavioral difficulties. Some of the most common include post-concussion syndrome, depression, post-traumatic stress disorder and generalized anxiety disorders, anger, agitation and aggression, impulsivity, impaired awareness of disability, sexual dysfunction, and substance use disorders. In general, an assessment of neurobehavioral issues following traumatic brain injury must address pre-injury vulnerability factors, injury-related factors, and post-injury factors.

## Pre-injury vulnerability factors:

Prior medical/neurological conditions, mental health disorders, substance use disorders, temperamental/personality factors, cognitive/intellectual ability, academic/vocational function, psychosocial circumstances.

### Injury-related factors:

Nature of injury (i.e., severity, focal vs. diffuse), cerebral involvement, anatomic injury location, extent of secondary injury, co-occurring extra cranial injury.

## Post-injury factors:

Psychological response/coping style, cognitive status, social/economic changes, newonset mental health disorders, medical conditions (such as seizures, sensorimotor changes, endocrine dysfunction, pain, sleep/wake disturbance), medication effects.

## SUMMARY OF MAJOR RECOMMENDATIONS FOR MEDICAL EVALUATION

- 1. Cultural Humility and trauma-informed care should be practiced when assessing all patients seeking services in settings that serve people who are homeless or marginally housed because this patient group is understood to have a high incidence of trauma.
- 2. Assessors should be alert to the evidence of trauma in physical appearance, including scars.
- 3. Medical screening should include endocrine functioning.
- 4. Medical screening should include neurological examination.
- 5. Medical imaging is only likely to be required for newly emerging or worsening impairments or symptoms. In mild TBI, imaging is only required when there is a deterioration in functioning and/or the patient is taking anticoagulant medication or has been diagnosed with a clotting disorder.
- 6. Blood and urine testing may be used to determine medication compliance and assess for substance use.
- 7. Assessment of neurobehavioral issues following TBI should address pre-injury vulnerability factors, injury-related factors, and post-injury factors.
- 8. Occupational, therapy assessment, where available, should be conducted to assess for impairments of daily functioning, and physical therapy assessment should be conducted for mobility impairments.
- 9. Neuropsychological assessment should be accessed to clarify diagnosis and/or to support disability claims and recommendations for service providers.

## INDIVIDUALIZED CARE PLAN

Patients are often unaware of how cognitive impairment may interfere with their ability to accept and benefit from care. It will often be necessary to build trust and develop routines for follow up before some treatment issues can be addressed. Developing a care plan that is based on an understanding of a patient's cognitive abilities and current goals and concerns is the best way to support a patient's engagement.

When supports are limited, the first goal of the care plan is to engage the patient. Goals should be short term in nature and consistent with the patient's ability and willingness to participate in services. Once the patient is engaged and/or support systems are available, more substantive goals can be established. The clinician and the patient should work together to determine what goals can realistically be addressed given the nature of current supports, and the patient's willingness and ability to follow through. The following is a suggested hierarchy of short-term goals:

Begin by developing a routine that encourages regular contact.

- Pair contacts with regularly occurring events, such as meals, other regular appointments, or activities.
- Maintain consistent appointment times or clinic hours.
- Establish a way to contact the individual.
- Prioritize obtaining case management/housing supports.
- Address acute medical issues.
- Address mental health/substance use issues.
- Address education and self-management.

In general, when a patient is unaware of a problem or impulsivity has been identified, care plans should not rely on self-management by the patient but rather focus on environmental supports. Examples include the use of trustees for distribution of daily spending money, daily medication observation/administration, or direct assistance to complete specific tasks or attend appointments.

Many patients with a history of TBI will have significant neurocognitive and behavioral difficulties. Care plans should be designed to accommodate cognitive impairments, and they should adapt to neurobehavioral difficulties that impede access to intervention. Ultimately, the nature of the care plan will depend on the amount of support and structure that is available in the environment. An interdisciplinary team that includes neuropsychology, occupational therapy, social workers, and rehabilitation support workers is recommended to ensure holistic care. However, even simple modifications to care planning can significantly improve outcomes.

The plan of care provided to an individual will depend on the context in which the care is being provided. However, the goal in any situation is to minimize the extent to which cognitive and neurobehavioral difficulties result in a barrier to services. State and local brain injury associations may serve as clearing houses for information related to benefits, and some offer case management supports and programming. Developing relationships with these organizations is essential for identifying and filling gaps in services.

## SUMMARY OF MAJOR RECOMMENDATIONS FOR INDIVIDUALIZED CARE PLAN

- 1. Clinicians should work collaboratively with the patient to develop realistic short-term goals.
- 2. When cognitive and functional impairments are observed or suspected, the care plan should include environmental supports including:
  - a. Written information using a simplified format;
  - b. Prompts and reminders provided with the permission of the patient;
  - c. Direct support to follow through with required tasks; and
  - d. Appointments that are scheduled on a routine basis, at the same place and time, and with familiar providers.
- 3. Where available, patients should be connected to targeted intensive case management designed for those living with disability. Case management services may include a focus on completion of functional activities and medical compliance as well as promoting engagement in meaningful activity.
- 4. For many patients, supportive housing will be required to ensure housing stability. Linkages with housing providers and landlords to increase the success of exiting from homelessness and sustaining supportive housing are recommended.
- 5. The use of small incentives such as coffee or food may be useful to encourage attendance and support engagement.
- 6. Programming that is offered on a routine basis and in a single location will improve patient engagement.
- 7. Functional cognitive assessment that is completed by or under the supervision of an occupational therapist and/or neuropsychologist is recommended where available.
- **8.** An interdisciplinary team that includes primary care, neuropsychology, occupational therapy, social workers, psychiatry, pharmacy, and rehabilitation support workers is recommended to ensure holistic care. Partnering with street medicine teams and transitional housing teams is particularly useful for people living with neurocognitive and neurobehavioral impairments.

## **MEDICATION MANAGEMENT**

This section gives an overview of practice adaptations for the most commonly observed chronic medical issues. The reader is encouraged to review the guidelines in the primary sources section for additional information.

Careful drug selection and monitoring of medications is required when initiating pharmacological interventions to minimize potential adverse effects on arousal, cognition, motivation, and motor coordination. The best strategy is to minimize the number of medications used by selecting treatments that can have a beneficial effect on brain-injury-related symptom/syndrome. For example, one medication may be used to treat both mood and insomnia or both headache and insomnia.

Because of the changes in the blood-brain barrier and multiple systems that may be affected by trauma, experienced clinicians recommend that any medication, particularly those with psychoactive effects, should be started at the lowest dose that is likely to be effective and titrated up slowly.

## Managing Seizure Disorders

If anticonvulsant medications are required, consideration should be given to choosing medications that minimize cognitive side effects. For example, although phenytoin may have negative effects on cognitive performance and recovery, it may still be considered a first-line drug for early seizures in the acute period in view of ease of administration and monitoring, and yet not be the best choice for patients with TBI. Clinicians should be particularly vigilant for adverse cognitive side effects of anticonvulsant medications and not assume these drugs are without risk to cognitive, behavioral, physical, and neuroendocrine function as well as having potential negative impacts on long-term recovery.

## Managing Sleep and Fatigue

In general, individuals who have sustained a TBI should be assessed for fatigue and sleep disorders and offered appropriate treatment. A presenting complaint of fatigue most often means that sleep is poor. The clinician should be sensitive to the significant challenges of getting a good night's rest when living in shelter situations. For the individual living with brain injury, sleeplessness can compound the problems associated with emotional control and cognition that the individual faces. Supporting the individual to prioritize getting a good night's rest can help with other difficulties that they may face. Earplugs and eye masks may be useful for some individuals.

For individuals who would benefit from a medical approach to insomnia, melatonin in doses of 2 to 5 mg has been shown to be of benefit. Trazadone in doses of 25 to 100 mg has also been found to be useful after brain injury. In general, the use of benzodiazepines should be limited due to potential effects on arousal, cognition, and motor coordination, and used as a last resort and prescribed for no more than 7 days.

## Managing Mood Disorders

Depression after TBI is amenable to pharmacologic interventions. There is evidence to suggest that treatment for mood disturbance may also benefit difficulties with sleep and irritability and in some cases impulsivity. When indicated, pharmacotherapy may be initiated with people who have a history of brain injury. However, the clinician must consider the likelihood of patient compliance.

Selective Serotonin Reuptake Inhibitors (SSRIs) are recommended as a first-line treatment for depression following TBI. A limited body of evidence supports the efficacy of sertraline (starting at 25 mg; aiming for 50–200 mg/day) and citalopram (starting at 10 mg; aiming for 20–40 mg/day).

If SSRIs are not effective or have produced unwanted side effects or drug interactions, the individual should be referred for review to a psychiatrist with expertise in treating individuals with TBI.

## Managing Anxiety

There is a lack of research concerning medication treatment of anxiety disorders after TBI; however, much evidence exists supporting their treatment in the non-TBI population

Given their favorable tolerability and broad utility, SSRIs may be considered for anxiety treatment of individuals with TBI.

The use of benzodiazepines as first-line therapy for anxiety in individuals with TBI is *not* recommended due to potential effects on arousal, cognition, and motor coordination. The potential for abuse/dependency associated with these agents is also of concern, given the elevated rates of preinjury substance use disorders observed among individuals with TBI. Nonetheless, short-term use of these agents may be helpful during periods of crisis or acute distress.

## Managing Psychosis

The use of second-generation neuroleptics is recommended for the treatment of psychosis as they are associated with fewer extrapyramidal symptoms than first-generation neuroleptics, and they exert their effects at sites other than the D2 receptor. In recent brain injuries, first-generation neuroleptics have been associated with greater negative impact on neuronal recovery. The ongoing need for antipsychotic medications should be periodically reassessed, and ongoing monitoring of weight, metabolic parameters, and late-emerging extrapyramidal symptoms is required. As all neuroleptics lower the seizure threshold to varying degrees, an initial trial with an anticonvulsant should be considered when heightened risk of seizures is of substantial concern.

## SUMMARY OF MAJOR RECOMMENDATIONS FOR MEDICATION MANAGEMENT

- 1. When medication is indicated for people living with brain injury, it should be introduced at the lowest possible dose and titrated slowly upward.
- 2. When prescribing any medical treatment, the provider should consider the patient's willingness and ability to comply with care and the potential for medications to be lost or stolen.
- 3. Medication dosing instructions should be simplified as much as possible. Patients with TBI may have difficulty following complex medication instructions or remember to take medications at multiple times per day.
- 4. Drug selection and monitoring are required to minimize the potential adverse effects on arousal, cognition, motivation, and motor coordination following TBI. The use of medications that target more than one brain injury-related symptom/syndrome is recommended if possible (e.g., one agent for both mood and insomnia or both headache and insomnia).
- 5. If seizure medications are required, consideration should be given to choosing medication that minimizes the negative impact on neuropsychological functioning.
- 6. Individuals with brain injury who report difficulty with sleep and fatigue should be assessed. The use of melatonin and trazadone should be considered.
- 7. Benzodiazepines (lorazepam) and other nonbenzodiazepine hypnotic (zopiclone) medications should be considered as a last resort treatment for sleep disorders and used for periods no longer than 7 days.
- 8. Because Selective Serotonin Reuptake Inhibitors (SSRIs) have a better side effect profile, they are recommended as a first-line treatment for depression after brain injury. Sertraline and citalopram have been found to be effective for some individuals.
- 9. If SSRIs have been trialed and are found to be ineffective or there have been unwanted side effects, referral to a psychiatrist with experience in brain injury is recommended.

## EDUCATION AND SELF-MANAGEMENT

People living with brain injury frequently have difficulty with self-management. However, there is evidence that when time is taken to provide education geared toward the individual's priorities; and abilities and to teach and reinforce self-management strategies, patients can be successful, and outcomes can improve. The clinician should be prepared to provide information over time, repeating messages as necessary, and supporting the patient to create a plan to follow through with recommendations.

A growing amount of literature supports the use of Motivational Interviewing (MI) as an effective intervention strategy for encouraging health-related changes and is being adopted as a best practice across health care settings (Coyne & Correnti, 2014). Specific evidence regarding the use of MI after brain injury is limited; and some adaptations may be required. For example, supporting a patient to recall their own history when asking open-ended questions, and helping a patient to remember the insights that occurred in counselling with repetition and written information may be useful (Lemsky & Godden, 2013) Appendix E includes some recommendations for supporting patients to remember and use new information.

Substance use after brain injury is particularly damaging. Patients should be provided with information about the risks of substance use after brain injury. The prevention messages developed by the Ohio Valley Center for Brain Injury Rehabilitation were developed to emphasize the particular difficulties that occur after brain injury (such as problems with balance and impulsivity and high risk of seizures) and how these may be affected by substance use. When offered in a motivational fashion, these messages may help patients make better decisions regarding substance use and/or their need to seek help with a substance use disorder. The clinician should be ready to review the information as required, taking care to ensure the patient is ready and willing to participate in the educational session.

The clinician should not take for granted that patients will engage in typical self-help behaviors when faced with fatigue, headache, or difficulty sleeping. Often, discussions about managing symptoms will be appreciated. Examples of simple suggestions to manage symptoms include using over-the-counter medication correctly, staying hydrated, taking rest breaks, or using earplugs in noisy environments to help with sleep.

