LOOKING FORWARD
ACQUIRED BRAIN INJURY

arbias

INTRODUCTION

Looking forward is a handbook for supporting people with acquired brain injury. It gives a basic introduction to brain injury and the challenges involved for people living with acquired brain injury.

It offers practical advice and strategies to enable practitioners to empower people to achieve their full potential.

PREVENTION

To identify and address factors leading to acquired brain injury including alcohol and other drug related brain impairment.

INTERVENTION

To provide immediate services through secondary consultation and crisis intervention.

TREATMENT

To provide a range of specialist services for people with acquired brain injury including alcohol and other drug related brain impairment and associated complex needs.

AWARENESS RAISING

To actively promote issues of acquired brain injury including alcohol and other drug related brain impairment with policy makers, service providers and the community.

EDUCATION

To develop and enhance the knowledge and skills required to work effectively with people living with an acquired brain injury including alcohol and other drug related brain impairment.

RESEARCH

Undertake research in acquired brain injury including alcohol and other drug related brain impairment which informs current and future service provision and policy development.

arbias "enabling our people and our partners to achieve their very best."

This is an information book on Acquired Brain Injury (ABI) for people working in the sector. This book provides the most up to date information in the area of ABI. The original book, 'Looking Forward' was developed with the assistance of a variety of representatives from the ABI, alcohol and other drug and health sectors.

arbias specialises in ABI in Australia and is the primary national provider specialising in the area of alcohol and other substance related brain impairment.

arbias provides information, training and consultancy services to health care professionals across Australia and internationally. In Australia, arbias provides services to over 3,000 people each year in the area of neuropsychological assessments, case management, accommodation and community support.

Whilst arbias continues to provide information and support to people living with ABI and the people who support them, prevention through activities such as education, awareness raising and research will also continue to be a strong focus for our services into the future .

All information relating to ABI cannot be contained within the one book therefore I encourage you to access arbias at www.arbias.org.au. The website provides up to date information in relation to ABI and ARBI, as well as referral processes, contact information and literature.

John Eyre
CEO

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WHAT IS ACQUIRED BRAIN INJURY?

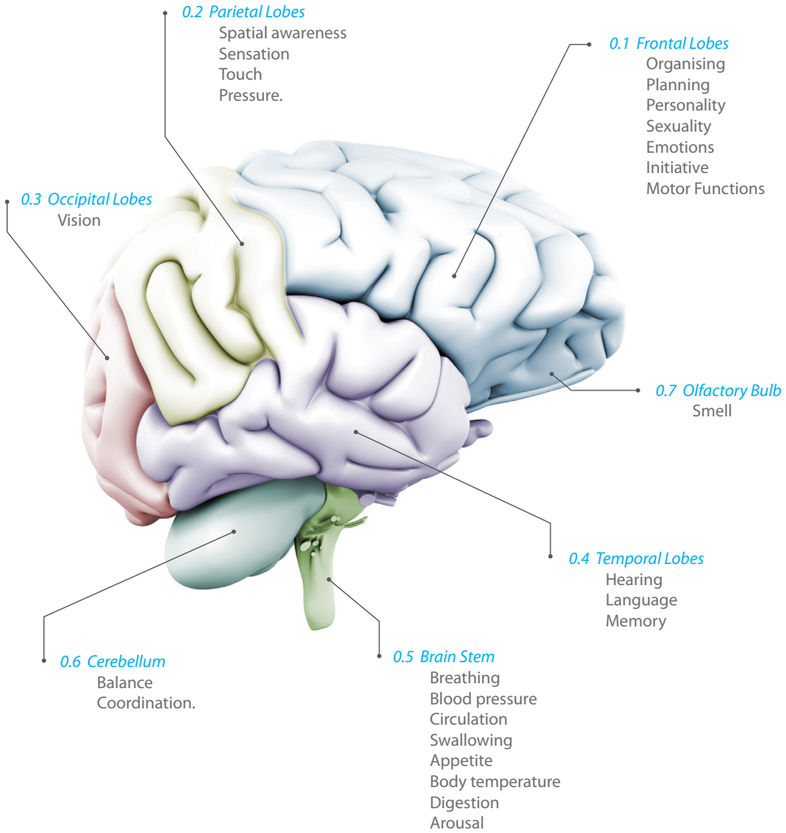
THE BRAIN

The Brain is made up of billions of nerve cells (neurons) which control everything we do, from the most basic bodily functions such as breathing to our most complex functions. All physical movement, sensation, cognition, emotions, behaviour and bodily functions are controlled by the brain and nervous system and can therefore be affected by a brain injury. The effects of an injury will depend on which part of the brain is injured and the severity of the injury.

The brain is an incredibly complex organ we are yet to fully understand. It is divided into the left and right hemispheres, the cortex of which are each divided into four lobes. Each lobe functions as part of the highly integrated brain but handle specific areas of function. It is this localisation of function which gives rise to the enormous variation of disabilities suffered.

ACQUIRED BRAIN INJURY

- Acquired brain injury (ABI) refers to any damage to the brain that occurs after birth, regardless of the cause.
- May also be referred to as Brain Injury (BI), Traumatic Brain Injury (TBI), Alcohol Related Brain Injury (ARBI), Substance Related Brain Injury (SRBI) or Head Injury (HI) depending on the cause of injury.
- Results in deterioration of cognitive, physical, sensory, emotional or independent functioning.
- The impairment to functioning may be temporary or permanent, and the effects and their severity will depend on which area of the brain is injured.
- ABI is not the same as an intellectual disability, mental illness or dementia (but can be present in addition to these diagnoses in a duel-disability)
- In some cases the disabilities may be severe and obvious, even life threatening. Other cases may be subtle, often going undetected.
- Onset may be instant, for example stroke or road accident, or spread over many years, for example ARBI.



CAUSES OF ABI

Traumatic Causes

- Accidents – including Traffic accidents, Work or Sports related accidents, and falls resulting in a blow to the head.
- Assault.

Non-Traumatic Causes

- Stroke.
- Brain Tumour.
- Infections such as meningitis, encephalitis.
- Prolonged Substance Abuse – alcohol and/or other drugs.
- Hypoxia (lack of oxygen) e.g. electrocution, near drowning, suicide attempt, cardiac arrest, drug overdose.
- Degenerative neurological conditions, such as Multiple Sclerosis, Motor Neurone Disease, Huntington's Disease, Parkinson's Disease.

PREVALENCE

ABI is sometimes referred to as the hidden disability as it often goes undetected, undiagnosed, and unreported. The incidence and prevalence of Acquired Brain Injury is therefore notoriously difficult to quantify.

The following estimates were published in 2003 (AIHW)

- ABI is recognised as a major disability group Australia.
- Approx. 1 in 45 Australians (438,300 people in 2003) have an ABI. This is approximately 2% of the population.
- Almost three-quarters of these people are aged less than 65 years
- ABI prevalence rates increase with age
- Prevalence rates are significantly higher for males than females.
- Approximately 20,000 children under 15 years of age have an ABI.
- Stroke is largest sub group of ABI.

DIAGNOSIS

CT or CAT scans (Computerised Axial Tomography) and MRI (Magnetic Resonance Imaging) testing can detect the site and extent of many brain injuries. They are not always able to detect small but important areas of damage. The best measure of the severity of an ABI is by assessing the impact it has had on a person's functioning.

People with an ABI will often present with preserved functioning of immediate and long terms memory, well learned skills, knowledge of facts and intact vocabulary. Neuropsychological Assessments can assist in diagnosing ABI and will assist the person, their carers and people working with them in knowing how to best support them.

Neuropsychological Assessments are conducted by neuropsychologists using a range of tests to provide very detailed information about how an injury is affecting the brain. Tests examine things like memory, problem solving skills, ability to concentrate, etc. The test results also identify preserved strengths and skills and are useful when designing support plans & providing strategies for individuals.

What Information is Provided in a Neuropsychological Report?

Neuropsychological reports vary according to referral questions and individuals. However, the following information should be available from most Neuropsychological Reports:

- A description of cognitive deficits - the nature and severity of each
- A description of preserved skills
- A diagnosis
- A detailed description of the functional implications of the cognitive deficits
- A description of support needs
- Strategies for compensating for cognitive impairment
- Recommendations for rehabilitation or case management as necessary
- Referral to other services if necessary

PROGNOSIS

Improvement and recovery following an ABI is very difficult to predict. Some people recover fully while others remain the same or deteriorate further. Research indicates the most significant improvement following a TBI will occur within the first twelve months, but improvement can continue slowly for a few years.

Other factors affecting the prognosis include:

- The cause of ABI
- The severity of ABI
- The age and health of the person with the ABI
- If further damage is occurring (alcohol, medications, drugs, trauma)

Even taking all of these factors into account it is nearly impossible to accurately predict an individual's rate and extent of recovery.

Alcohol Related Brain Impairment (ARBI).

ARBI is a term used to describe the physical injury to the brain sustained as a result of alcohol consumption. Having ARBI is not the same as having an intellectual disability, nor is it the same as having dementia.

How does Alcohol use Result in Brain Impairment?

