

# **Working with people with ABI: Training materials Handouts, Worksheets & Tools**

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## Introduction

People working with people with ABI need to:

1. Have an introductory understanding of ABI (and the similarities and differences with other work with which they may be familiar [e.g. aged care, intellectual disability, mental health, etc])
2. Be aware of the diversity of people with ABI and the impact of their injury
3. Be aware of the how to approach working with people with ABI (appropriate for their work role).
4. Identify new strategies for working with people with ABI that could be used in their work (appropriate for their work role).
5. Identify their learning needs in working with people with ABI and also strategies in their work place for knowledge building about working with people with an ABI (and be aware of relevant learning materials, other supports and how to use them).

The web site [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info) has self study modules and training resources to help people working with people with ABI to achieve these goals.

The learning materials have been designed for:

- Information and referral staff
- Support workers
- Program staff
- Case managers and
- Managers.

The learning materials have also been designed so that they can be used in staff meetings, staff development sessions, agency forums, staff supervision and by external trainers running training workshops.

This document includes:

- **A. Handouts**
- **B. Worksheets**
- **C. Tools**
- **D. Interactive graphics and graphics handouts**
- **E. Video stories and video clips**

There is a separate companion document ***Working with people with ABI: Materials for facilitators and presenters*** which provides suggested processes for presenting and facilitating learning in a variety of situations including staff supervision, team meetings, forums and workshops. These materials for facilitators and presenters include detailed notes on how to use the handouts, worksheets etc included here.

The materials for facilitators and presenters are available for download from the web site: [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info).

The learning materials have been developed by the Agency for Clinical Innovation in consultation with a wide range of stakeholders with funding from NSW Ageing Disability and Home Care an agency of NSW Department of Family and Community Services.

## A. Handouts

The following handouts are available from the web site [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info). Handouts 2, 3 and 4 have both short and long versions (2A, 3A and 4A are the long versions).

### **Handout 1: ADHC and ABI (2 pages)**

An overview of ADHCs current plans and priorities for working with people with ABI. This Handout includes the priorities in *Stronger Together The second phase: 2011- 2016*.

### **Handout 2 : Introduction to Acquired Brain Injury ( 2 pages)**

#### **Handout 2A : Introduction to Acquired Brain Injury (17 pages)**

An introduction to ABI covering: What is ABI? Causes of ABI. The rehabilitation process. Common effects and impacts. Working with people with ABI.

The short version would be useful for introducing the topic at a staff meeting. The long version would suit a staff development session.

### **Handout 3 : Approaching working with people with ABI (3 pages)**

#### **Handout 3A : Approaching working with people with ABI (12 pages)**

Key messages about how staff working with people with ABI need to approach how they go about their work. High level messages are about: unique individuals building independence; working through emotions and relationships; and working with services. Working with people with ABI is different to working with aged people, people with intellectual disabilities and people with mental illness.

The short version would be useful for introducing the topic at a staff meeting. The long version would suit a staff development session.

### **Handout 4 : Practical strategies (2 pages)**

#### **Handout 4A : Practical strategies (7 pages)**

An overview of tools and strategies available to help staff work with people with ABI. There are tools and strategies for information and referral workers, support staff, program staff, case managers and managers.

The short version would be useful for introducing a list of practical strategies at a staff meeting. The long version would suit a staff development session.

### **Handout 5 : Working with people with ABI: Practice wisdom (4 pages)**

Distilled wisdom from people with ABI, the family members and staff working with people with ABI. This practice wisdom highlights important take-home messages for anyone working with people with ABI.

### **Handout 6 : Building knowledge skills and service capacity (2 page )**

Opportunities for workplace learning. This could be used in a workplace exploring how to further build skills and knowledge about working with people with ABI. Opportunities for building individual skills and knowledge.

# Handout 1: ADHC and ABI

## A. ADHC and ABI Highlights

- *Stronger Together: A new direction in disability services in NSW 2006- 2016* is ADHC's 10 year plan to provide greater assistance and long term practical solutions for people with a disability.
- An *Interagency Agreement on the Care and Support Pathways for People with ABI* is in place.
- *New directions in Case Management 2008-10: The Case Management Framework* and the *Case Management Practice Policy* provide the overarching policy framework, values and approach to case management service provision for ADHC provided case management services.
- ADHC currently funds or provides an array of programs, sub-programs and services including services to those with ABI.
- As people with an ABI were not historically prioritised for funding under National Disability Agreement service types, the disability service system requires increased knowledge, skills and competencies now that people with ABI are prioritised.
- ADHC is committed to increasing ABI awareness and knowledge across all service types.

## B. People working with people with ABI

People working with people with ABI in NSW need to be able to:

1. Understand Ageing, Disability and Home Care's (ADHC) directions in relation to acquired brain injury (ABI).
2. Have an introductory understanding of ABIs (and the similarities and differences with other work with which they may be familiar [e.g. aged, intellectual disability, mental health, etc])
3. Be aware of the key building blocks of how to approach working with people with ABI (appropriate for the participants work role).
4. Identify new strategies for working with people with an ABI that could be used in their work (appropriate for the participants work role).
5. Identify what they need to know in working with people with ABI and strategies to build their knowledge about ABI
6. Identify strategies in their work place for knowledge building around working with people with ABI (and be aware of relevant leaning materials, other supports and how to use them).
7. Identify local service network issues (in working with people with ABI) and what could be done to address them locally.

## C. ADHC and ABI

**Stronger Together: A new direction in disability services in NSW 2006 -2016\*** is a 10 year plan aimed at providing greater assistance and long term practical solutions for people with a disability. ADHC has now set strategic priorities relating to this plan. These priorities include developing new approaches for people with adult onset disabilities including people with acquired brain injury (ABI).

**Stronger Together Phase 2 (2011/12 to 2015/16)\*** has been announced and includes an additional \$2 billion in new growth funding for disability services (including ABI) over the five years. Key features of the second phase of **Stronger Together** are the focus on people with a disability and families as key determiners of how resources are used, increased availability of individualised and portable funding arrangements, a service system with the right capacity and a lifespan approach to meeting people's needs.

**Stronger Together Phase 2 Policy Supplement Directions for adult onset disability services in NSW 2006-2016** to further address and strengthen the service response for people with an adult onset disability we aim to continue improving the service response by focusing on the following:

- Person-centred approaches
- A lifespan approach
- A service system with the right capacity.

An **Interagency Agreement on the Care and Support Pathways for People with an ABI\*** was signed in November 2008 by ADHC, NSW Health, Housing NSW and the Lifetime Care and Support Authority. This Agreement and its implementation plan commit the signatory agencies to a holistic planning approach and joint work on key referral and service delivery issues that impact on outcomes for people with an ABI.

**New directions in Case Management 2008-10: The Case Management Framework\*** and the **Case Management Practice Policy\*** provide the overarching policy framework, values and approach to case management service provision for ADHC provided case management services. These policies are currently used by ADHC Community Support Team case managers. These documents are "examples" that can be used as a resource demonstrating good practice.

ADHC currently funds or provides an array of programs, sub-programs, service models and initiatives for people with adult onset disabilities, including those with an ABI under both the National Disability Agreement (NDA) and the Home and Community Care (HACC) Program.

As people with an ABI were not historically prioritised for funding under NDA service types, the disability service system requires increased knowledge, skills and competencies to respond effectively to this target group. ADHC has commissioned ABI Awareness Training for ADHC provided and funded services staff.

ADHC is committed to increasing ABI awareness and knowledge across all service types particularly case management services, in-home support providers, accommodation, community participation, leisure and recreation providers and HACC funded services. Consultation across ADHC staff and stakeholders on the contents of the ABI training resources have supported the need for initial training and for continued professional development opportunities across service types.

\* Available from: [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)

## Handout 2 : Introduction to Acquired Brain Injury (ABI)

### A persons's abilities and their life span

It is useful to consider acquired brain injury within the context of a healthy person's abilities and lifespan. A healthy person's abilities include: understanding and communication, mobility, self-care, interacting with other people, being able to participate in life activities such as leisure, work and school, joining and participating in community activities.

A person's life span typically moves through the stages of birth, pre school years, school years, young adult, middle age, retirement and old age.

An acquired brain injury impacts on a person's abilities at any point in their life span. The nature and extent of the impact and the services and rehabilitation process that will be needed are related to the nature of the injury to the brain and the point in their life span when it occurs.

### What is acquired brain injury? Its causes?

An acquired brain injury is:

- an injury to the brain
- as a result of a cause e.g. trauma, stroke
- resulting in impairments to the person.

The primary causes of ABI are:

- trauma - acceleration/deceleration injuries and penetrating injuries
- stroke - blocked blood vessels and /or bleeding in the brain
- hypoxia/anoxia - lack of oxygen in the brain
- alcohol related - toxic effects of alcohol/toxins on the brain
- infection - infection leading to inflammation
- tumours - benign tumours and cancers
- degenerative diseases - e.g. Alzheimer's disease, Multiple Sclerosis

The causes of ABI vary with age and gender. For example traumatic brain injury is often caused by driving accidents and is more common in young adult males. Strokes are more common in older people. Trauma, stroke, hypoxia/anoxia and infection cause sudden onset ABI. Alcohol related, tumours and degenerative diseases cause gradual onset ABI.

### The brain and its functions

The brain has areas which specialise in specific functions, for example:

- the frontal lobe specialises in planning, organising, reasoning and decision making, judgement and the emotions
- the parietal lobes specialise in the perception of sensations such as touch, pressure, temperature and the understanding of words and sentences
- the temporal lobes have a role in language , particularly the ability to hear and understand it.

There are other brain areas each with their specialist functions - the occipital lobes, the cerebellum, the brain stem, and so on.

### Severity of ABI

The severity of an ABI can be mild, moderate, severe or extremely severe, e.g.

- Mild - e.g. good physical recovery, limited concentration, able to go back to previous work; 10% of all people with a mild brain injury experience lifetime problems with living and learning.
- Severe - e.g. decreased ability or inability to control movement, decreased ability or inability to communicate, requires support with daily living, possibly not able to work; 90% of people with a severe brain injury experience lifetime problems with living and learning.

## ABI: Cause to impact

When a person has an acquired brain injury:

- the cause (e.g. trauma or stroke)
- injures part(s) of the brain (e.g. frontal lobe, occipital lobe)
- the injuries affect brain functioning (e.g. in areas such as cognition & communication/language)
- resulting in specific impairments (e.g. memory difficulties or disinhibition)
- These impairments reduce the person's abilities at a point in their life span and can impact on their abilities (e.g. communication, self-care, relationships, work, etc) depending on the specific impairments.

## Rehabilitation

Rehabilitation facilitates ongoing recovery. Rehabilitation enables a person to become as independent as they possibly can. The goal is for the individual to return to their previous abilities, activities and way of life as much as they possibly can. The process of rehabilitation is unique for each individual. When a person has an ABI there are many different rehabilitation pathways depending on the cause of the ABI and point in the life span the injury occurred and the person's circumstances. For example:

- An adult with a severe traumatic brain injury could have the following pathway: Hospital Brain Injury Rehabilitation Unit; discharge to supported accommodation; community rehabilitation services.
- An adult with a serious stroke could have the following pathway: Hospital Stroke Unit; discharge to family home; community rehabilitation services.
- An adult with ABI caused by degenerative diseases could have the pathway: GP; medical specialists; outpatient services; support services in the home; specialist supported accommodation.

## Effects of ABI

Common areas of effects of acquired brain injury are:

- Cognitive - thinking skills
- Communication/language
- Physical/sensory
- Emotional/behavioural/personality.

There is overlap and interconnections between these areas of effects. The specific effects will be unique to each individual and their injury. The extent of the effects and challenges for the person with brain injury depends on:

- The severity of the ABI
- The location of the brain damage
- The length of time since brain injury
- The extent a person has been able to integrate back into the community
- The support available to the person.

## Working with people with ABI

Working with people with ABI is different from working with people in aged care, intellectual disability or mental health. People with ABI can grow in their skills for independence in the short and long term. Staff working with people with ABI need specific knowledge and skills to help them work appropriately e.g. understanding each person's injury, its effect, the behaviours that arise and how to manage them; understanding the person with ABI had a life before the ABI and working through loss and grief about what has been lost is a significant part of the rehabilitation process for the person with the ABI, their family and friends.



# Handout 2A: Introduction to Acquired Brain Injury (ABI)

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### Note:

1. ABI can be a hidden disability
2. ABI is different from *Intellectual Disability*
3. ABI is different from *Mental Illness*

**A. What is ABI**

Acquired brain injury (ABI) refers to damage to the brain that may be caused by a variety of mechanisms.

The Australian National Policy on Services for People with Acquired Brain Injury defines ABI as:

“an injury to the brain which results in deterioration in cognitive, physical, emotional or independent functioning. ABI can occur as a result of trauma, hypoxia, infection, tumour, substance abuse, degenerative neurological diseases or stroke. These impairments to cognitive abilities or physical functioning may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment.”

(Department of Human Services and Health, 1994)

**B. Causes of ABI**

The common causes of ABI are:

**Traumatic brain injury (TBI)**

Traumatic brain injury (TBI) occurs as the result of some external force being applied to the brain sufficient to impact on brain functioning, such as a blow to the head or by the head being forced to move rapidly forward or backward. There is usually some loss of consciousness. A TBI might be caused by a motor vehicle accident, fall, assault, sporting accident, gunshot wound or violent shaking. TBIs are also referred to as head injuries, however TBI is more accurate because people can sustain other types of injuries such as cuts or bruising to the face or scalp that are also referred to as head injuries but involve no damage to the brain.

**Stroke**

Stroke refers to a rapid loss of brain function occurring as the result of a haemorrhage or blockage of the blood vessels that supply blood to the various regions of the brain. Strokes are also referred to as cerebrovascular accidents or disease (CVAs).

**Hypoxia/anoxia (cerebral)**

Hypoxia/anoxia refers to the reduced or complete stopping of the flow of oxygen to the brain. This can lead rapidly to the death of brain cells in periods as short as 5 minutes. Causes may include drowning, hangings, overdoses or health events such as severe asthma attacks or heart attacks where an individual stops breathing.

**Infection**

Bacterial or viral infections can lead to an inflammation of the brain covering (meningitis) or the brain tissue (encephalitis). The inflammation leads to a swelling of the brain which can result in the death of nerve cells, or bleeding (haemorrhage) which results in brain damage.

**Tumour**

Brain tumours affect the brain tissue where they are located, and can damage surrounding brain tissue, structures, and neurological pathways as they grow.

**Alcohol and other drugs or toxins**

Toxins can cause brain damage from an acute exposure, or cause cumulative damage over repeated exposure (e.g., lead or mercury). Alcohol acts as a toxin and the long term misuse of alcohol can cause damage to the brain.

**Degenerative neurological diseases** (also called progressive neurological diseases)

Degenerative neurological conditions cause increasing disruption to neurological function as the disease progresses. Examples include Multiple Sclerosis, Huntington's Disease, Parkinson's Disease, Motor Neurone Disease and dementias such as Alzheimer's Disease.

### C. Incidence and prevalence

Incidence - refers to the number of new cases in a period of time e.g. per year.

Prevalence - refers to the total number of cases present in the community at a point in time.

There is considerable uncertainty about the incidence and prevalence of ABI in Australia.

The Australian Institute of Health and Welfare report *The definition, incidence and prevalence of acquired brain injury in Australia* concluded "This review of definitions of ABI and estimates of its incidence and prevalence overseas and in Australia has shown that there is a good deal of uncertainty in the field."

Nonetheless some broad observations are:

Cause of ABI	Hospital separations per 100,000
TBI	149
Stroke	280
Anoxic brain injury	19
Alcohol related brain injury	15
Brain injury arising early in life	13
Other including degenerative diseases	362

These rates vary by gender, age and location.

For example hospital separations for TBI varied from 71 per 100,000 in the ACT to 211 per 100,00 in Queensland.

While in the table above there are much lower rates of Anoxic brain injury and Alcohol related brain injury and Brain damage present at birth or arising in early childhood this does not necessarily mean that these latter subgroups of ABI are insignificant in comparisons with stroke, TBI and ABI caused by degenerative conditions as some subgroups of ABI are not readily identified in the hospital system.

The Australian Institute of Health and Welfare Bulletin 55 Disability in Australia: Acquired Brain Injury, December 2007 states (pages 1 & 2):

Based on analyses of the Australian Bureau of Statistics' (ABS) 2003 Survey of Disability, Ageing and Carers:

- ABI is common: around 1 in 45 Australians (432,700 people) had ABI with activity limitations or participation restrictions due to disability. Almost three-quarters of these people were aged less than 65 years
- About 20,000 children aged under 15 years had ABI
- ABI was the main disabling condition reported by about 27,300 people aged under 65 years. A traffic injury was the main cause for more than half (55%) of these people
- More than one in three people with ABI aged under 65 years needed help with cognitive and/or emotional tasks.
- ABI caused by a traumatic event, such as a traffic accident or blow to the head, is referred to as traumatic brain injury. According to hospital records there were almost 21,800 hospital stays relating to traumatic brain injury in 2004–05

## D. Anatomy

### The skull

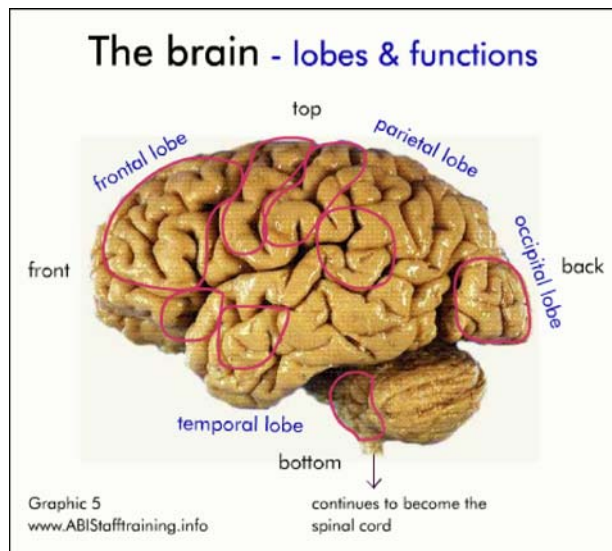


*Skull, brain and spinal column*

The brain sits within the skull and connects to the spinal cord.

### The brain

The brain is the body's control centre. It may only weigh about 1.5kg but it is made up of billions of cells. It controls everything we do from basic bodily functions such as breathing, heart beat and blood pressure, to our movements, speech, senses and our personality.



### Cerebral Hemispheres

The brain is divided into two cerebral hemispheres - the left hemisphere and the right hemisphere. These hemispheres are largely symmetrical in size and structure. The two hemispheres work seamlessly together, processing sensory information from the environment and initiating motor responses.

Generally speaking, the movement on the right side of our body (the actions of our arms and legs) is controlled by the left side of the brain (left hemisphere) and vice versa, movement on the left side of the body is controlled by the right side of the brain (right hemisphere).

Each hemisphere also has specialised functions. The left hemisphere tends to play a significant role in speech and language. The right hemisphere plays a special role in the perception and integration of nonverbal information including facial recognition.

### Lobes

The cortex of each hemisphere comprises four 'lobes' that handle specific areas of function.

**Frontal lobes:** The frontal lobes have different subdivisions. The back division of the frontal lobes are part of the brain's systems for controlling our movement. The front division of the frontal lobes play an important role in higher-level thinking skills (such as planning, organising, reasoning, decision-making and judgement.), as well as aspects of behaviour, emotions and personality. They rely on complex connections and information exchanges with other areas of the brain to perform these 'executive functions'.

**Parietal lobes:** The parietal lobes are divided into two zones. The front half of the parietal lobes are principally concerned with receiving data from the bodies' senses such as touch, pressure, temperature, and pain and then communicating this information to the frontal lobes. The rear section of the parietal lobes deals with spatial awareness, such as our ability to find our way around, and to reach for objects. Interestingly, this region also plays an important role in our ability to do arithmetic.

**Temporal lobes:** The temporal lobes also have a role in language, particularly in the ability to hear and understand. The temporal lobes are also concerned with memory, the emotions, the ability to enjoy music and to recognise and identify things we see, such as faces or objects.

**Occipital lobes:** The occipital lobes are primarily concerned with vision but also with our ability to recognise what we see in terms of identifying colours, locating objects in the environment and seeing objects accurately.

### Cerebellum and Brain Stem

Below the cerebral hemispheres are the cerebellum and the brain stem, which connect with the spinal cord.

**Cerebellum:** The cerebellum 'carries out' orders from the cerebral hemispheres and keeps a number of vital but routine functions kicking over, such as maintaining balance and ensuring our muscles move in a smooth, coordinated way.

**Brain stem:** The brain stem controls many vital functions including breathing, blood pressure, blood circulation, swallowing, appetite, body temperature and digestion, as well as the need for water, staying awake and sleeping, among other things. It is also the main route for nerve fibres running between the cerebral hemispheres and the spinal cord. Even small injuries to the brain stem can be life threatening.

## **The nervous system**

The brain communicates messages through a complex network of nerves that travels throughout our body. The brain nerves together make up the 'nervous system', whilst the brain and spinal cord together constitute the 'central nervous system'.

On their own, the nerves that run throughout our body are called the 'peripheral nervous system'. They relay information from the brain through the spinal cord to the rest of the body and back again.

The 'autonomic nervous system' is part of the peripheral nervous system. It conveys messages from all of the organs in our chest, abdomen and pelvis. For example, it manages our "fight and flight" responses, and our "rest and digest" responses. It looks after the automatic activities of our heart and blood vessels and plays an important part in sexual response and bladder control.

### **Neurons**

These are the basic components of the nervous system, also called nerve cells or neurons.

Neurons are a special type of cell that process and transmit information by electrical and chemical signaling.

We are born with about 100 billion neurons that must last a lifetime. Unlike all the other cells in the body, neurons usually cannot replace themselves if they die or are damaged.

The 'grey matter' of the brain is made up of neuronal cells. It can be found on the surface of the cerebral hemispheres and the cerebellum, as well as in the depths of the cerebrum, cerebellar nuclei, brainstem and inner part of the spinal cord.