Many brain injury associations provide psychoeducational materials or programs to support people living with brain injury. Patients are likely to need direct support to take advantage of these resources. Keep in mind that even when some patients would like to take more control of their health, they may have difficulty initiating the necessary behaviors. Clinicians should be alert to difficulties in implementing self-help strategies and assist the patient in accessing needed supports.

## SUMMARY OF MAJOR RECOMMENDATIONS FOR EDUCATION AND SELF-MANAGEMENT

- 1. Patients should receive results of cognitive assessments in a format they are able to understand.
- 2. Patients should be introduced to available compensatory strategies, such as smart phones, notepads, and calendars. Training and support will generally be required to ensure their effectiveness. The process of developing cognitive compensations should be collaborative, addressing specific functional needs the individual identifies.
- 3. Education about the particularly damaging effects of substance use after brain injury should be provided in multiple formats, including simplified written materials
- 4. Patients should be offered information about managing problems including headache, fatigue, and sleep disorders.
- 5. Patients should be encouraged to take advantage of any available support groups or educational materials provided by local brain injury support services.
- 6. Accompanying patients to introduce them to new settings and programs may be required to accommodate problems in initiation and planning. Programs designed for people living with cognitive impairment (e.g. programs for people living specifically with brain injury or other disabilities) may be required to encourage participation in meaningful activity.

Table 8. Levels of Recommendations and Practice Adaptations for Medical Evaluation and Development of Care Plan

	MEDICAL EVALUATION AND CARE PLAN
Basic Recommendation	<ul> <li>Complete physical examination should be conducted to include:</li> <li>Neurological Examination</li> <li>Seizure disorder</li> <li>Endocrine functioning</li> <li>Sensory functioning</li> <li>Sleep/Fatigue</li> <li>Post-concussive symptoms</li> <li>Additional screenings, tests and assessments as deemed appropriate by clinician.</li> </ul>
	Individualized care plan should be developed considering results of screening and assessments.
	When referring for health care, the team should provide information related to the history of brain injury as well as any cognitive and functional issues observed.
	The team can refer clinicians to evidence-based guidelines.
Specific Recommendation	<ul> <li>Complete physical examination should be conducted to include:</li> <li>Neurological Examination</li> <li>Neuropsychological Assessment</li> <li>Seizure disorder</li> <li>Endocrine functioning</li> <li>Sensory functioning</li> <li>Sleep/Fatigue</li> <li>Post-concussive symptoms</li> <li>ACE screening</li> <li>Additional screenings, tests and assessments as deemed appropriate by clinician.</li> </ul>
	Individualized care plan should be developed considering results of screening and assessments.
	Intensive case management support provided.
	The team includes a brain injury-aware provider to conduct a history and physical exam in consideration of the likelihood of cognitive impairment and history of trauma. Clinicians are aware of evidence-based guidelines.

	Program partners with brain injury programs as well as other social services to address health and behavioral health conditions identified.		
Specialized Recommendation	<ul> <li>Complete physical examination should be conducted to include:</li> <li>Neurological Examination</li> <li>Neuropsychological Assessment</li> <li>Seizure disorder</li> <li>Endocrine functioning</li> <li>Sensory functioning</li> <li>Sleep/Fatigue</li> <li>Post-concussive symptoms</li> <li>ACE screening and ongoing trauma assessments</li> <li>Additional screenings, tests and assessments as deemed appropriate by clinician.</li> </ul>		
	Individualized care plan should be developed considering results of screening and assessments.		
	Intense case management support is provided.		
	An integrated team consists of clinicians and includes specialty care providers and specialty services, including occupational therapist, social worker, speech and language therapist, neuropsychologist, psychiatrist, and rehabilitation nurse.		
	The team is able to complete diagnostic assessments and accesses specialized programs and health care services.		
	The program develops supportive housing options.		
Resources	<u>Clinical Practice Guidelines</u> for the rehabilitation of adults with moderate to severe TBI.		
	Clinical Practice Guideline Section 2: Assessment and Rehabilitation of Brain Injury Sequelae. Neurobehavior and Mental Health, Neurobehavioral Assessment View Full Recommendation		
	ERABI Module 9-Neuroendocrine Disorders View full module		
	Source: Medication Management Guidelines		
	Source: Clinical Practice Guideline, SECTION 2: Assessment and Rehabilitation of Brain Injury Sequelae, Medical / Nursing Management 9. Principles of Medication Management (Neuropharmacology) <u>View Full Recommendation</u>		
	ERABI Module 10- Post-Traumatic Seizure Disorder, p.12, 10.4 <u>View full module</u>		
	Source: SECTION 2: Assessment and Rehabilitation of Brain Injury Sequelae Medical / Nursing Management 3. Seizures <u>View Full Recommendation</u>		

**Source:** -ERABI Module 15-Fatigue and Sleep Disorders <u>View full module</u>; (Larson & Zollman, 2010)

**Source:** Clinical Practice Guideline Section 2: Assessment and Rehabilitation of Brain Injury Sequelae. Fatigue and Sleep Disorders. Assessment of Fatigue and Sleep <u>View Full Recommendation</u>

Source: ERABI Module 8-Mental Health Issues, View full module

**Source:** Clinical Practice Guideline 2: Assessment and Rehabilitation of Brain Injury Sequelae. Neurobehavior and Mental Health. Medication for Depression <u>View Full Recommendation</u>

Source: SECTION 2: Assessment and Rehabilitation of Brain Injury Sequelae Neurobehavior and Mental Health Medication for Anxiety <u>View Full</u> <u>Recommendation</u>

**Source**: Clinical Practice Guideline 2: Assessment and Rehabilitation of Brain Injury Sequelae. Neurobehavior and Mental Health. Medication for Psychosis <u>View Full Recommendation</u>

**Sources**: Clinical Practice Guideline Section F: Brain Injury Education and Awareness <u>View full recommendation</u>.

Ohio Valley Center for Brain Injury Prevention and Rehabilitation

Brainline.org

Brain Injury Association of America

Adverse Childhood Experiences

**Rationale:** Until recently, brain injury was viewed as a single health event—an insult to the brain—that had little or no impact beyond what was initially observed and following rehabilitation did not require additional treatment. However, over the past 10 years or so, clinicians and researchers have begun to conceptualize TBI as a chronic condition or disease process. As noted in their review of the relevant literature, (Malec et al., 2013) TBI conforms to the World Health Organization's definition of chronic disease process, in that the associated physical pathology is permanent, requires specialized rehabilitation, and may require long-term follow-up or supervision. TBI history significantly increases the long-term risk for seizure disorders, dementia, and neuroendocrine disorders, as well as shortened life span.

**Evidence:** Recommendations are based on expert consensus of practitioners experienced in both brain injury and homelessness. Evidence Based Review of Acquired Brain Injury ERABI. Recommendations are based on expert consensus of practitioners experienced in both brain injury and homelessness.

Sources: Masel & Dewitt, 2010; Malec et al., 2013.

## ADAPTATIONS TO ACCOMMODATE PEOPLE LIVING WITH TBI

This section will address recommendations for making services accessible, including the process of service delivery and the physical settings in which services are provided. There is a surprising lack of evidence regarding accommodations for people with cognitive impairment, though many practices have evolved that do make settings more accessible.

### Outreach

Patients with cognitive impairment may lack the planning and initiation skills to seek out appropriate services. Primary health care providers may need to support patients in getting the care they need through case management services and referrals. The practice of clustering services in places where patients are going to meet basic needs is a promising practice for those living with cognitive impairment. When case managers or other staff members are available to meet and work with patients who drop into meal programs, engagement becomes more likely.

### Service Intake

Many patients with cognitive impairment will have difficulty understanding or tolerating a wait for services or intake procedures that include multiple steps. Even returning for a second appointment may present a barrier to care. The memory and planning needed to follow through, particularly given the gauntlet of distractions people without stable housing face, greatly reduces the likelihood of follow-through.

When possible, intake procedures should be completed in a single visit. When paperwork is required, choices for completion should be offered. Often completing as much as possible with the patient in an initial visit is the best strategy. A failure to complete tasks associated with intake should not be considered a lack of motivation or cooperation, and relevant assistance should be offered. Throughout the process, intake workers should ensure that the client is aware of the voluntary nature of the services, and their right to decline to provide personal information.

## Service Delivery and Design

Service delivery systems should recognize that brain injury is an invisible disability. Cognitive impairments may cause people to appear uninterested in getting support or unmotivated to change their situations. Simple adaptations are often all that is necessary to help a person living with brain injury benefit from direct services. People living with complex comorbid conditions that include brain injury are often excluded from or have difficulty accessing care. Forging partnerships across service sectors is often the best way to address complex needs. Partnerships may make cross-referrals more efficient. More importantly, though, partnerships can help reduce the barriers to service. Coordinating efforts and care enables individuals to access all the care they need without waiting for specialized brain injury services.

## Service Delivery

- Make programs and groups more accessible.
- Use nametags.
- Limit groups to five or six participants. Some people with cognitive impairment may become distracted by who is in the room, making it difficult to pay attention to the task at hand.
- Use a consistent format:
  - Time to settle in/brief mindfulness
  - Reminder of important rules
  - Brief summary of the previous group
  - Goal for the current session
  - Interactive sessions with breaks are likely to be tolerated best.
  - o Brief summary at the end of groups
- **Promote learning through consistency and supportive structure.** Remove distractions before beginning a session, and develop a routine of using written agendas, which may be formulated with the patient at the beginning of the session. This can be done by making a list of topics of interest developed collaboratively with the patient and then determining together when and how the items will be addressed. Leaving the agenda visible will help the patient to focus on the topic at hand.
- Begin sessions with a summary of the previous session and reminders of the purpose of the interaction.
- Keep notes being taken visible to the patient and offer the patient a copy of the clinician's notes for the session. Using simplified notes in outline format or simple illustrations will help a patient track the course of the conversation. Jointly writing a brief summary can be a useful way to consolidate gains in the session and clarify next steps.
- Minimize errors to support and reinforce learning. Avoid asking or allowing patients to guess at information. Speculating and exploring hypothetical situations is often confusing for people with TBI. It is generally more successful to use supportive cues (i.e., give examples) when asking the patient to summarize information. For example, have the patient fill in one fact at a time until all the information has been learned.
- Support the application of new information to new settings. People with brain injury often have difficulty in transferring knowledge or skills from one setting to another. For example, a patient may be in a habit of writing doctor's appointments in a specific place, but not making similar notes for other types of appointments or tasks. Be sure patients are aware of how to use their compensation strategies to accomplish different types of task.

• Encourage patients to enlist supportive people in the environment. Anything they can turn into a routine is helpful.

## **Physical Space**

- Universal design (accessible design): These principles should be used in the design of any clinical program or living space. This includes accommodating individuals with mobility impairments in using examination tables and accessing all programming.
- Signage: Careful consideration should be given to the configuration of signs to help with navigation and as labels to indicate where items are to be kept. Navigation may also be facilitated by using distinctive features that may act as landmarks. Posting rules and reminders can be helpful.
- Visual cues to increase orientation: Using large clocks and calendars that clearly indicate the current day and time will support orientation.
- **Daily schedules**: Activity schedules should be simple in format and placed near entries or in main spaces where they can be easily noticed.
- Sensory stimulation: People differ in the amount of sensory stimulation they find comfortable. Offer spaces remote from busy areas that offer respite from noise or crowds. Having the option of quiet music or nature sounds rather than silence may be helpful.
- Maximize natural daylight: Connection to outdoor spaces increases orientation.
- Offer spaces to rest: Fatigue is a common problem after brain injury. Offering places to rest during the day for brief periods can improve wellbeing and participation.

## Street and Shelter-Based Care

In street and shelter settings, simple accommodations can be effective in making services more accessible to people with brain injury. Simply being aware that the cause of an individual's difficulties may be related to cognitive difficulties is an important start. Workers should suspect cognitive impairment when an individual seems to have difficulty adhering to rules, has poor follow-through with recommendations, or seems to have difficulty in sticking to a plan or goal. Brain injury often causes problems with emotional regulation and social behavior. In short, when an individual's behavior does not match their stated goals, cognitive impairment must be considered as a possible cause. A primary goal of services in street and shelter-based care is to identify those individuals who will require additional services to achieve stable housing and provide appropriate referrals.

In many cases, shelter workers will be able to identify those individuals who are experiencing cognitive impairment simply by observation. This may be followed by screening for brain injury history and neurocognitive screening. Partnerships with community providers may provide

additional support to provide an assessment. For example, the Fred Victor Centre, a comprehensive service center for people experiencing homelessness in Toronto, Ontario, and Community Head Injury Resource Services of Toronto developed a partnership to address the need to provide documentation of individuals' injuries to help them qualify for services and benefits. Service workers identified those patients who would benefit from assessments and support patients in attending the testing appointment. A brief neuropsychological assessment was completed, and feedback provided to the patient and to the support workers. Assessment and consultation clinics were run at the Fred Victor Centre and used as a training opportunity for neuropsychology students.