- Alcohol has a toxic effect on the central nervous system
- It causes changes to metabolism, heart functioning and blood flow
- It interferes with the body's use of thiamine (vitamin B1, an important brain food)
- It is often associated with a poor diet
- It can cause dehydration which may lead to cell death
- It can lead to falls that injure the brain.

Cerebellar Atrophy

Impairment to the part of the brain called the cerebellum causes balance and coordination difficulties which typically affect the lower limbs and results in a wide-based gait (walking with the legs wide apart) called ataxia.

Peripheral Neuropathy

Peripheral neuropathy is a sensory disturbance affecting the hands, feet and legs. It usually begins in the feet with numbness, pins and needles, burning sensations and pain, and may progress to loss of knee and ankle reflexes and muscle wasting.

Disorders associated with ARBI

The degree of brain impairment resulting from excessive alcohol consumption depends on many factors, including the amount and pattern of consumption, age, sex, nutrition and individual differences. ARBI may be mild, moderate, severe or very severe. ARBI is associated with changes in cognition (memory and thinking abilities), difficulties with balance and coordination and a range of medical and neurological disorders. The following are common disorders related to ARBI.

Hepatic Encephalopathy

Hepatic encephalopathy is the neuropsychiatric syndrome seen in patients with liver disease. The syndrome features changes in sleep, mood and personality. Impairment and fluctuation of consciousness is accompanied by confusion, delirium and hallucinations and in the latter stages will progress to coma.

Executive Dysfunction

Impairment to the frontal lobes of the brain results in changes in thinking patterns, behaviour and personality. Executive dysfunction makes it difficult for people to plan and organise, to monitor and control behaviour, to think flexibly, and to adapt to change or unfamiliar situations. Frontal lobe dysfunction is often an early sign of ARBI, while memory function is intact.

Wernicke's Encephalopathy

Wernicke's encephalopathy is the acute neurological reaction to severe thiamine (Vitamin B1) deficiency and is characterised by disturbances of vision, ataxia, and global confusion. It may be reversed by large doses of thiamine, but left untreated may progress to coma and death.

Korsakoff's Amnesic Syndrome

Korsakoff's amnesic syndrome is a profound impairment of short term memory that results in an almost complete inability to acquire any new information. An associated feature is confabulation, or tendency to fabricate missing memories.

SUBSTANCE RELATED BRAIN IMPAIRMENT.

Substance related brain impairment (SRBI) is physical damage sustained by part or parts of the brain as a result of drug or substance use. The cognitive and physiological effects of volatile substances, cannabis, stimulants, opiates and benzodiazepines are detailed in this section.

Volatile substances

Volatile substances (sometimes called solvents or inhalants) are compounds which give off a vapour or fumes at room temperature and include petrol, glue, paint, varnish and varnish removers, and aerosols. The recreational sniffing of solvents has become relatively common, particularly amongst adolescents in Australia, with the mean age of solvent use initiation being 17. Solvent use frequently occurs while the central nervous system is still in the process of developing.

Acute effects

Euphoria, slurred speech, nausea & vomiting, ataxia, drowsiness, dizziness, increased salivation, hallucinations, delusions, convulsions, aggression, confusion, slowed thinking, drowsiness, disinhibited behaviour.

Long term effects

Memory impairment, paranoia & psychosis, reduced insight and judgement, decreased attention, reduced ability to reason, reduced capacity for abstract and complex thinking. Overdose with respiratory arrest can result in hypoxic brain impairment

Cannabis

The active ingredient in cannabis, tetrahydrocannabinol (THC), is fat soluble and may stay in body stores for as long as 6-8 weeks following ingestion. There is evidence to

suggest THC accumulates in body stores and is related to acute and chronic psychiatric reactions. Studies addressing the long term effects of heavy cannabis use on the brain have shown it to be related to deficits of focused attention; that is the ability to screen out irrelevant information.

Acute effects (up to 24 hours after)

Increased self confidence; relaxation; euphoria; difficulty sustaining and dividing attention; memory problems; altered time and space perception and motor coordination; dissociation of ideas; delusions & hallucinations.

Long term effects

More longitudinal research is required to map the long term cognitive effects of chronic cannabis use.

Stimulants

Stimulants, including amphetamines, ecstasy and cocaine have surprisingly received little research attention. The most commonly used amphetamines in Australia, in decreasing order of potency, are dexedrine, methedrine and benzedrine. Ecstasy is a derivative of amphetamine.

Acute effects

Restlessness, euphoria, anxiety, repetitive behaviours, slowed thinking, decreased attention, disinhibition, aggressiveness, agitation, psychotic symptoms.

Long term effects

Distractability, difficulty in sustaining and dividing attention, working memory, reasoning and impulse control associated with changes in neurotransmitter systems, insomnia, psychiatric disturbances, depression. Overdose with respiratory arrest can result in hypoxic brain impairment.

Opiates

Opiates include heroin and heroin derivatives. The research on the long term effects of opiates is limited. Some researchers have found long term opiate users to have impaired visuospatial and visuomotor functions. Other research has related long term use of opiates to high level cognitive impairment affecting the brain's ability to integrate and coordinate a range of cognitive skills.

Acute effects

Euphoria, analgesia, nausea & vomiting, calmness, pinpoint pupils, sleepiness, shallow breathing.

Long term effects

Constipation, blood poisoning, risk of blood borne viruses, risk of death via overdose, risk of hypoxic brain impairment following overdose.

Benzodiazepines

Benzodiazepines or minor tranquillisers, are the most commonly used psychotropic drugs in the Australian community.

Benzodiazepines may be associated with disorders of concentration and memory.

Acute effects

Drowsiness, muscle weakness, slowed thinking, attention, memory, coordination, blurred vision, slurred speech, ataxia, nystagmus, dilated pupils, lowered impulse control.

Long term effects

Impaired attention & concentration, impaired short term memory and learning ability & visuospatial skills. Overdose can cause respiratory arrest resulting in hypoxic brain impairment, particularly in combination with alcohol or other substances.

Idiosyncratic Reactions

Some drugs may cause idiosyncratic responses. This means that some individuals have an increased susceptibility to adverse drug reactions for reasons yet unknown. For example, clinical and research observations have found that some individuals are particularly prone to psychosis induced by cannabis. Similar observations have been made in users of amphetamines.

Cocktail Effects

An inherent danger for all drug users is the potential effect caused by interaction with other drugs, medication and alcohol. A medical practitioner is the best person to seek advice from regarding any interactive effects of drugs.

Research

Further research is necessary to clearly establish the long term effects of many drugs on cerebral functioning. There are many variables that make it difficult for researchers to study the casual relationships between drug use and brain impairment. Poly drug use in particular can make it difficult to study the effects of individual drugs. In reading this information it is important to keep in mind that significantly more research is required to complete our understanding of the impact of substance use on the brain.

STRENGTHS AND DIFFICULTIES FOLLOWING ABI

COMMON DEFICITS ASSOCIATED WITH ABI

The range of difficulties associated with Acquired Brain Injury is diverse and as individual as the people suffering them. ABI is sometimes referred to as a 'hidden disability' and is often undiagnosed especially among people who have a mild disability or where onset has been very gradual. In other cases it is anything but hidden as the person, their family, friends, and support workers struggle to cope with the challenges involved. All ABI's can, however, result in significant restrictions on an individual's ability to participate fully in education, employment, relationships and other aspects of life.

People may experience one, or a combination of the following:

SENSORY
Visual impairments
Hearing loss
Loss of Smell
Loss of Taste
Body Temperature disturbance
Chronic Pain

PHYSICAL
Paralysis –total or partial
Fatigue
Limb weakness
Visual-motor dis-coordination
Tremor
Headaches
Seizures
Balance disturbance

COMMUNICATION
Slurred speech
Reading/writing difficulties
Expressive disorder
Word finding difficulties
Difficulty understanding

COGNITIVE
Mental Fatigue
Poor Concentration
Memory Loss
Planning difficulties
Problem solving difficulties
Reasoning difficulties
Difficulties with learning
Initiation difficulties

BEHAVIOURAL/PSYCHOSOCIAL
Disinhibition
Verbal Abusiveness
Physically aggressive
Increased Impulsivity
Sexually inappropriate
Agitation
Depression
Emotional instability
Irritability
Inappropriate behaviour
Paranoia
Loss of self-awareness

MARK'S STORY

Husband, brother, son, uncle, dog-lover, health care professional, cycling enthusiast.

It was lovely and sunny on the first day of Mark's long service leave so he was looking forward to a long bike ride, but it was tragically cut short. He was hit from behind by a motorist who didn't see him until it was too late. Mark was flung into the air before crashing head first onto the road. He was quickly airlifted to the hospital for emergency brain surgery but the prognosis wasn't good. Mark was in a coma in ICU. As the days became weeks, Mark's family were being prepared for the worst.

The neurosurgeon told Greg's wife, Claire that the damage to Mark's brain was so severe and diffuse that there was no possibility that he would ever regain consciousness. Claire refused to believe this and sent him packing.

On day 27 after the accident Mark regained consciousness. Although very confused at first Mark steadily improved. He was moved out of ICU and began rehabilitation. After 12 weeks in hospital Mark was discharged.

Mark has left sided weakness, balance and coordination difficulties and double- vision. He has difficulty with initiating activity, planning ahead and learning new information. Claire has left her job to care for Mark at home. Mark's other cognitive and social skills, including memory and language, are preserved.