'White matter' is found in the inner part of the brain and outer part of the spinal cord. It is made up of bundles of myelinated nerve fibres called axons, which connect various grey matter areas to each other, and carry nerve impulses between neurons. These axons are covered by a white, fatty substance called myelin (hence the term 'white matter'), which insulates them, like the plastic coating of an electric wire. Myelin acts as an insulator, increasing the speed of transmission of all nerve signals. The axons then bundle together, like the individual telegraph wires in a cable, to form a nerve.

### **How it all Works**

The brain is in constant contact with all parts of the body, sending instructions and receiving feedback from the senses. The axons carry these messages as tiny electrical currents or nerve impulses.

*Outgoing messages:* Messages sent from the brain to activate the muscles of the body travel along the motor pathways. The neurons that make up these pathways are called motor neurons.

*Incoming messages:* Messages sent from the senses back to the spinal cord and brain come along the sensory pathways. These are called sensory neurons.

Damage to the brain may affect many different functions and abilities. An injury can result in a serious disability that will interfere with a person's daily functioning and personal activities, often for the rest of their life. While the outcome of the injury depends largely on the nature and severity of the injury itself, long-term effects are difficult to predict and will be different for each person. It is common for people with a brain injury to get tired more quickly, have difficulty with short-term memory and find it more difficult to concentrate and to remember information.

The areas in which people with ABI may experience long-term changes include:

- Medical difficulties (e.g., epilepsy)
- Changes in physical and sensory abilities (e.g., weakness, tremor, impaired vision or smell)
- Changes in the ability to think and learn (cognition)
- Changes in behaviour and personality (psychological)
- Communication difficulties (e.g., slow or slurred speech, difficulty following conversation).

## E. Severity of ABI

Common categories for severity of ABI are:

- **Mild**  
e.g. good physical recovery, limited concentration, able to go back to previous work  
10% of all people with a mild brain injury experience lifetime problems with living and learning.
- **Moderate**  
e.g. motor coordination difficulties, inability to organise, may require different work  
33% of all people with a moderate brain injury experience lifetime problems with living and learning
- **Severe**  
e.g. decreased ability or inability to control movement, decreased ability or inability to communicate, requires support with daily living, not able to work or return to work with adequate support programs.  
90% of all people with a severe brain injury experience lifetime problems with living and learning.
- **Extremely severe**  
e.g. inability to control movement, inability to communicate, requires 24 hour support  
All people with an extremely severe brain injury experience lifetime problems with living and learning.

### Trauma, stroke and hypoxia-anoxia - at the time of the injury

For ABI caused by trauma, stroke and hypoxia-anoxia there is an indication of the severity of the injury at the time of the injury.

Injuries from these causes have a sudden onset and at the time of the injury the indicators of the severity of the injury are:

- the level of consciousness (measured by the Glasgow Coma Scale)
- the length of unconsciousness.

An additional indicator at the time of the injury of the severity of the injury for TBI is the length of post traumatic amnesia ( a period during which the person is not orientated to time, place, person, and is unable to learn, and may display disinhibition, irritable or agitated behaviour).

These indicators allow an initial assessment of the degree of severity to be made at the time of the injury.

### Alcohol, tumors and degenerative neurological diseases

For injuries caused by alcohol, tumours and degenerative neurological diseases indicators such as length of unconsciousness do not apply.

The severity of the brain injury caused by degenerative diseases is linked with the progression of the disease. A medical assessment provides an indication of the degree of severity of the associated brain injury and likely progression of the disease.

The severity of the brain injury from alcohol is determined by extent of cognitive impairments and impacts on behaviour. These can be assessed through neuropsychological assessments and functional independence assessments.

### Ongoing indicators of severity

The ongoing severity of the brain injury is determined by extent of cognitive impairments and impacts on behaviour. These can be assessed through:

- neuropsychological assessments (which assess cognitive functioning)
- functional independence assessments (which assess the degree of supports required).

## **F. Rehabilitation**

### **Process**

Rehabilitation facilitates ongoing recovery. Rehabilitation enables a person to become as independent as they possibly can. The goal for the person is to return to their previous abilities, activities and way of life as much as they possibly can. It means enabling the person to live with their remaining abilities and develop strategies to compensate and overcome new difficulties.

The process of rehabilitation experienced by each person is unique. Just as a brain injury is unique, the type of rehabilitation program the person is engaged in is uniquely tailored to target individual needs. Rehabilitation addresses specific areas of physical difficulty, thinking or cognitive processing, perception, social skills and relationships. It also addresses broader areas of returning to work, getting about in the community, and adjusting to changes a person may experience following a brain injury.

Rehabilitation is ongoing; it becomes part of the person's everyday living.

Rehabilitation is something that is done with the person, not to the person.

Rehabilitation is based on working with the person to achieve things that matter to them. Therefore, for it to be successful, the person needs to participate actively in the rehabilitation process. The type of rehabilitation offered needs to be meaningful and relevant to the person. This means the individual, their culture, pre-injury lifestyle, family and environment are critical to ensuring the success of rehabilitation.

The person's abilities will determine how the individual is able to participate in the rehabilitation process.

Integrating back into pre injury activities can start while still an inpatient after a ABI. The person begins to experience the effect of the changes after the brain injury and identify areas they need to improve.

Rehabilitation is most effective when it occurs in the community integrating therapy with everyday living situations.

Understanding changes after ABI can assist the person, the family, therapists and others to set realistic rehabilitation goals and improve outcomes by participation in meaningful goal planning.

### **Pathways**

When a person has an ABI there are many different rehabilitation pathways depending on the cause of the ABI and point in the life span the injury occurred and the person's circumstances. For example:

- An adult with a serious traumatic brain injury could have the following pathway: Hospital Brain Injury Rehabilitation Unit; discharge to supported accommodation; community rehabilitation services
- An adult with a serious stroke could have the following pathway: Hospital Stroke Unit; discharge to family home; community rehabilitation services
- An adult with ABI cause by degenerative diseases could have the pathway: GP; medical specialists; outpatient services; support services in the home; specialist supported accommodation



## G. Common effects of ABI

Common effects of acquired brain injury are:

- Cognitive - thinking skills
- Communication/language
- Physical/sensory
- Emotional/behavioural/personality.

There is overlap and interconnections between these effects.

The specific effects will be unique to each individual and their injury.

The extent of the effects and challenges for the person with brain injury depends on:

- The severity of the ABI
- The location of the brain damage
- The length of time since brain injury
- The extent a person has been able to integrate back into the community
- The support available to the person.

### a) Changes in thinking skills - cognitive

Thinking difficulties are common after an ABI.

Thinking difficulties can have a big impact on everyday life.

Some common thinking difficulties are:

- slower thinking processes
- reduced flexibility in thinking
- memory difficulties
- difficulties learning new information
- attention and concentration problems
- poor planning and organisational skills - executive ability
- poor reasoning and judgement
- difficulties in recognizing objects (changes in visual perception).

### b) Changes in speech, language and communication

The brain controls speech and language. If the parts of the brain responsible for speech and language are damaged there can be difficulties with communication.

The difficulties will depend on the nature and extent of the damage to the brain.

Speech, language and communication difficulties can have a major impact on everyday life.

Some common speech, language and communication difficulties are:

- difficulty understanding what is said to you
- difficulty finding the words you are looking for
- difficulty in moving and coordinating the muscles used for speaking.

In addition cognitive difficulties such as memory problems, information processing problems and control problems impact on language and communication.

### c) Changes in physical functioning

Our body functions are controlled by our brain.

After a severe ABI motor difficulties, swallowing difficulties, sensory deficits, loss of bladder and bowel control and epileptic seizures are common.

After a severe ABI there can be difficulties with movement.

Dizziness, headaches and fatigue also occur after both mild and severe ABI.

There are rehabilitation strategies to help with most of these symptoms.

Some common difficulties are:

- motor/movement problems e.g.
  - o muscle weakness (e.g. weakness on one side of the body, weakness in both legs)
  - o muscle spasticity (e.g. where limbs become stiffer and when you try to move them you can feel resistance and the person with the ABI can feel pain).
- sensory problems e.g.
  - o loss of vision
  - o loss of smell
  - o loss of hearing or ringing in the ear (tinnitus)
- dizziness and balance problems
- pain and headache
- fatigue
- bladder and bowel problems
- epileptic seizures.

### d) Changes in emotions, behaviour and personality

Changes in emotion and behaviour are common after an ABI.

The emotional and behaviour changes are often what families and friends find most difficult to deal with.

The emotional and behaviour changes are both:

- a consequence of the areas of the brain that have been damaged
- the process of dealing with having an ABI and the impact on your life and those around you.

Common emotional reactions to an ABI include:

- depression
- anxiety and fear
- anger
- frustration
- mood swings.

Common behaviour changes include:

- apathy or reduced motivation
- increased irritability
- aggressive behaviour (verbal and/or physical)
- socially inappropriate behaviour
- difficulties relating to others
- restlessness /agitation.

Changes in sexual functioning after an ABI are also common. Sexual functioning involves physical, emotional, social factors all of which can be affected by an acquired brain injury.

### Challenges and difficulties

These common effects of ABI create challenges for people with ABI.

Just as the specific effects will be unique to each individual and their injury, the specific challenges will also be unique to each individual and their injury.

Some common challenges and difficulties are:

- Having difficulty in paying attention
- Being easily confused and overwhelmed
- Having problems in learning new information
- Being slower in processing information
- Difficulty in being able to use their knowledge in new situations
- Experiencing difficulty in keeping up with conversations
- Having difficulty in starting activities
- Experiencing word-finding difficulties
- Having problems in producing or understanding language
- Having problems getting or staying organised
- Having problems in planning
- Fixed in thinking patterns
- Difficulty following the social rules and conventions of communication
- Loss of self-esteem and self-confidence
- Changes in personality, egocentric, outgoing/introverted
- Irritability and “short fuse” / increased anger outbursts (very common) / difficulties in emotional control
- “Before/now” comparisons
- Impaired social and personal coping skills
- Impulsivity
- Sexual disinhibition
- Lack of initiative & drive / apathy, low motivational states
- Adjustment issues-depression, anxiety
- Relationship changes

## **H. Impacts on life and relationships**

The common effects of ABI described above impact on peoples lives and relationships.

People with ABI who look physically well can still have significant and extensive impacts on life and relationships.

### **Work**

Many people are unable to return to the work they had.

For people with severe TBI, a Melbourne study found that only 40% of people were employed at five years post-injury.

### **Leisure pursuits**

Many people either lose all their leisure activities or have to change activities.

A Melbourne study found that at five years post-injury, 63% of people with severe TBI had had to make changes to the sort of leisure activities that they had enjoyed prior to their injuries.

### **Marriage / partner**

Marriage or relationship breakdown are common.

A Sydney study found that at six years post-injury for people with severe TBI, 55% of marriages had broken down. For marriages that do stay together, there can still be a number of changes, for example, the loss of the sexual component of the relationship.

### **Friendships**

Loss of friendships is common.

The Melbourne study found that at five years post-injury for people with severe TBI 50% of people with TBI reported that they had lost friends and become more socially isolated since the injury.

### **Family**

The majority of people with a brain injury are discharged from an acute rehabilitation unit to return to their parents or partners. This often produces enormous changes and stress for the family unit as well as for individual family members.

Many families find it a rewarding experience to provide support for a family member with ABI. However, in other cases, it can be extremely stressful.

Sources of stress can relate to:

- Family members having to give up work, and being financially worse off
- Increased level of conflict due to temper control problems
- Family members (especially partners) having to take on new roles if partner with TBI no longer able to play these roles (e.g. financial manager, home maintenance, disciplinarian with children, etc.)
- Family members who play a caring or support role losing touch with their own social networks, becoming more socially isolated
- Family members experiencing grief or depression mourning for the person "they knew before" the ABI
- Family members experiencing post traumatic stress if they witnessed or were involved in the accident that caused the injury
- Changed relationships with siblings taking on greater responsibilities and needing to be more grown up.

## I. People with an ABI

Some things to keep in mind are:

### Characteristics

People with an ABI:

- Remember they once had all their brain functioning reasonably well. Now they don't
- Cannot recover from these effects with a good night's sleep, a new job or operation
- Work very hard for many years to overcome these effects
- May not fully recover from their brain injury
- Cannot always control themselves like they used to or would like to
- Get frustrated with themselves and take it out on others.

### Challenges

Challenges they face include:

- Lack of community awareness and discrimination
- Changed access to social activities
- Relationship changes
- Attending work and training opportunities
- The need for long term support.

## J. Issues for carers, friends and family members

Issues that carers, friends and family members may have to work through and/or deal with are:

- The extent of personality & behaviour changes
- Changes to accommodation needs
- Managing respite for themselves and their family member with ABI
- Access to social support
- Access to behaviour support
- Understanding and managing mental health issues following ABI
- Involving others in their lives, loss of privacy.

## K. Working with people with ABI: Key messages

When you are working with people with ABI there are ways of approaching the work that have been found to be useful.

They are described in detail in *Handout 3: Approaching Working With people with an ABI: Key Messages*.

The three central ideas are:

- a) Supporting unique individuals to build independence
- b) Working through emotions and relationships - for the person with the ABI, their friends, family members and carers
- c) Working with services.

### **Note 1 : ABI can be a hidden disability**

Acquired brain injury (ABI) is often called a hidden disability because its effects are often not easy to see and recognise, for example effects in areas of thinking and behaviour.

Physical issues can be quite obvious yet it is often the "unseen" changes to the way a person thinks that can pose the greatest difficulties for people with ABI.

People with ABI may be misunderstood and ignored by others as a consequence of the invisibility of their disability. How they act and respond to others can be misinterpreted and not linked to their ABI.

### **Note 2: ABI is different from Intellectual Disability (ID)**

People with ABI and ID can present with similar symptoms and impairment, such as cognitive and sensory difficulties. However, an acquired brain injury can occur at any age after birth, in contrast to an Intellectual Disability, which most commonly exists from birth. What most distinguishes ABI from ID is the fact that most people with an ABI retain their pre-injury intellectual abilities, the injury having merely impaired the expression of these abilities. With treatment and support, most people with an ABI can expect their symptoms to improve and to recover some of their former capabilities through rehabilitation. By contrast, people with an ID are more likely to be involved in habilitation programs (being able to make the most of their current capabilities).

### **Note 3: ABI is different from Mental illness**

A person is said to have a mental illness if an appropriately qualified professional can elicit the necessary symptoms to meet pre-set criteria that diagnose certain conditions (somewhat like using a recipe book). The diagnosis of mental illness is not always a reliable and consistent process, particularly for complicated cases such as patients who have a co-existing intellectual disability, a drug and alcohol problem, or an acquired brain injury.

The relevant point here is that both ABI and mental illness are difficult to diagnose and indeed, like many other medical conditions, often go undiagnosed. The key point of difference is that the symptoms of mental illness are usually treatable with drugs, whereas ABI is not.

ABI is often mistaken for mental illness and people may be treated with drugs that don't help recovery. Depression, for example, may be a normal psychological response in people who experience an acquired brain injury, but may also result from the injury itself.

ABI is however distinct from mental illnesses, such as schizophrenia, bipolar disorder, depression or obsessive compulsive disorder. Treatments for these mental illnesses (most commonly medication and psychological therapy) are very different to the support required by people with ABI. Different health services are involved in managing and treating people with mental illness and severe ABI.

It should be noted however that mental illness, like ABI, can affect a person's cognitive processes. Also, mental health problems such as depression can be significant issues for people with ABI

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  - J. *Issues for carers, friends and family members*  
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  - K. *Working with people with ABI*  
Consultations for [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)
- Notes 1, 2 & 3  
Department of Human Services Victoria

See: [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info) for full details.

## Handout 3 : Working with people with ABI

*Staff working with people with ABI need specific knowledge and skills to help them work appropriately. Working with people with ABI is in some respects quite different to working in aged care, intellectual disability and mental health services. Here are three sets of key messages for working with people with ABI.*

### **A. Unique individuals building independence**

#### **a) Uniqueness of the individual**

All people are unique individuals. Yet the most important message for people working with people with ABI is: people with ABI are unique individuals. The specific effects of ABI on an individual depend on, for example, the severity of the ABI, the location of the brain damage, the length of time since brain injury, the extent a person has been able to integrate back into the community and the support available to the person.

#### **b) Injury- effect - behaviour - support strategies**

People with an ABI have a brain injury. The injury has an effect on the working of the brain. The working of their brain affects their behaviour. People working with people with an ABI have to manage behaviours. The effects of the injury are unique to the person.

#### **c) For many people with ABI - being the proxy for the frontal lobe**

People who have damage to the frontal lobe of the brain often have difficulty with planning, coordinating, getting started, sticking to the task, finishing the task and so on.

One of the consequences of this is that people who have frontal lobe damage need someone to be the proxy for their frontal lobe. They need someone to help them with planning and coordinating, making important decisions. Often this is a family member's role. Sometimes it is the case manager's role.

#### **d) Building independence**

People with an acquired brain injury can grow in their skills for independence in the short and long term (except where the ABI is caused by a degenerative disease). The rate of development can be slow and so not noticed. People give up too soon.

Most people with a traumatic brain injury and many others are young - they have a lot of life ahead of them and plenty of time to develop. People with ABI may need support to manage independent skills for life when they can't maintain a skill on their own.



## **B. Working through emotions and relationships**

### **e) The person with the ABI - the effects of the injury and dealing with the effects of the injury**

A person with an acquired brain injury has had a life before the injury. Unless they are very young when they had the injury they will remember the life they had.

The acquired brain injury may have effected their thinking skills, communication/language, physical/sensory and emotional/behavioural/personality. In addition to experiencing these changes the person with the ABI has to respond to and come to terms with their new life situation. They also have to deal with their family members and friends coming to terms with the changes in them. As with any major life change loss, grief and rediscovery are part of the process.

### **f) Family members**

Family members have also to be able to deal with: the changes in the family member because of the ABI; the responses to the family member in coming to terms with the ABI; their own coming to terms with all of this, and the impact of the change on the family.

Family members have a key role in helping the person with ABI recover. Loss, grief and rediscovery are part of the process.

### **g) Workers - Building relationships and looking after oneself (including self-understanding about handling own stress, what pushes your buttons).**

A key to working with a person with an ABI is building a relationship with them. Working with people with acquired brain injury can be difficult.

- It can be hard to get to know them.
- It can take time to get to know them.
- Behaviours can be difficult to deal with.
- They can be different from other people you have worked with.

Workers need self-understanding about handling their own stress and what pushes their buttons.

### **h) Managers**

Managers of workers working with people with ABI need to understand a key to working with a person with an ABI is building a relationship with them. Working with people with acquired brain injury can be difficult. The difficulties create stress for workers and the stress needs to be managed so it doesn't lead to disillusionment.

### **i) Case managers**

Case managers also need to know a key to working with a person with an ABI is building a relationship with them. Case managers also have to work with the person with the ABI and their family members in the grief process. Case managers also have to change how they do case management to make it appropriate to working with people with ABI.

### **j) Working through grief and loss**

Grief is how we respond when we experience loss. Grief is a normal, natural and inevitable response to loss and it can affect every part of our lives. Working through grief and loss is often part of the process of working with people with ABI. Grief can seem like a roller-coaster ride with ups and downs. It can affect our feelings, thoughts, physical reactions, behaviours and beliefs.

People working with people with ABI need to understand the emotional process of grieving; be prepared to listen and show care and concern and recognise the possibility that grief may not be resolved or be able to be resolved.

## C. Working with services

### k) Pathways for life after an ABI (including rehabilitation, moving into community, etc)

Unique individuals mean that service pathways are unique. At the same time staff need to be aware of typical service pathways; local barriers to pathways and strategies for dealing with pathway barriers.

### l) Case management 'for life' as required

As noted above people who have damage to the frontal lobe of the brain often have difficulty with planning and coordinating, etc. One of the consequences of this is that often people who have frontal lobe damage are also the ones who need ongoing case management. In these situations the case manager's role is to act as their frontal lobe by adding the structure needed to make sense of different situations.

### m) The family, community and support staff are where change happens

Change happens in the day to day. If a person without an ABI goes to see a psychologist a lot of progress can be made in the interview. The person generates their own plans for integrating therapy in day to day life. If a person with an ABI goes to see a psychologist, and they have for example problems with planning, coordinating, memory then they will need additional support for these impairments in order to make progress. The support will be to provide day to day strategies, processes and systems - e.g. putting memory aids in place to enable a person with ABI to integrate the therapy into their everyday life.

### n) Part of a team - who's who - including accessing specialist assessments

Working with a person with an acquired brain injury often means being part of a team. It is important to understand everyone's role. There can be different teams at different stages in the process: acute care staff and family and friends; rehabilitation team; community living team.

### o) Working with the services network

The services network of people with ABI is imperfect. There are some great parts. There are good parts. There are missing parts. The primary drivers for working with the services network are:

- What are the person with ABI's goals?
- What does the person with ABI want/need in order to achieve their goals?

The approach is: Do what it takes - to meet the goals of the person with the ABI

The priorities for services are:

- Generalist services where possible
- Disability services where necessary
- Specialist ABI services where necessary.

# Handout 3A:

## Approaching working with people with an ABI:

### Key messages

#### Contents

##### Introduction

#### A. Unique individuals building independence

- a) Uniqueness of the individual
- b) Injury - effect - behaviour - behaviour management
- c) For many people with ABI - being there as the proxy for the frontal lobe
- d) Building independence

#### B. Working through emotions and relationships

- e) The person with the ABI
  - The effect of the ABI
  - Dealing with the effect of the ABI
- f) Family members
  - Understanding the person with the ABI
  - Rebuilding relationships
- g) Workers
  - Getting to know the person with the ABI
  - Aware of self and one's own responses
- h) Managers
  - Managing stress and the disillusionment process
- i) Case managers
  - Working with others and aware of their own responses
- j) Loss and grief
  - What it is and how to respond

#### C. Working with services

- k) Pathways for life after an ABI (including rehab, moving to community, etc)
- l) Case management 'for life' as needed
- m) The family, community and support staff are where change happens
- n) Part of a team
  - Who's who - including accessing specialist assessments
  - Working as a team
- o) Working with the services network
  - To achieve goals
  - Creatively

**Introduction**

These key messages have been developed in discussions with people working with people with ABI, people with ABI, their family members and friends.

They are the essence of the take home messages that everyone working with a person with an ABI needs to understand.

**A. Unique individuals building independence****a) Uniqueness of the individual**

All people are unique individuals.