## Building a Brain Injury-friendly Interdisciplinary Team

- Teams should reach out to brain injury service organizations within their local communities to access information, training, and knowledge about local programming.
- Teams should support members in getting brain injury training.
- Teams should seek members with skills that will aid in assessment and intervention at the level of functional abilities.
- Case management and direct supports are often required to allow a person living with brain injury to benefit from care. Teams should provide or support access to such services.
- Teams should combat stigma using the following strategies:
  - o Get to know individuals' unique needs and abilities
  - Focus on support to complete functional activities
  - Ensure easy access for people with mobility and sensory impairments
  - Take the time to learn how patients compensate and use assistive devices.

## Follow-up

Because of difficulties with initiation and memory as well as problem solving, people with brain injury are likely to require an assertive approach to follow-up. Frequent brief visits may encourage better follow-up and enable development of a positive routine. As noted above, scheduling visits at regular times and intervals and making it clear where a client can check-in between visits may increase follow-up. Re-confirming contact information should be completed at each visit. Clients are most likely to follow-up when services are offered by the same provider, in the same place at the same time of day.

## Living Spaces

There is very little evidence regarding the best arrangement for shelter or sleeping arrangements. It is understood that an individual's temporary, transitional, or permanent housing should allow for adequate privacy and a sense of security. Many individuals with brain injury are very sensitive to noise in the environment. Difficulty reading others' social cues is another factor that makes sharing living spaces difficult. On the other hand, social isolation and difficulty in initiating daily

activity argues for having others in the environment. The ideal situation allows for quiet, private sleeping and a sense of independence while supporting access to others as well as supervision and support for activities of daily living that does not feel restrictive or in some way pejorative. Single person rooms are the ideal situation.

A balance of independence and shared space should be a key design consideration. For example, in transitional housing, a bachelor's apartment (a room that offers a sleep space, bathroom, and kitchen or food storage and can be viewed from the door of the apartment) that is connected to a common space that allows for communal meals and socialization is ideal. This type of arrangement provides the opportunity to demonstrate independence in activities of daily living while allowing interdependence in a home community. Shared spaces should be large enough to prevent competition for key resources (e.g., comfortable chairs). They should also be large enough and free of clutter to support the use of walkers, canes, and wheelchairs where required.

However, obtaining and maintaining stable housing will often require longer-term supports. In many jurisdictions, supported housing services are provided by a patchwork of agencies that serve specific populations. Supported housing options vary from infrequent visits by housing workers to 24 hours of onsite support and daily support with basic and advanced activities of daily living. The ideal supported housing environment will depend on an individual's abilities and their willingness to engage in supports. However, given the likelihood of barriers to accessing services, such as a limited awareness of needs, having onsite support enables unobtrusive monitoring of a client's functioning and environment. When possible, onsite supports can identify and manage small difficulties before they develop into larger problems. In general, small settings with fewer clients are better than large environments with many clients.

## CASE STUDY

Alex is a 42-year-old single man who was referred by a shelter worker for case management. The case manager witnessed Alex having a seizure and began the process of helping him get health care. He had been known to the shelter services for about 2 years and presented to local emergency rooms regularly. The available records suggested that ER visits sometimes included notations about reported seizures. He was usually described as intoxicated and sometimes disoriented. There were several hospitalizations related to suicidal ideation and depressed/anxious mood.

Because he tended to use the ER as a place to go when distressed, ER staff members sometimes had difficulty in distinguishing real from feigned complaints. To the staff members he met, he seemed a bit uncooperative. He usually responded with "I don't know" when asked about his history or current complaints. He learned to say that he was ready to kill himself or that he had had a seizure if he wanted to be able to stay at the hospital a while. He was usually assessed quickly, allowed to sober up, and dismissed with the direction to get help at a health team in the community center. The staff was confused about the fact that he never seemed to ask for the help he needed.

It was not until the social worker walked him over to the health team that he was fully assessed at a time when he was not distressed or trying to get into a hospital bed. The worker noticed that his speech seemed slow and his mood looked a bit anxious. She assumed that he might have some trouble with thinking and memory, so she found a quiet place to talk. She was careful to explain the reason for the assessment—to see if he needed any medical care or help finding a place to stay. When he agreed to continue, she slowly asked one question at a time and gave him a lot of time to answer.

When asked directly if he had ever been knocked out, he disclosed being in a car accident at the age of 13, with 2 weeks being in a coma and 8 months of hospitalization. He was aware that he sometimes had seizures, but he was unable to describe their frequency or their nature. He acknowledged that there had been times when he had been on medication for depression, paranoia, and anxiety as well as seizures, but he could not say which ones. He also reported that he had been assaulted a few times and knew that he would often hit his head after seizures.

When asked about his current health concerns, Alex mentioned that he was worried about his substance use and readily talked about his fears related to shelter living. He was tired of having things stolen and needing to work so hard to get a drink or find food. He was happier when he had a place to live. One year ago, he left a group home in another city after fighting with a roommate over alcohol. He assumed he was not welcome to return. He thought he was in trouble and would be arrested, so he did not ask for help.

Once aware of his history of brain injury, Alex was screened for cognitive impairment and endocrine disorders by his physician. He demonstrated moderate difficulty with attention,

memory, and problem solving, but he was able to read at a sixth-grade level. No endocrine problems were observed.

It was clear that he would be unable to remember information given to him, and that he was likely to become distracted and fail to follow through with appointments. However, simple notes and reminders would be likely to improve his follow-through. It was clear he would need assistance applying for housing and benefits and learning how to use a calendar to keep appointments. There was also concern about his ability to manage medications on his own. It seemed likely that he would be vulnerable to exploitation. He was also easily distracted from his goals by panhandling to get cigarettes or alcohol. This type of impulsive behavior was viewed as a part of his brain injury.

Alex was given a small notebook with information about his doctor's appointment. Notes were brief and simple and read over with him to be sure that he understood them. He agreed to get a better assessment of his seizures as well as blood work. It was arranged that he would meet his case manager on a routine basis at a breakfast program that he attends to make plans for attending his appointments. It took several trials, but he eventually became aware of the appointments and started to attend on time. Each time he and his caseworker made a decision or a plan, notes were placed in his book and reviewed. He lost his book a few times before he learned to keep it in his right front pocket.

Alex was accepted into an inpatient detox program, during which a seizure disorder was diagnosed, and medication was prescribed. He agreed to attend a residential addictions program designed for people who have concurrent mental health and addiction disorders. His case manager directly supported the referral, providing information regarding the nature of cognitive impairment. He agreed to attend a long-term recovery home program.

# SUMMARY OF MAJOR RECOMMENDATIONS FOR SERVICE DELIVERY AND DESIGN

- 1. Evaluate existing resources for individuals living with brain injury to identify gaps in services.
- 2. Service providers should consider developing partnerships with state and local brain injury societies or providers.
- 3. Service providers should be aware of the programs and benefits designed for people living with disability.
  - a. Adult survivors of childhood injuries (such as Adverse Childhood Experiences) may qualify for benefits for people with developmental disability, where available.
  - b. Programs that screen for and document disability may support access to services and benefits.
- 4. The design of intake and intervention should allow adequate time to build a working alliance and engagement. Patients with cognitive impairment will usually require additional time in individual appointments and longer periods of intervention.
- 5. Workers providing outreach services to individuals with brain injury may need smaller caseloads that enable greater intensity of care, which includes accompanying patients to appointments and providing direct support in the community.

Table 9. Levels of Recommendations and Practice Adaptations to Accommodate Cognitive and Behavioral Symptoms

PR	ACTICE AND SERVICE DELIVERY ADAPTATIONS		
Basic Recommendation	Staff members develop a team that creates a culture welcoming to those with brain injury by following the recommendations for basic cognitive accommodation.		
Specific Recommendation	The team creates individuals support plans based on the recommendations of brain- injury guidelines and trained professional		
	Active case management support is provided.		
Specialized Recommendation	The team provides specialized care. Specific programming and service delivery design is developed and implemented to accommodate cognitive and functional impairments.		
Recommendation	Active case management support is provided.		
	The program develops supportive housing options.		
Resources	Appendix E provides more detailed information about general accommodations for cognitive impairments.		
	Appendix F provides more detailed information about accommodations to support patients in attending appointments.		
	Appendix G provides more detail regarding case management.		
	A model of case management is provided in Appendix H, which includes recommendations for adapting care according to an individual's level of engagement and awareness.		
	Appendix I is an overview of cognitive rehabilitation.		
	<b>Sources</b> : Clinical Practice Guideline Section F: Brain Injury Education and Awareness <u>View full recommendation</u> .		
	Ohio Valley Center for Brain Injury Prevention and Rehabilitation		
	Brainline.org		
	Brain Injury Association of America		

**Evidence:** Recommendations are based on expert consensus of practitioners experienced in both brain injury and homelessness. Recommendations are based on expert consensus of practitioners experienced in both brain injury and homelessness: Evidence-based Review of Acquired Brain Injury (ERABI).

Table 10. Levels of Recommendations and Practice Adaptations to Integrate with Comm	aunity
Resources	

INTE	GRATING WITH COMMUNITY RESOURCES		
Basic Recommendations	Clinicians and teams should reach out to local and state brain injury associations to learn about available community-based programs.		
	Clinicians and teams should be aware of resources for developmental disability and aging.		
Specific Recommendations	Clinicians and teams develop active partnerships with brain injury and other social services and may co-manage the care of the individual.		
	Active case management is provided.		
Specialized Recommendations	Teams have knowledge of brain injury and are able to provide some specialized care. Assessments and triage may be focused on obtaining benefits and supports from other providers.		
Resources	Links to locate state and provincial associations:		
	Brain Injury Association of America <u>http://www.biausa.org/</u> Brain Injury Canada		
	http://braininjurycanada.ca/		
	A compendium of information related to brain injury: http://www.brainline.org/		
	Online training to learn how to screen for brain injury: http://ohiovalley.org/tbi-id-method/		
	Online training to work with people who have brain injury: <u>http://www.abistafftraining.info/</u> http://ohiovalley.org/informationeducation/accommodatingtbi/		
	Brain injury in the military: <u>http://dvbic.dcoe.mil/about/tbi-military</u> <u>http://www.brainlinemilitary.org/</u>		

## **SOURCES & RESOURCES**

**Primary Sources** 

Accessed May 23, 2018

<u>The Evidence-Based Review of Moderate to Severe Brain Injury</u> provides an evidence-based review of moderate to severe brain injury from acute management to chronic care. This review includes detailed information related to the management of neurobehavioral and physical outcomes of brain injury.

The <u>Centers for Disease Control and Prevention: Updated Mild Traumatic Brain Injury and</u> <u>Concussion Guideline for Adults</u> provides an overview of concussion management.

VA/DoD Clinical Practice Guideline for the Management of Concussion-Mild Traumatic Brain Injury Department of Veterans Affairs Department of Defense

http://www.healthquality.va.gov/guidelines/Rehab/mtbi/mTBICPGFullCPG50821816.pdf

<u>Ontario Neurotrauma Foundation and Institut national d'excellence en santé et en services soclaux</u> (2013) Guidelines for Concussion/mTBI & Persistent Symptoms: Second Edition

#### Resources

(Hopper et al., 2010) Trauma-Informed Care in Homelessness Services Settings. Full text can be found at http://www.traumacenter.org/products/pdf\_files/shelter\_from\_storm.pdf

#### Websites with training and information about brain injury

Ohio Valley Center for Brain Injury Prevention and Rehabilitation <u>http://www.ohiovalley.org/</u>

Brainline.org <u>https://www.brainline.org/</u>

Podcasts: Assisting Patients with TBI: A Brief Guide for Primary Care Physicians

NIH Traumatic Brain Injury Page

Brain Injury Association of America

Brain Injury Canada

Substance use and Brain Injury Workbook

www.SUBI.ca and <u>https://www.brainline.org/article/substance-abusebrain-injury-patient-workbook</u>

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## APPENDICES

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# **APPENDIX A: BACKGROUND INFORMATION**

## What is Traumatic Brain Injury (TBI)?

According to the Centers for Disease Control, "A TBI is caused by a bump, blow, or jolt to the head or a penetrating head injury that disrupts the normal function of the brain" (CDC, 2015). Not all trauma to the head results in brain injury, and not all injuries are caused by a direct force to the head. TBI may be caused by rapid acceleration/deceleration such as occurs in motor vehicle accidents or as the result of exposure to a blast. The severity of a TBI is graded by the duration and extent of the resulting change in mental status, which may include loss of consciousness; retrograde amnesia (a loss of memory for events before the event) or post-traumatic amnesia (events after the injury); or alteration in speech, language, and thought processes. It may also include neurological impairments, such as changes in vision, balance, or muscle strength.

The CDC estimates that each year there are 2.5 million emergency department visits associated with brain injury (Faul, Xu, Wald, & Coronado, 2010). It noted, however, that these numbers do not include those injuries treated in outpatient, military, or Veterans affairs facilities, nor do they include those injuries that were not treated at a health care facility. The CDC's 2015 report to congress estimates that there are currently between 3.2 and 5.3 million people in the United States living with lasting disability resulting from TBI. CDC data from 2006 to 2010 indicated that most common causes of TBI are falls (40.5%), motor vehicle traffic crashes (14.3%), being struck by or against an object (15.5%), and assaults (10.7%; (Faul et al., 2010).