Support for Mark includes outpatient rehabilitation twice weekly, counselling sessions with the psychologists, and a support worker twice weekly to relieve Claire. As time goes on and rehabilitation finishes support requirements will be reviewed.

Mark is aware of the severity of his brain injury and is grateful for the amazing recovery he has made against all odds. He knows the outcomes could have been much worse but still he can't help but ask "why me?" He is tired of people saying "aren't you lucky!" when they see him, but he bites his tongue and smiles politely. He will probably never work again, he will never drive again, he feels guilty that Claire gave up her job and has to shoulder most of the burden of his care, his movement is restricted and doing anything is mentally fatiguing. He says that when the doorbell rings and it takes so much effort, mentally and physically, for him to struggle the door that he collapses back into the chair exhausted, he feels anything but lucky.

MEMORY

Memory disturbance is a common consequence of Acquired Brain Injury. Memory is the result of many complicated processes including acquiring, encoding and retrieving information. There are different types of memory and different areas in the brain which contribute to the processes, therefore memory disturbance can takes many forms.

1. Immediate memory
Short pieces of information held for a matter of seconds, eg; the ability to repeat back information immediately or holding a conversation.

2. Short term memory (STM)
To lay down a permanent memory trace, information is stored in STM. STM capacity is a person's ability to form new memories, learn new skills and information and retrieve information when needed. STM allows people to remember things day to day, week to week.

3. Long Term Memory (LTM)
Stores information, events knowledge and skills acquired in the past. For example life events, reading and writing ability, words and vocabulary and skills learned at work.

To explain the basics of how memory works we can use the analogy of a computer. Think of the screen as your attention and the information displayed on it is what you are thinking about.

You enter information onto a document on your screen. As you type in the information you can see what you have written. But as you type more and more the page will move up so you can now only see the latest information you wrote.
→ *mmediate memory is limited.*

If we do not press "save" the information will be gone when we close the document. We can save some information to the desktop by pressing the save button and giving the information a name or code.The more meaningful and organised your system is the easier it will be to retrieve the information.
→ *We encode memories using various techniques. If encoding does not occur no new information will be remembered.*

Info stored on the desktop is easily retrieved when needed. Short term memory allows us to use memories from day to day or week to week. Sometimes we organise our documents into files which are stored away until we need them. Usually we only create files for things that are important to us.
→ *Some Information and events knowledge are stored in long term memory.*

We use the computers tools to automatically help us work so we don't have to concentrate on repetitive tasks. For example auto spell check will attend to the spelling leaving us free to focus on what we want to type.
→ *Learned skills or procedures, for example tying a shoelace or touch typing, are also stored in long term memory, but are used without having to consciously think about them.*

To retrieve information from our computer and bring it back to the screen we need to locate it. Sometimes we have trouble locating information among the many files so we need to use a strategy to help. Scrolling though the file names or using a search can help.
→ *Memory failure can be the inability to retrieve stored information. Sometimes strategies can be useful.*

Sometimes we just can't find a file and so some information may be unavailable to us.
→ *Some memory failure is periodic. For example a person may not be able to recall the last ten years but has clear memories of events prior to this, or there may be a "gap" where memories cannot be recalled.*

If we lose a file but need the information it contained we occasionally try to replicate the document. Sometimes the new document differs greatly from the original.
→ *Confabulation is the fabrication of memories as a response to an inability to remember*

If something goes seriously wrong with our computer we need to seek help from the IT specialists. We usually resist this option for as long as possible and try every thing we can think of to avoid having to call them!
→ *Neuropsychological testing will determine the type and extent of memory failure and suggest strategies to manage them.*

PRE AND CO-EXISTING ISSUES

DISORDERS OF AWARENESS

Disturbances of executive functioning may result in difficulties in planning ahead; using foresight; organizing information; monitoring, regulating and controlling behaviour; generating ideas; initiative; motivation; abstract reasoning; ability to adapt to change; self-awareness; and impulse control.

This is perhaps the most complicated and frustrating aspect of ABI. Disorders of awareness may also reflect emotional difficulties in adjusting to disability.

Common disorders include:

- Denial of disability – reflects a defence mechanism associated with psychological adjustment to disability.
- Poor insight – ranges from being unaware of one's impairment to being aware of the disability but not appreciating its implications.
- An attitude of unconcern – may appear to be unconcerned about their impairment
- Rationalization – when faced with feedback about cognitive impairment, many people with reduced insight formulate elaborate excuses to explain their problems and behaviour
- Lack of motivation

Some of the difficulties previously discussed can make other problems worse. They can cause:

- Anxiety & Depression
- Confusion
- Problems in dealing with and controlling anger
- Reduced frustration tolerance
- Suspicious or paranoid behaviour
- Refusal of support
- Alienation of family and friends

PRESERVATION OF FUNCTION

Whilst the list of cognitive deficits is lengthy, it is the cognitive functions that are preserved or unaffected that can mask ABI to health workers, the person and their family.

Some skills often preserved:

- Immediate memory and basic concentration
- Vocabulary and language – verbal expression, understanding of language, reading & writing, holding conversations
- Long term memory
- Well learned skills – driving, making a cup of tea, brushing teeth, playing golf, skills required for working
- Knowledge of facts and understanding of the world
- Knowledge of the social world – well-learned social skills, manners and pleasantries (this may not be the case if person is intoxicated)
- Everyday procedures for daily living

ANN'S STORY

Mother, daughter, wife, community leader, artist, chocolate lover.

Ann attended her doctor for a sprained wrist. During the consultation Ann also revealed she felt depressed and was worried her memory was "going". The doctor conducted a thorough examination and noticed old bruising and scarring that raised concerns. The doctor had known Ann for years, having treated her quite often for injuries she never suspected were caused by anything other than "accidents". This time things looked suspicious, so the doctor quizzed a reluctant Ann to discover that the current injury was the result of domestic violence. Ann told the doctor that her husband often beat her, sometimes until she was unconscious. Ann had kept it a secret for years because she was embarrassed and ashamed. She wanted to leave but didn't have anywhere to go. She was terrified of taking the first step. After discussing her options with the doctor, Ann decided on a course of action to secure safer accommodation and end the abuse.

Ann's doctor was able to help her find support and counselling during this difficult time. The doctor was also understandably worried about the ongoing physical damage Ann had sustained, and later suggested a neuropsychological assessment.

The neuropsychological assessment showed that Ann did indeed have a brain impairment. Ann's results showed she had significant difficulties with short term memory, information processing and non-verbal reasoning. The assessment report gave a description of the nature, severity and implications of Ann's cognitive deficits, and strategies to compensate for them. Case management was recommended and Ann received a referral to an appropriate service provider. With Ann's consent the assessment report was shared with everyone involved in supporting her to ensure continuity and encourage the best possible outcome.

COMPLEX NEEDS & PEOPLE WITH AN ABI

The term co-morbid refers to the co-existence of another disorder – in this case, the co morbidity of ABI with other disorders.

People with an ABI may present with a range of co-occurring conditions of varying severity. How they present in a person may impact significantly on their functioning and support outcomes.

Some people will have combinations of:

- Mental illness
- Substance abuse issues
- Intellectual impairment
- Acquired brain injury
- Forensic issues

Often these individuals pose a risk to themselves and to the community and require intensive and individualised support. They face significant social problems, family and relationship difficulties, legal problems and many others. They may also be in contact with a number of different health services that may, or may not have an understanding of ABI. Management of ABI requires a multi-disciplinary approach that includes providing education to other workers about the impairments associated with ABI.

People with co morbidity often present with a more complex and severe profile. This may include poorer general physical and mental health and poorer functioning. It is not only the person and their workers who must cope with this burden, but their families and people close to them can be strained both emotionally and financially.

Issues involved in complexity when working with a person with an ABI may also include:

- Cultural
- Social
- Vocational
- Justice
- Grief / loss
- Accommodation
- Behavioural
- Co-morbid disorders
- Mental health
- Medical / physical including trauma and PTSD.
- Alcohol/ drug addiction or withdrawal

CULTURAL & CONTEXTUAL FACTORS

Australia is a very culturally diverse nation, however our melting pot of difference includes so many more factors than culture as we traditionally know it, including:

- Cultural association
- Age and gender
- Sexual orientation
- Stability of accommodation
- Social
- +/- remote location
- +/- treatment coerced

Challenges can include:

- Cultural differences between person with an ABI and the worker,
- Conventions of interpersonal communication,
- Views of mental illness and alcohol abuse,
- Expectations of family,
- Social stigma
- Social group and social group norms
- Family and friends, relationships – unable to maintain or establish
- Cultural
- Vocational
- Economic
- Housing – homelessness
- Isolation
- Personal hygiene
- Knowledge / education / literacy level (i.e. How accessible information is to the person)

People with an ARBI or ABI due to domestic violence often do not present to health services. As a result, community awareness of both ABI and ARBI is limited.

Often, the presentation of an ABI is invisible and will go unrecognised by the person and others.

Some people affected by ABI can function well in familiar situations, where no demands are placed on their cognitive weaknesses, thus masking the problem.