Yet the most important message for people working with people with an acquired brain injury is: people with an acquired brain injury are unique individuals.

So what is going on?

When working with people we usually make assumptions:

- If you have the flu you assume that you will have a fever, aches and pains, a week off work ...
- If there has been a bereavement in a family you assume that there will be a grief process possibly including denial, shock, anger ... acceptance...
- If you are working with a person with an intellectual disability you assume that the disability will be maintained for life...

A person with an ABI has a brain injury. What can you assume? Not much.

- People have injuries to different parts of the brain, so the effects of the injury will be different from one person to another
- Even where two people have a similar injury to the same part of the brain the effects can be different
- How people emotionally respond to what has happened to them will be different from one person to the next and the process is not typically linear.

**Rules of thumb**

1. Don't make assumptions:

- When someone slurs their speech or can't speak don't assume they are not thinking well. Question a little deeper.
- When someone presents well and seems to be functioning don't assume they are. Question a little deeper.

2. Get to know the person when they are fresh and when they are fatigued. Get to know them over weeks, months and longer periods.

One worker noted:

*ABI is often a hidden disability. The person seems the same. They look the same as they did before. They may chat for ten minutes and nothing seems to be wrong - but after half an hour the deficits become clear.*

**b) Injury - effect - behaviour - behaviour support**

People with an ABI have a brain injury.

The injury has an effect on the working of the brain.

The working of their brain affects their behaviour.

People working with people with an ABI have to manage behaviours.

**Rules of thumb**

1. Understand:
  - What is the injury?
  - What is the effect?
  - How is the effect expressed in behaviour?
  - What are strategies for managing the behaviours?
2. Get to know the person
3. Get to know what strategies work for this person.

See TOOLS for practical strategies.

**c) For many people with ABI - being the proxy for the frontal lobe**

People who have damage to the frontal lobe of the brain often have difficulty with

- planning
- coordinating
- getting started
- sticking to the task
- finishing the task.

One of the consequences of this is that people who have frontal lobe damage need someone to be the proxy for their frontal lobe. They need someone to help them with planning and coordinating, making important decisions.

Often this is a family member's role. Sometimes it is the case manager's role.

**Rules of thumb**

1. Get to know the person.
2. Understand their cognitive abilities.
3. Identify the scenarios where they are likely to need additional support.
4. Ensure there is a process in place to enable them to get the support when they need it.

### d) Building independence

Quality human services are designed to promote independence. Most government funding accreditation standards and non-profit organisations espouse building independence as a value. So why is building independence a key message for working with people with ABI?

Building independence for people with ABI is not the same as when you are providing services in a disease model, an aged care model, or an intellectual disability model of service.

In a disease model independence is in the context of the known progression of the disease.

In an aged care service independence is in the context of the ageing process.

In an intellectual disability service independence is in the context of a known intellectual disability.

Within the ABI context independence can grow over time - even the long term (except where the ABI is caused by a degenerative disease).

Building an independent life will include (where possible) working on:

- work
- leisure
- finances and
- legal implications.

Rehabilitation is the process of building independence.

#### *Rules of thumb*

1. People with an acquired brain injury can grow in their skills for independence in the short and long term (except where the ABI is caused by a degenerative disease).
2. The rate of development can be slow and so not noticed. People give up too soon.
3. Most people with a traumatic brain injury and many with other forms of ABI are young - they have a lot of life ahead of them and plenty of time to develop.
4. People with an ABI often have some very good skills in some areas but very poor skills in other areas.
5. People with ABI may need support to manage independent skills for life when they can't maintain a skill on their own.

## B. Working through emotions and relationships

### e) The person with the ABI - the effects of the injury and dealing with the effects of the injury

A person with an acquired brain injury has had a life before the injury. Unless they are very young when they had the injury they will remember the life they had.

The acquired brain injury may have effected their:

- thinking skills - cognitive
- communication/language
- physical/sensory
- emotional/behavioural/personality.

In addition to experiencing these changes the person with the ABI has to respond to and come to terms with their new life situation.

They also have to deal with their family members and friends coming to terms with the changes in them.

As with any major life change loss, grief and rediscovery are part of the process.

However it is not a neat linear emotional process that everyone works through in a given time.

#### **Rules of thumb**

1. Understand the injury, its effects and effects on behaviour including social changes
2. Understand the individuals and family responses in dealing with this change
3. Understand the individual person and their life goals prior to the ABI.

### f) Family members

Family members have also to be able to deal with:

- the changes in the family member because of the ABI
- the responses to the family member in coming to terms with the ABI
- their own coming to terms with all of this, and
- the impact of the change on the family.

Family members have a key role in helping the person with the ABI recover.

Some of the key challengers for family members are:

- understanding the injury and its effects
- understanding the hospital and services network
- coping with the person with the ABI and the ways they have changed
- adjusting to family role and relationship changes
- managing and dealing with the practical problems that need to be solved day to day
- supporting family members and friends in dealing with what's happened and what's happening
- supporting and planning for the future.

The emotional process for family members is not linear with a series of pre-known phases. It is more like:

- a roller coaster
- a struggle
- working on the unexpected
- moving forwards and having setbacks.

Some of the elements in the mix of what's happening are:

- shock
- numbness
- guilt
- denial

- anxiety
- anger
- frustration
- emotional relief
- depression
- grief and
- acceptance.

Some strategies that can help:

- sharing the experience with others who have had first hand experience of this
- work closely with the members of the team
- acknowledge there will be constant change
- develop strategies for dealing with the day to day
- develop strategies for your own well being
- recognising the different issues for different family members - mother, family, spouse, brother, sister and children.

### **Rules of thumb**

1. Understand the impact of the ABI on the person with the ABI.
2. Understand the impact on the family.
3. Be aware of the family's need to develop strategies for working on the changes that have happened.
4. Be aware of the family's need to develop strategies to sustain themselves.
5. Be aware of the family's need to develop services and networks to support goals.

### **g) Workers - Building relationships and looking after oneself (including self-understanding about handling own stress, what pushes your buttons).**

A key to working with a person with an ABI is building a relationship with them.

As noted earlier it is important to not make assumptions. Working with people with acquired brain injury can be difficult.

- It can be hard to get to know them
- It can take time to get to know them
- Behaviours can be difficult to deal with
- They can be different from other people you have worked with.

As one worker put it.

*Everyone is different. Everyone has got different problems and everyone has got different attitudes and you never try and make any judgment. Basically you try to accept them as they are and deal with it.*

*At first it takes a while for them to trust you. That's the biggest issue. They tend to become a bit aggressive at first, or shy away from you, don't want to know. Sometimes they don't even want to listen to you. And that's a big problem because that kind of puts you on the back step to try to help them... especially if you are new.*

Working with people with ABI can be challenging. Workers have to understand what pushes their buttons so they can develop strategies to respond appropriately.

As one worker put it:

*I think the biggest challenge for me at first was when they become abusive. And sometimes it becomes very personal. And it is hard to kind of ignore it because there are a lot of bad words thrown around at you, they might become more aggressive and push you or they might decide to ignore you or yell at you or even in public is another big issue where they have become very aggressive in public and they might even embarrass you.*



*And it makes it very hard to deal with. You have to not take it personally. I think it is basically that you just kind of click off and just accept he's got a brain injury and don't worry about what other people think, just focus on him, and it usually goes all right.*

### **Rules of thumb**

1. Take time to get to know the person and their uniqueness.
2. Understand the connections between the injury, effect on their brain and effect on their behaviour.
3. You don't have to take behaviours personally.
4. Understand what pushes your buttons and develop strategies for dealing with this.
5. Understand your role with the person with ABI.
6. Identify your professional support network.

### **h) Managers**

Managers of workers working with people with ABI need to understand a key to working with a person with an ABI is building a relationship with them. Working with people with acquired brain injury can be difficult.

- It can be hard to get to know them.
- It can take time to get to know them.
- Behaviours can be difficult to deal with.

The difficulties create stress for workers and the stress needs to be managed so it doesn't lead to disillusionment.

One manager said:

*I think that the challenge is the unpredictability. Because you can work with one person one day and the next day it can be a totally different scenario and that's due to their injury, the nature of their injuries. So it can be the littlest thing that has changed for them that has totally upset them. So from day to day you don't quite know what you are walking into and how you can best support your client.*

### **Rules of thumb**

1. Be clear on what good management and supervision of staff entails,
2. Be aware of the disillusionment process,
3. Take steps to prevent stress for workers so the disillusionment process does not set in.
4. Understand what pushes your buttons and develop strategies for dealing with this.

### **i) Case managers**

Case managers also need to know a key to working with a person with an ABI is building a relationship with them. Working with people with acquired brain injury can be difficult.

Case managers also have to work with the person with the ABI and their family members in the grief process.

Case managers also have to change how they do case management to make it appropriate to working with people with ABI. They are also often involved in other services changing their work practices in order to provide a better service for people with ABI.

Changing one's own work practices and processes and practices of one's own and other organisations can be challenging.

Case managers need self-understanding about handling their own stress and what pushes their buttons.

One case manager said:

*What's the big thing that you have learned in the last six months in changing to case manager?*

*The biggest thing is to help maintain my stress levels and to be patient. To be more supportive to the other service coordination managers, the support workers and work as a team, because it is a big effort. You have got to rely on each other.*

**Rules of thumb**

1. Take time to get to know the person and their uniqueness.
2. Understand the connections between the injury, effect on their brain and effect on their behaviour.
3. You don't have to take behaviours personally.
4. Understand what pushes your buttons and develop strategies for dealing with this.
5. Understand your role with the person with ABI.
6. Understand how case management has to be different with people with ABI.
7. Identify your professional support network.

**h) Loss and grief**

Grief is how we respond when we experience loss. Grief is a normal, natural and inevitable response to loss and it can affect every part of our lives.

Grief can seem like a roller-coaster ride with ups and downs, or it may feel like we are being battered about like a little boat in a storm. Sometimes it can seem overwhelming and frightening. Grief allows us to gradually adjust to our loss and find a way of going on with our life. Everyone experiences grief in their own way. There is no 'correct' way to grieve, and no way to 'fix it'.

**Feelings** – We may experience intense feelings such as shock, chaos, sadness, anger, anxiety, disbelief, panic, relief, or even numbness.

**Thoughts** – We may experience confusion and find it difficult to concentrate.

**Physical reactions** – Sometimes we may have trouble sleeping. Grief can also lead to physical symptoms such as tiredness, loss of appetite, nausea or pain.

**Relationships** – Relationships can be affected. Sometimes we will be preoccupied or tense, or feel disinterested in other people and things.

**Behaviours** – We may experience lethargy or overactivity, pay little attention to self care, sleep a lot, desire to resort to alcohol or non-prescribed drugs and other potentially harmful behaviours.

**Beliefs** – Our beliefs about life may be challenged. Often grieving people wonder why this has happened to them.

**Helping others**

No one can take away the pain and sadness of grief, but knowing that people care is comforting and healing for grieving people. You cannot fix it, but you can help.

Here are some suggestions for things that might help:

- keep in touch and be prepared to just listen
- be open in showing your concern and care.

Sometimes people with ABI are not able to resolve their grief.

**Rules of thumb**

1. Understand the emotional process of grieving.
2. Be prepared to listen and show care and concern.
3. Recognise the possibility that grief may not be resolved or be able to be resolved.

## Working with services

### i) Pathways for life after an ABI (including rehab, moving into community, etc)

Unique individuals mean that service pathways are unique.

At the same time staff need to be aware of:

1. typical service pathways
2. local barriers to pathways
3. strategies for dealing with pathway barriers.

In 2008, an Interagency Agreement was signed between Ageing, Disability and Home Care (ADHC), NSW Health, Housing NSW and the Lifetime Care and Support Authority (LTCS). The purpose of the Interagency Agreement was to improve equity of access in the interface between health, housing and support services to meet the needs of people with ABI in the community.

A Pathways and Protocols Working Group comprising members from each of the inter-agency partners was convened to identify appropriate referral pathways and related issues for an adult with an ABI moving through health, disability and community services. This work has produced *"Care and Support Pathways for People with an Acquired Brain Injury, Referral and Service Options in NSW"*.

This document includes 7 Example pathways and detailed information about all of the services mentioned in the example flow charts.

The seven pathway examples are:

- 1: Person with a recent ABI requiring housing and support
- 2: Person with a recent TBI requiring support up to 35 hours/week
- 3: Person with a previous TBI/ABI with drug/alcohol or mental health issues
- 4: Person with TBI/ABI with challenging behaviours
- 5: Person with previous TBI/ABI exiting prison system
- 6: Applicant or existing tenant of Housing NSW with a diagnosed or undiagnosed ABI/TBI
- 7: Person with TBI/ABI requiring formal support for more than 35 hours per week

The document also includes referral and service options in NSW.

People who sustain injuries in motor vehicle accidents (MVA) may have access to compensation (Workcover, LTSCA). This can increase service options and needs to be considered when planning service support.

#### **Rules of thumb**

1. Be familiar with the pathway examples.
2. Identify referral contacts and access options.
3. Identify local barriers.
4. Identify strategies for dealing with pathway barriers.
5. Liaise with insurers when they are involved.

### **j) Case management 'for life' - case management is - more or less - episodic or continuous - depending on what's required**

As noted above people who have damage to the frontal lobe of the brain often have difficulty with planning and coordinating.

One of the consequences of this is that often people who have frontal lobe damage are also the ones who need ongoing case management. In these situations the case manager's role is to act as their frontal lobe by adding the structure needed to make sense of different situations.

One case manager noted:

*When everything is running smoothly the person can seem to be functioning well. They may hold down a job, be able to get themselves to and from work. But if their job role were to change or if they had to decide whether or not to sell a property they are no longer able to cope. Case management is needed at this point.*

Many people with an acquired brain injury and particularly those with frontal lobe damage will effectively require case management for life. In these situations case management is often not continuously required. It is required from time to time when planning, coordinating, decision making are required during periods of transition or change in circumstances (e.g. change of job, death of a carer).

#### **Rules of thumb**

1. Get to know the person. Build trust and understanding. See how they are when they are fatigued and upset.
2. Identify the kinds of situations where case management will be required.
3. Ensure the person has ease of access back to case management if these kinds of situations arise.

### **k) The family, community and support staff are where change happens**

Change happens in the day to day.

If a person without an ABI goes to see a psychologist a lot of progress can be made in the interview. The person generates their own plans for integrating therapy in day to day life.

If a person with an ABI goes to see a psychologist, and they have for example problems with planning, coordinating, memory then they will need additional support for these impairments in order to make progress. The support will be to provide day to day strategies, processes and systems - e.g. putting memory aids in place to enable a person with ABI to integrate the therapy into their everyday life.

Professionals working with people with ABI have an additional aspect to their work - identifying how to embed in the day to day what's required and liaising where appropriate with other people working with the person with ABI to make it happen.

#### **Rule of thumb**

1. Ask yourself:
  - What changes need to be put in place to enable change to happen in the day to day?
  - What ongoing support is needed to maintain the changes?
  - Who else needs to be involved in this?

**I) Part of a team - who's who - including accessing specialist assessments**

Working with a person with an acquired brain injury often means being part of a team. It is important to understand everyone's role.

The nature of the team can change over time with the stage of the rehabilitation process:

*Stage 1: Acute rehabilitation*

This acute stage involves initial management to ensure the person is medically stable in the Intensive Care Unit and high dependency wards. Acute rehabilitation normally occurs within hospital with a strong focus on physical recovery and regaining independent living skills.

**The Team:** Acute care staff and family and friends

*Stage 2: Post-acute rehabilitation/community re-settlement*

This stage involves managing the transition from hospital back home, and the ongoing process of rehabilitation that occurs after discharge. The focus of rehabilitation at this stage may include return to work or study, finding alternatives where this is not possible and relearning skills for community living.

**The Team:** Rehabilitation team

*Stage 3: Social rehabilitation*

This is the long-term rehabilitation aimed at maintaining and enhancing the level of participation in community life that people with ABI can achieve over their life span (community integration).

**The Team:** Community living team

**The Rehabilitation Team members**

In addition to family and friends some of the common roles are:

- Rehabilitation Specialists
- Nurses
- Case Managers
- Physiotherapists
- Social Workers
- Occupational Therapists
- Neuropsychologists
- Clinical Psychologists
- Recreation Officers
- Speech Pathologists
- Residential Care Staff

The rehabilitation team's primary responsibility is to the individual who has the brain injury. They are working with this individual to achieve his or her goals. The extent the brain injury has limited that person's ability to make informed decisions is determined by the Team through the assessments and observations conducted.

If the Team feels the individual is not able to understand the complexities of the information being given in order for a decision to be made, they will approach another who is perceived to make decisions that are in the best interest of the person who has the brain injury. This may be a family member or a close friend. If it appears there is conflict or discrepancies in what different people feel is most appropriate for that person, the rehabilitation team may consider making an application for an independent decision-making body. An application may be made to the **Guardianship Tribunal**. A substitute decision-maker may be appointed in areas of accommodation, medical and dental management, finances and service utilisation. If no family person is identified as suitable then a **Public Guardian** or **Estate Manager** can be appointed.

### Rules of thumb:

1. See yourself as part of a team - not just the team in your organisation but part of a team of all the people involved with the person with ABI.
2. Identify the people in this team
  - For example if the person has just come through acute hospital care the team will include the rehabilitation team.
  - If the person has been living in the community for many years the team may primarily include local community service providers.
3. Understand others roles.
4. Connect with other members of the team when you need to.

### m) Working with the services network

The services network of people with ABI is imperfect. There are some great parts. There are good parts. There are missing parts.

The primary drivers for working with the services network are:

- What are the person with ABI's goals?
- What does the person with ABI want in order to achieve their goals?

The approach is:

- Do what it takes - to meet the goals of the person with the ABI.

The priorities for services are:

- Generalist services where possible
- Disability services where necessary
- Specialist ABI services where necessary.

When thinking about generalist services think broadly, for example:

- Centrelink
- Schools
- TAFE
- GPs
- Recreation services
- Self help groups
- Local service clubs (for outings and social contact).

In working creatively and flexibility with services

- Discuss the possibilities with others who have experience
- Enlist family and friends.

A useful resource:

- "Care and Support Pathways for People with an Acquired Brain Injury, Referral and Service Options in NSW".

### Rules of thumb

1. Keep the person with the ABI's goals and wishes to the forefront of working with the services network.
2. Understand how the services network can support the person with ABI achieve their goals.
3. Aim for generalist services where possible and then disability or ABI specialist services where necessary.
4. Know the local services network.
5. Be prepared to work creatively and encourage others to work creatively.

Sources:

Consultations for [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)

See: [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info) for full details.

# Handout 4: Working with people with ABI

## Practical strategies

### A. Changes after an ABI

The person with an ABI is both the same person they were before and also a different person. The ways in which they are different vary from one person to the next. People with an ABI can have changes in:

1. thinking skills - cognitive
2. communication / language
3. physical / sensory functioning
4. emotions, behaviour and personality.

People with an ABI and people living and working with people with an ABI may need to develop strategies to deal with these changes.

### B. Practical strategies for working with people with ABI

#### a) Information and referral workers

Two common situations information and referral workers and others need to address are:

- a) If you don't know the person has an ABI what should you be alert to that may indicate an ABI
- b) If you do know the person has an ABI and there are communication difficulties - what are some conversation tips.

For practical tips see for example:

TOOL 1: Open to the possibility a person has an ABI

TOOL 2: Conversation tips

#### b) Support workers

Two common situations for support workers are:

- a) Building rapport with people with ABI and
- b) Dealing with behaviours arising from cognitive impairments.

For practical tips see for example:

TOOL 2 : Conversation tips

TOOL 4: Strategies for dealing with specific cognitive changes.

#### c) Program staff

Program staff can have three common situations:

- a) If you don't know the person has an ABI what should you be alert to that may indicate an ABI
- b) If you do know the person has an ABI and there are communication difficulties - what are some conversation tips?
- c) If you know the person has an ABI what do you need to know to help understand the person and their needs?

For practical tips see for example:

TOOL 1 : Open to the possibility a person has an ABI

TOOL 2 : Conversation tips

TOOL 3 : Looking for indicators of ABI

### **d) Case managers**

There are different models of case management.

ADHC has two types of case management services - one offered through HACC services and the other through ADHC Disability Funding.

It is important for case managers to understand their own model and other's models of case management.

When case managers are working with people with ABI it is useful in setting goals and developing individual program plans to be aware of:

- the range of issues that may need to be considered in setting goals and developing plans
- the sources of information that are available that may help set goals and develop plans
- the elements of an individual program plan
- tips for setting goals for people with ABI.

See for example:

TOOL 5: Case manager's issues checklist

TOOL 6: Sources of information to assess needs

TOOL 7: Individual program plan

TOOL 8: Tips for setting goals.

### **e) Managers**

Where the staff are working with people with ABI two interconnected issues that managers need to be particularly aware of are:

- The disillusionment process that can happen when staff are working with people with ABI
- Preventing stress

as these are common issues for support staff working with people with ABI.

These issues need to be addressed through having good management and supervision practices.

See for example:

TOOL 9: Managing and supervising staff

TOOL 10: Working with ABI: the Disillusionment process

TOOL 11: Preventing stress

### **f) All staff**

TOOL 12: Essential survival tips for working with people with ABI.



# Handout 4A: Working with people with ABI

## Practical strategies

### Contents

#### A. Changes after an ABI

Cognitive  
Communication/language  
Physical/sensory  
Emotional/behavioural/personality

#### B. Practical strategies for working with people with ABI

- a) General
- b) Information and referral workers
- c) Support workers
- d) Program staff
- e) Case managers
- f) Managers

### TOOLS

TOOL 1 : Open to the possibility a person has an ABI  
TOOL 2 : Conversation tips  
TOOL 3 : Looking for indicators of ABI  
TOOL 4 : Strategies for dealing with specific cognitive changes  
TOOL 5 : Case manager's issues checklist  
TOOL 6 : Sources of information to assess needs  
TOOL 7 : Individual program plan  
TOOL 8 : Tips for setting goals  
TOOL 9 : Managing and supervising staff  
TOOL 10: Working with ABI : The disillusionment process  
TOOL 11: Preventing stress  
TOOL 12: Essential survival tips for people working with people with ABI

Sources:

[www.TBIStaffTraining.info](http://www.TBIStaffTraining.info) Modules 1 to 8 and Working Together Promoting Independence

Consultations for [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)

## A. Changes after an ABI

The person with an ABI is both the same person they were before and also a different person.