Approximately 85% of all brain injuries are mild (CDC, 2015). Mild injuries are often referred to as concussions. The clear majority of people will recover completely from mild TBI; however, those with moderate to severe injuries, multiple mild TBI, or mild TBI (mTBI) complicated by mental health or other diagnoses may have lasting effects. mTBI is addressed in the separate guideline: Adapting Your Practice: Mild Traumatic Brain Injury.

The term acquired brain injury (ABI) is used to indicate not only TBIs but also injuries that are the result of exposure to substances such as drugs of abuse, alcohol, or environmental toxins that damage brain tissue as well as the damaging effects of medical conditions such as stroke, infection of the central nervous system, or anoxia. Because of the specific links between TBI and homelessness, this guide focuses primarily on TBI. However, given that cognitive and neurobehavioral difficulties are common to a variety of conditions, this guide will also reference ABI where appropriate.

## Why are practice adaptations for TBI necessary?

Over half of all people served in programs addressing the needs of people who are homeless report a history of mild to severe TBI (Hwang et al., 2008). This constitutes a prevalence rate over five times that of the general population (Topolovec-Vranic et al., 2013). There is evidence that brain injury is both a risk factor for homelessness, as well one of the myriad interacting risks associated with being homeless (Clark, Peiperl, Veitch, Wong, & Yamey, 2008; Hwang et al., 2008; Mackelprang, Harpin, Grubenhoff, & Rivara, 2014). The cognitive and behavioral difficulties that accompany a history of brain injury have a significant and negative impact on the individual's ability to access to health care and social services, adhere to medical recommendations, and maintain a home once they are housed. Both as a potential cause of homelessness and because of its interaction with other health, psychosocial, and environmental factors associated with homelessness, brain injury presents a major concern for service providers.

## What is known about the relationship between brain injury and homelessness?

Although experienced clinicians have long recognized the high rate of neurological impairment and resulting cognitive challenges in this population (Shipley & Tempelmeyer, 2012; Topolovec-Vranic et al., 2013), efforts to understand the incidence and causes of cognitive impairment are relatively recent (Dams-O'Connor et al., 2014; Hwang et al., 2008; Oddy, Moir, Fortescue, & Chadwick, 2012; Stergiopoulos et al., 2015; Topolovec-Vranic et al., 2013). Estimates of the incidence of TBI and cognitive impairment vary according to the type of screening or assessment measure used; however, convergent evidence suggests that brain injury is a risk factor for becoming homeless, and those individuals who report a history of TBI also present with the most complex needs.

Having a history of TBI results in neurocognitive impairment and physical disability along with an increased risk of a variety of adverse outcomes, including comorbid mental health conditions (Gould, Ponsford, Johnston, & Schönberger, 2011), substance use disorders (Corrigan, Adams, & Larson, 2013), incarceration, and mortality (CDC, 2015). Having had a brain injury greatly increases the risk of subsequent brain injury resulting from an increased vulnerability to assault and other injurious events (Mackelprang et al., 2014).

# Substance use disorders, mental health problems, and other medical conditions are more difficult to accurately diagnose and manage when they are combined with brain injury.

People living with brain injury and cognitive impairment may lack insight into their difficulties or lack the ability to provide an accurate medical history. The overlap in clinical presentation between neurobehavioral impairments and psychiatric disorders can also create diagnostic confusion.

# The conditions of homelessness pose unique challenges for individuals with impaired memory, attention, and executive cognitive skills.

For people living with these disabilities, environmental supports and routines are the best strategies for improving function. But the need to leave a shelter or temporary living setting during the day makes building routines difficult; the daily search to meet basic needs may easily overwhelm a patient's cognitive resources, making planning for the future an impossibility. Difficulties with regulating emotions may make coping with changing groups of people particularly challenging. Difficulties with self-regulation and social cognition may also make an individual more vulnerable to exploitation and substance use as well as to aggression and criminal acts.

# Cognitive failures and behavioral changes associated with brain injury are easily mistaken for a lack of motivation for change or an attempt to manipulate care providers.

It is easy to understand how problems with memory, initiation, planning, and problem solving may result in difficultly navigating social systems, following through on recommendations, and meeting the expectations of property owners and care providers. Problems with communication may result in unexpressed needs or rejection of services due to misunderstandings.

## Traumatic brain injury also shares common risk factors with homelessness.

Vulnerable populations are known to make up a majority of homeless individuals—including those raised in low-income homes, victims of domestic abuse, justice-involved populations, and people living with substance use disorders and serious mental illness—are at significantly increased risk for brain injury. It is estimated that as many as 87% of incarcerated individuals have experienced a traumatic brain injury. (CDC, 2015). Veterans, who have been shown to be overrepresented in the population of people who are homeless, are also at high risk for having a history of TBI (Russell et al., 2013).

### Service providers are often unaware of the prevalence of TBI in the people that they serve.

There are several reasons why TBI survivors might not spontaneously report their history of brain injury. Survivors of childhood injuries may not be fully aware of the relationship between their early trauma and the outcomes they are experiencing in adulthood. The repeated mild injuries associated with abuse from traumatic or violent events may accumulate slowly over a period of time, never coming to the attention of a clinician. Therefore, signs of TBI are not recognized by the individual as an important part of their health history. These are the same reasons; TBI may be missing from the medical record. TBI also may result in impaired awareness of disability, which may render an individual entirely unaware of impairments that in some cases are evident to observers. However, for some TBI survivors, the nature of cognitive impairment is subtle and therefore less obvious to the care provider. For example, it is easy to mistake forgetfulness and poor judgment as a lack of motivation for change. (Topolovec-Vranic et al., 2013).

## Pathophysiology of TBI

TBI may result in damage to the brain, including contusions, lacerations, hemorrhage, and diffuse axonal injury. TBIs may be focal (limited to specific areas of tissue, such as occurs in penetrating injury) or diffuse (widespread throughout the brain).

**Diffuse axonal injuries** (DAIs) are the result of the stretching and twisting of axons and their myelin sheaths as the result of the sudden movements caused by the forces applied to the skull. DAIs may be seen on MRIs as tiny areas of hemorrhage. However, it is understood that not all DAI injuries are observable in typical MRI scans because these scans do not actually detect changes to the neurons unless bleeding has occurred. Special types of images (e.g., diffusion tensor imaging) have shown that DAI results in changes to the way neurons function, but this technology is not available for clinical use yet. For the present, clinicians judge the degree of DAI by the length of loss of consciousness and the degree of cognitive difficulty observed in the period following the injury.

### The Physiology of Secondary Injury

The rapid release of neurotransmitters, which alters the balance of calcium and potassium along cell membranes, is known as the neurometabolic cascade of concussion (Giza & Hovda, 2001). When this occurs, there is an increased demand for glucose in the brain, which may not be met as the result of reduced cerebral blood flow. For this reason, hypotension and hypo-perfusion, hypoxia, and ischemia are common causes of secondary injury after moderate to severe brain injuries, as reviewed in (McKee & Daneshvar, 2015). McKee and Daneshvar also review the evidence related to the damaging impact of neuroinflammation post-injury. They noted that within hours of trauma, cellular and vasogenic fluid accumulations in the brain causes cerebral edema, elevated intracranial pressure, and cerebral ischemia, which may cause additional damage to brain tissue.

Secondary Injury: After TBI, some of the immediate biological body's responses, including inflammation and an increased demand for nutrients, can add to the injury that resulted from the initial blow to the brain. The amount of secondary injury that occurs after injury depends on the individual's particular biology and the type of treatment received. This is one-way genetics and general health may influence outcomes from traumatic brain injury. It also explains why individual outcomes vary so much after brain injury, and damage after brain injury is not only limited to the places in the brain that suffered mechanical damage.

Secondary injury may result in swelling in the brain that causes pressure within the skull (intracranial pressure) to rise. If allowed to continue, swelling may cause downward pressure on the brain, resulting in compression of areas of the brainstem responsible for maintaining vital bodily functions and ultimately leading to death. To prevent this, some survivors of severe brain injury will undergo a craniectomy (temporary removal of a portion of the skull). Patients who have undergone this procedure will have scars that

are often visible in the scalp above the temple and over the top of the head.

Blast exposure is the most common cause of TBI in military populations (Baker, 2014), and affects an estimated 10–20% of U.S. military service members deployed to Iraq and Afghanistan. Blast injury appears to be the result of blast winds, which have been shown in animal studies to deliver forces like multiple concussive impacts, occurring in a very brief period measured in microseconds (McKee & Daneshvar, 2015). Given the nature of battle field situations, blast injuries are often accompanied by other injuries. Animal studies have suggested that the pathophysiology associated with blast injury is the same as seen in other TBIs, including axonal injury, neuroinflammation, and microvascular injury.

Emergency protocols for the management of TBI have improved significantly over the past 20 years. Modern emergency and acute care protocols more aggressively treat the causes of increased intracranial pressure, seizures, and hematoma both medically and surgically. Their effectiveness in limiting the degree of secondary damage that occurs in TBI continues to improve, and therefore so do long-term outcomes. However, those treated many years ago or whose treatment was delayed or

inadequate may suffer more lasting impact of their injuries than individuals receiving current evidence-based practices.

## Severity of Injury

Ratings of severity (Table A1) refer to the injury itself and not the long-term outcome. While the initial injury rating is correlated with long-term outcomes, it is possible for a person with a mild injury to have a poor long-term outcome. Likewise, individuals with moderate to severe injuries may experience a good outcome. Grading of TBIs primarily relies on the duration and degree of changes in consciousness.

Severity Rating	Mental Status change or LOC
Mild	Mental status change or LOC < 30 minutes
Moderate	Mental status change or LOC 30 minutes to 6 hours
Severe	Mental Status change or LOC > than 6 hours

Table A1.	. TBI Rating	by Duration	of Altered Mental State
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Note: Source: (Greenwald, Burnett, & Miller, 2003)

The Glasgow Coma Scale provided in Table A2, (GCS;(Teasdale & Jennett, 1974) is a behavioral rating of responsiveness, and is used throughout the developed world immediately post-injury. In TBI, GCS taken at the time of injury has been found to be predictive of long-term outcome, particularly in the case of closed brain injury, and therefore has become a major component of grading systems of TBI (Corrigan, Kreider, et al., 2014).

Table A2. Glasgow Coma Scale

Score	Best Motor Response	Best Verbal Response	Eye Opening
1	None	None	None
2	Decorticate posturing	Mutters unintelligibly	Opens to pain
3	Decerebrate posturing	Inappropriate speech	Opens to command
4	Withdraws to pain	Confused	Opens spontaneously
5	Localizes to pain	Alert and oriented	N/A
6	Obeys commands	N/A	N/A
Total*	1-6	1–5	1-4

*Notes.* Source: Teasdale and Jennett, 1974; NA = not applicable.

\* The total of the motor, verbal, and eye-opening scores (range, 3–15) indicates the severity of a TBI, as follows: 3–8 is severe TBI, 9–12 is moderate TBI, and 13–15 is mild TBI.

Severity of injury is also judged by the length of time it takes for a person to return to a fully oriented state. The period between injury and return to full orientation is known as posttraumatic amnesia (PTA). During PTA, the individual is usually unable to create full, continuous memories of events, and is therefore unable to clearly recall this period. In addition to memory difficulties, individuals in the period of PTA show signs of confusion, which often includes irritability and restlessness.

As shown in Table A3, the longer the period of PTA, the more severe the injury is considered to be. (Walker et al., 2010).

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Mild	< 24 hours PTA	
Moderate	1 to 7 days PTA	
Severe	Greater than 7 days PTA	
Very severe	4 weeks PTA	
Extremely severe	8 weeks PTA	

Table A3. Severity Based on Posttraumatic Amnesia (PTA)

The period of PTA is often estimated during an interview by asking an individual to identify their first post-injury memory and then placing that memory in the timeline of the individual's recovery (e.g., whether they recall staying in an acute treatment setting or if their first memory occurred after transfer to a rehabilitation setting). Clinicians should be aware that people living with brain injury are often very poor historians for events that occurred around the time of injury. For this reason, PTA as a predictor of outcome is most accurate when the person has been observed by professionals during the immediate post-injury period using a standardized measure of orientation (Friedland & Swash, 2016).

When an individual injury meets the criteria for mild TBI but still has findings on imaging such as subarachnoid hemorrhage, the injury is graded as "complicated mild" TBI (Williams, Dusablon, Williams, Blais, & Hennessy, 2013). Fewer than 10% of all people treated in emergency departments who meet the criteria for mild TBI have positive findings on imaging. While there is little consensus regarding how to grade complicated mild brain injuries, there is some evidence that their recovery and long-term prognosis more closely resembles those who meet the criteria for moderate TBI (Iverson, Brooks, & Young, 2009).

## Outcomes of Traumatic Brain Injury

There is a lot of variation in the nature and extent of difficulties people demonstrate after TBI. In general, rates of recovery and long-term impairment are correlated with the severity of the initial injury.