The stigma can vary between individual people and cultural groups. However, stigma can act to prevent people from accessing assistance.

COMPETENCY & GUARDIANSHIP

Although decision making capacity and competency both describe peoples' ability to make decisions, they are not synonymous.

Competency is determined by a court of law, Competency is a legal term – to say a person is incompetent indicates that a court has ruled the person unable to make valid decisions and has appointed a guardian to make decisions for the person. Sometimes courts restrict the guardian's decision-making authority to particular domains in which the person has a specific lack of capacity, such as financial decisions or health care decisions. Though the legal process of determining incompetence varies from state to state, it is often lengthy, expensive, and emotionally draining. For this reason, the legal process is typically reserved for people who are very impaired, not expected to recover, and making decisions that adversely affect their well-being.

Decision-making capacity
is determined in a clinical assessment as an everyday part of clinical care. Decision-making capacity is defined as the ability to understand and appreciate the nature and consequences of health decisions and to formulate and communicate decisions concerning health care. Although clinicians do not have the power to determine whether a person is incompetent as a matter of law, they do have the de facto power to determine that a person is incapable of making health care decisions and to identify a surrogate decision maker to act on the patients' behalf.

We may not always agree with other people's decisions. What must be determined is whether the person is simply making 'bad' decisions or whether the person lacks capacity to make decisions. It is important to remember that a person who has capacity is permitted to make unsound decisions and entitled to reject doctor's advice for any reason, however rational, the same as anyone else.

In the absence of a formal assessment, we must assume that a person has capacity. Therefore, administration and / or guardianship should not be foremost on the mind of the worker. Less restrictive approaches should be explored before resorting to an assessment or assumption of decision making capacity. Do not address decision making capacity unless there is an immediate, specific decision that needs to be made, or there is a significant risk of harm to the person or others from an unwise decision. When there is disagreement about capacity, an assessment should be sought to provide evidence about a person's capacity. Such an assessment could be performed by a clinical neuropsychologist or other trained health professional.

A person who lacks the capacity to make one decision does not necessarily lack the ability to make all decisions, often having decision-making capacity with regard to some decisions but not others. Each type of decision requires different skills and therefore requires a separate, independent assessment. People should be empowered to make their own decisions, except those for which they lack specific capacity with the least restrictive option as possible.

Guardianship for people with an ABI

Guardianship is the appointment of a guardian to make decisions for an adult with a disability when they are unable to do so. Once appointed, a guardian has authority to decide where and with whom the person lives; whether the person should / should not work, the nature of work, who they work for; and consent to health care that is in the person's best interests.

Administration orders for people with an ABI

Administration is the appointment of a person to make financial and legal decisions for an adult with a disability when they are unable to do so. An Administrator will manage the person's estate, and collect & manage funds. An administrator may also sell or dispose of or administer any property which forms part of the person's estate. The appointment of an Administrator can cause a person considerable distress and once in place is extremely difficult to undo.

A Guardian or Administrator is appointed by the courts unless, when they were competent, the person with a disability appointed someone of their own choice enduring powers of guardianship and/or attorney.

The goal should always be to maintain independence by working with the person to;

- Establish current income / expenses.
- Ascertain ability to maintain current financial obligations.
- Establish budget and assess ability / willingness to maintain budget.
- Assist client with further strategies as needed. Eg. Direct debit, payment plans, weekly accounts.

Some strategies may be more effective than others and if client's financial situation does not improve the appointment of a financial administrator may need to be considered.

RUBY'S STORY

Schoolgirl, daughter, dog owner, netballer, spaghetti lover, sister.

Ruby had come home from school and gone outside to play with the dog, when her mum, Megan noticed her lying on the grass. Megan thought she had fallen over so went out to see if she was ok. As Megan approached Ruby she could see something was seriously wrong. Ruby was trying to speak but one side of her face didn't seem to be working. Her right arm and leg were limp on the ground – she couldn't move them.

Megan didn't know what was wrong. Perhaps Ruby had fallen and hit her head? She didn't want to move her, so ran inside and grabbed the phone, dialling 000 as she ran back to Ruby. Ruby was looking more confused than scared but didn't seem to be in any pain. Megan was terrified and the wait for the ambulance seemed interminable.

At the hospital an MRI scan revealed that Ruby had suffered an ischaemic stroke - an embolism had blocked a blood vessel in the brain, interrupting blood flow. A distressed Megan was asked to think back over the last few weeks. Had she noticed any changes in Ruby. Megan thought Ruby had been fine, although she had been very clumsy lately. The doctors advised Megan that this could have been a precursor to stroke.

Ruby was taken straight to theatre where the surgeons drained some fluid to relieve the build up of pressure in the skull. Later in ICU the pressure was carefully monitored.

When Ruby was finally discharged from hospital months later her prognosis was a bit daunting to Megan. 20 to 40 percent of children who have strokes will have another one. Approximately 70 per cent of survivors will have life long problems.

Three years later Ruby, now 10, has a slight learning disability and epilepsy, which is well controlled with medication. Her right arm and leg regained movement with extensive physiotherapy and rehabilitation.

Stroke is the biggest subset of Acquired Brain Injury. Stroke is relatively rare among children. It is thought that around two out of every 100,000 children are affected worldwide each year. More research is needed to better understand both the causes and the effects of stroke in children.

STRATEGIES TO SUPPORT PEOPLE WITH AN ABI

REDUCING DEMANDS ON COGNITIVE FUNCTIONING

A central principle in assisting people with ABI is "compensation". This means:

- Reducing demands on impaired cognitive skills
- Tapping a person's strengths and preserved skills

Cognition, the mental processes involved in thinking, learning, memory, judgment, problem solving, planning and perception, is often impaired in people with an ABI. Reducing the demands on cognition is therefore an important step in reducing anxiety and depression that may be associated with feelings of inadequacy.

Avoid overloading people

- Break down information and present one idea at a time. When breaking information down ensure that relevant information is grouped together.
- Discuss one point at a time – ensure that the point being discussed is understood (especially if an important piece of information) before moving onto the next point.
- Tackle one problem at a time, one step at a time. Allow the person to focus solely on the issue at hand. Once achieved then move onto the next step.
- Allow sufficient time for people to work at their own pace. Don't expect the person with ABI to process the information at the same speed as you. Allow the information to be processed and a response to be generated.
- Minimise distractions and stressors in the environment. For the best results an environment where the person's attention is solely on the task at hand is ideal. Turn off televisions, radios, move away from a noisy office etc.
- Allow frequent breaks or rest periods: avoid the person becoming fatigued.

Structure the environment

- Assist to develop a routine that is predictable and that encompasses all aspects of life (eg: personal hygiene, chores, meals, work, social activities, exercise, and appointments).
- Ensure all activities follow a predictable pattern; for example, chores and appointments can be organised to occur at precisely the same day and time each week. This also applies to worker visits.
- Display prominent prompts in the environment to help remind and initiate activities.
- Help carers and family members understand the person's need for predictability and structure.

Minimising change in the environment

- Minimize change in the routine: if a routine has been established try to avoid any changes to this. Changes to routine can result in undoing a lot of hard work and result in frustration from the client.
- If change is inevitable, plan ahead and allow sufficient time to discuss plans. Involve the person in changes to give them a sense of "ownership" in the changes that are being made.
- Change needs to be tackled in small increments and incorporated gradually. Large changes can result in chaos.
- Explain clearly what is occurring before initiating any activity – surprises may be distressing. Provide the person with both verbal and written information about potential changes.
- In times of change surround the person with familiar objects and people. This is especially useful when a person is moving accommodation.

Be available to the person with ABI

- Generate ideas and alternatives. Write them down so the person has a visual cue to refer back to.
- Develop a plan of action to tackle problems. Once again put them in writing so if the person gets off track there is a document to refer them back to.
- Prioritize steps. By putting the steps in a sequential order it allows the person with ABI to see each step and also to have a cue for when each step is complete (i.e. encouraging them to cross out completed steps).
- Follow through with plans by prompting people at each step.
- Provide encouragement and reinforcement at each stage. Also reinforce steps that have already been completed.
- Help the person to focus on relevant discussion by redirecting their attention if they become stuck on an idea or re-focus them if their conversation becomes tangential.

Encouraging Preserved skills

The aim of assisting people to compensate for their impairment is to increase feelings of coping and competency. An important step in increasing feelings of coping is identifying and making use of preserved skills and talents.

- Use familiar language
- Some people with a severe ABI can talk of the past with greater ease than recent years. A useful distraction (for agitation and depression) can be to initiate conversation about the past. However, be aware that some events in the past may be emotionally sensitive to the person.
- Many people with ABI respond well to prompts or cues to trigger their memory and respond better to specific closed ended questions than open ended questions.
- Where practical, encourage people to pursue old interests and hobbies, (i.e.: mowing lawns, walking dogs, working on cars) and in doing so increase their experience of success.

Managing Poor Concentration

Do not exceed the cognitive resources of the individual
If you know they can only cope with one demand at a time, only give one command at a time. If 2 is their max, then leave it at two.

Help provide environment free from distractions
This includes not only auditory distractions, such as the television, but also visual distractions. A workspace that is messy will make it more difficult for someone to concentrate

Break down activities into short bursts with regular breaks
The number of breaks needed will depend on the person and how much they can take on at a time. A good guideline may be 30 minutes activity, 10 minute break.