The ways in which they are different vary from one person to the next.

People with an ABI can have changes in:

- thinking skills - cognitive
- communication / language
- physical / sensory functioning
- emotions, behaviour and personality.

People with an ABI and people living and working with people with an ABI may need to develop strategies to deal with these changes.

Some of the kinds of changes and strategies for dealing with them are below.

### a) Changes in thinking skills - cognitive

Thinking difficulties are common after an ABI.

Thinking difficulties can have a big impact on everyday life.

Some common thinking difficulties are:

- slower thinking processes
- reduced flexibility in thinking
- memory difficulties
- difficulties learning new information
- attention and concentration problems
- poor planning and organisational skills - executive ability
- poor reasoning and judgement
- difficulties in recognizing objects (changes in vision perception).

### b) Changes in speech, language and communication

The brain controls speech and language. If the parts of the brain responsible for speech and language are damaged there can be difficulties with communication.

The difficulties will depend on the nature and extent of the damage to the brain.

Speech, language and communication difficulties can have a major impact on everyday life.

Some common speech, language and communication difficulties are:

- difficulty understanding what is said to you
- difficulty finding the words you are looking for
- difficulty in moving and coordinating the muscles used for speaking.

In addition cognitive difficulties such as memory problems, information processing problems and control problems impact on language and communication.

**c) Changes in physical functioning**

Our body functions are controlled by our brain.

After a severe ABI motor difficulties, swallowing difficulties, sensory deficits, loss of bladder and bowel control and epileptic seizures are common.

After a severe ABI there can be difficulties with movement.

Dizziness, headaches and fatigue also occur after both mild and severe ABI.

There are rehabilitation strategies to help with most of these symptoms.

Some common difficulties are:

- motor/movement problems e.g.
  - muscle weakness (e.g. weakness on one side of the body, weakness in both legs)
  - muscle spasticity (e.g. where limbs become stiffer and when you try to move them you can feel resistance and the person with the ABI can feel pain).
- sensory problems e.g.
  - loss of vision
  - loss of smell
  - loss of hearing or ringing in the ear (tinnitus).
- dizziness and balance problems
- pain and headache
- fatigue
- bladder and bowel problems
- epileptic seizures.

**d) Changes in emotions, behaviour and personality**

Changes in emotion and behaviour are common after an ABI.

The emotional and behaviour changes are often what families and friends find most difficult to deal with.

The emotional and behaviour changes are both:

- a consequence of the areas of the brain that have been damaged
- the process of dealing with having an ABI and the impact on your life and those around you.

Common emotional reactions to an ABI include:

- depression
- anxiety and fear
- anger
- frustration
- mood swing.

Common behaviour changes include:

- apathy or reduced motivation
- increased irritability
- aggressive behaviour (verbal and/or physical)
- socially inappropriate behaviour
- difficulties relating to others
- restlessness /agitation.

Changes in sexual functioning after an ABI are also common. Sexual functioning involves physical, emotional, social factors all of which can be effected by an acquired brain injury.

## B. Practical strategies for working with people with ABI

### a) General strategies

The impact of difficulties can be minimised by:

- making changes in the environment
- altering the demands placed on the person with the ABI
- developing specific strategies to respond to specific behaviours - including using a range of simple aids.

Specific strategies can be put in place to manage behaviours arising from cognitive impairments.

See TOOL 4 Strategies for dealing with cognitive changes.

Problem behaviours need to be understood in the light of the cognitive impairment causing the behaviour problem.

A useful checklist for analysing problem behaviour is:

- When does it occur?
- Where does it occur?
- Who does the behaviour occur with?
- Does it start suddenly or build up gradually?
- How long does it last?
- What is the history of the problem?
- What solutions have been tried in the past?
- How are people reacting?

When analysing problem behaviours other factors to consider are:

- Physical factors, ie: excess noise, overcrowding, appropriateness of house or room.
- Are they treated with respect?
- Are they part of the decision making process/do they have choices?
- Are they able to communicate effectively?
- Will they benefit from being taught coping skills, i.e. relaxation etc?

People working with people with ABI also need to look to their own needs.

See TOOL 12: Essential thriving guide - for people working with people with ABI

**b) Information and referral workers**

Two common situations information and referral workers and others need to address are:

- a) If you don't know the person has an ABI what should you be alert to that may indicate an ABI
- b) If you do know the person has an ABI and there are communication difficulties - what are some conversation tips.

For practical tips see for example:

TOOL 1: Open to the possibility a person has an ABI

TOOL 2: Conversation tips

**c) Support workers**

Two common situations for support workers are:

- a) Building rapport with people with ABI and
- b) Dealing with behaviours arising from cognitive impairments.

For practical tips see for example:

TOOL 2 : Conversation tips

TOOL 4: Strategies for dealing with specific cognitive changes

**d) Program staff**

Program staff can have three common situations:

- a) If you don't know the person has an ABI what should you be alert to that may indicate an ABI?
- b) If you do know the person has an ABI and there are communication difficulties - what are some conversation tips?
- c) If you know the person has an ABI what do you need to know to help understand the person and their needs?

For practical tips see for example:

TOOL 1 : Open to the possibility a person has an ABI

TOOL 2 : Conversation tips

TOOL 3 : Looking for indicators of ABI

**e) Case managers**

There are different models of case management.

ADHC has two types of case management services - one offered through HACC services and the other through ADHC Disability Funding.

It is important for case managers to understand their own model and other's models of case management.

When case managers are working with people with ABI it is useful in setting goals and developing individual program plans to be aware of:

- the range of issues that may need to be considered in setting goals and developing plans
- the sources of information that are available that may help set goals and develop plans
- the elements of an individual program plan
- tips for setting goals for people with ABI.

See for example:

TOOL 5: Case manager's issues checklist

TOOL 6: Sources of information to assess needs

TOOL 7: Individual program plan

TOOL 8: Tips for setting goals

**f) Managers**

Where the staff are working with people with ABI two interconnected issues that managers need to be particularly aware of are:

- The disillusionment process that can happen when staff are working with people with ABI
- Preventing stress

as these are common issues for support staff working with people with ABI.

These issues needs to be addressed through having good management and supervision practices.

See for example:

TOOL 9: Managing and supervising staff

TOOL 10: Working with ABI : the Disillusionment process

TOOL 11: Preventing stress

The following tables shows the Tools most relevant to each worker.

TOOL	Information and referral workers	Support workers	Program staff	Case managers	Managers
TOOL 1 - Open to the possibility a person has an ABI	✓	✓	✓	✓	✓
TOOL 2 - Conversation tips	✓	✓	✓	✓	✓
TOOL 3 : Looking for indicators of ABI			✓	✓	✓
TOOL 4: Strategies for dealing with specific cognitive changes		✓			
TOOL 5: Case manager's issues checklist				✓	
TOOL 6: Sources of information to assess needs				✓	
TOOL 7: Individual program plan				✓	
TOOL 8 Tips for setting goals		✓		✓	
TOOL 9: Managing and supervising staff					✓
TOOL 10: Working with ABI: the disillusionment process					✓
TOOL 11: Preventing stress					✓
TOOL 12: Essential survival tips for working with people with ABI	✓	✓	✓	✓	✓

## **Handout 5: Working with people with ABI**

### **Practice wisdom**

This handout includes practice wisdom from people with ABI, their families, friends, carers, support workers program managers and other who work with people with ABI. It has been grouped here to highlight key messages one could give to people with ABI and people working with them.

#### **The person with the ABI**

1. You are the same and you are different.
2. Sometimes the differences are obvious.
3. Other times they are hard to see. Sometimes you are not able to see some of the differences that other people can see.
4. It is difficult to predict the amount of recovery that will occur after an acquired brain injury.
5. Recovery is typically the fastest in the first six months and gradually slows down after that. However improvement can continue for years. (ABI from degenerative diseases progresses differently).
6. The changes you have experienced from the ABI may make it more difficult for you to relate to family and friends.
7. To get on with day to day life it is important to identify issues to be addressed, set goals, work out strategies. You may need help with this.

#### **Family**

1. Having a family member with a brain injury is one of the most serious challenges a family can face.
2. Families cope in many different ways.
3. Learn about acquired brain injury.
4. The person with the ABI will be the same but different.
5. Understanding how they are different is a key part of moving on.
6. The person with the ABI needs to be part of the decision making.
7. Identify specific strategies that help you deal with specific problems (labelling drawers, using memory aids, etc).
8. Creatively find ways around ongoing difficulties and see this as steps towards recovery.
9. You are part of a wider team of people.
10. Sharing information will help with the provision of services.
11. Gains are possible but often slow in coming.
12. All members of the family have needs. Understand your family dynamics and your family's needs.
13. Everyone in the family will go through loss, grief and re-discovery.
14. The process of coping with a family member with an ABI constantly changes.
15. Families often have less stress when they actively try to find solutions to problems than when they avoid the problems trying not to think about it or avoiding dealing with it.
16. Looking after yourself is essential. Notice what forms of practical and emotional support you need and how to get them.
17. Having a break is OK.
18. It is OK to ask.
19. It is OK to complain.
20. Don't get swamped by information - look for useful information when it will be relevant to you.



## Friends

1. The person with the ABI needs friends.
2. It is easy for friends to drop away because they no longer understand the person with the ABI.
3. The person with the ABI will be the same but different.
4. Understanding how they are different is a key part of moving on.
5. Understand what the future is for this person.
6. What do I need to know to understand how to relate with my friend now.
7. The person with the ABI needs to be part of the decision making.
8. You are not alone with this experience.
9. You are part of a wider team of people.
10. Friends go through grief, loss and re-discovery of their friendship.
11. Sometimes social boundaries can be crossed, stepping across previous boundaries - friends - sexual boundaries.
12. Be clear about your friendship and the degree of commitment that's realistic for you to stay connected with this person's life - visiting once a week, once a month, define what you do together, etc.
13. How can you support this person to be connected into the wider community?

## Support workers

1. Have some general knowledge about ABI.
2. Know some key messages:
  - Uniqueness of the individual
  - Injury - effect - behaviour - behaviour support
  - Time line for progress of an ABI
  - The plan for the client - part of a team
  - The services network.
3. Know this person as an individual - understand their new uniqueness.
4. Flexibility in the role - and problem solving ability - how do I best manage?
5. Understanding triggers to behaviour.
6. Be attuned to managing your self, and your own emotions when working with people with ABIs - e.g. working with clients your own age or a client the same age as your children can be very difficult.
7. Keep expectations realistic - it is easy to be unrealistic.
8. Look for the gradual changes over time.
9. Be part of a team - professionals, family, friends, community.
10. Just because you can't see or hear a problem doesn't mean there isn't one.
11. Be sensitive to religious, cultural and language differences - e.g. a Muslim person with sexualised behaviours - not something the family had to cope with before; e.g. If English is a second language that may be significantly effected - it may be better to speak to them in their first language. Engage an interpreter.
12. What is the one page summary of what I need to know to work with this client?

## Information and referral workers

1. Have some general knowledge about ABI.
2. Know some key messages:
  - Uniqueness of the individual
  - Injury - effect - behaviour - behaviour management
  - Time line for progress of an ABI
  - The plan for the client - part of a team
  - The services network.
3. A person with an acquired brain injury has had a life before the injury. Unless they are very young when they had the injury they will remember the life they had. Grief and loss will be part of the process of rebuilding their life. Family members also have to work through this.
4. When taking queries the essence of approaching a good response is to:
  - a) not make assumptions and
  - b) ask specific questions to tease out what is happening and
  - c) gather more information at a later time and/or from others if necessary
  - d) pick the parts of the issue that can be worked on and follow up on those.

Ask specific questions. For example:

What's going wrong?  
 Have you got anyone coming now?  
 Who pays for them?

Don't make assumptions. For example:

It may be that he is getting the cleaning but he is not letting them clean.  
 Just because the person thinks they need more workers doesn't mean that is the answer.

Get more information at a later time from him or another person. For example:

What about you go away and write down what the problems are and ring me again.  
 Who lives with you? Can I talk to them about this?

5. Sometimes people with ABI can be abusive or aggressive or difficult to relate to in other ways. I need to not take this personally.

## Case managers

1. It can be hard to get to know people with ABI - I need to give myself the time I need to do this. I need to get to know them both when they are fresh and when they are fatigued. I need to get to know them over weeks, months and longer periods of time.
2. A person with an acquired brain injury has had a life before the injury. Unless they are very young when they had the injury they will remember the life they had. Grief and loss will be part of the process of rebuilding their life. Family members also have to work through this.
3. Sometimes people with ABI can be abusive or aggressive or difficult to relate to in other ways. I need to not take this personally.
4. Gains with ABI clients can be slow in coming - I need to make sure I don't give up too soon. Or get caught in the disillusionment process.
5. In working with services I need to have an approach of: Do what it takes to get the person with the ABI's goals met.

6. See yourself as part of a team - not just the team in your organisation but part of a team of all the people involved with the person with ABI. Identify the people in this team - professionals, family, friends, community.
7. The priorities (in order of priority) for services are:
  - a) Generalist services where possible
  - b) Disability services where necessary
  - c) Specialist ABI services where necessary.
8. Changes for people with ABI happens in the day to day. Ask yourself: What changes need to be put in place to enable change to happen in the day to day for this person?
9. Service providers are often not flexible enough for the needs of people with ABI. I will need to advocate on the behalf of people with ABI for services to be more flexible and change their policies to make them more appropriate. I may need to be ready for some fights.
10. For people with frontal lobe damage case management may be episodic as needed for life - e.g. as major decisions are needed or significant change happens someone may need to be the proxy for the frontal lobe for this person - and this may be the case manager.

## **Managers**

1. People with ABI are unique.
2. Working with them is about building independence.
3. To work with people with ABI workers need to understand each person's injury, the effect, the effect on behaviour and the strategies that can be used to manage the behaviour.

A person with an acquired brain injury has had a life before the injury. Unless they are very young when they had the injury they will remember the life they had. Grief and loss will be part of the process of rebuilding their life. Family members also have to work through this.
4. Working with people with ABI is being part of a bigger team. It is important to know who is in the team - professionals, family, friends, community.
5. Working with people with ABI can be stressful.
6. A common problem is where workers expectations are too high and the disillusionment process sets in. The disillusionment process moves through the following five phases:
  - Enthusiasm
  - Stagnation
  - Frustration
  - Apathy
  - Staff members leave with negative experience
7. Some of the strategies for preventing the disillusionment process from setting in are:
  - Realistic expectations for the client
  - Staff understanding of ABI generally
  - Staff understanding each clients ABI: injury - effects - behaviour - strategies
  - Staff training with the skills to manage the behaviours for each of the clients they work with.

## **Handout 6 : Building knowledge & skills and service capacity**

*Staff working with people with ABI need specific knowledge and skills to help them work appropriately. The service network also needs the capacity to work effectively with people with ABI.*

### **Building individual knowledge and skills**

There are many roles in working with people with ABI including information and referral staff, support workers, program staff, case managers and managers.

*All staff need:*

- a) **An introduction to ABI**
- b) **An introduction to appropriate ways of working with people with ABI**

There are on-line self-study modules available for each of these topics on the web site [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)

*Staff with specific roles may need additional skills, for example:*

Information and referral staff - conversation skills & being open to the possibility a person may have an ABI

Support workers - strategies for managing specific behaviours, communication skills, skills for building independence

Program staff - strategies for managing specific behaviours

Case managers - making case management appropriate for people with ABI and goal setting for people with ABI

Managers - skills in identifying and managing the disillusionment process that can happen with support staff working with people with ABI.

There are on line learning materials available for these and other topics. There are also self-study modules available on many topics for example building independence, communication, mobility, management. Links to these learning resources are available from [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)

**Questions:** What knowledge and skills do I need for my role? What are the learning opportunities available for me to gain this knowledge and skills?

### **Building knowledge and skills in the workplace**

While staff have some individual responsibility for building their own knowledge and skills workplaces are also responsible and need processes and systems in place for example:

Staff meetings

Staff development forums

Supervision

Participation in interagency meetings

Training workshops

There are links to learning resources that can be used in these situations available from [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)

**Questions:**

How can we embed relevant knowledge and skills in our workplace?

What processes and systems need to change to more appropriately provide services to people with ABI?

## Building capacity in the services sector

The services network of people with ABI is imperfect. There are some great parts. There are good parts. There are missing parts. The primary drivers for working with the services network are:

- What are the person with ABI's goals?
- What does the person with ABI want in order to achieve their goals?

The approach is: Do what it takes - to meet the goals of the person with the ABI

Local services need to work together to appropriately meet the needs of people with ABI.

### Questions:

What are the local service network issues in working with people with ABI?

What could be done locally to address these issues?

## Resources at [www.ABIstafftraining.info](http://www.ABIstafftraining.info)

There are a wide range of resources at this web site. The structure of the web site and resources is:

### Self Study Modules

1. Introduction to ABI
2. Working with ABI

### ABI, People and practicalities

3. Types of ABI
4. People with ABI
5. Practical strategies
6. Practice wisdom

### Case management and services

7. Case management
8. Services network
9. Tools for services

### Building knowledge

10. Building skills
  - Understanding ABI
  - Support worker skills
  - Case managing skills
  - Staff managing skills
11. Workplace learning
  - Orientation
  - Team meetings
  - Supervision
  - Workshops
12. For reference
  - Fact sheets
  - Videos
  - Books
  - Organisations

## **B. Worksheets**

There are five worksheets that can be used in staff meetings, staff development sessions and training workshops.

They are available as PDFs from the web site [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info).

### **Worksheet 1 : Check what you know**

This is a one page test to check what a person knows about ABI.

It is a starting point for discussion, not a comprehensive test.

### **Worksheet 2 : ABI Questions in the workshop**

This is a worksheet for use in a workshop. It asks key questions that will be used throughout the workshop and provides space for people to record their responses to the key questions.

### **Worksheet 3 : Case study**

#### **Worksheet 3A : Case study : Suggested answers to some questions**

Worksheet 3 is a case study and questions for use in a staff development session or workshop.

Worksheet 3A is discussion points for the facilitator to use in the discussion of the answers to the questions in Worksheet 3.

### **Worksheet 4 : Improving working with people with ABI : Learning and service network issues**

This is a Worksheet for use in a staff development session or workshop.

### **Worksheet 5 : Working with people with ABI ... Can you?**

This is a checklist of competences needed by staff who are working with people with ABI.

It is a list to help identify what areas a person feels competent in. It is not a comprehensive test of their competence.

# Worksheet 1: Check out what you know

1. What are two essential ingredients of Acquired Brain Injury?
  - Cognitive impairment
  - Injury to the brain
  - Impairment of brain functioning
  - Permanent impairment
  - Stroke
2. What is the most common cause of acquired brain injury for people 18 to 25 years?
  - Trauma  Stroke  Alcohol related  Anoxic / Hypoxic  Degenerative disease
3. What is one of the frontal lobe's primary functions?
  - Sensation  Language  Breathing  Vision  Planning & coordination
4. What are two causes of stroke?
  - Blow to the head  Blocked artery  Toxins
  - Internal bleeding  Breakdown of myelin
5. ABI can be mild, moderate, severe, very severe. A person with a mild brain injury could be someone who has good physical recovery and is able to go back to previous work. What percentage of people with a mild ABI experience lifetime problems with living and learning?
  - 0%  10%  20%  30%  40%  Half  Two-thirds  90%
5. Rehabilitation aims to facilitate ongoing recovery. Rehabilitation enables a person to become as independent as they possibly can. Where does rehabilitation take place?
  - Hospital acute beds  Specialist rehabilitation services  Hospital general beds
  - In community services  At home  Generalist rehabilitation services
6. Common effects of Acquired Brain Injury include: Cognitive; Communication/language; Physical/sensory; Emotional/behavioural/personality. Which of the following are cognitive effects:
  - difficulty paying attention  muscle control difficulties  paralysis
  - loss of sense of smell  reduced memory  dizziness
7. For people with ABI what are two examples of:  
Brain injury - effect - impairment - behaviour - behaviour support strategy
8. Which of the following are good rules of thumb?
  - People with an acquired brain injury can grow in their skills for independence in the short and long term (except where the ABI is caused by a degenerative disease).
  - The rate of improvement can be slow but is easy to see.
  - Understand the injury, the impairment and effects on behaviour
  - Take behaviours personally
  - When working with the services network work creatively and do what it takes to meet the goals of the person with the ABI
9. If you are working on reception or an information and referral role and you don't know the person has an ABI what strategies will be useful in talking with clients/potential clients?
10. If you do know the person has an ABI what are five things it would be most helpful to know to help understand the person with the ABI and the impact of the ABI?

## Worksheet 2 : Questions in the Workshop

1. What are your questions around ABI?

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2. What are your challenges around ABI?

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3. What do you want from the workshop?

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4. Check what you know

Worksheet 1

5. Understanding the key messages - How would I change the way I work?

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6. Understanding the key messages - How would we in our organisation change the way we work?

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7. What are practical strategies I could find useful?

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8. What do I need to learn? How can I learn it?

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9. How can learning be embedded in our workplace? What needs to happen?

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10. What are the local service network issues?

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11. What could be done to address them locally?

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# Worksheet 3 : James: Case study and practical strategies

## James

James is 28 years old and sustained a traumatic brain injury following an assault. He participated in a 3-month inpatient rehabilitation program at a Brain Injury Unit in a hospital. As a result of his injury, James has weakness down his left side, making it difficult for him to walk long distances or carry heavy objects. James also has difficulty planning and organising his time. Often on the ward in the hospital he became frustrated because he couldn't seem to get to his appointments on time.

It is now eight weeks since James's discharge. He has returned to live in his two-bedroom unit. He is living alone and receiving carer support for main meal preparation and heavy household cleaning tasks. James has been finding that he is tired all the time and that he is not managing to get on top of all the household chores. He is finding this very frustrating and is often having aggressive outbursts due to this frustration.

James also has difficulty remembering exactly what he has done during the week and what appointments he needs to attend. This often makes it difficult when James meets up with friends who inevitably ask, "what have you been doing lately?" It also means that he has to be extremely careful that he doesn't double-book himself.

James has parents and a sister who regularly keep in touch with him.