# Multiple Mild Brain Injuries

Clinicians generally accept the notion that having had more than one brain injury increases the likelihood of lasting symptoms and poorer outcomes. In fact, research related to the cognitive and emotional impact of multiple mild injuries has been limited and has mainly focused on sports-related injuries (Belanger, Spiegel, & Vanderploeg, 2010). An association between mental health and cognitive symptoms has been found in those who have had a previous brain injury of any severity in those receiving rehabilitation for a subsequent moderate to severe injury (Corrigan, Bogner, et al., 2013). Corrigan et al. (2013) noted that their findings suggest that injury in childhood, even when mild, may have a significant impact on recovery from subsequent injuries. Other evidence of the additive impact of mild brain injury comes from studies of people seeking mental health and addictions services. As noted above, having had more than one brain injury with loss of

consciousness has been associated with even greater symptom severity and complexity than do single injuries in this population (McHugo et al., 2016).

While more research is needed, most clinicians agree that impact of multiple mild injuries combined with the impact of substance use and the stress of abusive and/or dangerous living situations increases the risks for both mental health and cognitive difficulties.

## Moderate to Severe TBI

The combination and severity of symptoms observed after any TBI depend on the severity of the damage, the areas of the brain affected and the state of the brain at the time of the injury. More severe injuries have a longer course of recovery. The majority of individuals who have sustained moderate to severe injuries are likely to have some lasting consequences from their injury (Corrigan, Cuthbert, et al., 2014).

The first 6 months post-injury are marked by rapid improvements in functional capacity that may reflect the return of function in areas of the brain that have sustained limited or no damage but had been restricted as the result of post-injury factors such as intracranial swelling or the presence of blood. As swelling goes down and the brain's biochemistry returns to a more normalized state, the most obvious signs of recovery slow. For most survivors of moderate to severe TBI, substantial improvements continue to be observed over the first year or two. Thereafter, the accommodation and functional improvements that are observed are understood to be the result of much slower neuroplastic processes (the development of new connections) and the individual's cognitive and behavioral compensation. These improvements appear at a much less dramatic pace but can be functionally relevant (Corrigan & Hammond, 2013).

## Recovery

It is important to recognize that recovery depends on the individual. While there is strong evidence that initial depth of coma and length of post-trauma confusion are good predictors of long-term outcome, improved acute care protocols and individual differences in genetics, personality, and environment make significant contributions to long-term outcome. Many people who have survived very severe injuries have stories about how they have greatly exceeded the initial expectations for their recovery. Others with milder injuries seem to have chronic and functionally devastating impairments. Generally, the more severe the initial injury (i.e., the deeper the loss of consciousness and the longer the period of PTA), the greater the degree of long-term impairment. However, even when there are limits to the degree of neural recovery experienced, cognitive compensation and new learning remain possible indefinitely.

Age at the time of injury is also an important factor. On one hand, those injured in early childhood may be vulnerable to the long-term effects of the injury on the developing brain. On the other, the aging brain—beginning as early as age 40—may not recover as well from injury as the brain of a younger person (Esopenko & Levine, 2015).

Likewise, clinical experience and research indicate that healthy people with more social supports are likely to have better outcomes as measured by return to productive activity and psychological and physical health. It appears that substance use, stressful environments, and preinjury mental health diagnoses may limit neural recovery as well as functional outcomes (Bachman, Mari-Lynn, & Tobias, 2004). Many individuals who are homeless or marginally housed have a host of risk factors, such as poor access to health care and limited social supports, which are also risk factors for poor outcome from TBI as it relates to functional ability and return to social roles after brain injury.

## TBI as a chronic health condition

Traditionally, brain injury has been viewed as a single health event—an insult to the brain—that had little or no impact beyond that which was initially observed, and did not require additional treatment following rehabilitation. However, over the past 10 years or so, clinicians and researchers have begun to reconceptualize TBI as a chronic condition or disease process. As Masel and Dewitt (2010) noted in their review of the relevant literature, TBI conforms to the World Health Organization's definition of chronic disease process in that the associated physical pathology is permanent, requires specialized rehabilitation, and may require long-term follow-up or supervision. Masel and Dewitt reviewed the evidence that brain injury may accelerate or cause disease states in multiple organ system in a process that is likely lifelong. The implication is that the same research and clinical strategies applied to other chronic conditions should also be applied to TBI (Corrigan & Hammond, 2013).

For the health care provider, this means being alert to the potential for decline over time and the emergence of symptoms or conditions across organ systems that are related to an individual's TBI history but that are not necessarily a part of that individual's presentation soon after injury. It also means it is essential to encourage appropriate self-management in patients in the same way as is helpful in any chronic disease, such as diabetes. Much of the long-term care occurs in the community–outside of specialty contexts.

When there is a history of brain injury, providers need to take a collaborative and nonjudgmental approach to problem solving issues that arise, complete appropriate assessments of any identified areas of difficulty, and set priorities for addressing problems and reducing barriers to healthy living in a holistic way. The clinician's role will be to provide guidance and feedback on an ongoing basis. Nevertheless, just as with other chronic disorders, interventions should promote the individual's self-efficacy and knowledge and engage anyone in the environment (including peers or paraprofessionals) who may be of assistance.
## TBI and Mortality

Survivors of TBI have been found to have a shortened life span and to be at increased risk for death related to seizure disorders, circulatory problems, pneumonia, and digestive problems and suicide than the general population (Masel & DeWitt, 2010).

#### TBI Survivor Mortality Risk

3 times the risk of death by suicide 22 times the risk of death by seizure 49 times the risk of death by aspiration pneumonia (Harrison-Felix et al., 2009)

The risk of death in individuals with all severities of injuries from all causes who survived at least 1year, post injury is estimated to be between 2.5 to 3 times greater than the general population (Masel & DeWitt, 2010). Using longitudinal data from 12,480 people sustaining TBI of all severities and across the life span. Brooks, Shavelle, Strauss, Hammond, and Harrison-Felix (2015) found that life expectancy after brain injury varies widely and has been associated with age at injury and severity of disability. For example, these authors found expected survival varied from less than 40% of normal life expectancy for those who are unable to walk and are fed completely by others to approximately 85% of normal life expectancy for those who walk well without assistance (Brooks, Shavelle, Strauss, Hammond, & Harrison-Felix, 2015).

### Epilepsy (Seizure Disorders)

Brain injury is understood to be a significant cause of epilepsy and the leading cause of new seizure disorders in young adults (Masel & DeWitt, 2010). Post-traumatic seizures can develop immediately (within 24 hours), early (within 1 week), and late (more than 7 days post-Using the Traumatic Brain Injury injury). Model Systems Database (TBIMS), which includes primarily moderate to severe injuries, Ritter et al. (2016) reported a prevalence rate of 8.9% for immediate post-traumatic seizures. However, within 1 year, that prevalence increased by an additional 12%, and continued to climb at the 2-year (16.8%) and 5-year marks (20.5%; (Ritter et al., 2016). These authors

Risk Fac	tors for Post-I raumatic Seizures
•	Moderate to severe injury
•	Childhood inju <del>ry</del>
•	Injury after the age of 65
•	Surgery related to TBI
•	More abnormality on imaging
•	Penetrating injury
•	Seizure during the early post-
	injury phase
•	Pre-existing psychiatric disorder
•	Drainium incorcoration

- Pre-injury incarceration
- Pre-injury substance use

(Ritter et al., 2016)

suggested that the development of epilepsy is associated with TBI-related pathology, which exerts its effects over the course of many years.

### **Sleep Disorders**

Sleep disturbance is reported by more than half of all survivors of TBI, but it is often undiagnosed and untreated (Grima, Ponsford, Rajaratnam, Mansfield, & Pase, 2016). In studies using polysomnography, objective sleep disturbance—including reduced sleep efficiency and increased

sleep onset latency—has been observed in groups of TBI survivors (Ponsford et al., 2012). Sleep disturbance after brain injury has been linked with daytime sleepiness and fatigue as well as mood disturbance and cognitive impairment. Because of the interaction among mood, cognition, and fatigue, and their impact on quality of life, sleep disturbance is an important target for intervention.

## Neurodegeneration and Neurodegenerative Disease

Studies have found that some people begin to develop signs of dementia and decline, including areas of atrophy in the brain, after brain injury (Green, 2016). In people with single moderate to severe injuries, as many as one in three are found to deteriorate functionally in the 10 years post injury (see review in (Corrigan & Hammond, 2013). Injuries sustained in later years as well as more severe injuries and penetrating injuries seem to be risk factors for decline after TBI (Masel & DeWitt, 2010).

Findings from epidemiological studies have provided strong evidence that TBI is a risk factor for several different types of dementia, including Alzheimer's disease, frontotemporal dementia, Lewy Body disease, Parkinson's disease, and chronic traumatic encephalopathy (CTE; (Washington, Villapol, & Burns, 2016). Risk factors for the development of dementia after TBI include more severe or frequent injuries and having the APOE4 genotype. While single mild TBIs were not associated with the development of dementia in most studies, an

### Hormone Deficiencies after Brain Injury

- Anti-diuretic hormone
- Adrenal Insufficiency
- Diabetes insipidus
- Growth Hormone
- Gonadatropic insufficiency
- Adrenocorticotropic Hormone

#### Less Common

• Thyroid Stimulating Hormone

increased risk for dementia did occur when the mild TBI was sustained after age 65.

### Neuroendocrine Disorders

The pituitary gland sits on a slender stalk at the underside of the frontal lobes, making it very vulnerable to traumatic injury. The pituitary plays an important role in the delicate balance of feedback systems in the brain, including the hypothalamus. For these reasons, TBI is linked to a number of neuroendocrine disorders. Endocrine functioning is commonly disrupted in the acute phase following moderate to severe injury but resolves in a short time in most cases. In a minority of patients, endocrine disorders develop in the long term and are associated with poor functional outcomes. Because of their impact on overall health, endocrine disorders should be assessed and treated. The only endocrine disorders that have not been associated with an adverse functional impact are hyper/hypoprolactinemia.

A comprehensive review of the impact of brain injury on neuroendocrine functioning can be found at the <u>ERABI</u> website.

## Emotional and Behavioral Consequences of Moderate to Severe TBI

Behavioral changes and psychiatric disorders are often the most disabling outcomes of traumatic brain injury. While the best predictor of psychiatric disturbance post injury is having a preinjury history of these disorders (Whelan-Goodinson, Ponsford, Schönberger, & Johnston, 2010), the high incidence of new-onset problems in the long-term suggests the need for screening and ongoing monitoring in long-term survivors.

Disorders that appear in the acute stage of recovery may be directly associated with lesion location. For example, left temporal lesions may be associated with depressed mood in the first months after brain injury (Whelan-Goodinson et al., 2010). There is also evidence that long-term neurodegenerative processes can cause the development of behavioral symptoms as in the case of chronic traumatic encephalopathy (Asken et al., 2016).

Cognitive impairments such as inflexible thinking, emotional lability, or poor problem solving present similarly to psychiatric symptoms such as mood disorders, paranoid or delusional thinking, and personality disorders. Having poor memory means losing continuity of experience, which may range from remembering experiences with loved ones to maintaining a coherent sense of self. Probably most disabling, are changes in emotional regulation—the ability to perceive and respond appropriately to one's own emotional state and to social cues—which are often beyond the control of the survivor, yet survivors are usually held to the same standards of behavior as those living without injuries. The same cognitive factors, including impulsivity, make psychological treatment of psychiatric disturbance after TBI particularly challenging. Adjustment to losses associated with brain injury occurs in the context of brain functioning that has been altered by the injury itself.

In addition to biological factors, the stress of surviving severe injury also plays a role in the development of psychiatric disturbance. After the initial trauma, survivors and those around them are faced with the difficult task of adjusting to sudden changes in physical and cognitive abilities. Often there is a loss of valued social roles and important relationships and a diminished sense of self. The physical, cognitive, and personality changes that commonly occur after brain injury may result in a loss of social roles and personal relationships and result in financial hardship. These unwelcome changes may be the initiating factors in depressed and anxious mood.

Both cross-sectional and longitudinal studies have found an increased risk for psychiatric disturbance, including mood disorders, in survivors of childhood and adolescent injuries of all severities (Ilie, Boak, Adlaf, Asbridge, & Cusimano, 2013; McKinlay, Grace, Horwood, Fergusson, & MacFarlane, 2009). In children, the mood disorder may be associated with symptoms of conduct disorders and attention deficit hyperactivity disorder (McKinlay et al., 2009), placing them at greater risk for substance use and other psychiatric disorders later in life.

Many survivors of injuries in adolescence and adulthood talk about having to learn, understand, and like the "new person", they have become after injury. In the case of childhood injury, it is likely that injuries affect social and emotional development, creating long-term risks for psychiatric disorders and problematic substance use. For injuries sustained across the lifespan, the primary

impairments may be cognitive or behavioral, making the actual disability invisible to the observer. For these reasons, cognitive and behavioral difficulties occurring after injury need to be considered from a social, psychological, and biological perspective.