Focus on physical activities requiring less concentration eg. Walking / exercise, gardening, housework.
In particular, schedule these activities at a time when the individual is less able to concentrate, and keep more difficult tasks requiring concentration for times of peak alertness, such as the morning.

Consider the role of anxiety / depression on concentration
A preoccupied mind will have greater difficulty concentrating

MANAGING MEMORY PROBLEMS

Many people – with or without memory impairment – rely on external memory aids. For example, some people use diaries to remember appointments, others use lists to go shopping or alarms to remind them of a cake in the oven. People with ABI can benefit from a range of memory aids, and can be encouraged to find an aid or combination of aids that works best for them. The strategies for improving memory need to be adapted for each individual person. Some strategies may not be relevant to some people with an ABI, and a strategy that works for one person may not work for another. You may need to be creative.

Memory aides

- Making lists
  Lists are a great way to ensure that nothing is forgotten (or extra is purchased like chocolate biscuits). It can be rewarding to cross out items when they are completed. Many people with ABI try to compensate by writing endless lists and notes. While this is good in practice, they should only be used as an aid, as lists are easily lost. It is a good idea to date the list.

- Keeping a diary
  Using a diary is a useful strategy as it reminds people what they have to do and can also act as a memory jogger for what they have done A diary can also act as a planner to record plans and goals for a day. A diary that allows for hourly entries can also be useful as a time management aid. However, don't assume that all people are able to use a diary. A diary can be a new concept to some and thus may rely on new learning, which may be tricky due to the ABI.

  A useful strategy for people with mild to moderate ABI is to have them write a list of jobs to be done the next day and then to prioritise them and note in a diary.

One main advantage of a diary is that it can be carried everywhere. All people involved can assist the person with ABI by constantly asking them if they have their diary with them when making appointments. This will assist to establish routine.

- Using a whiteboard
  A whiteboard is a useful way to show a weekly, fortnightly or monthly timetable for people with severe ABI. A whiteboard can be placed in a prominent position (on the fridge, next to a phone, on the back of a door) and can clearly display all aspects of the routine. For people with severe ABI a whiteboard can also be good as it can display a day & date, reducing a person's confusion.

- Alarms & Timers
  Alarms and timers can be a useful way to prompt people to look at their diary or take medication. Eventually the timer may be gradually withdrawn once a routine has been established.

One great reminder system is contained in "Microsoft Outlook". Before implementing something as technical as this system the person with ABI should be computer literate and comfortable using a computer each day.

- Other prompts
  A common issue for people with an ABI is forgetting to take new medication. Medication can be placed next to something that the person uses each day (next to the kettle, next to the toothbrush) to act as a visual reminder to take the medication.

  Posters are also a good way of information being placed in prominent positions. Information is best presented where it is regularly seen (back of toilet door, back of front door, next to bathroom mirror, fridge door) to allow for repetitious learning.

  Labels on drawers, doors, cupboards, etc are good prompts especially if moving into new accommodation or workplace.

  Organise set places for things. For example, a bowl on the table near the door for keys, a tray on the dresser for glasses or phone, a hook on the wall for a handbag, etc. Make them in prominent places and label them.

IMPROVING COMMUNICATION

Often an ABI can make communication difficult. The following strategies may help to engage the person with an ABI to optimise communication.

- Ensure the environment is free from distractions, including other conversations and background noise (televisions, radio, etc).
- Choose a time of day when the person is alert but relaxed, if possible.
- Obtain eye contact and the person's attention before beginning the conversation.
- Begin the conversation with information that orientates the person to the situation. Identify yourself and call the person by their name.
- Allow plenty of time for the person to process what you say and to formulate a response.
- Use familiar language. Avoid the use of jargon or technical terms.
- Break information down into points. Present one point at a time.
- Match language and conceptual difficulty to the client's level of communication impairment
- You may need to repeat important points or write them down.
- Use a calm, respectful manner at all times. Avoid a condescending, patronising, or overly sympathetic manner.
- Don't overload people. Watch for signs of mental fatigue or wandering attention.
- Ask people to repeat or paraphrase the important points to ensure it was encoded into memory.

Non-verbal aspects of communication — 'How do I present'

In order to gain trust from the person with ABI you need to be perceived as:

- Non-judgmental – reluctance to accept help may be related to judgmental or moralistic attempts to help them in the past
- Non-threatening – people with ABI are unlikely to respond if they feel intimidated
- Supportive – People with ABI need to perceive that people working with them are "on their side" and that the working relationship is a collaborative one
- Confident – People with ABI are re-assured by workers who come across as knowing what they are doing
- Attentive – All people need to feel listened to and understood.

Structuring conversations & providing information

Tangential conversation

- Give feedback – for example informing the person they have wandered off the topic.
- Calmly re-direct the conversation by repeating the question.
- Try not to get involved in or respond to tangents until the main issue has been addressed.
- Try to use a pen and paper to direct or focus discussion.

Memory & Retrieval problems

Many people with memory deficits caused by ABI respond best to closed ended (yes / no) questions rather than open ended questions (tell me about your day yesterday). Instead try – did you go out yesterday.
Communication can also be improved by providing cues or prompts to trigger memory wherever possible.

Rigid and inflexible thinking

People with rigid thought processes may become easily stuck in a particular way of thinking, or on a particular idea, and have difficulties switching to a new topic. Once stuck on an idea the person may have trouble seeing alternatives.

- Break the persons attention by distracting them with something completely different (ie: introduce a different topic, go for a walk, change rooms, make a coffee etc)
- Rigidity may be related to negativism (persistently answering "No"). Ask an open ended question to obtain an answer that isn't a yes / no response.
- Sometimes when "stuck" on a topic a person may need to talk through that topic before they are able to move on. It is sometimes quicker to let them get it out of their system and then move on.

COUNSELLING & THERAPY

Cognitive impairment can make it difficult for people to keep up with, cope with and benefit from counselling and therapy. The following provides strategies for counselling people with ABI.

People with ABI may have difficulties:

- Keeping up with the pace of sessions
- Remembering what was discussed
- Carrying information through from session to session
- Coming up with ideas and alternatives
- Thinking abstractly, complex thinking, linking ideas, seeing patterns.
- Structuring information and ideas – they may be less organised and goal focused
- Setting realistic goals
- Applying what they have learned – They may be good at verbalising their difficulties, but lacking in the ability to move beyond intellectualising to acting.
- Monitoring behaviour and conversation – for example, excessive talking or difficulty staying on a topic.
- Switching between ideas – people may become easily stuck on one idea and be unable to move on unaided.
- Lack of self-awareness and insight (particularly with regard to their cognitive impairment) may mean that people rationalise their problems. Often it is easier for people to accept psychological or emotional causes for their problems, rather than their ABI. There may be a tendency in counselling for unhelpful discussion of life stressors as the cause of maladjustment. This can be particularly challenging for counsellors and therapists.

Counselling People with Cognitive Impairement

Counselling people with cognitive impairment requires a highly directive and structured approach. Psycho dynamic, psychoanalytic and other insight-oriented therapies may be too abstract and unstructured for people with ABI.

People with an ABI are often most suited to a behavioural approach that aims to teach specific and concrete strategies to maximise their ability to cope or adjust. For example, a person with aggressive tendencies associated with their ABI is unlikely to benefit from abstract discussion of negative emotions, nor from exploring the causes of the destructive emotions. A more helpful approach would be to teach strategies he or she can apply in situations likely to provoke an aggressive response.

Counselling people with ABI may mean being more active in planning sessions, focusing interactions and prompting action. People with mild ABI may benefit from a combination of cognitive and behavioural

approaches that aim to teach more constructive ways of thinking. A problem solving approach whereby goals are set, and there is an overt structure and plan to guide sessions, is an ideal way to compensate for cognitive impairment in counselling and therapy.

Counselling Strategies

- Sessions need to be individually paced to suit the person's needs
- Break information down into manageable components and help organise it for the person
- Frequent repetition of material is important, as is asking the person to repeat information covered to check their understanding and retention
- The use of a logbook or diary to record what was discussed in sessions is invaluable
- Frequent summing up of material covered helps to organise information for memory
- Set concrete, realistic goals for therapy. Break them down into well-defined steps and tackle one at a time. Provide a written outline of the goals and steps and refer to it constantly
- Difficulties with self-monitoring and tangentiality often mean a counsellor or therapist has to be more assertive and directive in their interactions than they would normally deem appropriate. People with cognitive impairment may need constant prompting and re-focusing.

UNDERSTANDING CHANGED BEHAVIOUR PATTERNS

Behaviour is the observable activity in a person in response to internal and external stimuli. Behaviour is meaningful, purposeful and goal driven for the person. Everything we do has a goal however sometimes the goal is not obvious to others or even to the person themselves. To understand the behaviour you must first understand the person. All behaviour is communicating something. Often the behaviour of a person will change following an ABI. Sometimes this can be to the person's benefit , eg. A healthier lifestyle following a stroke. Sometimes the change can be negative, for instance lack of initiative, impulsiveness, irritability.

What makes behaviour concerning?