## The questions

Think about how you might assist James to manage and to live independently.

Choose one or more of the roles below and answer the respective questions.

### Support workers

1. Identify the skills and tasks that James has difficulty with.
2. What are some of the strategies you might use to help James to manage these difficulties?

### Information and referral workers

3. James rings your service up wanting additional support for cleaning in the home? How do you respond?
4. James' parents ring up wanting to know what services are available to help James with his frustration and anger. How do you respond?

### Program staff

5. James has started to attend your social activities program. He often misses his appointments. When he does come he gets frustrated easily and makes other participants uncomfortable. What do you do?

### Case managers

6. James' case has been referred to you. You are to work with James to develop a plan for the next 12 months. What are the sources of the information you need?
7. What services in your area would be relevant for you to be considering?
8. What are some of the barriers (if any) to accessing these services?
9. How could you creatively work with the situation?

### Managers (of support workers and others)

10. James' support staff are finding working with James difficult because of his anger outbursts. How will you deal with this?

# Worksheet 3A : James: Case study and practical strategies

## Suggested answers to some questions

### Support workers

#### 1. Identify the skills and tasks that James has difficulty with.

1. Difficult for him to walk long distances or carry heavy objects.
- 2, Difficulty planning and organising his time.
3. He is tired all the time and he is not managing to get on top of all the household chores.
4. He is having difficulty managing frustration.
5. James also has difficulty remembering what he has done and the appointments he has.

#### 2. What are some of the strategies you might use to help James to manage these difficulties?

1. Difficult for him to walk long distances or carry heavy objects.
  - Use a small shopping trolley for carrying items (e.g. shopping) for small distances.
  - Plan ahead so that heavier items that must be moved can be moved by someone else (so frustration with things not being done is minimised).
2. Difficulty planning and organising his time.
  - Use a weekly planner on a whiteboard.
  - Provide specific lists of steps for specific tasks e.g. the steps to take for specific household chores.
  - Keep belongings and things he needs to work with in regular places.
3. He is tired all the time and he is not managing to get on top of all the household chores.
  - Schedule the chores into the weekly planner. Ensure there is not too much to do on any one day.
4. He is having difficulty managing frustration.
  - Identify what causes the frustration.
  - Put in place strategies to reduce the causes.
5. He has difficulty remembering what he has done and his appointments.
  - Use a whiteboard for bigger events.
  - Use a mobile phone to put in future events with an alarm before the event.
  - Use a diary to record what has happened at events.
  - Use the calendar function in a mobile phone to record things that have been done.

## Information and referral workers

### 3. James rings your service up wanting additional support for cleaning in the home? How do you respond?

The essence of a good response is to:

- a) not make assumptions and
- b) ask specific questions to tease out what is happening and
- c) gather more information at a later time and/or from others if necessary
- d) pick things that you can work on

Ask specific questions. For example:

- What's going wrong?
- Have you got anyone coming now?
- Who pays for them?

Discover why he is asking for additional support.

Don't make assumptions.

- It may be that he is getting the cleaning but he is not letting them clean.
- Just because the person thinks they need more workers doesn't mean that is the answer.
- Question his assumption that his answer is the answer.
- E.g. he may not be at home and so they don't come.

Get more information at a later time from him or another person.

- What about you go away and write down what the problems are and ring me again.
- Who lives with you? Can I talk to them about this?

Pick things that you can work on.

- If he has difficulty remembering appointments, is he using a diary? If not who could help him with this?

### 4. James' parents ring up wanting to know what services are available to help James with his frustration and anger. How do you respond?

The essence of a good response is also to:

- a) not make assumptions and
- b) ask specific questions to tease out what is happening and
- c) gather more information at a later time and/or from others if necessary
- d) pick things in the case that you can work on.

Ask specific questions:

- When do these things happen?
- What services are being provided?
- What happens when he is frustrated?

Do not make assumptions:

- It may be that James only experiences frustration at specific events, e.g. missing appointments.
- If so the solution may be practical e.g. using a diary and a reminder in a mobile phone rather than psychological.
- It may be that James experiences frustration in a wide range of different situations, he may need an assessment from a clinical psychologist. If so do they know if there has been an assessment done? Is he seeing a clinical psychologist? What is the history? This will help identify what the referral network was/needs to be.

It may be that the parents are having difficulty dealing with the frustration because they are tired, worn out and need some respite.

Pick the things in the case that you can work on.

He is missing appointments. He has a memory problem.  
Has he got a diary or a weekly planner? Who can help him with this.  
If the parents need respite, who can help with this?

## **Program staff**

**5. James has started to attend your social activities program. He often misses his appointments. When he does come he gets frustrated easily and makes other participants uncomfortable. What do you do?**

Look at the referral information to see if it is adequate.

Adequate equals: this person has been referred to us because he has a brain injury and this is the effect of the injury on the person and strategies you may need to take to work with these effects.

Don't make assumptions:

Ask specific questions of both him and his family members.  
e.g. Is there something going wrong for you?  
e.g. I don't like the person.  
There is loud music in the background and I can't concentrate  
I have this problem every time I go anywhere.

Do you want to do something about this?

What's the goal?  
How do we work on this goal?

Is he being sent along because other people thought it was a good idea?

Does he like the activity?  
What are his likes/wants/goals?

Is there something he would prefer to be doing?

If the specific issues are identified then explore strategies for how to address them.

If he can't concentrate: What support is needed for him to concentrate?

If there is one particular person he doesn't get on with: What can we do to minimise this as a problem?

If he needs support to do some of the activities and he is not getting it: How can we get him the additional support he needs?

Examine how what he is being asked to do matches with his skills and abilities.

If he is being asked to do things he does not have the skill to do: Are there alternative activities he could do? Could he do the activity with support? What supports are needed? Where will they come from?

What support is needed to achieve the same outcomes as other people are achieving?

Has he attended other groups? What kinds of problems if any did he have with them?  
What did they do for him to help him achieve things?

What strategies is he using to help with memory problems and missing appointments? Would other strategies be useful?

Does he have a whiteboard weekly planner?

Does he have a mobile phone calendar and reminders?

If not would these be helpful to address the specific issue of missing appointments.

Could he, for example, get a text message reminder 2 hours before the activity?

### Case managers

**6. James' case has been referred to you. You are to work with James to develop a plan for the next 12 months. What are the sources of the information you need?**

#### Agency reports

Obtain copies from family, hospitals, legal representatives

**Discharge summaries** - can be obtained from acute hospitals or rehabilitation services, Commonwealth Rehabilitation Service, private rehabilitation providers.

**Neuropsychological reports** – done by neuropsychologist or clinical psychologists. Usually focus on changes to cognitive function. Some assessments include I.Q. score, usually not very helpful as the overall score does not usually vary greatly from the preinjury score.

**Rehabilitation/medical reports** – done by rehabilitation specialists, physiotherapists, speech pathologists, social workers, rehabilitation counsellors.

**Other therapist reports** – include occupational therapy, physiotherapy, speech pathology, social work and rehabilitation counsellor reports.

#### Self report

**Pre-morbid functioning vs. current status** - It is important to get an idea of a person's ability before the injury and compare that with current functioning. Otherwise you can make any number of erroneous conclusions about the impact of the TBI.

**Verbal vs functional ability** - Some people are verbally articulate, but still have significant problems at a practical level that may be identified in an interview.

**Difficulties with insight** - Some people have reduced awareness about their needs, and may not fully understand the level of support being provided by key people in their lives.

#### Family report

**Impact on the family** - Families are often a key support for people with ABI. Information from families can provide valuable additional information in making an assessment.

**Under reaction vs over-reaction** - Family members sometimes minimise or over-emphasise the disabilities of their relative.

#### Others

Other people may have valuable additional information - This may include agency/staff/friends/employers, etc. The more sources of information, the better the quality of the assessment.

Where relevant sources of information are not available Case managers may need to make arrangements to have a person with an ABI assessed appropriately.

**7. What services in your area could be relevant for you to be considering?**

No suggested answers - they will depend on what's in the local area.

**8. What are likely to be some of the barriers to accessing services for James? What can you do about these potential barriers?**

All of the following are common barriers if they are **not** present:

**The service is available in the area.** If the most appropriate service is not available then what are the alternatives? Would the service be suitable if James had support? Would the service be suitable if modified in some way?

**Diagnosis** - if James doesn't have a diagnosis he may find he doesn't get in to the service. Get a diagnosis if he doesn't have one.

**The program aims and James' needs matched:** What is the program aiming to achieve? What are James' goal? Do they match? If no, could the service be modified in some way to match James' goals?

**There is adequate support for James to participate.** What support does James need to participate in the program? Maybe he needs a worker to facilitate interaction with other people.

**Social inclusion** - e.g. there may be a men's social group for Vietnamese people - but the problem for James in this men's group is he isn't social - so they may not want him to/ he may not want to continue coming.

**Affordable** - Can he afford any associated costs? Has he got the skills to manage the money?

**Transport available** - Is he able to get to the service?

**9. How could you creatively work with the situation?**

No suggested answers - the creative work will depend on what's in the local area.

## Managers (of support workers and others)

10. James' support staff are finding working with James difficult because of his anger outbursts. How will you deal with this?

Have the support staff had appropriate orientation and training for working with people with acquired brain injury? If not, provide them with the orientation/ training e.g. Self-Study Module 1 : An Introduction to ABI

Work with the support staff on reinforcing key messages:

Uniqueness of the individual

Injury - effect - behaviour - behaviour management

You are part of a team

Be attuned to managing yourself, know what pushes your buttons and what you will do when it happens

Stick to your role.

Analysing the problem behaviour:

When does it occur?

Where does it occur?

Who does the behaviour occur with?

Does it start suddenly or build up gradually?

How long does it last?

What is the history of the problem?

What solutions have been tried in the past?

How are people reacting?

Other factors to consider when analysing problem behaviour

Physical factors ie: excess noise, overcrowding, appropriateness of house or room.

Are they treated with respect?

Are they part of the decision making process/do they have choices?

Are they able to communicate effectively?

Will they benefit from being taught coping skills i.e. relaxation etc?

Develop strategies to specifically deal with the problem behaviour.

Work with all the staff on agreeing on the specific strategies to be adopted - so there is consistency across all staff.



# Worksheet 4 : Improving working with people with ABI: Learning and service network issues

## Building knowledge and skills in the workplace

While staff have some individual responsibility for building their own knowledge and skills workplaces are also responsible and need processes and systems in place, for example:

- Staff meetings
- Staff development forums
- Supervision
- Participation in interagency meetings
- Training workshops.

There are links to these learning resources that can be used in these situations available from [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)

### Questions:

How can we embed relevant knowledge and skills in our workplace?

What processes and systems need to change to more appropriately provide services to people with ABI?

## Building capacity in the services sector

The services network of people with ABI is imperfect. There are some great parts. There are good parts. There are missing parts. The primary drivers for working with the services network are:

- What are the person with ABI's goals?
- What does the person with ABI want in order to achieve their goals?

The approach is: Do what it takes - to meet the goals of the person with the ABI.

Local services need to work together to appropriately meet the needs of people with ABI.

### Questions:

What are the local service network issues in working with people with ABI?

What could be done locally to address these issues?

# Worksheet 5 : Working with people with ABI: ... can you?

## 1: ADHC Directions and Intro to ABI

1.  Understand Ageing, Disability and Home Care's (ADHC) directions in relation to acquired brain injury (ABI)
2.  Define 'acquired brain injury'
3.  Identify at least five different causes of ABI
4.  Identify the sex ratio and age distribution for TBI and stroke
5.  Describe the basic anatomy of the skull and brain
6.  Recognise the common effects of ABI
7.  Recognise the process of recovery and stages of rehabilitation
8.  Identify impacts on life and relationships
9.  Identify issues and challenges for the person with the ABI and their family, friends and carers

## 2: Approaching working with people with an ABI

10.  Reflect on being introduced to a variety of people with ABI (through video etc)
11.  Be aware of the key building blocks of how to approach working with people with an ABI (appropriate for the participant's work role)
12.  Be able to describe the four key messages related to "Unique individuals building independence"
13.  Be able to give examples of key things involved in "working through emotions and relationships" for the person with the ABI, for family members and for workers
14.  Be aware of pathways for life after an ABI
15.  Be aware of the ABI team and be able to work as a team
16.  Be aware of the differences between working with ABI and working with aged care, intellectual disability, mental health, etc

## 3: Practical strategies

17.  Identify new strategies for working with people with an ABI that could be used in their work (appropriate for the participants work role)
18.  Identify tools that may be useful

## 4: My own learning, workplace learning and service network capacity building

19.  Identify what they need to know in working with people with ABI and identify strategies for themselves to build their own knowledge about ABI
20.  Identify strategies in their work place for knowledge building about working with people with an ABI (and be aware of relevant learning materials, other supports and how to use them)
21.  Identify local service network issues (in working with people with ABI) and what could be done to address them locally

## C. Tools & checklists

There are 12 Tools and Checklists.

They are available as PDFs from the web site [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info).

### **Tool 1 : Open to the possibility a person has an ABI**

All staff in services, especially those on reception or information and referral workers need to be open to the possibility of a person having an ABI. This Tool provides tips.

### **Tool 2 : Conversation tips**

People with ABI often have difficulty with communication and language. This Tool provides some conversation tips.

### **Tool 3 : Looking for indicators of ABI**

If you think a person may have an ABI you may need to ask questions to help understand the person, their ABI and their needs. The Tool provides some useful questions to ask the person with ABI, and/or family members or support workers. It is not a diagnostic tool. It is intended to help identify the possibility of an ABI.

### **Tool 4 : Strategies for dealing with specific cognitive changes**

People directly supporting people with an ABI need strategies for dealing with specific cognitive changes. This Tool outlines the :

- o cognitive impairments that can occur after an ABI
- o problems that arise because of the impairment and
- o management strategies that can be used to deal with the problems.

### **Tool 5 : Case manager's issues checklist**

This Tool is a checklist a case manager can use to ensure they have considered all the relevant issues with a person with ABI when they are setting goals and developing plans.

### **Tool 6 : Sources of information to assess needs**

This Tool is a list of sources of information that may be relevant when a case manager is setting goals and developing individual program plans.

### **Tool 7 : Individual program plan**

This Tool is a list of headings one might use in an individual program plan.

### **Tool 8 : Tips for setting goals**

This Tool provides tips for setting goals when working with people with ABI.

### **Tool 9 : Managing and supervising staff**

This Tool is an overview of what good staff management and supervision includes. It sets the context for Tools 10 and 11.

### **Tool 10 : Working with ABI : The disillusionment process**

Staff working with people with ABI can experience a disillusionment process - especially when staff management practices are not working. This Tool outlines the disillusionment process and strategies for dealing with it.

### **Tool 11: Preventing stress**

Good management processes will prevent stress and the disillusionment process from occurring. This Tool outlines causes, symptoms and prevention strategies for staff stress.

### **Tool 12 : Essential survival tips for people working with people with ABI**

This Tool outlines essential survival tips for all staff working with people with ABI.

## **TOOL 1 - Open to the possibility a person has an ABI**

All staff in services, especially those on reception or information and referral workers need to be open to the possibility of a person having an ABI.

### **Principles**

Useful principles to underpin your interactions with people are:

1. Treat people with respect
2. Be non-judgemental
3. Be open
4. Listen
5. Be patient

### **Noticing**

What do you notice?

- A person having difficulty finding words
- A person regularly forgetting appointments
- A person getting agitated when things aren't going right
- A person slurring their words, not speaking properly.

### **Tips**

Ask the person's permission to ring a family member, friend, or key contact (to ask for more information)

Use direct questions e.g.

- Have you got an acquired brain injury?
- Do you have difficulty finding the right words?
- Do you have a memory problem?

### **Question your assumptions**

- Not keeping appointments - intentionally OR could there be a memory problem?
- Difficulty finding words - not understanding what's said - OR understanding what's said but has difficulty finding the right words to verbalise an answer.
- Getting agitated - an irritable client OR - a person with an ABI who gets stressed when routine breaks down.

## **TOOL 2 - Conversation tips**

People with ABI often have difficulty with communication and language. Here are some conversation tips.

### **To help the person's expression**

- Give the person plenty of time to respond
- Encourage all attempts to communicate
- Do not interrupt or answer for the person
- Give questions or choices to clarify what the person means, for example:
  - "Do you mean ... ?"
  - Ask what their topic is
  - Give a choice of two options ("Do you want to watch TV or go outside?")
- The most important thing is the meaning behind the communication, not how well the person can put a sentence together.

### **To help the person's understanding**

- Avoid background noise
- Speak naturally but clearly
- Ensure eye contact
- Speak in short, simple sentences
- Try rephrasing what you said if the person does not understand
- Talk about events, objects and people in the here and now
- Clearly identify people and topics
- Do not change topic quickly
- Be aware that the person will understand better when they are not tired.

### **Tips to help manage difficult social situations**

#### ***Problem: Poor conversational turn-taking***

- Give feedback about the need for people to take turns in conversation.
- Say "It's \_\_\_\_'s turn now. Let them finish and then you can say what you want to say".

#### ***Problem: Talking about the same topic for too long.***

- Give feedback that the topic is finished.
- Have an agreed upon non-verbal signal to prompt the person to move on (e.g. tapping your watch discreetly).
- Say "We've talked about \_\_\_\_\_, and now we're talking about \_\_\_\_\_".

*Problem: Talking about inappropriate topics/giving too much personal information.*

- Give feedback that this is inappropriate.
- Say "It's not appropriate to talk about \_\_\_\_\_ in this situation/with this person".

*Problem: Invading people's personal space.*

- Give feedback that the person is too close, direct them where to stand/sit.
- Change the environment (e.g. have a table between you and the person, position the chairs in the room before the person arrives).

*Problem: Inappropriate eye contact (staring or avoiding eye contact during conversation).*

- Position yourself in the person's line of sight.
- Give verbal prompts to make eye contact and give praise when it is done.
- Look away and don't engage someone in conversation if they are staring.

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### **TOOL 3 : Looking for indicators of ABI**

If you think a person may have an ABI you may need to ask questions to help understand the person, their ABI and their needs.

Asking these questions can be useful to get a sense of the client's cognitive status, and information about prior accidents, etc.

You may need to ask these questions of a family member or friend. A person with cognitive deficits may not be able to give you an accurate answer to these questions.

The following questions are not a diagnostic tool. They are intended only to identify the possibility of an ABI.

#### ***Cognitive status***

1. Does he/she have problems with day-to-day memory?
2. Does he/she have problems with attention/concentration (e.g. while reading a book, watching TV or watching a movie)?
3. Does he/she make a mess of simple tasks they could previously complete?
4. Does he/she get easily confused when things are explained?
5. Does he/she get stuck on a point and become unable to think or talk about anything else?
6. Does she/he find it hard to change their opinions or their routine, and become easily upset by small changes?
7. Does he/she generate unrealistic plans?
8. Does he/she act before they think?

#### ***A prior accident?***

1. Have you ever had an injury to your head because of a car accident, fall, fight, blow to the head, or gunshot? If so, when did this happen?
2. Did you get knocked out or lose consciousness? If so how long did this last?
3. Did you experience confusion after the injury? Is there a gap in your memory for events that happened around the time of the injury?
4. Did you go to hospital?
5. Did you receive treatment?
6. Have you noticed changes in your emotional functioning since the injury? If so what changes have you noticed?

#### ***A prior stroke?***

1. Have you ever had a stroke?
2. Did you lose consciousness? If so how long did this last?
3. Did you experience confusion after the stroke? Is there a gap in your memory for events that happened around the time of the stroke?
4. Did you go to hospital?
5. Did you receive treatment?
6. Have you noticed changes in your emotional functioning since the stroke? If so what changes have you noticed?

*Alcohol related brain injury?*

1. Do you drink alcohol? If so, how much?
2. Cognitive status questions as above.

*When you know the person has an ABI from trauma, stroke, hypoxia or anoxia*

1. Date and type of incident
2. Did you lose consciousness? If so how long did this last?
3. How long did you have post-traumatic amnesia (PTA)?
4. Did you go to hospital? For how long?
5. Did you receive treatment? What kind?
3. Rehabilitation history
  - Acute
  - Post-acute rehabilitation/community re-settlement
  - Social rehabilitation
4. What types of impairments?
  - Cognitive
  - Communication/language
  - Physical/sensory
  - Emotional/behavioural/personality
5. What level of functioning?
  - Self-care
  - Living skills
  - Work/vocational
  - Relationship skills
  - Behavioural problems (e.g. aggression, sexuality, disinhibition)
6. What level of functioning before the injury?
  - Self-care
  - Living skills
  - Work/vocational
  - Relationship skills
  - Behavioural problems (eg. aggression, sexuality, disinhibition)
7. Current social situation
  - Accommodation
  - Finance
  - Social supports
  - Current support
8. Compensation status
9. Other agencies involved



## TOOL 4: Strategies for dealing with cognitive and behavioural changes

This TOOL outlines the :

- cognitive impairments that can occur after an ABI
- problems that arise because of the impairment and
- management strategies than can be used to deal with the problems.