# Mood Disorders

As in the general population, depression and anxiety are the most common psychiatric problems to develop after brain injury of all severities. It is estimated that half of all adults living with moderate

to severe TBI experience depression and/or anxiety that is severe enough to have an impact on functioning and quality of life (Bombardier et al., 2010; Jorge, 2005; Koponen, Taiminen, Portin, Himanen, & et al., 2002). Both

biochemical and psychosocial factors contribute to the development of depressed and anxious mood and likely lead to a lifelong increased risk for mood disorders (Barlow, 2016; Zgaljardic et al., 2015).

Clinicians need to be aware that many symptoms of depressed and anxious moods, including sleep disturbance, loss of libido, poor appetite, and difficulty in initiating activity, may be a direct result of injury to the brain. Difficulties with memory and awareness may lead to under diagnosis.

# Post-traumatic Stress Disorder

outcomes.

Post-traumatic stress disorder (PTSD) has been found to be a very common psychiatric diagnosis after mild to moderate TBI, with most estimates of incidence varying between 3% to 30% (Jorge, 2005; Zgaljardic et al., 2015). Those with limited memory loss around the time of the injury are most likely to develop PTSD, though symptoms of PTSD such as irritability, avoidance of stimuli related to the trauma, and exaggerated startle may be observed in people who have only a very limited and fragmented recall of the event that resulted in injury.

When TBI is sustained in the battlefield, the likelihood of PTSD seems to be significantly higher. (Hoge et al., 2008)

found that 43.9% of combat military personal whose injuries resulted in a loss of consciousness and 23% with altered consciousness met the criteria for PTSD. When correlated with long-term outcomes, TBI itself did not predict adverse health and quality of life outcomes, though the presence of PTSD did. As Bryant (2008) pointed out, these findings point to a complex interplay between the physiological, psychological, and psychosocial outcomes associated with co-occurring TBI and PTSD. It is possible that TBI does create a vulnerability to the emotional dysregulation that occurs in PTSD, but it is likely the circumstances of injury and subsequent care also play a role in long-term

# **Risk Factors for PTSD after Brain** Injury

- Limited memory loss at the time of the accident
- Combat-related injury

Irritability, avoidance, and exaggerated startle may be found in those with limited recall of the injury itself.

PTSD is highly associated with substance use and poorer long-term

Anxiety and depression are observed in over half of all brain injury survivors.

## **Psychotic Disorders**

It has been estimated the incidence of psychosis post-TBI is between less than 1% to 9% (Zgaljardic et al., 2015). TBI may be one of several influential factors related to the express of psychosis in individuals who have a genetic predisposition to this disorder (Kim, 2008). It has been widely observed that neuroleptic medications are effective in the medical management of psychotic disorders after TBI.

## Suicidality

There is a growing body of evidence that having a history of TBI does create a significant increase in risk for suicidality in survivors of all ages (Boyle et al., 2014; Fisher et al., 2016;

Ilie et al., 2014). Fisher (2016) noted that rates of suicidal behavior range from 22% to 28%. Cooccurring substance abuse, PTSD, and other psychiatric symptoms exacerbate this risk (King & Wray, 2012). These findings suggest the need for monitoring for suicidality in all patients who report a history of TBI.

## Aggression, Anger, and Irritability

An elevated risk of aggression has been associated with brain injury (Zgaljardic et al., 2015). Irritability and impulsivity in the acute period following injury are associated with confusion (Stefan & Mathe, 2016; Wood & Thomas, 2013). In the post-acute period, the co-occurrence of depressed mood, substance use, and impaired social functioning may be better predictors of aggression than mTBI on its own. Damage to the orbitofrontal cortex is often associated with a greater risk of aggressive behavior as the result of impaired behavioral regulation, while damage to other areas of the frontal lobes and the underlying structures may be associated with impairments of emotional control (Cusimano, Holmes, Sawicki, & Topolovec-Vranic, 2014). History of TBI is associated with more self-reported interpersonal aggression and history of violence in people seeking treatment for substance use (McHugo et al., 2016), as well as in prison populations (Shiroma et al., 2010).

Wood and Thomas (2013) proposed that following brain injury, chronic irritability and aggression may take on two basic forms: irritable and episodic. They describe the irritable type as "constantly intolerant, irritable and emotionally fragile, leading relatives to describe life as characterized by having to 'walk on eggshells'" (p. 256). Those who exhibit episodic aggression are described as having "transient swings of mood" (which includes the angry outburst), but then resume their 'normal' pre-accident disposition, leading families to state "that' it's like living with Jekyll and Hyde'" (p. 256). Wood and Thomas hypothesized the irritable type was associated with orbital frontal dysfunction while the episodic type was associated with epileptiform activity in the temporal lobe.

# Risk factors for psychotic disorders after TBI

- Family history of schizophrenia
- Preinjury substance use
- Longer loss of consciousness
- Aphasia
- Damage to the frontal/temporal cortices

(Zgaljardic et al., 2015)

## Substance Use Disorders

As with other behavioral disturbances, the increased incidence of problematic substance use after brain injury appears to result from a combination of factors that include damage to self-regulatory mechanisms in the brain, preinjury substance use, and post injury psychosocial stresses (Bjork & Grant, 2009). As many as half of all brain injury survivors have experienced problems with substance use after brain injury, and the proportion is likely to be higher in those who are unstably housed or homeless.

## Pain and Headache

More than 50% of people suffer from chronic pain disorders in the years following a brain injury (Nampiaparampil, 2008).

As Nampiaparampil noted, headaches are the most common site of pain; however, headache pain is more common in people who have sustained mTBI (75.3%) than for those with moderate to severe injury (31%). For those who

#### Brain Injury and Substance Use Disorders

- Intoxication creates a risk for brain injury.
- Half of all noncombat brain injuries occur while intoxicated.
- Preinjury history of hazardous substance use is a risk factor for post injury hazardous substance use.
- New problems with substance use may develop as a self-medication strategy for dysregulated emotions.
- Substance use and TBI in combination create an elevated risk for mental health disorders.
- Early childhood injuries increase the likelihood of substance misuse.
- Cognitive impairment and impulsivity complicate treatment of substance use disorders after brain injury.

(Bjork & Grant, 2009; Corrigan & Mysiw, 2013; Parry-Jones, Vaughan, & Miles Cox, 2006; Taylor, Kreutzer, Demm, & Meade, 2003; West, 2011).

suffer headache, roughly 80% will have a resolution of their symptoms within the first year after injury. Those whose headaches do not resolve by 1 year are considered to have chronic headache.

Interestingly, the character of headaches differs between civilian and military populations. The most common type of headache in civilian populations presents as tension headache, while in the military population, most of whom sustained blast injuries, headaches are described as more like migraine headaches (Holtkamp, Grimes, & Ling, 2016). In both military and civilian populations, chronic headache is commonly associated with distress, poor quality of life, mood disorders, and PTSD (Holtkamp et al., 2016).

In survivors of moderate to severe brain injuries, common causes of pain include the lasting impact of orthopedic trauma, spasticity (increased muscle tension from brain injury), heterotopic ossification (bone forming outside the skeleton), deep venous thrombosis, and genitourinary and gastrointestinal disorders (Nampiaparampil, 2008). Assessment and treatment of chronic pain after brain injury may be complicated by the presence of memory or other cognitive impairments that make it difficult for patients to accurately report their experiences and to engage in self-management strategies and use medications as recommended.

## **Cognitive Impairments**

Although each brain injury survivor is unique, there are patterns of impairment that commonly occur after traumatic brain injury. Cognitive functions most likely to be affected are those mediated by the frontal and temporal lobes and their underlying structures because these are most vulnerable to mechanical forces. However, when we consider functional cognition—that is, the abilities that

allows one to accomplish tasks from day to day— it depends on how well different parts of the brain are working together rather than at damage in any one particular area of the brain on its own. In cognitive neuroscience circles, this concept is called *functional connectivity*.

To function effectively, units of the brain must be intact, and must communicate efficiently with one another. When in doubt, assume the patient is doing their best to meet their goals, and provide supports accordingly.

Understanding cognitive impairment and helping patients to compensate can increase the effectiveness of all interventions offered.

Often the impaired abilities after a mild injury and in the long term after moderate to severe injury are the result of both damage to primary functional units of the brain along with their ability to communicate effectively with one another. This can lead to situations in which a brain injury survivor presents with islands of intact functioning—most commonly the ability to speak, read, write, and remember facts learned in school—but seems to have great difficulty pulling together or organizing their behavior to accomplish tasks and interact socially. Very commonly, behavior will be inconsistent; what a person is able to do in one context (such as the quiet environment of a testing office) does not translate to busy or emotionally laden situations or when vigilance is required to maintain accuracy. Because it can be very difficult to determine what may be causing a problem behavior to occur—whether it is of psychological, physiological, or behavioral origin—it is usually most productive to assume people are doing their best to meet their own goals and that any difficulty observed is based on an impairment that may be beyond their control.

## Executive Functioning/Frontal Lobe Functioning

The set of abilities that coordinate and monitor all other cognitive functions is known as executive

functioning. These functions are largely mediated by specific areas of the frontal lobe, which is why the terms *executive dysfunction* and *frontal dysfunction* are often used interchangeably. Frontal lobe functions can be thought of as having four main divisions: energization, executive functions (task setting and monitoring), integrative-metacognitive functions, and emotional and behavioral self-regulation (Stuss, 2011).

1. *Energization* refers the ability to initiate and sustain a response. Research has suggested that damage to the dorsal-medial portion of the brain (or areas that rely on connections to this part of the brain) cause difficulties in energization which include slower overall responding and

### **Primary Executive Functions**

- **Energization**: Initiating and sustaining a response
- **Executive:** Monitoring and Task-setting
- Meta-cognition/ integrating: Strategic, analytic, and abstract thinking
- Self regulation: Emotional regulation, self-monitoring, and insight

problems with sustained attention such as responding consistently over time on an attention task. An individual with initiation problems in their most severe form may not speak or move without some stimulus and may experience very slowed or limited cognition. People with milder forms may simply be slow in completing tasks and/or have difficulty in getting started tasks on or staying with tasks until they are complete.

- 2. *Executive functions* include monitoring and task setting. Damage to the right lateral areas of the frontal lobe may result in problems with monitoring—that is, the ability to keep one's place in a task and respond consistently, accurately, and efficiently. Damage to the left lateral part of the frontal lobes may result in difficulty in using if–then types of logic and focusing attention on the right thing at the right time. Problems with task setting may result in a person who seems to become distracted, derails from a task that has been started, or makes many errors because they are not consistently able to follow the rules of a task.
- 3. *Metacognition/integration* is the function that is often referred to as higher-order cognitive functioning. This type of cognitive functioning is sensitive to damage to several areas in the frontal lobes, particularly the tip of the frontal lobe but also the ventro-medial prefrontal cortex. The integration of cognition allows the brain to use all the data on hand, including emotional responses to accomplishing new tasks, thinking through problems, and recognizing relationships between diverse ideas. Metacognition, or the ability to consider one's own thought processes, allows for both strategic thinking and to understand how one's vantage point might differ from others'. Problems with these functions may look like difficulty understanding others' perspectives; appreciating humor; and knowing the difference between what one knows, believes, or remembers.
- 4. Behavioral/emotional self-regulation refers to cognitive processes that mediate the development of motivation, understanding risks and rewards and social behavior. These are some of the basic functions that allow people to meet their obligations, plan for the long term, and respond to social circumstances in a consistent and productive way. Damage to areas in the ventral-medial prefrontal cortex and/or pathways that connect this area with the emotional centers in the temporal lobe (limbic system) may result in difficulty in recognizing the benefits of delaying gratification, demonstrating empathy, and/or understanding and responding to emotional cues. It is possible to have damage to these areas and have great difficulty with behavioral regulation while still maintaining all other intellectual abilities. When this is the case, individuals may be able to describe what they should do but behave impulsively if there is a distraction or the promise of some immediate reward. Examples might be difficulty controlling gambling behavior or failure to participate in self-care. The difficulties with anger and substance use are outcomes of impaired behavioral and emotional self-regulation.

## Impairments of Awareness

The term, *impaired self-awareness* (anosagnosia) refers to difficulty with insight based on neurological damage. Lesions in the right cerebral hemisphere, specifically in the insular and frontal cortex, are associated with anosagnosia (Prigatano, 2009). Although individuals may be able to hear and understand feedback regarding their disability, they may discount others' accounts and appear undisturbed by problems that are obvious to others. Denial or impairment of insight are terms used to refer to the psychological process that includes a willingness to acknowledge one's weaknesses and accurately identify one's strengths. After brain injury, memory impairment and other cognitive difficulties may make it difficult for a person to develop a full and accurate picture of their own abilities. Most often, it is difficult to make a clear distinction between the cognitive, psychological, and neurological processes that enable individuals to accurately identify their strengths and weaknesses and have a clear and relatively accurate understanding of their personal and social situations.

In most people, awareness varies over time and according to the situation. Factors like fatigue, distraction, and anxiety can alter a person's level of self-awareness. Sometimes, especially right after making a mistake, people seem to have great self-awareness, only to forget what they learned later. People can also be aware of one type of problem and have a blind spot when it comes to something else. For example, it is common for people to have strong awareness of physical impairments, which have consistent and frequently felt consequences, while their ability to recognize interpersonal difficulties, which may have more intermittent and subtle consequences, is more often impaired.