- A safety risk to self or others
- Limits access to community facilities
- Socially unacceptable
- Makes other uncomfortable
- Is distressing to self or others

Behaviours of concern should fall under one or more of these areas. If a behaviour doesn't fall under one of these areas, you should question whether the behaviour really is of concern.

Behaviours of concern & ABI

Some people with an ABI may display behaviour of concern. The type, severity, and endurance of the behaviour is as variable as the injuries. Some behaviour will resolve itself whilst others will persist depending on the injury. Behaviour of concern includes:

- Aggressive behaviours – physical or verbal
- Socially inappropriate behaviours - may range from mere social awkwardness and lack of adherence to social conventions to committing crimes
- Adynamia - can be called a range of different terms: abulia, anergia, amotivation, apathy and implies decreased activity.
- Sexually inappropriate behaviours – may be verbal or physical and may range from inappropriate comments to rape.
- Maladaptive service seeking behaviours - the inappropriate use of a service such as constantly calling for an ambulance or the police department for minor issues.

Post Traumatic Amnesia.

If a person has been in a coma they will pass through a stage called Post Traumatic Amnesia (PTA). PTA may last for days, weeks or months and during this time the person is confused, disorientated, and sometimes agitated and aggressive. They are not fully aware of where they are or what is happening, and will fatigue very quickly. It is impossible to predict how long PTA will last, but generally the more severe the injury the longer it lasts, and the lower the chance of positive outcomes. People with PTA will be inpatients and require intensive support . The following strategies are not for people in PTA .

Causes of Ongoing Behaviour of Concern.

All behaviour is controlled by the brain therefore damage to specific areas may cause a person to behave differently compared to before their injury. Sometimes the ABI may only be indirectly responsible for ongoing behaviour of concern. Medical, psychological, environmental and cognitive problems may also be contributing.

Medical Causes

- Fatigue – is the person sleeping adequately?
- Physical discomfort – is the person in pain? Constipated?
- Adverse effects of medication – sedatives, tranquillisers or psychotropics
- Impaired vision or hearing – causing misinterpretation of sights or sounds
- Infection – urinary tract and chest infections may underlie confused and disorganised behaviour
- Thiamine deficiency – may also underlie confused or disorganised behaviour

A full medical evaluation is necessary to rule out the many physiological causes of behavioural problems.

Psychological Causes

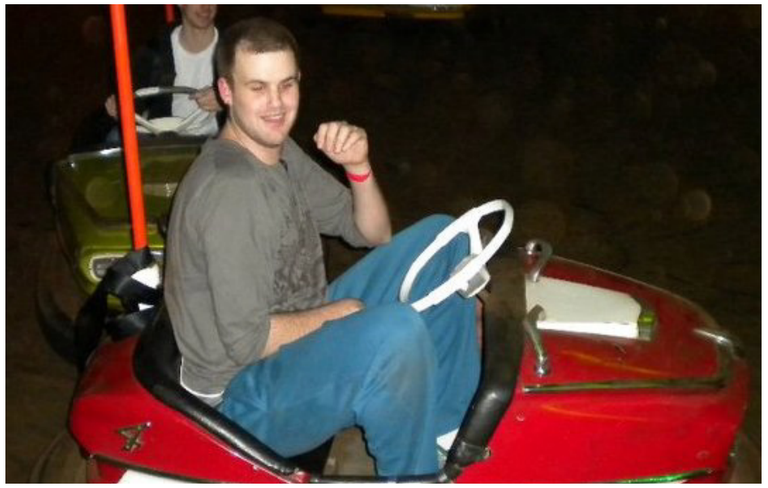
People with ABI may be reacting to real stressors in their life, but not be able to identify what is upsetting them. It is always helpful to speak to family or carers to find out about issues causing adjustment difficulties.

Environmental Causes

- Change or disruption to the daily routine
- Unfamiliar people, places or sounds
- Change to rooms, furniture, people
- Sensory overload – too much distraction, noise or activity in the environment
- Unrealistic expectations – people are distressed when faced with failure, eg: when given tasks beyond their capability

Co-Morbidity

- Mental Health Issues
- Substance Abuse Issues
- Intellectual Impairment
- Personality Issues



Supporting positive behaviour patterns.

Severe and extreme behaviour of concern will require referral to a clinical psychologist or neuropsychologist trained in behaviour modification. The safety of all concerned should be a primary consideration.

For minor behavioural issues which are distressing to the person here are some strategies to try. Not all will apply in every situation.

There are three important points to keep in mind when working with people who are struggling with behaviour of concern:

- Do not take the behaviour personally or hold grudges
- Modify the behaviour, not the person
- Every behaviour has a reason

Keeping these three points in mind, here are some strategies to promote more positive behaviour.

- Encourage and praise appropriate behaviour or interactions.
- Avoid reacting to behaviour of concern.
- Ignore negative behaviour (but not the person) wherever possible. Alternatively, provide clear immediate feedback about the behaviour.
- Speak in a calm, soothing tone
- Avoid defensive posturing
- Model calm, controlled behaviour
- Give praise when a person regains composure after an outburst – ask them how they managed it and reinforce whatever they did as a good strategy
- Reassure people that you are there to help
- Involve people in their own care as much as possible
- Avoid arguing or attempting to reason with people who are agitated
- Allow people to express themselves – even negatively
- Be prepared to listen – all people need to feel listened to and understood.
- Acknowledge feelings.
- Avoid negativity by rewording questions. For example, instead of "Are you ready to take a shower?" ask "Would you prefer to shower now, or after dinner?"
- Phrase instructions as suggestions and not commands. For example, instead of "Go and take a shower now" try "You could have a shower now instead of after dinner."
- Use distraction techniques – some people with ABI can be suggestible and easily distracted
- Avoid leaving agitated people alone – unless there are safety issues.
- Avoid surprises – always give explanations before initiating activity.
- During confusion or agitation, surround the person with familiarity – people and objects
- Structure the person's time as much as possible to keep them motivated.
- An orientation board detailing the date, the routine, personal details, and important events in the person's (and family's) life can reduce confusion.

Some Basic Principles to Modifying Behaviour.

This section provides some general principles of behavioural change to assist carers and workers to develop and implement simple behaviour modification programs.

1. Observe and record data about the behaviour

- When behaviour occurred
  What time of day did the behaviour happen?
- What triggered it?
  What was happening immediately prior to the behaviour? Who was around? What was the person doing? What else was going on in the environment?
- Consequences of behaviour
  What was the response to the behaviour? Did the person obtain something as a result of the behaviour? Did they avoid something?

2. Analyse the behaviour

Once data has been collected that spans all times and context in which the behaviour occurs, the information needs to be studied for emerging patterns. The two important questions to answer are:

- What triggers the behaviour?
- What maintains the behaviour?

In many cases, once the behavioural trigger has been identified, environmental change may be all that is required. In other cases, changing the environment is not the answer. At these times a behaviour modification program can be considered.

3. Modify the behaviour

Behaviour modification is a highly effective method of changing behaviour. Here are the two keys: ignore problem behaviour and reward appropriate behaviour. Below are some general principles for modifying behaviour.

- Treat one behaviour at a time
- Allow time for behaviour change – it can be a slow process
- Be hard on the behaviour, not the person
- Always treat the person like an adult and with respect.
- Reward appropriate behaviour immediately.
- Reward appropriate behaviour with praise and frequent encouragement.
- Where practical, ignore the target behaviour.. Alternatively, give immediate feedback about the behaviour
- Model calm and controlled behaviour.
- Set clear, firm limits that are repeated as often as possible.
- Response to the target behaviour needs to be uniform and consistent – this means recruiting the assistance of all staff, other workers and significant others.

PETE'S STORY

Brother, mate, son, heroin user, uncle, brother-in-law, car racing enthusiast, ACDC fan, tie hater, souvlaki lover.

Pete was 27 years old when he accidentally overdosed on heroin causing severe hypoxia resulting in an ABI. Pete left school at 16 and had never held a job. He slept on his brother's couch and survived on the dole, supplemented by the occasional burglary. He was well known to the police in his neighbourhood. After a long stint in hospital and rehabilitation Pete was discharged and went back to his brother's house. Pete had sustained permanent injuries to his brain resulting in balance and coordination difficulties, and left side facial weakness. Pete was able to walk but he couldn't walk in a straight line, kept bumping into things and people, and fell often. The facial weakness meant extremely slurred speech and an inability to stop saliva dripping from his mouth. His neuropsychological assessment also showed difficulties with attention, concentration, problem solving, and mental flexibility. Pete also experienced high levels of impulsivity and inappropriate behaviour, although it was impossible to determine if these and the cognitive difficulties were present before the hypoxic event. After a week Pete's sister-in-law was unable to cope and threw Pete out.