<b>Cognitive &amp; behavioural changes</b>	<b>Problems arising</b>	<b>Management strategies</b>
<b>Attention and Concentration</b>	<ul style="list-style-type: none"> <li>• have difficulty concentrating</li> <li>• being distractible</li> <li>• finding it hard to cope with more than one thing at once</li> <li>• getting bored quickly</li> <li>• switch off and appear not to listen</li> <li>• not remembering what others have said</li> <li>• not completing things they start</li> <li>• changing the subject often</li> </ul>	<ul style="list-style-type: none"> <li>• reduce distractions (eg. noise, other people)</li> <li>• use short, simple sentences</li> <li>• encourage the person to stay with the activity for longer periods</li> <li>• change activities when necessary</li> <li>• when distracted, interrupt and bring back to task</li> <li>• give reminders of next step</li> <li>• keep to a routine</li> </ul>
<b>Speed of information processing</b>	<ul style="list-style-type: none"> <li>• taking longer to complete tasks</li> <li>• unable to keep track of lengthy conversations and instructions</li> </ul>	<ul style="list-style-type: none"> <li>• make allowances and give the person extra time</li> <li>• present information slowly</li> <li>• present information in chunks</li> <li>• present one thing at a time</li> <li>• check that the person is keeping up</li> </ul>
<b>Fatigue</b>	<ul style="list-style-type: none"> <li>• having an overall reduced ability to cope</li> <li>• getting irritable and distressed</li> <li>• having other problems exacerbated</li> </ul>	<ul style="list-style-type: none"> <li>• encourage the person to take rest breaks</li> <li>• schedule more demanding tasks when the person is at their best (often mornings)</li> </ul>
<b>Memory</b>	<ul style="list-style-type: none"> <li>• finding it hard to remember new things</li> <li>• forgetting appointments</li> <li>• forgetting things people say</li> <li>• frequently losing things</li> </ul>	<ul style="list-style-type: none"> <li>• give reminders</li> <li>• repeat information when necessary</li> <li>• encourage person to rehearse and repeat information</li> <li>• encourage use of external reminders, i.e. diaries, post-it notes</li> <li>• structure a routine by breaking tasks into small steps</li> <li>• keep belongings in regular places</li> </ul>

<b>Cognitive &amp; behavioural changes</b>	<b>Problems arising</b>	<b>Management strategies</b>
<b>Problem solving</b>	<ul style="list-style-type: none"> <li>• reduced ability to find solutions to problems</li> </ul>	<ul style="list-style-type: none"> <li>• train the person to approach new tasks in a systematic manner, eg. break the task into small parts</li> <li>• reduce the demands made on the person</li> <li>• help educate the family and others about the person's problems</li> <li>• avoid giving the person open-ended tasks</li> </ul>
<b>Planning and organisation</b>	<ul style="list-style-type: none"> <li>• having difficulty working out the steps involved in a task</li> <li>• not considering the end result of their actions</li> <li>• having trouble organising their thoughts and explaining things to others</li> </ul>	<ul style="list-style-type: none"> <li>• avoid becoming frustrated with the person</li> <li>• give prompts for the following steps</li> <li>• provide a written list which outlines the steps in order</li> </ul>
<b>Rigid and concrete thinking</b>	<ul style="list-style-type: none"> <li>• taking statements literally</li> <li>• insensitive and unable to consider feelings of others</li> <li>• having a simplistic understanding of emotions</li> <li>• being resistant to change</li> <li>• keeping doing things incorrectly despite feedback</li> </ul>	<ul style="list-style-type: none"> <li>• use simple and direct language, avoid abstract terms</li> <li>• avoid using hints or sarcastic humour</li> <li>• encourage person to imagine how they would feel in other situations</li> <li>• explain any change in routine in advance, giving reasons</li> </ul>
<b>Disinhibition</b>	<ul style="list-style-type: none"> <li>• being impulsive and act without thinking of consequences</li> <li>• making rash decisions</li> <li>• acting inappropriately toward people (including sexually)</li> <li>• behaving in a silly, flippant or childish way</li> <li>• disclosing personal information too freely</li> </ul>	<ul style="list-style-type: none"> <li>• give immediate feedback, briefly asking person to stop behaviour and explain why</li> <li>• provide appropriate external controls eg. over finances</li> <li>• remind person of the sensitive nature of some information, giving clear examples</li> <li>• ignore the behaviour where possible</li> </ul>

<b>Cognitive &amp; behavioural changes</b>	<b>Problems arising</b>	<b>Management strategies</b>
<b>Reduced self-control</b>	<ul style="list-style-type: none"> <li>• losing temper quickly</li> <li>• being physically/verbally abusive</li> <li>• having a lower frustration tolerance</li> </ul>	<ul style="list-style-type: none"> <li>• distract or remove the person from anger-provoking situation</li> <li>• withdraw attention when appropriate</li> <li>• try not to escalate the situation by shouting back</li> <li>• identify anger-provoking triggers and avoid when possible</li> </ul>
<b>Egocentricity and self-absorption</b>	<ul style="list-style-type: none"> <li>• not considering consequences of their behaviour on others</li> <li>• being unable to 'put themselves in someone else's shoes'</li> <li>• appearing selfish to others</li> <li>• not appreciating carers</li> </ul>	<ul style="list-style-type: none"> <li>• try to explain situation from another's or your point of view</li> <li>• try not to take offence, understand why the person is like that</li> </ul>
<b>Emotional lability</b>	<ul style="list-style-type: none"> <li>• laughing and crying inappropriately</li> <li>• changing moods quickly</li> </ul>	<ul style="list-style-type: none"> <li>• try to identify triggers which result in mood swings</li> <li>• be prepared for changes by having alternative plans</li> </ul>
<b>Perseveration</b>	<ul style="list-style-type: none"> <li>• talking about the same topic repeatedly</li> <li>• returning to the preferred topic when doing something else</li> </ul>	<ul style="list-style-type: none"> <li>• remind person gently they've told you the information before</li> <li>• distract the person back to the preferred activity</li> <li>• ignore, as much as possible, future references to the topic</li> <li>• try not to get into arguments, walk away if you're getting irritated</li> </ul>
<b>Reduced insight</b>	<ul style="list-style-type: none"> <li>• being unaware of both cognitive and physical limitations</li> <li>• having unrealistic goals, plans and expectations</li> <li>• resisting efforts of carer/staff</li> <li>• not realising that they have made errors because they haven't checked their work</li> </ul>	<ul style="list-style-type: none"> <li>• gently remind person of deficits</li> <li>• explain why proposed action is useful, reason through the steps</li> <li>• point out possible negative consequences of person's unrealistic plans</li> <li>• place external limitations where necessary (eg. removal of driver's licence/access to car)</li> <li>• gradually expose person to reality testing experiences</li> </ul>

<b>Cognitive &amp; behavioural changes</b>	<b>Problems arising</b>	<b>Management strategies</b>
<b>Poor self monitoring</b>	<ul style="list-style-type: none"> <li>• not realising that they are 'hogging' conversations</li> <li>• being verbose and keep talking when others are no longer interested</li> </ul>	<ul style="list-style-type: none"> <li>• encourage them to check over their work</li> <li>• use signals, agreed in advance, to let them know they're talking too much</li> <li>• encourage turn-taking in conversation</li> <li>• use external aids, eg. graphs and tables to help the person monitor their behaviour</li> </ul>
<b>Reduced social skills</b>	<ul style="list-style-type: none"> <li>• interacting poorly with others because of all the above problems</li> <li>• losing their ability to relate well with others</li> <li>• not picking up the usual social cues (eg. looking at watch)</li> </ul>	<ul style="list-style-type: none"> <li>• teach specific strategies like maintaining eye contact, asking questions of others, turn taking in conversation</li> <li>• try to encourage awareness of others' reactions</li> </ul>
<b>Inertia</b>	<ul style="list-style-type: none"> <li>• appearing to have no motivation and seem apathetic</li> <li>• not acting until prompted</li> <li>• not completing tasks</li> <li>• knowing how to do something, but not doing it spontaneously</li> </ul>	<ul style="list-style-type: none"> <li>• encourage person to commence activity</li> <li>• prompt first step of the task</li> <li>• try to find things that are most interesting for the person</li> <li>• reward and encourage any self-initiated activity and persistence</li> <li>• accept that the person may need less activity to keep them occupied and happy</li> </ul>
<b>Restlessness</b>	<ul style="list-style-type: none"> <li>• complaining of boredom and being restless and agitated</li> </ul>	<ul style="list-style-type: none"> <li>• remind person of activities they usually enjoy</li> <li>• promote physical activity which may expend some energy</li> </ul>

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## **TOOL 5: Case manager's issues checklist**

### **For sudden onset ABIs**

The following is a checklist a case manager can use to ensure they have considered all the relevant issues with a person with ABI when they are setting goals and developing plans.

#### **History of injury**

- date of injury
- type of injury
- period of unconsciousness/post traumatic amnesia (if TBI)
- type of accident (if TBI)
- rehabilitation history

#### **Rehabilitation**

- rehabilitation reports
- rehabilitation goals
- rehabilitation contact

#### **Pre-morbid status**

- pattern of behaviour
- education/employment
- social background
- medical issues

#### **Status post-injury**

- activities and daily living skills
- communication/language difficulties
- cognitive impairments
- personality/behaviour problems
- emotional states (depression, anxiety, anger)
- adjustment difficulties
- awareness of disability
- sexuality issues
- relationship issues
- medical issues (brain-injury related and non brain-injury related)
- medication
- substance use or abuse
- psychiatric status

#### **Client's needs and goals**

- identify and establish

#### **Family and "significant other" assessment**

- impact on the family
- relationship issues
- behavioural issues
- adjustment to disability issues, including understanding of disability

#### **Issues**

- recreation/leisure
- work/education
- accommodation
- respite care
- finances
- legal
- compensation
- other agencies.

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## **TOOL 6: Sources of information to assess needs**

When a case manager is setting goals and developing individual program plans there are multiple sources of information that may be relevant.

### **Agency reports**

(obtain copies from family, hospitals, legal representatives)

- Discharge summaries can be obtained from acute hospitals or rehabilitation services, Commonwealth Rehabilitation Service, private rehabilitation providers.
- Neuropsychological reports – done by neuropsychologists or clinical psychologists. Usually focus on changes to cognitive function. Some assessments include I.Q. score, usually not very helpful as the overall score does not usually vary greatly from the preinjury score.
- Rehabilitation/medical reports – done by rehabilitation specialists, physiotherapists, speech pathologists, social workers, rehabilitation counsellors.
- Other therapist reports – include occupational therapy, physiotherapy, speech pathology, social work and rehabilitation counsellor reports.

### **Self report**

- Pre-morbid functioning vs. current status  
It is important to get an idea of a person's ability before the injury and compare that with current functioning. Otherwise you can make any number of erroneous conclusions about the impact of the ABI.
- Verbal vs functional ability  
Some people are verbally articulate, but still have significant problems at a practical level that may be identified in an interview.
- Difficulties with insight  
Some people have reduced awareness about their needs, and may not fully understand the level of support being provided by key people in their lives.

### **Family report**

- Impact on the family  
Families are often a key support for people with ABI. Information from families can provide valuable additional information in making an assessment.
- Under-reaction vs over-reaction  
Family members sometimes minimise or over-emphasise the disabilities of their relative.

### **Others**

- Other people may have valuable additional information.  
This may include agency/staff/friends/ employers, etc. The more sources of information, the better the quality of the assessment.

Where relevant sources of information are not available Case managers may need to make arrangements to have a person with an ABI assessed appropriately.

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## **TOOL 7: Individual program plan**

An individual program plan could include:

### **1. Physical/mobility/transport**

- Physical abilities, driving ability, public and alternative transport.

### **2. Relationships**

- Maintenance of existing relationships, sexuality
- Support to develop new relationships.

### **3. Accommodation**

- Pre injury arrangements may not be appropriate so new options need to be explored.
- Includes respite.

### **4. Autonomy**

- Goals regarding decision-making.

### **5. Communication**

- Speech, non-English-speaking background, phone, reading, writing, computers.

### **6. Living skills**

- Personal care – showering/shaving/grooming/dressing/eating/hair and nail care
- Health – health and medication/substance use/abuse issues
- Food preparation
- Household chores – washing dishes/vacuuming/bed making/washing and ironing
- Money management – budgeting
- Time management – organising and keeping appointments.

### **7. Social and personal skills**

### **8. Recreation and leisure**

### **9. Vocational**

- Education and training.

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## TOOL 8: Tips for setting goals

The following are tips for setting goals when working with people with ABI.

### Factors to consider when developing goals

- Client centred not staff actions
- Goal development vs goal imposition
- Giving exact behavioural description of goals
- Stating goals positively rather than negatively
- Creating short-term goals vs long-term goals
- Looking at improvement vs maintenance.

### Writing goals

Remember: Goals need to be specific, measurable and time limited.

Some examples are:

*I will remember all my appointments in two weeks*

*I will have enough food in my house for all my needs for two weeks.*

*I will keep track of when my bills are due and pay them on time within two weeks.*

*I will identify places to keep things in my house so I don't lose them, in one month.*

To achieve each of these goals would require developing strategies (and identifying any necessary resources).

For example to achieve: I will have enough food in my house for all my needs for 2 weeks will required:

- menu plan
- shopping list
- work with support worker
- etc

The following are too broad and general to be useful goals:

- independently use public transport
- increase opportunities for social interaction
- improve arm function
- improve personal hygiene
- improve cooking skills

### How to deal with unrealistic goals

- allow learning through experience (consistent with cognitive abilities and achievable goals)
- develop compensatory strategies
- investigate alternatives
- set priorities
- break into smaller steps
- give clear feedback about progress/lack of progress
- don't challenge unrealistic goals, try to focus on achievable smaller goals
- link achievable goals with unrealistic goals (rather than challenging unrealistic goals)

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## **TOOL 9: Managing and supervising staff**

Good staff management and supervision includes:

### **How to get the right person for the job**

- Recognise the value of the recruitment process
- Identify important criteria in selecting staff to work with people with ABI.

### **Developing and retaining staff**

- Identify key strategies to retain and develop staff working with people with ABI.
  - orientation
  - training and education
  - performance management

### **Good management practice**

- Identify key issues in working with clients with a brain injury
- Identify strategies and good practices for effective supervision and support of staff working with people with ABI
- Identify good management practices
- Explore basic concepts in the provision of client services
- Identify the value of policies and procedures
- Recognise the stressors that often exist for staff due to the nature of brain injury
- Identify management strategies in response to staff stress.

### **The role of the manager**

- Identify essential skills and responsibilities for managers
- Link recruitment with a Management Framework.

### **Good management practices**

- Consistent approach to client management
- Good written and verbal communication
- Clinical and critical pathways
- Develop and foster a team approach
- Hold regular meetings to review, monitor and evaluate plan
- Provide in service education and training to staff
- Provide crisis management, intervention and debriefing
- Rotate staff to prevent burnout and stress
- OH&S issues for staff – safe workplace
- Accessible and user-friendly policies and procedures
- Recognise staff stress – disillusionment process and stress.

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## **TOOL 10: Working with ABI: the disillusionment process**

Staff working with people with ABI can experience a disillusionment process - especially when staff management practices are not working.

The disillusionment process moves through the following phases:

### ***Enthusiasm***

- Unrealistic expectations for the client
- Inadequate skills
- Over identification with the client - not professional relationship
- Over investment of self - personally involved.

### ***Stagnation***

- Lose enthusiasm with client due to unrealistic expectations
- Other needs assume greater importance
- Sense of unfulfilled expectations - feeling of non-achievement.

### ***Frustration***

- Questions effectiveness - feels client is not achieving
- What's the point?
- Staff member loses respect for the client
- Hostility towards colleagues and superiors.

### ***Apathy***

- Staff member does the minimum
- Disinterested
- It's only a job
- Emotional detachment.

***Staff members leave with negative experience***

### **Strategies for preventing the disillusionment process**

Some of the strategies for preventing the disillusionment process from setting in are:

- Realistic expectations for the client
- Staff understanding of ABI generally
- Staff understanding each client's ABI - injury - effects - behaviour
- Staff training with the skills to manage the behaviours for each of the clients they work with.

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## **TOOL 11: Preventing stress**

Good management processes will prevent stress and the disillusionment process from occurring. Understanding the causes, symptoms and prevention strategies for staff stress enables the manager to act early. Positive staff management practices within an organisation maintain enthusiasm and involvement of staff with the client and the organisation. It is the key to retaining staff:

### **Symptoms of staff stress**

- absenteeism and poor time keeping
- regular extended breaks
- high Staff turnover
- tiredness, apathy, depression, avoidance of clients and colleagues
- extreme cynicism
- no team work
- negativity
- loss of professionalism.

### **Causes of staff stress**

- working in isolation without support
- long periods of intensive work with little relief
- aspects of work tasks which assault personal dignity; individual differences coping with stress
- exposure to pressure when least able to cope
- lack of training
- no crisis intervention or debriefing from Managers
- lack of communication, direction and responsibility from Managers
- no plan or goals to work toward
- lack of understanding & acceptance of capabilities & limitations of the person with ABI.

### **Stress prevention**

- provide relevant training and orientation
- remove staff from the stressful situation, encourage them to leave their work at work
- provide crisis intervention, support and counselling
- have clear OH&S policies and procedures
- expand on the staff member's individual skills
- approve leave and roster changes
- provide opportunities for peer support and working with a more skilled colleague
- involve staff in decision making, to contribute ideas and problem solving
- hold regular meetings where grievances can be aired constructively and support refocused
- communicate realistic expectations, from the perspective of staff
- assume responsibility for and deal with organisational matters that create stress
- communicate clear organisational aims and have written policies and procedures
- set up a method of evaluation and review related to client's goals and aims.

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## **TOOL 12: Essential survival tips for people working with people with ABI**

Some of the essential survival tips when you are working with people with ABI are:

### **Getting to know the person with ABI**

Understand:

- What is the injury?
- What is the effect?
- How is the effect expressed in behaviour?
- What are strategies for managing the behaviours?
- How the person with ABI is dealing with this change
- The impact of their ABI on family and friends.

### **Realistic expectations**

Set realistic expectations:

- People with an acquired brain injury can grow in their skills for independence in the short and long term (except where the ABI is caused by a degenerative disease).
- The rate of development can be slow and so not noticed. People give up too soon.
- Most people with a traumatic brain injury and many with others forms of ABI are young - they have a lot of life ahead of them and plenty of time to develop.

### **Know yourself**

- What pushes your buttons?
- How do you respond appropriately when your buttons are pushed?
- How do you sustain yourself when the day to day work stresses build up?

### **Be part of a team**

- See yourself as part of a team.
- Who's in the team?
- What are their roles?
- Who can I get support from...in regards to what?

### **Notice signs of disillusionment and identify strategies for dealing with it**

What best describes your current work with this person / these clients:

- Enthusiasm
- Stagnation
- Frustration

What do you need to do to build a relationship and set realistic expectations?

### **Notice signs of stress and identify strategies for dealing with it**

- What's your level of stress in working with this client / these clients?
- What strategies work for you in reducing stress?

## D. Interactive graphics and graphics handouts

### 1: Interactive graphics

There are 19 interactive graphics that highlight key messages in the learning materials. They are available from the web site [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)

These graphics:

- are embedded in the two self-study modules on the web site
- can be used as handouts
- can be used as interactive graphics in presentations using data projectors or small group work around a PC.

These 19 graphics taken together contain the essence of the take home messages all staff need to understand in working with people with ABI.

Graphics 1 to 10 combine to form an **Introduction to ABI**

Graphics 10 to 19 combine to form an introduction to **Working with people with ABI**.

### *An introduction to ABI*

#### **Graphic 1: A person's abilities**

A person's abilities: self-care; getting along with others; life's activities; participation; cognition; and mobility. This interactive graphic highlights a healthy person's abilities. A useful starting point before exploring ABI.

#### **Graphic 2: A person's life span and ABI**

Lifespan: birth; preschool years; school years; young adult; middle aged; retirement; old age.

This interactive graphic highlights the point of impact of an ABI in the lifespan; and principles for person centred planning.

#### **Graphic 3: What is acquired brain injury?**

Definition of ABI: an injury to the brain; as a result of a cause; resulting in impairments for the person.

#### **Graphic 4: Primary causes of acquired brain injury**

Primary causes of ABI: trauma; stroke; hypoxia/anoxia; alcohol related; infection; degenerative diseases; other.

#### **Graphic 5: The brain - lobes and functions**

An interactive graphic highlighting areas of the brain and their respective functions.

#### **Graphic 6: ABI: Severity**

An interactive graphic highlighting common categories of severity and indicators of severity.

#### **Graphic 7: ABI: Cause to impact**

An interactive graphic highlighting for different individuals: cause; injury; effect; specific impairments; impacts.

#### **Graphic 8: Rehabilitation**

An interactive graphic highlighting the essence of rehabilitation.

#### **Graphic 9. ABI: Rehabilitation pathways**

An interactive graphic overview of the stages of rehabilitation for sudden onset ABI: hospital; from hospital to home; social rehabilitation; and impacts.

#### **Graphic 10. Working with people with ABI**

An interactive graphic highlighting the key messages for working with people with an ABI. The three high level domains are: unique individuals building independence; working through emotions and relationships; working with services. There are sub-points within these and key messages for each sub-point.

## *Working with people with ABI*

### **Graphic 10. Working with people with ABI**

An interactive graphic highlighting the key messages for working with people with an ABI. The three high level domains are: unique individuals building independence; working through emotions and relationships; working with services. There are sub-points within these and key messages for each sub-point.

### **Graphic 11. ABI: Unique individuals building independence**

An interactive graphics highlighting key messages in relation to building independence and that working with people with ABI is different from working with people in aged care, intellectual disability, mental health, etc.

### **Graphic 12. ABI: Cognitive impairment - problem - support**

An interactive graphic highlighting for different individuals: cognitive impairment; problems arising; and support strategies.

### **Graphic 13. ABI: Working through emotions and relationships**

An interactive graphic highlighting key messages about working through emotions and relationships.

### **Graphic 14. ABI: Grief and loss**

An interactive graphic highlighting the grief and loss process and specific reactions for different individuals and what's unique about the process for people with ABI

### **Graphic 15. ABI: Working with services**

An interactive graphic highlighting five key messages about working with services: pathways for life, case management is different, friends and family are where change happens, teamwork and working with the services network.

### **Graphic 16. ABI: Service pathways**

An interactive graphic highlighting common service pathways for individuals with ABI.

### **Graphic 17. ABI: Case management**

Highlights how the case management process wraps around and interacts with the person with the ABI: engagement; assessment; planning; implementation; monitoring; review. Case management settings and key points for case managers.