Table A4 provides an adaptation of a model presented by (Crosson et al., 1989). It is important to realize that the degree of awareness shown in one area of functioning (e.g., physical impairment) may be different from the degree of awareness in another (e.g., social interaction). Understanding how an individual's awareness of their own difficulties provides an important key for managing that patient's care.

#### ADAPTING YOUR PRACTICE Recommendations for the care of Patients who are Homeless or Unstably Housed Living with the Effects of Traumatic Brain Injury

Levels and Description	on	Examples
Little or No Self-awareness	People are not able to recognize their difficulties.	I do not have a brain injury. Everyone has some problems with memory. I never did that very well.
Intellectual	Comments focus on others or the environment. People can name difficulties but cannot identify how they interfere with day-to-day functioning.	People say I am forgetful. The doctor tells me I have bad judgment.
Emergent	People acknowledge problems but limit their importance or attach the problem to a person or circumstance. They may know what to do to prevent a problem but cannot make a commitment to using the strategy regularly.	There are times when I forget things, but it is no big deal. I do not remember things that are not important to me.
Anticipatory	People state the problem and can see the need to plan ahead, even if they have not yet figured out what to do.	I have a lot of trouble with names, so I take notes. I have the hardest time when I am tired. I need some help to learn new information at work.

## Table A4. Levels of Self-awareness

## Impairments of Emotional Perception or Regulation

Difficulty in recognizing and managing emotions is another common problem after brain injury. Damage to structures in the middle of the temporal lobe (including the amygdala and hippocampus) and the frontal subcortical circuits that connect these structures to the frontal lobes as well as areas in the parietal lobe may produce difficulties with perceiving, processing, and modulating emotion. Table A5 below summarizes the type of difficulties that might be observed.

Problem	Social Presentation
Emotional lability (pseudo- bulbar affect)	Uncontrolled laughter or crying that seems to be out of proportion to affect
Difficulty in recognizing emotion in self or others (alexithymia)	Emotionally distant or unempathetic Behave in an egocentric manner Socially awkward Seem unaware of the signs of strong emotions
Emotional dyscontrol (disinhibition)	Emotional expression that seems to be out of keeping with the situation. Most often, this is observed as difficulty in managing one's temper or irritability. However, patients or those around them may complain about difficulty with containing emotional states.
Flat affect	Limited, overt emotional expression. The individual may lack vocal prosody (emotional expression in speech) and demonstrate very limited facial expressions.

Table A5. Impairments of Emotional Perception and Regulation

## Attention

Attention is mediated by the frontal lobe and is the result of a combination of the brain's energizing and executive abilities. It is the gateway to other cognitive processes. To learn and recall information, problem solve, or perform tasks well, it is necessary to be able to focus attention to the task.

## **Cognitive Processing**

Speed of cognitive processing is often affected by brain injury. Often, cognitive speed is generally slow. However, sometimes, one type of cognitive processing may be slower than others. For example, a person may be very slow in

processing language but have little difficulty with visual information or physical coordination. Speed of processing also places a limit on the speed at which information can be taken in and recalled and how quickly information can be used to solve a problem.

## Memory

Memory is mediated by structures in the limbic system, including the hippocampus and the amygdala, but in fact, it involves the entire brain working together. Learning requires attending to information, processing or organizing it to be filed away, and then getting the right cues to draw it

### Signs of Difficulty with Attention

- Difficulty managing distractions
- Trouble staying on topic
- Looking fatigued/tired/disinterested
- Thrill seeking
- Fidgeting or seeking sensory stimulation
- Becoming overwhelmed in busy places

back out of memory. Because memory requires much of the brain's resources, it is often impaired after brain injury. The memory system most vulnerable to injury is declarative memory, the type of memory that allows us to recall events and facts. Generally speaking, procedural memory—is the ability to learn skills, patterns, and routines—is less prone to disruption and may function well, even when a person's memory for events and newly learned facts is quite poor.

## Sensory Impairments

Visual, auditory, tactile, and olfactory sensation may all be disrupted by TBI. Functional visualspatial impairments may include hemianopsia (neglect of visual information presented to one side usually the right) as well as difficulty with visual memory and path finding. Changes in sensation, generally one-sided, may also occur, often with weakness on the same side.

Deafness in one ear or a tendency to neglect information presented to one ear may occur. The individual may also demonstrate difficulty in processing auditory information and have greater difficulty in focusing attention when background noise is present.

When there is damage to the superorbital portion of the frontal lobes, impairments of olfaction are common. Because these are associated with damage to this area of the frontal lobes, problems with sense of smell are often associated with impaired behavioral self-management. Signs of impaired olfaction include excessive use of salt and sweeteners and poor appetite. The social impact of impaired olfaction includes safety risks, including an inability to identify spoiled food, toxic odors, or the smell of smoke. It also can have an impact on personal hygiene.

## Language and Communication

Communicating effectively requires understanding other's ideas and being able to express ideas. Language-based communication, speaking, listening, reading, and writing are central to communication; however, effective nonverbal communication is essential in the social uses of communication. Nonverbal communication includes body language, vocal tone, and pragmatics (i.e., the conventions of communication such as taking turns, choosing topics, and staying on topic). Table A6 provides an overview of the types of difficulties that can occur with speech as well as the social pragmatics. These difficulties may occur in different combinations and severities, depending up on the nature of the injury. For example, if the problem is with the motor part of speech it is possible to have difficulty speaking but have little difficulty understanding language. For the most part, though, a person's facility with using language is a good indication of how well they are able to understand what you are saying. It is important to remember that the brain uses many of its systems to enable social communication. It is useful to think about a person's overall cognitive functioning when thinking about their communication.

Language	Expressive aphasia Receptive aphasia Agrapha Alexia	Difficulty to use words in communication—types of aphasia include varying degrees of impaired word finding. The ability to understand/use language—speech itself may be unaffected, but what is produced may sound jumbled, and include nonsense syllables Inability to write Inability to read
Motor Speech	Broca's aphasia	The motor aspects of speech are affected resulting impairments ranging from being mute to having non-fluent speech
Social Pragmatics	Difficulty in managing the social aspects of conversation	Impaired turn-taking Topic selection Topic maintenance
Aprosodia	Use of vocal intonation	Perception and use of vocal intonation to communicate emotion

Table A6. Impairments of Speech and Language.

# **APPENDIX B: SCREENING FOR BRAIN INJURY**

Quick Screening for Lifetime History of TBI from the OSU TBI-ID

- 1. Please think about injuries you have had during your entire lifetime, especially those that affected your head or neck. It might help to remember times you went to the hospital or emergency room. Think about injuries you may have received from a car or motorcycle wreck, bicycle crash, being hit by something, falling down, being hit by someone, playing sports, or during military service.
  - a. Thinking about any injuries you have had in your lifetime, were you ever <u>knocked out</u> or did you <u>lose consciousness</u>?
    - \_\_\_\_ Yes

\_\_\_\_ No (IF NO, STOP HERE)

- b. What was the <u>longest time</u> you were knocked out or unconscious? (Choose just one; if you are not sure, please make your best guess.)
  - \_\_\_\_\_ knocked out or lost consciousness for less than 30 min
  - \_\_\_\_\_ knocked out or lost consciousness between 30 min and 24 hours
  - \_\_\_\_ knocked out or lost consciousness for 24 hours or longer
- c. How old were you <u>the first time</u> you were knocked out or lost consciousness? \_\_\_\_\_ years old

## NOTES:

This question allows three indicators of lifetime history of TBI to be computed:

- 5. Positive for a lifetime history for TBI with loss of consciousness (yes/no)
- 6. Worst TBI with loss of consciousness (LOC) was mild, moderate or severe (no TBI with LOC, mild TBI with LOC, moderate TBI, severe TBI)
- 7. Age at first TBI with loss of consciousness (in years) \_\_\_\_\_

# APPENDIX C: ASSESSMENTS FOR COGNITIVE IMPAIRMENT

Measure	Admin. Timo	Availability	Comments
Mini Mental Status Examination (MMSE; (Folstein, Folstein, & McHugh, 1975)	5–10 min. May be used by any trained personnel	Public domain (forms can be found on multiple websites).	Designed to assess dementia and delirium, not focal impairments or TBI. Less sensitive to mild but potentially significant impairment. Overestimates impairment in less-educated populations.
Mini Mental Status Examination 2; MMSE; Folstein and Folstein, & Mc Hugh, 1975)	5 min. (brief) to 20 min. (extended form).	Proprietary. Available at <u>MMSE-2.</u> Several languages available.	Normed using elderly clinical samples.
Montreal Cognitive Assessment (MOCA; (Nasreddine et al., 2005) et al., 2005)	20 min. May be used by any trained personnel	Public domain (forms can be found on multiple websites). Many languages available.	Results are also affected by education and age and require careful interpretation. Designed for people 60 years and over, though it is often applied to younger populations.
Brief Cognitive Screening Examination (BCSE; (Wechsler, 2009)	15 to 20 min.	Proprietary license for purchase by qualified health professional. Available at: <u>BCSE</u>	Designed for a broad age range. Observed to be more sensitive than the MMSE, although at extremely low scores, the two tests displayed similar sensitivity. The BCSE seems to have diagnostic utility as a cognitive screening measure

# APPENDIX D: SCREENING FOR FUNCTIONAL STATUS / DISABILITY

Measure	Admin. Time	Availability	Comments
World Health Organization Disability Assessment Schedule (WHODAS 2.0)	5 min. (self); 20 min. (inter- view)	In the public domain: <u>WHO-DAS</u>	<ul> <li>Designed to be a generic measure of disability in the domains of cognition, mobility, self-care, social interaction, activities of daily living, and social participation. Available in many languages.</li> <li>Designed as a self-report measure, interviewer administered or for a proxy to complete</li> <li>Available in a brief format (12 items) and long format (36 items).</li> </ul>
Adaptive Behavior Assessment System- Third Edition (ABAS-3; Harrison & Oakland, 2015	20 -30 min.	Proprietary, available for purchase. <u>ABAS-3</u>	Designed to assess three functional domains (conceptual, social, and practical) in 11 skill areas: communication, community use, functional academics, health and safety, home or school living, leisure, motor, self-care, self- direction, social, and work. Forms for self-report and proxy ratings.
Mayo-Portland Adaptability Inventory–4 (Malec, 2005)	15 to 30 min.	In the public domain. Available at <u>MPAI-4</u>	Designed to assist clinical evaluation of people living with the effects of brain injury. Three domains are addressed: abilities (cognitive, motor, and sensory, including pain); adjustment (includes mood, social interaction and behavior), participation (social role). Designed to be administered as a self-report, professional assessment or proxy report. Several languages available.

# APPENDIX E: GENERAL ACCOMMODATIONS FOR COGNITIVE IMPAIRMENTS

Even when people's behavior differs from their stated goals and intentions, assume that they are doing the best they can and determine what supports will allow them to be successful.

- Support clear communication
  - Choose quiet, distraction-free environments.
  - Deliver information slowly.
  - Use simple but complete messages.
  - Provide organizing statements, such as identifying the topic being discussed.
  - Use language familiar to the patient.
  - Check comprehension by asking for a demonstration of information provided.
  - Assist the patient with obtaining a phone. Ensure the patient is aware of and able to use the texting feature so important information and reminders can be transmitted.
- Support organization, learning, and memory
  - Use routines (such as keeping appointments on the same day of the week).
  - Keep recommendations simple.
  - Where possible, prioritize treatments rather than attempting several interventions simultaneously.
  - If a patient seems to be struggling to recall information, provide the correct information with repetition and discourage guessing, which may result in perpetuating incorrect information.
  - o Provide simple, written instructions, in one place if possible, for all important information.
  - Use simple calendars and reminders that can be carried with an individual.
  - Consider the use of simplified medication regimes and packaged medication.
  - Seek permission to include collateral informants.
  - When making referrals, talk through the plan of attending the appointment when it is made.
  - Where possible, arrange for support at important follow-up appointments.

## Enlist environmental supports

0 Use case management services where they are available.

- 0 Consider services such as voluntary trustees.
- Ask permission to contact other service providers (e.g., someone who can provide a cue such as the time of an appointment or medication).
- Identify people who are often with the patient and from whom they would be willing to ask for and accept support.

#### Ensure informed consent

- Check the communication of risks, benefits, and alternatives of treatment by asking the patient to repeat what has been understood.
- Review consent information at each visit to ensure retention of the information.

# APPENDIX F: SUGGESTIONS TO SUPPORT PATIENTS IN ATTENDING APPOINTMENTS

- Use appointment cards as reminders and include the purpose of the visit.
- Support the patient to use the reminder/calendar function of cell phones.
- Consider reminder phone calls and/or text messages.
- Schedule appointments for times when the patient is most alert. Many patients will know when they are at their best. It is important to ask. For some, morning appointments will find the patient at their freshest; for others, afternoon appointments will work better.
- Actively plan with patients about how they will remember to attend the appointment, working out reminders, timing and payment for transportation, and other matters such as getting meals and childcare.
- Link critical appointments to an event that is routine for the patient, such as attending a meal.
- Consider providing support to accompany patients to critical appointments.
- Be flexible about the length of appointments. Some patients may have difficulty tolerating longer appointments. Others have difficulty leaving any aspect of a task until it is complete or need more time to settle into a task.