Pete was placed in emergency housing, until a permanent place was found for him. Pete continued to use heroin and alcohol. His brother came to visit on pension days and they would go straight to their dealer. Once the heroin ran out the brother would disappear until next pension day. A number of support staff attempted to establish a rapport with Pete but were met with great resistance and distrust. It took Dave a long time and lots of patience and persistence to gain Pete's trust. Dave, in his 50's and looking very daggy in his brown cardigan didn't look like an obvious match for Pete, and at first Pete would not let him in. Dave would arrive daily and knock on the door, but Pete wouldn't let him in. Dave sat out on the front porch for 1 hour every day for a week, resisting the temptation to force things along. Early in the second week when Dave knocked on the door he was surprised when Pete opened the door and asked him if he knew anything about speakers. Pete needed help to plug in some leads. Dave came in and even though he was repulsed by the mess and smell inside the house, was able to help with the leads. He then went back out to the porch and told Pete to call him if he wanted some more help. After a few more days, Pete came out and sat with Dave and they chatted about cars. The next day when Dave knocked Pete let him in to show him an old car magazine he had. They chatted and Dave left after the hour was up. From there the relationship grew slowly. Dave was careful not to seem judgemental or pushy. Eventually Pete actually seemed glad to see Dave each day.

When Dave first mentioned Support Planning Pete rejected it outright. Eventually, Pete reluctantly agreed to help Dave out by attending the meeting but he didn't believe it would be of any use. Pete stated his goals were to get a job, be able to drive, and "be normal" so everyone would leave him alone. With Dave's help, and after many unsuccessful job attempts, Pete settled into mowing lawns as a regular job. Dave got him started with this by asking him to help out a "mate" who was unable to mow his lawn. Because he could hold on to the mower Pete found he was able to keep his balance, and because he was outside it didn't matter if he dribbled a bit. He started off mowing lawns for "mates" and with Dave's help was able to land a job helping a landscape gardener. This was only part time and required Dave's help but was a great boost to Pete's self esteem.
Driving was a more challenging goal so they started out with dodgem cars. Dave in one car and Pete in another. Because Dave was so genuinely enthusiastic, Pete had a great time and as his driving skills improved, Dave organised some go-carting which they both enjoyed.

As Pete's self-esteem, confidence and trust in Dave grew, Dave was able to introduce other support workers. Dave still maintained close professional contact but was wary of co-dependence and over reliance. Although some things were working out well for Pete, he still continued use heroin. Nearly two years after his first overdose Pete was found unconscious in his home by his support worker. He died in the ambulance on the way to hospital.

MANAGING ANGER

This section is designed to provide support staff and health professionals with the foundations for assisting people to develop more constructive ways of dealing with anger. Anger is a feeling that expresses tension and communicates frustration. It is a feeling to which we are all entitled. Aggression is an act that causes harm (to self, others or objects). Anger need not lead to aggression.

Anger becomes a problem when:

- It is too frequent
- It is too intense
- It lasts too long
- It leads to aggression
- It disturbs work or relationships

Anger and ABI

People with an injury to the brain, particularly the frontal lobes, may have difficulty controlling or modifying their behaviour. They may be prone to poor impulse control, frustration, intolerance and inability to foresee the consequences of their behaviour. As a result, people can become stimulus-bound, meaning that they become more reactive to environmental factors. At these times, well-learned automatic behaviours and responses are triggered. The brain injury may mean that the person lacks the ability to inhibit these automatic responses once they have been triggered. They sometimes occur without the person's awareness.

People with mild ABI may regain control over anger and prevent it from escalating to aggression by undergoing anger management training. People with moderate or severe ABI usually benefit most from environmental changes.

Anger Management

Effective anger management involves understanding what triggers the emotion and developing strategies that allow the person to own their anger, rather than allowing anger to own and control them. Generally people with ABI benefit most from being taught concrete, specific strategies to deal with negative emotions. They do not benefit from abstract discussion about emotions.

An anger management plan may be broken down into stages:

1. Monitoring of anger.
   Have staff or the person monitor their anger. Use a sheet to note the situation and trigger, thoughts and feelings, strategies and outcomes. An important aim of the monitoring stage is to encourage the person to become aware of physical sensations (for example, heart racing, fists clenching or muscles tensing), and identify anger before it escalates to aggression. The earlier they are able to use strategies, the easier it will be to control their anger.
2. Assist with the identification of early warning signs of anger before it progresses to aggression – thoughts, sensations or mental images.
3. Identify any existing strategies the person uses.
4. Teach new coping strategies.
5. Rehearse strategies in counselling sessions (role playing).
6. Evaluate effectiveness of strategies in real situations.

Some Strategies.

An individual approach to teaching anger management strategies means helping people find what works for them. Some people with mild ABI may benefit from focusing on the "thoughts" aspect of anger – replacing unhelpful thoughts with more helpful ones. For example, an angry thought "How dare he say that to me!" will probably fuel anger, whereas a thought like "He is angry and upset" may be helpful in diffusing angry situations.

People with more significant ABI and people who have problems controlling impulses are more likely to find behavioural and distraction techniques effective, and can be encouraged and assisted to:

- Identify and avoid provocative situations
- Take time out or leave provocative situations
- Distract themselves with thought or activity – for example: go for a run, or picture a soothing image

Collaboratively, people with ABI and their workers can develop many imaginative behavioural strategies and distraction techniques. In addition, time can be spent educating staff and significant others about recognising triggers and the early signs of anger before it escalates into an outburst. All significant others in the person's environment (family, friends, carers and health professionals) can be trained to respond in a uniform, consistent manner.

MANAGING CHANGE

Change is particularly stressful for a person with ABI. This information provides practical methods for assisting and supporting people with ABI to move to new accommodation.

Before Moving

The two most important factors in moving are planning ahead and allowing ample time for adjustment. Below are some ideas designed to aid in a smooth transition between accommodation settings:

- Plan the move and inform the person well in advance. Write the date on the calendar and encourage the person to cross off the days as the time nears
- Provide photos of the new residence if these are available
- If it is to be a shared room, a prior meeting with the room-mate is useful
- Keep introductions to a minimum and explanations simple. Avoid overloading the person with new information. Allow the person to become familiar with one or two rooms at a time. Avoid the temptation to show as much as possible to demonstrate how great the new surroundings will be. This can lead to confusion or panic
- Where possible, reproduce the layout of the previous residence. Arrange furniture and belongings in a similar position
- If the person has been evicted from their present accommodation, the notice can be handed directly to them, and reinforced several times. They may forget having received the notice, or what the notice said.
- For some people, a break in the previous routine is the best way to pre-empt a move. For example, a holiday or spending time with family can be a helpful way to break the old routine before moving to the new residence

During the Move

- During the move, the emphasis needs to be on continuity, stability and familiarity
- Have some of the person's belongings in their room prior to the move
- Keep the number of people involved in the move to a minimum. Unfamiliar staff in the new residence can wear a name tag to help orient people
- Use an orientation board detailing personal information, the address and the new routine
- Initially it may be necessary to have signs and labels on rooms and cupboards to prevent confusion
- If there is a tendency to wander, it may be necessary to use a badge or wristband on which the name and address is printed
- If people return to their old address, take them back to the new residence as soon as possible, without fuss
- Encourage regular visits from familiar people
- If possible, arrange with staff for some aspects of the old routine to be kept up until the person settles into the new routine.

Following the Move

- Teach the person about any new equipment with which they may be unfamiliar (microwave, taps, DVD players, kettles, or igniter switches)
- Be prepared to offer ongoing support, reassurance and assistance until the person is settled. You may be one of the only familiar people to the person during and after a move
- Change the address on all personal identification and ensure it is carried with them at all times

People with Severe ARBI

When the person's impairment is so severe that they are unable to appreciate or understand what is happening, a different approach may be necessary. Instead of introducing people to the move gradually, it may be better to move them quickly, quietly and with minimal fuss. It is necessary to balance need for participation in decision making with the ability to understand the consequences of decisions.

GOAL SETTING AND INDIVIDUAL PLANNING

Developing support plans with people can be very rewarding and satisfying for all involved. Sometimes however, the person's needs are so complex with multiple co-morbidities that it can seem confusing and overwhelming.

Crisis management is a classic service response to an individual with complex needs. More so when ABI is part of the complex needs mix. Crisis management will not promote independence or facilitate long-term change. On the contrary, it can render the person increasingly reliant on "the system" and also results in worker fatigue and burn out, and a loss of enthusiasm and energy that is needed when working with this particular group of people.

An individually tailored support plan will set small achievable steps along the path to a life which is as fulfilling, healthy and independent as possible.

The importance of your working relationship with the person.

- Before developing a support plan, we need to develop a satisfactory, but professional relationship with the people we support.
- Be Genuine - people know when you are genuinely interested in them.
- Work within your capacity – know your own strengths and limitations.
- Be realistic in your goal setting and plans of progress.
- Ensure the approach encompasses all aspects of the person's life, with their needs, wants and aspirations at its centre.
- Workers need to be non-judgemental of the person they are working with and the situation they are in.
- Team work – foster collaborative partnerships – liaise with others; this includes knowing when to request assistance and having clearly defined roles within the plan.
- Avoid the temptation to handball the "problem" to another service.
- Ensure continuity of support between services.
- Demonstrate respect for the person regardless of their behaviour or issues.

Assessing individual needs

An assessment of individual needs may be time consuming and involves careful evaluation of the individual and their environment. Family members and other services involved can be a great source of information about the person's daily functioning and existing strategies.

- obtain a comprehensive assessment of person's needs:

  Strengths.
  Cognitive function.
  General health.
  Mobility.
  Co-morbidities.
  coping strategies and existing skills.
  Services already in place and strategies useful to date.
  Support from family and friends.
  Accommodation.
  Other resources already established.