### **Graphic 18. ABI: Roles and practice tips**

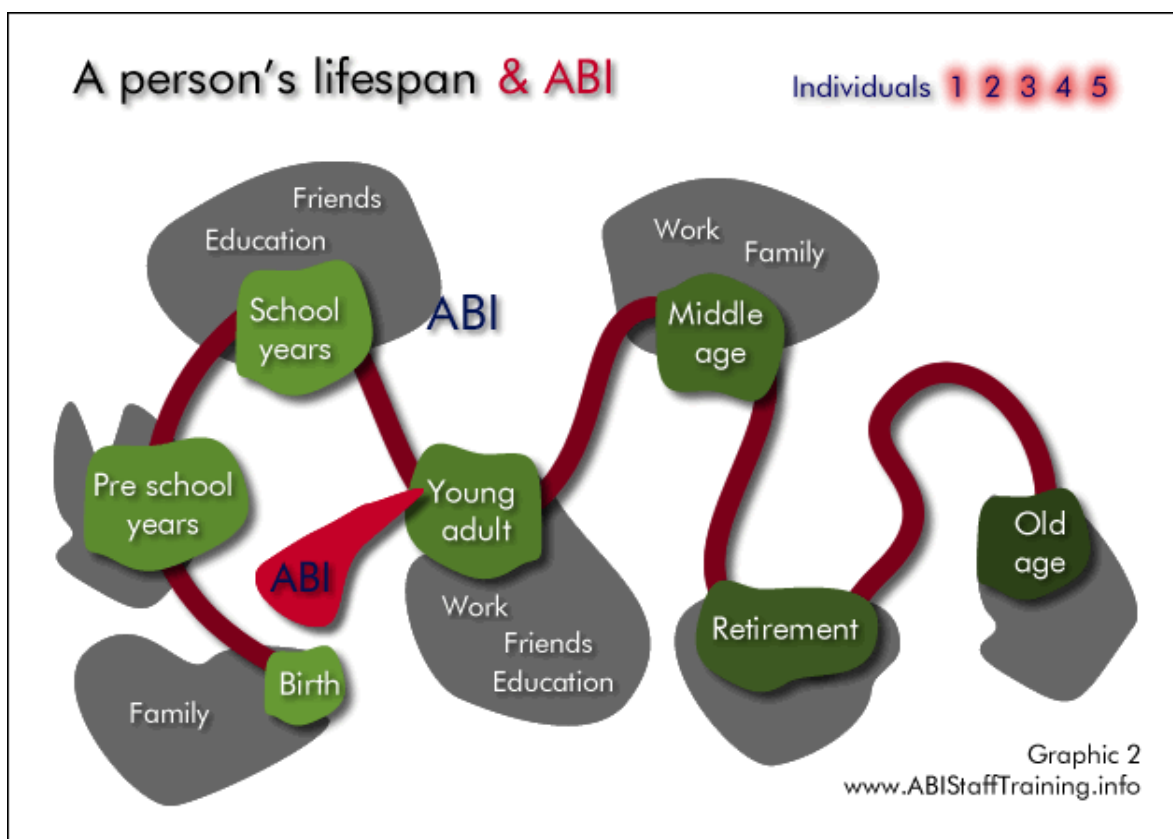
Interactive graphic highlighting practice tips and strategies for different roles: information and referral; support worker; program staff; case manager; manager; family and friends.

### **Graphic 19. ABI: Building knowledge & skills and service network capacity**

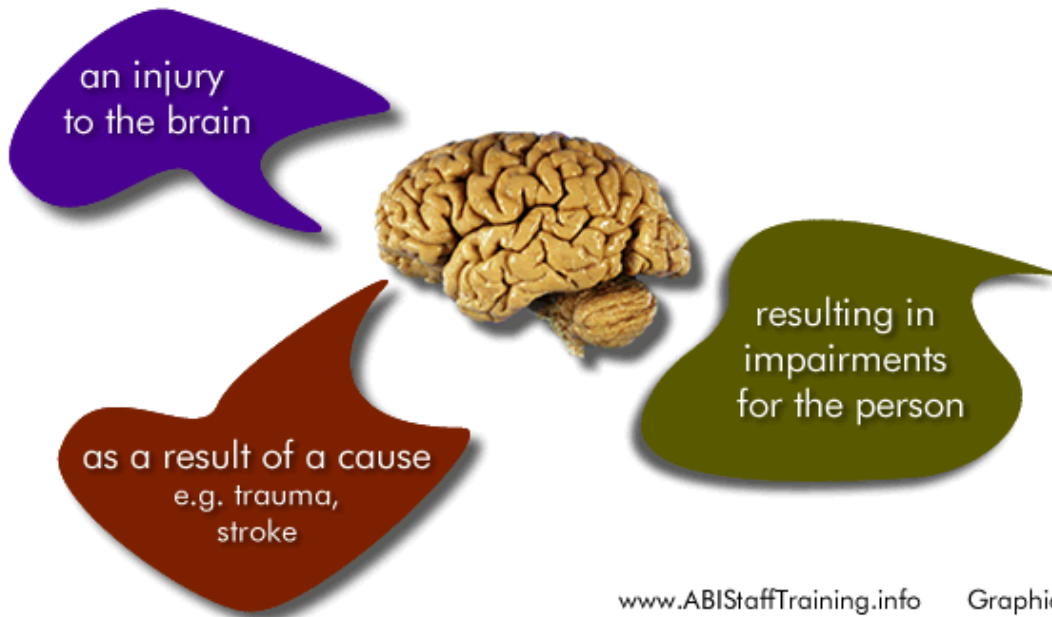
Interactive graphic highlighting knowledge and skills for staff in different roles: information and referral; support worker; program staff; case manager; manager; family and friends. It also notes service network capacity building.

The two sets of interactive graphics are also available in summary form as handouts. See below.

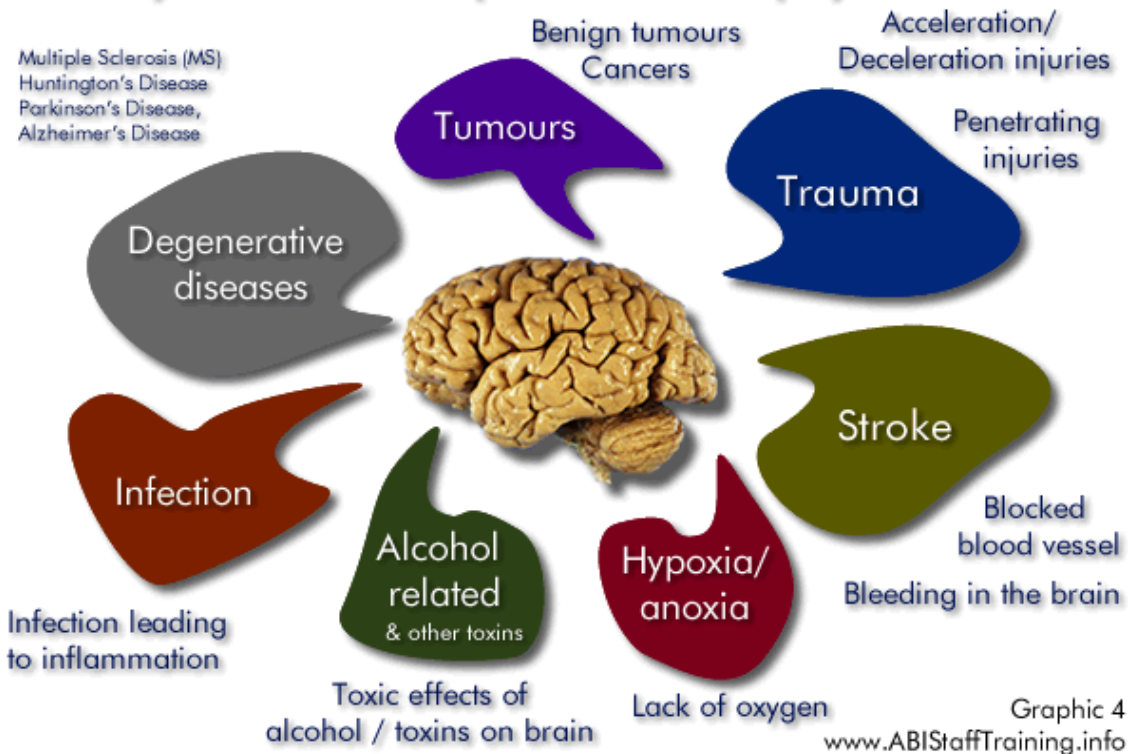
## 2. Graphics handouts: Introduction to Acquired Brain Injury



## What is acquired brain injury?

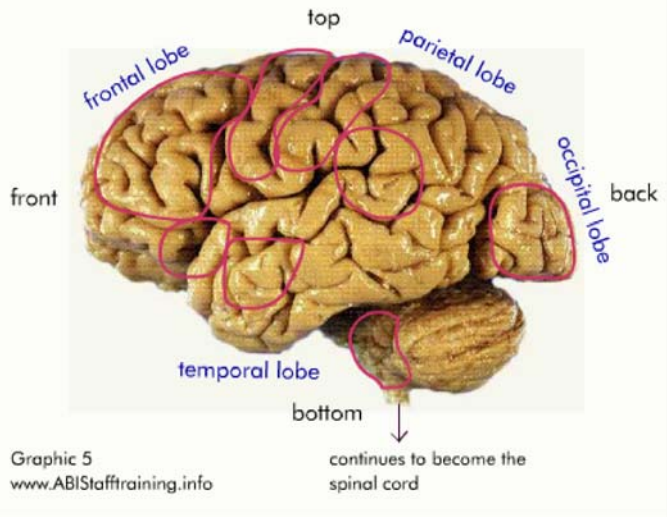


## Primary causes of acquired brain injury





## The brain - lobes & functions



## ABI: Severity



Common categories for sudden onset ABI

Mild

e.g. good physical recovery, limited concentration, able to go back to previous work

Moderate

e.g. motor coordination difficulties, inability to organise, may require different work

Severe

e.g. decreased ability or inability to control movement, decreased ability or inability to communicate, requires support with daily living, possibly not able to work or requires support programs to work

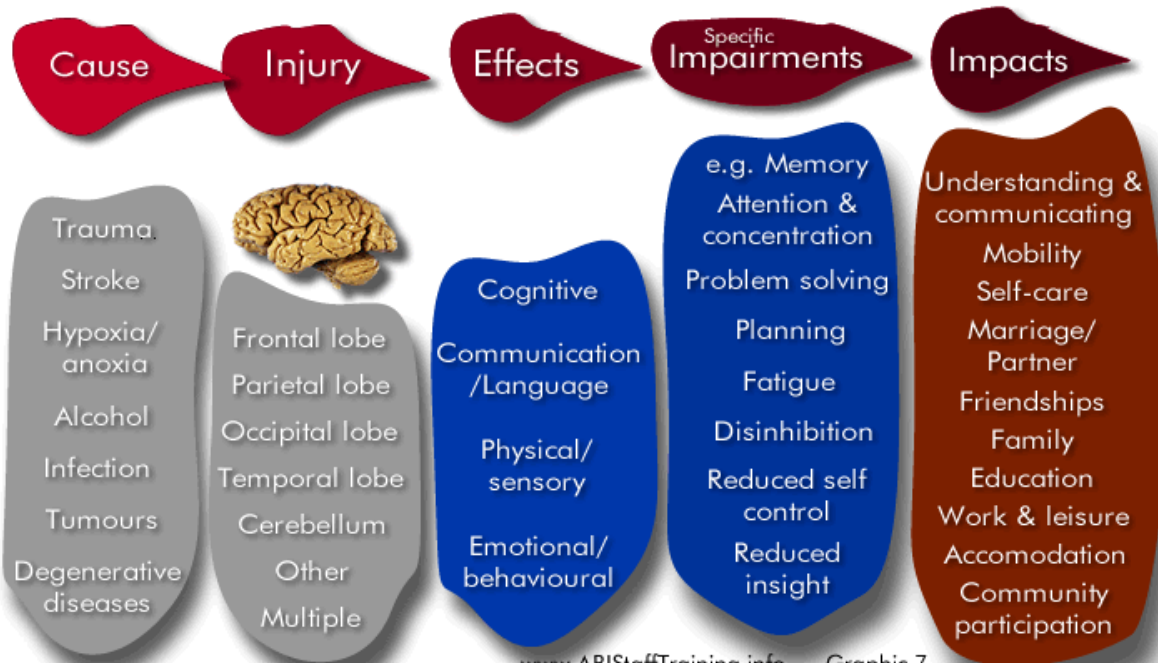
Very severe

e.g. inability to control movement, inability to communicate, requires 24 hour support

www.ABISstafftraining.info Graphic 6

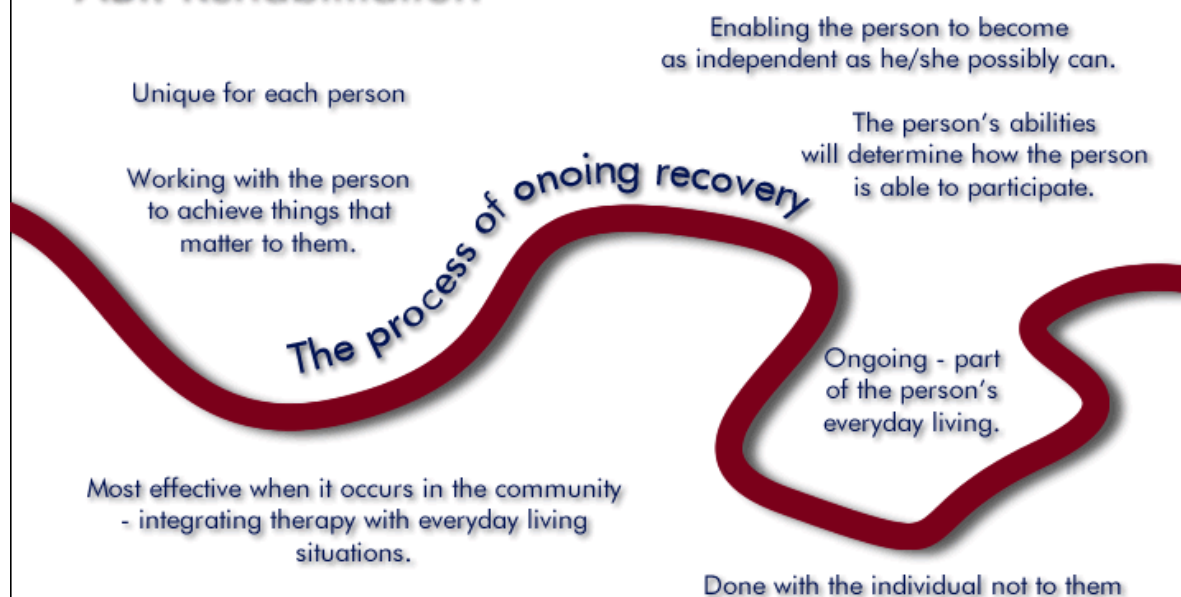
# ABI: Cause to impact

Individuals 1 2 3 4 5



www.ABIStaffTraining.info Graphic 7

# ABI: Rehabilitation

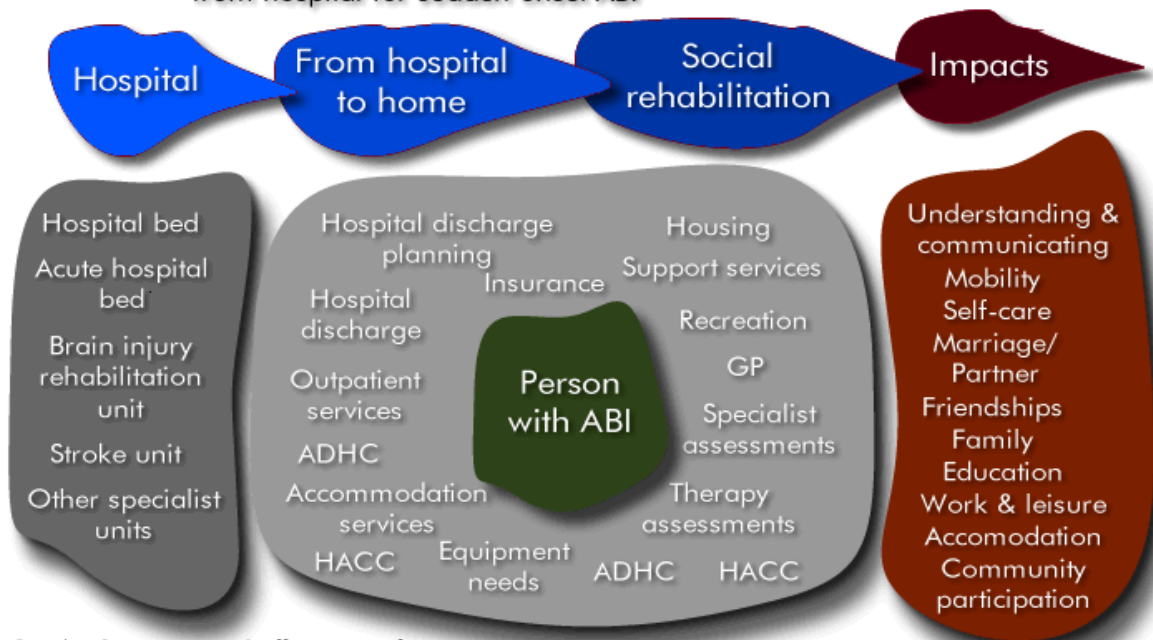


www.ABIStaffTraining.info Graphic 8

# ABI: Rehabilitation stages

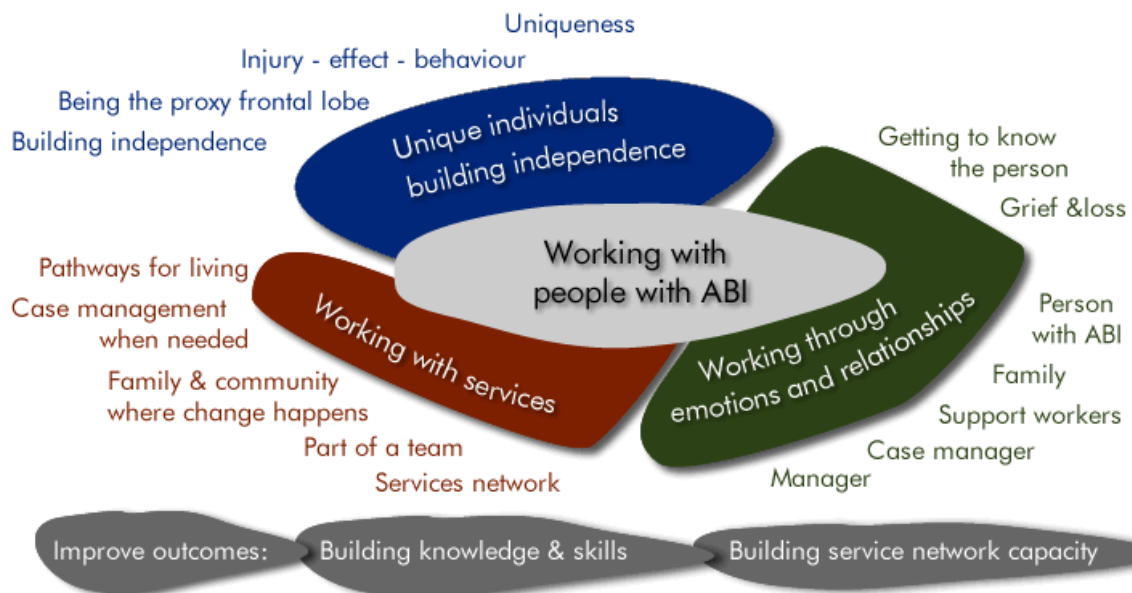
from hospital for sudden onset ABI

Individuals 1 2 3 4 5



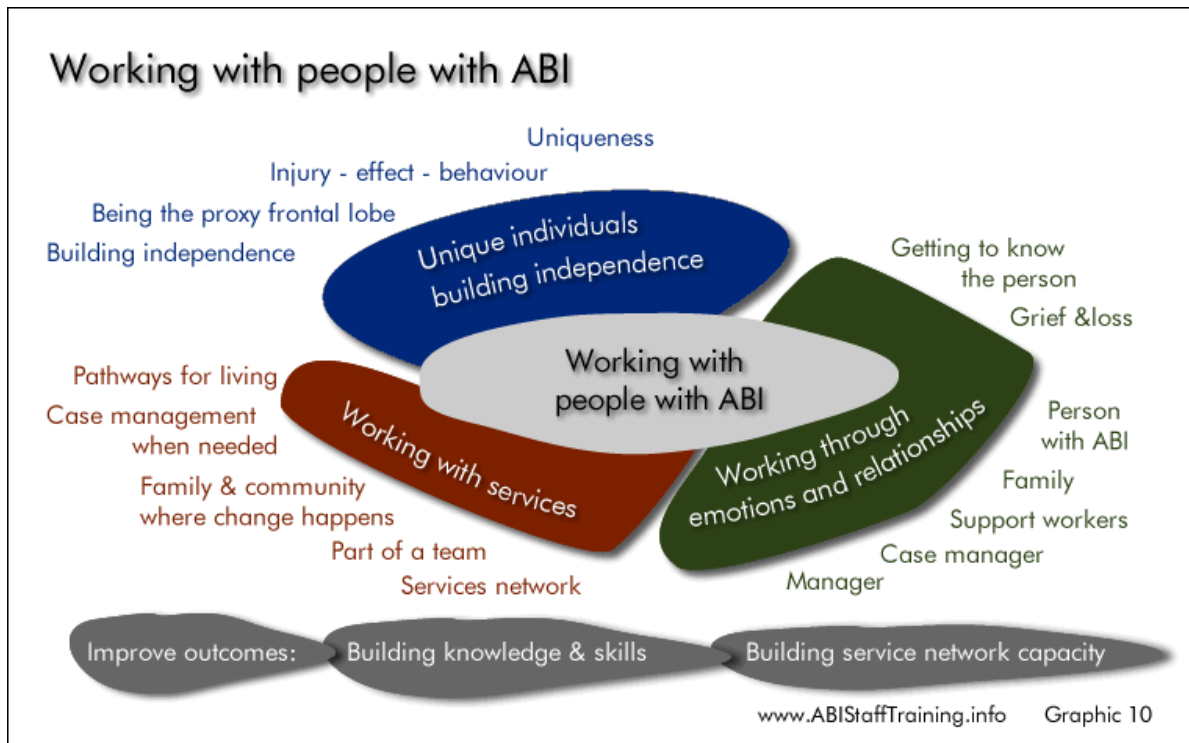
Graphic 9 www.ABIStaffTraining.info

## Working with people with ABI



www.ABIStaffTraining.info Graphic 10

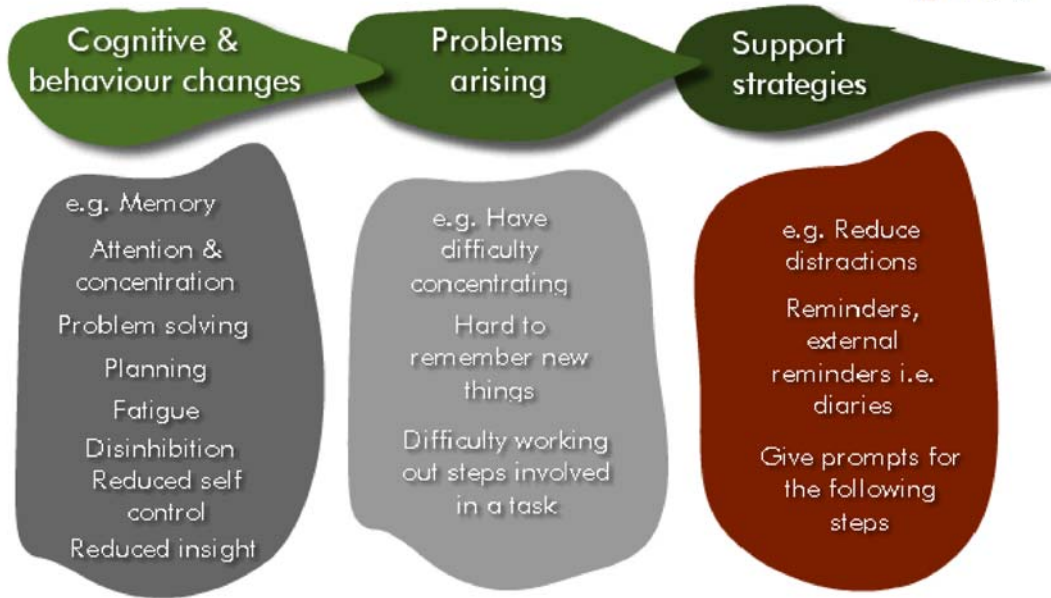
### 3. Graphics handouts : Working with people with ABI