## Supporting Patients in Learning and Remembering New Information and Tasks

- Information should be presented at a slowed pace, one concept at a time.
- Written information should be provided in easy-to-read text and format.
- Key information and instructions should be repeated.
- Engage the patient in learning:
  - Ask patients to summarize what they have learned.
  - Help patients take their own notes.

- Help patients to organize their use of notes. Smartphones may have a notepad function. Setting an alarm to read the note at a specific time can help. Putting written notes near often-used items can be helpful.
- Keep the reminder system simple. There should be one way to record new information, and it should be easy to get rid of old information.
- Highlight important information (e.g., dosing schedule on medication bottles).
- The voice recorders and videos on phones can be used to record important instructions. Be sure the patient knows how to use the app and how to access the information when needed.
- Pictures can be used for instructions, street signs, addresses, and people.
- Provide clear, specific instructions (e.g., "Let's start by putting your clothes in the bag" is better than "Clean up").
- Model tasks: Talk through tasks while demonstrating.
- Use pictures to support step-by-step information, such as a sun for morning meds and a moon for evening meds. Take a picture of items needed for the day. Long educational messages in text format are less useful for patients with cognitive impairment from TBI.
- Call patients' attention to landmarks when teaching way finding or to help patients visualize new/unfamiliar locations.

## Helping Patients Organize Belongings

- Store items that are used together in the same place (e.g., folders for medical information, a Ziploc bag for medication)
- Choose a specific place for important items (e.g., keys and wallet always in the same pocket)

## Supporting Patients Who Have Difficulty with Attention

Use quiet areas to complete more difficult tasks (e.g., teaching the use of insulin in a quiet office space).

- Timers can be used to cue a patient to sustain or move on from an activity. For example, set a 10-minute timer for the patient to do the activity, and then take a break.
- Earplugs and headphones can be used to help a patient screen out environmental noise.
   Earphones without music playing can help a patient focus in a noisy environment.

## Supporting Patients Who Have Difficulty Following Through with Tasks

- Be sure that the patient is aware of and interested in pursuing the goal.
- Use strategies for communication, learning, and memory.
- Small incentives such as coffee or food may improve a patient's willingness to return for an assessment or intake appointment.
- Make meeting times/days of the week routine for the patient. Allow several attempts to help the patient create a routine that improves their attendance. Strict rules regarding timeliness for appointments may be a barrier to receiving care.

## **APPENDIX G: WHATEVER IT TAKES CASE MANAGEMENT MODEL**

*Whatever It Takes* operates on the assumption that no two people are alike—and no two brain injuries are, either. No matter the cause (e.g., stroke, injury, or illness), living with cognitive and behavioral impairment is an enormous challenge—one that requires creativity, persistence, and optimism. This is particularly true because the individual may not be fully aware of changes resulting from their injury. Although the availability of services is improving, people who leave rehabilitation centers with ongoing difficulties may find services that fit their unique needs are not available in the right location, at the right time, or in the desired quantity.

## Whatever It Takes Principles

## 1. No two individuals with TBI injury are alike.

Think of the brain as a set of highly interconnected structures. When one or more structures are affected by brain injury, the whole system can be disrupted in ways that are not easy to predict. As discussed in Appendix A, we see a wide array of problems resulting from brain injury; these problems can be present in very different forms in each individual. Now consider the fact that a person's preinjury characteristics most certainly affect the outcome of the injury. To be successful, programming needs to be adapted and individualized to suit the patient's individual needs.

# 2. Skills are more likely to generalize when taught in the environment where they will be used.

Generalization means transferring a skill from one setting to another. Because of changes in reasoning, memory, and initiation, teaching a patient something in a classroom or therapy gym often does not get used in real life. The more complex the skill, the less likely it is to generalize. If the goal is to teach a person to cook a meal, the best place to review the steps is in the kitchen where the cooking will actually occur.

## 3. Environments are easier to change than people.

Self-management is tough for everyone, and the challenge increases after brain injury. Difficulties with self-awareness, impulsivity, and memory can make habit change very difficult. At times, the easiest, most robust plans for change involve altering some part of the environment. For example, it is probably easier to change roommates than it is to counsel a patient not to drink when their housemates are partying.

## 4. Community integration should be holistic.

This theme is repeated throughout this manual. All areas of one's life interact. Clinicians should avoid thinking about patients only in terms of their specific area of practice; rather, services should be designed around a patient's goals and needs. In this way, the team can support the patient in achieving success in resuming meaningful activities and roles. For example, motivation to stop substance use can be supported by a patient's desire to get a job.

## 5. Life is a place-and-train venture.

People generally work better when the link between meaningful goals and their own efforts are clear. It is more motivating to get right down to the real thing rather than spending time in training on a simulated task. In vocational rehabilitation, this means finding a job placement and providing training on the job. Because of problems with generalizing skills, this model is recommended with patients. The same sort of approach is also useful in learning other life skills, such as navigating the community, home care, and finances. Often patients will not accept the principle of using a date book, but if their job requires making notes and using a calendar (and others on the job do the same) this compensation strategy is more likely to be accepted.

## 6. Natural supports last longer than a professional.

Social interactions often change after brain injury. Friends before the injury may not remain involved. Intervention should seek to involve natural supports i.e. faith or community-based organizations, and help the patient identify new social opportunities that will be available in the long-term. In general, unpaid supports should be encouraged over paid supports.

## 7. Interventions must not do more harm than good.

The goals of intervention should be clearly defined, and interventions must be considered for all of their potential effects. For example, when workers are the most available social contacts in the environment, patients may not develop other relationships.

# 8. Service delivery systems present many of the barriers to community integration.

Sometimes patients will have to use a service that is not what is needed because it is the only service available. Other times, admission criteria may limit access to a needed resource. For example, a patient's behavioral difficulties may be most effectively managed in their home environment, but only inpatient services are funded. Rehabilitation programs may limit services to an individual if they are still using substances. Service providers may need to advocate for helping patients identify the services they need.

## 9. Respect for the individual is paramount.

It is an unfortunate fact that health centers and clinicians develop shortcuts to address competing demands. It often happens that individual rights get lost in the bargain. It is important to ensure patients are offered privacy, the right to make personal decisions, and to be addressed directly and in a dignified manner.

## 10. Needs of individuals last a lifetime: So, should their resources.

#### ADAPTING YOUR PRACTICE Recommendations for the care of Patients who are Homeless or Unstably Housed Living with the Effects of Traumatic Brain Injury

Service systems should ideally allow patients to re-enter programs as required. Unfortunately, public resources are limited, and advocacy may be required. When there are private sources of funding, such as legal settlements, it is the responsibility of the treating health care provider to monitor the use of resources to ensure they are not depleted within a short period after injury. Family may be available now, but in the future, outside assistance may be needed.

## APPENDIX H: CASE MANAGEMENT (CARE PLANNING MODEL)

When an individual's needs are complicated by cognitive impairment, the period of intervention will likely be longer than expected. One reason is that it may take more time to engage with the person and build routines such as attending appointments, participating in self-care, and engaging in meaningful activity.



In general, the less aware patients are of their cognitive impairments, the more structure or assistance they will need from the environment or caregivers.

Table H1 illustrates how health care providers can assist patients with different levels of self-awareness.

Level of Self- Awareness	Goals/Tasks	Useful Strategies	Case Management Issues
Little or no self-awareness and intellectual self-awareness	<ul> <li>Establish contact with patients and encourage engagement.</li> <li>Remove any barriers to attending appointments or activities.</li> <li>Develop an understanding of patient's goals, preferences, and immediate needs.</li> <li>Align yourself as an ally in meeting the patient's goals.</li> <li>Relate all therapies and activities to patient's goals and needs.</li> <li>Focus on participation in real life and relevant functional tasks.</li> <li>Avoid using labels. Encourage patients to predict their performance and monitor their outcomes.</li> </ul>	Introduce specific compensation strategies, such as lists, schedules, and reminders for tasks the patient is interested in completing. Help the patient identify and use strengths. Where possible, arrange to have a supportive person available for new activities and difficult situations to model behavior.	<ul> <li>Include people with specialized ABI training on support team.</li> <li>Make links and/or develop structure and support to promote participation in meaningful activity and desired social roles.</li> <li>Provide the support and assistance needed to attend therapy sessions.</li> <li>Engage the intervention of others (e.g., family and rehabilitation workers) to manage immediate risks and develop and implement care plans.</li> <li>Develop daily routines that compensate for cognitive difficulties.</li> </ul>

## Table H1. Level of Awareness and Care Planning

#### ADAPTING YOUR PRACTICE Recommendations for the care of Patients who are Homeless or Unstably Housed Living with the Effects of Traumatic Brain Injury

Level of Self- Awareness	Goals/Tasks	Useful Strategies	Case Management Issues
Emergent self-awareness	<ul> <li>Begin to develop goals related to cognitive compensation.</li> <li>Help patients develop increased selfawareness.</li> <li>Help patients recognize areas of control and mastery.</li> <li>Introduce metacognitive strategies.</li> </ul>	<ul> <li>Cognitive compensation may emphasize how strategies can be used in a variety of settings.</li> <li>Give supportive feedback as patients begin to acknowledge impairments.</li> <li>Help patient identify and use strengths.</li> <li>Have a caregiver present in difficult or new situations to model behavior.</li> </ul>	Coordinate care with rehabilitation providers. Encourage the use of peer mentors and group support. Facilitate access to meaningful activity and desired social roles. Encourage active planning and problem solving.

Level of Self- Awareness	Goals/Tasks	Useful Strategies	Case Management Issues
Anticipatory self-awareness	Consolidate the gains and promote the development of a positive self-image that includes the cognitive disability. Help patients generalize strategies across situations. Help patients address the social aspects of a disability in a dignified way.	Help patients anticipate difficult situations and discuss compensatory strategies.	Maintain rehabilitation links. Encourage involvement in meaningful activity and desired social roles. Help patients with transitions in life and help them develop new strategies for new challenges.

## **APPENDIX I: OVERVIEW OF COGNITIVE REHABILITATION**

Cognitive rehabilitation is generally undertaken by a clinician such as a neuropsychologist, speech and language therapist, or occupational therapist in the context of a specialized program; however, understanding what cognitive rehabilitation may is be useful in all levels of practice. Table H1 lists the types of cognitive strategies.

Restorative	Focus is on restoring the lost function when possible
Compensatory	Focus is on assisting the individual to compensate for a deficit using prosthetic devices (e.g., memory books)
Environmental	Focus is on creating a disability-friendly environment
Behavioral	Focus is on use of behavioral methods for skill training

## Table I1. Types of Cognitive Rehabilitation Strategies

There is some evidence that **restorative therapy** for attention and concentration is helpful. For example, researchers have used computerized tasks to help people practice staying more mentally alert and focusing their attention in specific ways. However, evidence-based practices for cognitive rehabilitation after the first couple of years after brain injury, focus on ways to improve functioning by helping a person living with brain injury learn new ways to cope with functional tasks. This means helping patients find and get in the habit of using compensatory strategies, including new ways of thinking-through a task. The emphasis is on creating environments that are supportive as well as providing the right training to generalize skills across settings. Because neural plasticity relies on repetition for new connections to occur, functional practice may lead to very gradual restoration of abilities in the long-term. A review of evidence-based practices for cognitive rehabilitation after brain injury can be found in the ERABI review, (Coetzer & Balchin, 2014; Radomski, Anheluk, Bartzen, & Zola, 2016)

Compensation is the use of strategies or activities that help an individual cope with an issue they may have with functioning. For example, taking notes can help compensate for a problem in remembering information. Most people, (not just people living with injuries), use some compensation strategies to maximize their strengths and minimize their weaknesses.

**Meta-cognitive strategies:** Meta-cognitive refers to thinking about thinking. Everyone uses metacognitive strategies or patterns to problem-solve, whether they are conscious of it or not. When faced with a difficult problem, the first thing a person does is to define an issue as difficult, and then they think through a series of operations and develop a plan of action. This kind of thoughtful action may not come as naturally after brain injury, and training in specific strategies can help a person to respond less impulsively.

Туре	Examples
Behavioral reminders	Ask someone to remind you Put something in a special place Wear a colored rubber band
Memory aids	Tape recordings, pictures, and notes Medication organizers Post-it notes Checklists Appointment cards
Technology	Calculator Smartphones (video, note, alarm, etc.)
Reference materials	Cue cards Books Lists
Cognitive art	Chart summarizing important information Floor plan Map
Environmental	Signage Way-finding cues, such as landmarks Organizing materials by task Basket to keep essential items such as keys and wallet
Meta-cognitive Strategies	Goal management e.g., goal, plan, do, check Strategy training Problem solving Stop and think

## Table I2. Examples of Cognitive Compensation Strategies

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