## ABI: Cognitive and behaviour changes - problems - support

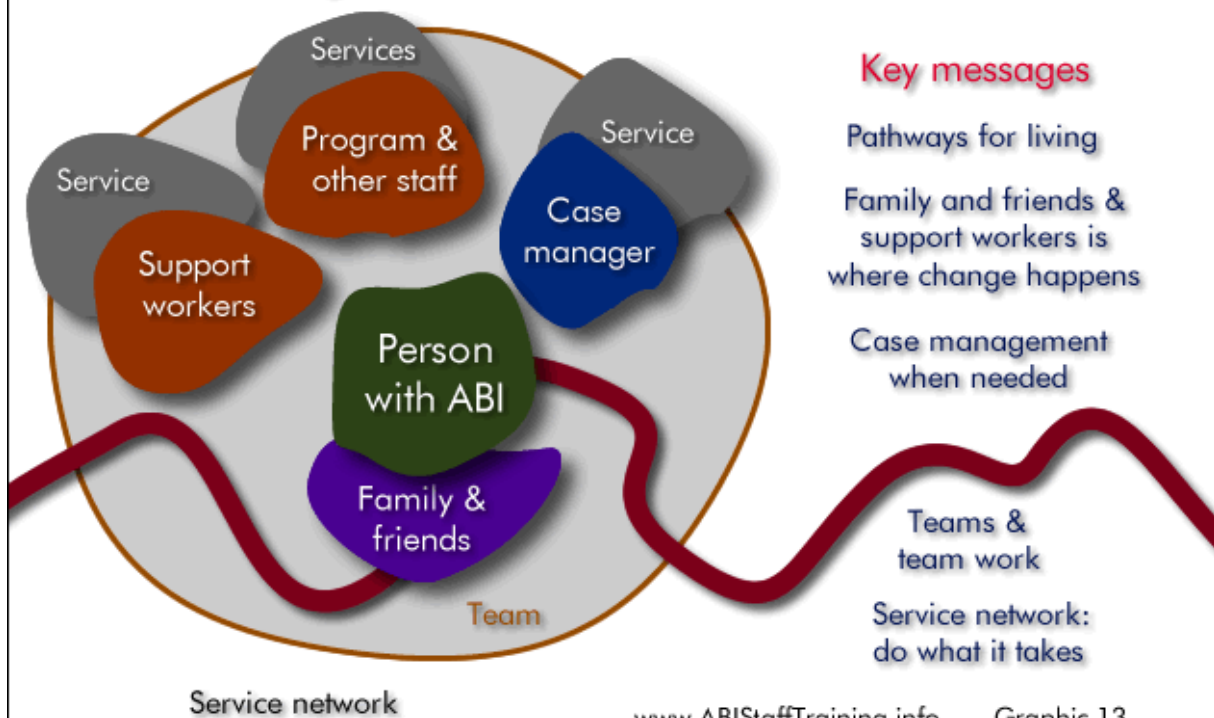
Examples

A B C D



www.ABIStaffTraining.info Graphic 12

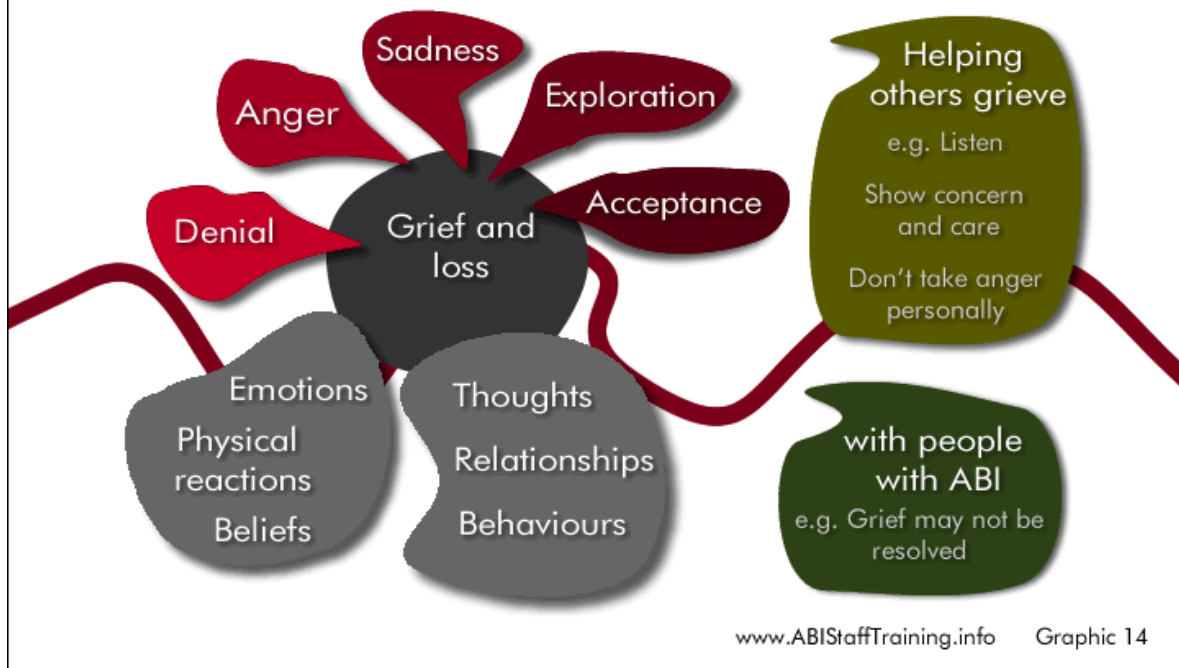
## ABI: Working with services



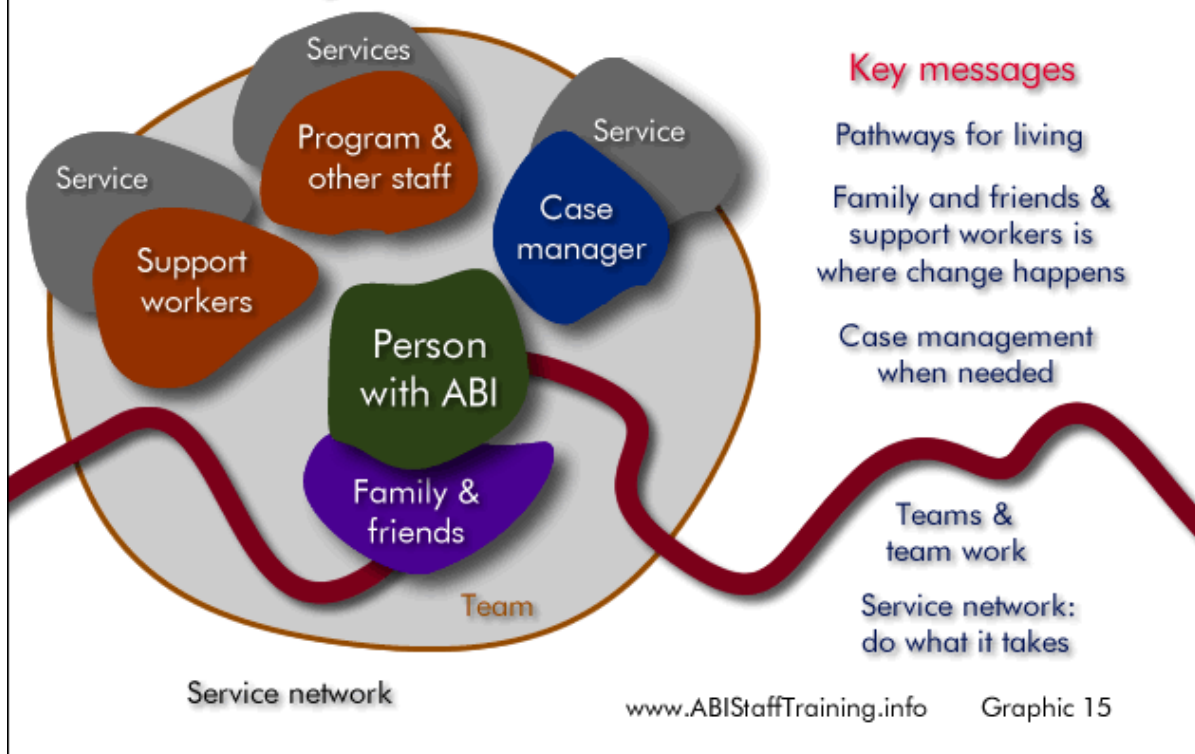
www.ABIStaffTraining.info Graphic 13



## ABI: Grief and loss

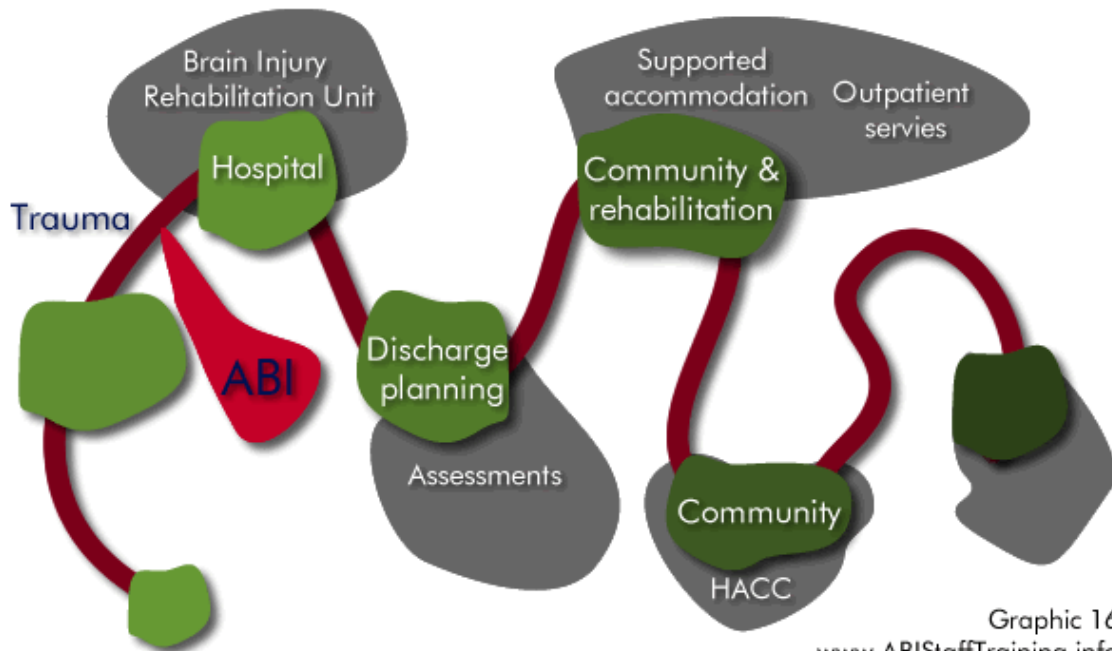


## ABI: Working with services



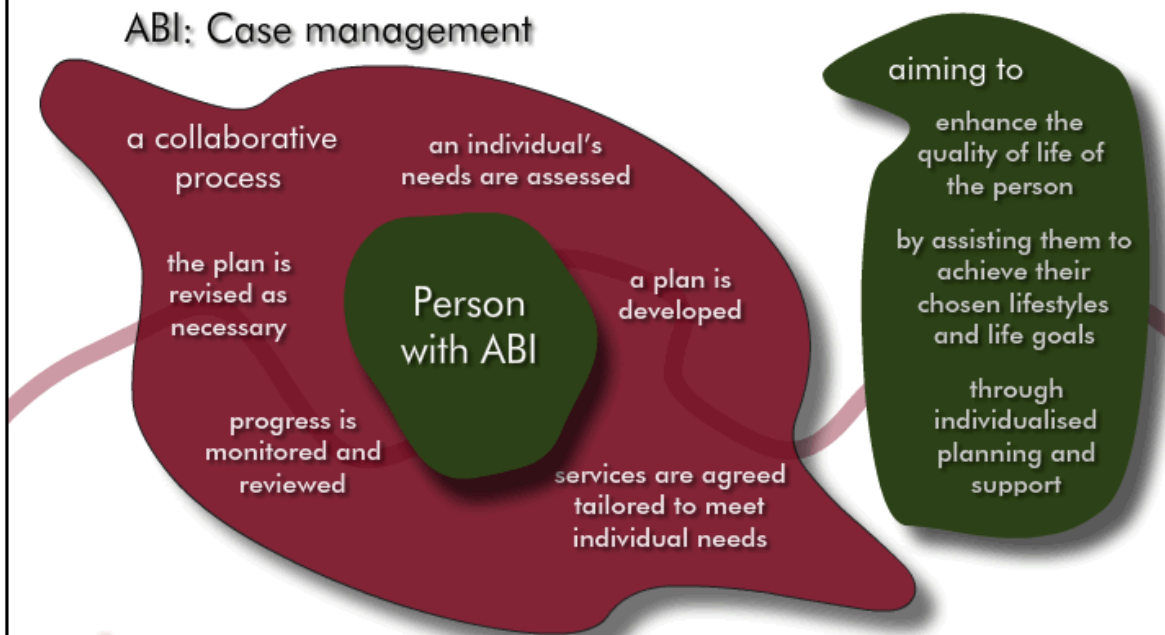
# ABI: Service pathways

Individuals 1 2 3 4



Graphic 16  
www.ABIStaffTraining.info

# ABI: Case management



A B C D E

www.ABIStaffTraining.info Graphic 17

## ABI: Roles and practice tips



### Practice tips

- Open to the possibility of a person having an ABI
- Conversations tips
- Indicators of ABI
- Strategies for working with cognitive changes
- Case managers issues checklist
- Sources of information
- Individual program plan
- Tips for setting goals
- Disillusionment process
- Preventing stress
- Essential survival tips

www.ABISTaffTraining.info Graphic 18

## ABI: Building knowledge & skills and service capacity

### Self study modules and resources



- Understanding ABI**
- Working with people with ABI**
- Building independence**
- Building trust, relationships & understanding**
- Goal setting**
- Strategies for working with cognitive changes**
- Communication**
- Sexuality**
- Case management**

### Service network capacity

- Service pathways & networks**
- Workplace learning**

www.ABISTaffTraining.info Graphic 19



## E. Video stories and video clips

### 1: Video stories

There are 8 video stories. They range in viewing time from 3 minutes to 11 minutes.

Each is a **stand alone short story**.

The video clips provide more in depth background material around each of these 8 video stories.

Collectively the 8 video stories provide the viewer with an introduction to a wide variety of people with a wide variety of ABIs.

At a staff meeting one or two of these video stories could be used to introduce the topic *What is ABI?* In a one day Workshop one might use 1 or 2 or the video stories in each session so that participants see 6 or 7 video stories in a one day workshop.

The videos are all available from the web site [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info)

#### 1. Jonathan (11 mins)

Jonathan was hit by a car when he was 12 years old. He had a severe traumatic brain injury. At the time of the injury he had a very poor prognosis - unlikely to regain any previous function. He had extensive rehabilitation. He is now in his mid 20's living with his family. He is learning to drive and has several part time jobs.

#### 2. Ian (9.5 mins)

Ian was an electrician. He has two children. He had a stroke while at work about 20 years ago. He is now in his 50s'. He has spasticity down the right side of his body and memory and speech problems. He now lives by himself in supported accommodation. His parents are also an important support.

#### 3. Gabby (3.5 mins)

Gabby worked in workers compensation. She was a tri-athlete. She is in her mid 30s. She was training on her bike for her first iron man triathlon and was hit by a car 10 months ago. She has optical, memory and concentration issues. She lives with her parents.

#### 4. Ray (5 mins)

Ray had a heart attack in a fun run and suffered hypoxic brain injury. He was in his mid 40s. He is now 50. He has returned to work and driving. He has some cognitive impairments. He was married. He now lives by himself.

#### 5. Gabrielle (11 mins)

About two and a half years ago Gabrielle went to a beach party and then back to her friend's unit. She fell over a balcony railing onto a concrete garage roof four floors below. She was in a Brain Injury Unit for about 7 months. She is 18, living at home and finishing Year 12.

#### 6. Scott (5 mins)

Four and a half years ago at the age of 25 Scott suffered an hypoxic brain injury. He had an extremely severe brain injury. He has severe mobility and communication problems. His muscles have atrophied. He is now confined to a wheelchair and has 24 hour support.

#### 7. Andrew (4 mins)

Andrew is in his 40s. He was a pedestrian in a car accident about five years ago. He had a partner. He has children. He has cognitive and behaviour issues. He now lives in supported accommodation with 24 hour support.

#### 8. Wazza (10 mins)

Wazza was in a car accident about 30 years ago. He was in hospital for a number of years. He has mobility and memory problems. He can't walk for long periods. He now lives in supported accommodation with another person who also has a brain injury. He gives talks in the community to educate people about the impact of driving offences causing accidents.

## 2: Video clips

These 22 short video clips vary in length from 45 sec to 6 minutes. They are all available from the web site [www.ABIStaffTraining.info](http://www.ABIStaffTraining.info).

These video clips provide more in depth background material around each of the 8 video stories in the previous section c) Video stories.

The video clips are all embedded in the two self-study modules in the web site.

They are clips of people with ABI, support workers, case managers and family members talking about their experiences and what they have learnt.

In the self-study modules they are linked with other learning materials.

The ones marked with an \*\* are longer and would be especially useful to view in a workshop or a staff forum as a stand alone video on a specific topic.

The shorter ones are useful discussion starters on specific topics.

The title of each video clip includes who is speaking and the topic under discussion.

All video clips that are directly referring to the people in the video stories begin with the name of the person in the video story.

### **Clip 1 : Andrew's Support Worker : Challenges. (1 min)**

The challenges of being a support worker.

### **Clip 2 : BIU Case Managers : Role & service process (2 min)**

Being a Brain Injury Unit case manager: roles and service processes

### **Clip 3 : BIU Case Managers : Challenges on Discharge (1 min)**

The challenges on discharge from a Brain Injury Unit.

### **Clip 4 : BIU Case Managers : Specialist Roles. (1 min 45 sec)**

The specialist roles working with people in the Brain Injury Unit and also in moving back into the community

### **Clip 5 : Gabby : Before and After (2min 30 sec) \*\***

Gabby describing how she was before the accident and how she is after the accident.

### **Clip 6 : Gabby's Mother : Service Pathway (3 min)**

Gabby's mother describing Gabby's service pathway.

### **Clip 7 : Ian's Parents : Event, Impact, Learnings, Hope (6 min) \*\***

Ian's parents talking about the event that caused the ABI, the impact that it had, what they have learned and what they are hoping for.

### **Clip 8 : Ian's Support Worker : Unique & Getting to Know (45 sec)**

People with ABI are unique and it takes time to get to know them.

### **Clip 9 : Ian's Support Worker : Not Personal (1 min 45 sec)**

It is important not to take things personally when working with people with ABI.

### **Clip 10 : Case Manager : Learnt in 6 Months (1 min 20 sec)**

A case manager talking about what they have learnt about case managing people with ABI.

### **Clip 11 : Case Manager : Clients In Community (1 min 45 sec)**

A case manager talking about people with ABI's experiences in the community.

### **Clip 12 : Case Manager : Friends (1 min)**

A case manager talking about people with ABI and friends.

### **Clip 13 : Jonathan & Mother : The Story (7 min)**

Jonathan's mother (& Jonathan) talking about what happened - the impact, rehabilitation, etc

### **Clip 14 : Jonathan & Mother : 2 The Emotional Impact (3 min 40 sec) \*\***

Jonathan's mother (& Jonathan) talking about the emotional impact of what happened.

### **Clip 15 : Jonathan's Mother & Father : Paper Cranes (3 min 45 sec) \*\***

Jonathan's mother (& father) talking about the value of writing a diary and how it turned into the book Paper Cranes.

**Clip 16 : Case Manager ABI and Disability (2 min)**

A case manager talking about the difference of case managing people with ABI and people with disability.

**Clip 17 : Case Manager : Experience Of Case Management (6 min) \*\***

A case manager talking about the experience of what it is like being a case manager.

**Clip 18 : Case Manager : Role As Case Manager (2 min)**

A case manager describing her role as a case manager.

**Clip 19 Scott's Worker : Role & What Others See (1 min 45 sec)**

Scott's worker talking about his role and how other people see Scott.

**Clip 20 Wassa's Support Worker : Before and after (1 min)**

Wassa's support worker talking about before and after the ABI.

**Clip 21 Wassa's Support Worker 2: Tips for new workers (1 min)**

Wassa's support worker suggesting tips for new workers.

**Clip 22 Wassa's Support Worker 3: People with ABI are different (45 sec)**

Wassa's support worker talking about how people with ABI are different / unique.