- know the person's expectations and what they hope to achieve.
- take in cultural considerations
- ascertain the person's readiness for change
- ascertain motivating factors and interests.
- A Neuropsychological Assessment will be helpful, if possible.

Although time consuming, a comprehensive assessment is absolutely essential to ensure the success of the Support Planning meeting.

Support planning.

Developing an individual support plan requires cognitive tasks such as concentrating, evaluating options, integrating concepts etc. Therefore it will be important to understand the person's cognitive strengths & weaknesses so the meeting and the goals can be tailored accordingly. Being flexible is obviously critical here and the most important aspect of the planning is ensuring the person is at the centre of the plan.

Developing a support plan involves:

- Organising the meeting at a time convenient to the person, the family and support people the person has invited.
- Establishing what is important to and for the person.
- Prioritise the goals. Do you need to deal with mental health issues first – e.g. correct medication?
- Goal setting: incorporating cognition, mental health, medical, social etc.
- Representing the plan to the person in a way that makes sense to them- a contract, pictures, audio tape, a letter etc. Be creative!

Setting Goals

- For many people who you support with an ABI setting goals in itself is a goal and an achievement – emphasise the importance of this.

- Individually tailor goals.
- Larger seemingly unrealistic goals can be broken down into smaller steps /parts which may be achievable or able to be addressed.
- Determine risk and need.
- Determine what is to be achieved by the goals so that the outcomes can be measured easily.
- Decide who and how goals / tasks will be addressed so that everyone can understand the importance and take responsibility to enable the goal to be achieved.

The person at the centre of the plan needs to take as much responsibility for their plan as they can. However, the worker and people who also support the person may need to assist or prompt with undertaking some tasks. They can also offer encouragement to maintain motivation around the goals.

Prioritising Tasks

First, decide if the goal is urgent. Then, is it important? What is important to the person or important for the person? The more information you were able to gather during the assessment period, the more valid the goals will be.

Some goals can be acted upon simultaneously, but keep it simple to maximise the chance of success.

In people with an ABI who have complex needs and co-morbid presentations:

- mental health issues may have flow-on improvement in everyday cognitive functioning.
- medical and mental health issues may reveal the "underlying" severity & nature of the ABI.

Using cognitive strategies when developing support plans

- When you work with (including history-taking and goal setting) the people you support, you will need to use cognitive strategies to compensate for limitations of memory, attention and executive function skills.
- Think about compensation, or compensatory strategies that are effective with the person.
- Provide structure within the session.
- Outline expectations / goals for the session.
- Write down what you have done/ said in each session so the person can keep it.
- Present ideas in concrete ways.
- Write and / or use diagrams.
- Break down goals into small achievable steps.

CARING FOR THE CARERS.

A common saying is that when a person acquires a brain injury they are not the only victims. The whole family suffers from an ABI.

When working with people with ABI more often than not you will also be working with their families, and other support people, both formal and informal. It is important when working with families to establish a good working relationship with them. If the family and support staff are all comfortable working as part of the team the chances of positive outcomes are greatly increased.

ABI is different to other injuries or illnesses in that it is very unpredictable. The experts still have a lot to learn, so it is understandable that some family members will be fearful and feel inadequate to the task of caring for a loved one with ABI. If their loved one had a broken leg or glandular fever, for instance, it would not be so daunting. Family members can be overwhelmed by the amount of new information they are learning, the responsibility of making decisions in an area they don't fully understand and the burden of changed family dynamics.
Family members can experience a bewildering array of emotions and feelings including shock, anger, disbelief, denial, depression, fear, stress, frustration, and relief. They will also experience grief over the loss of the person, lifestyle, and relationship they had before the ABI. Often this is accompanied by guilt.

Sometimes family members will refuse counselling or support believing they should just be grateful that their loved one is still alive. Often they will take on more than they should, and refuse to let anyone else help them. This can come from feeling that they nearly lost the person once, so need to be there to protect them now.

When working with families and other support people:

- Make sure they understand the consequences of the ABI on their loved one. Don't assume they know the deficits involved. They may have been told at a time when they were under stress and being bombarded with information. Explain in clear, specific terms in a way that makes sense to them.
- Take time to build a relationship with them. Include them in all decisions. The best chance for positive outcomes is to have everyone working as a team.
- Be aware of family dynamics. Not all families are The Brady Bunch. If the person with an ABI indicates they do not want someone included, respect that wish.
- Encourage them to seek support if you see it is required. Validate their feelings – it is ok to feel resentful of the person with ABI.
- Be patient – some of them have been on a rollercoaster of mixed feelings and emotions. They may be very vulnerable. They may vent their frustration and fear on you for no apparent reason. Don't take it personally.
- Always remember they are victims too.

KRISTA'S STORY

Girlfriend, secretary, daughter, former wine lover, AFL Fan, romantic novel fan.

Krista had been working as a secretary in a law firm for 20 years, during which time she had established a reputation for efficient and accurate work. Her excellent employment record meant that when called in to see her supervisor she was overwhelmed to hear that complaints had been made about her work. Over the last 12 months there had apparently been several incidents where she had failed to meet deadlines. Krista was told her work was becoming less accurate, that she was slow getting work finished and that she seemed to spend too much time talking to other staff – meaning that important work was being left until the last minute. The law firm were concerned that Krista was experiencing personal difficulties that were interfering with her work. They valued her as an employee, and so referred her to the company psychologist for counselling. During counselling it became apparent that Krista had been drinking about half a bottle of wine each night for the past 10 years or so. Sometimes she would have more on weekends but was rarely drunk.

Krista confided to the counsellor that she had recently been drinking more because she'd been feeling less able to cope with life and work. She'd been finding her work more difficult and was unsure what was going on.

After being referred for alcohol and drug counselling, and being pleased with her efforts at abstaining, Krista was still concerned that the work situation was not improving. The psychologist referred her for neuropsychological assessment, which found she had mild to moderate ARBI. The report stated that she was slow in her thinking and that her planning and organisational skills had been affected. There was also some mild reduction in her short term memory capacity. The psychologist, neuropsychologist, Krista and her supervisor met to discuss the situation. Assessment of Krista's work environment and duties highlighted ways in which her workload could be altered so as to maximise her work efficiency. In discussions with Krista's supervisor it became apparent that Krista was typing for several of the partners, that she was required to prioritise jobs and that it was not always clear which work was more urgent. After several meetings, it was agreed that the partners would give their work to the supervisor with clear information about when the job was to be completed. The supervisor would then prioritise the work and pass on jobs to Krista one at a time. Larger pieces of work were to be broken down and given to Krista in manageable sections. Changes were also made to Krista's work station. Divider walls were assembled to minimise distraction from colleagues walking by and reduce general noise in the environment. A recent meeting with Krista and her supervisor proved the restructuring of her job to be extremely successful. Krista's work performance had improved, she was feeling good about her job and had managed to abstain from drinking.

FURTHER RESOURCES

arbias PROVIDES THE FOLLOWING SERVICES

Specialists in Acquired Brain Injury.

arbias is a specialist service which works together with families, support networks, employers and service providers to assist people with ABI including alcohol and other substance related brain impairment to live and function to their full potential in the community.

arbias Ltd was established in 1990 to provide services for people with alcohol and other substance related brain impairment. It is a not for profit company managed by a Board of Directors.

Secondary Consultation
Provides specialist consultation to people with ABI, their families, carers and service providers. Services include: information, support and advice related to accommodation, dual diagnoses, drug and alcohol issues.

Information Services
Producing a range of literature and electronic information for people with ABI, families/carers, members of the Indigenous community and people from a non-English speaking background.

Workforce Training, Development & Capacity Building
Training modules on ABI including alcohol and other substance related brain impairment for health practitioners. Particular emphasis is given to understanding the implications of the impairment and working effectively with associated health and behavioural issues, information, support and advice related to accommodation, dual diagnoses, drug and alcohol issues.

Neuropsychological & Neurobehavioral Assessments
Provides a full neuropsychological assessment and diagnoses for people with suspected brain impairment.

Case Management
Provides and crisis response, complex case support, outreach case management, monitoring and support for people with ABI including alcohol or other substance related brain impairment. Compensable and non-compensable recipients recieve.

Accommodation
Provides transitional and long-term accommodation for people with ABI including alcohol or other substance related brain impairment.

Community Access
Provides assistance with community participation to people with ABI and their families.

Community Inclusive Services
Provides social, health and well being programs to people with a disability residing in Supported Residential Services, and to people with ABI including alcohol or other substance related brain impairment residing in the community.

GOVERNMENT & FURTHER RESOURCES

Government Resources

NSW Department of Family and Community Services
Ageing, Disability and Home Care
(ADHC) www.adhc.nsw.gov.au

VIC Department of Human Services
Disability Services
www.dhs.vic.gov.au/disability

Further Resources

Beyond Blue
1300 22 4636
www.beyondblue.org.au

Careline
(24 hour urgent respite assistance)
1800 052 222

CBDATS
ABI behaviour consultancy
(03) 9490 7366

Centrelink
13 27 17
TTY 1800 810 586
www.centrelink.gov.au

Child Protection
13 12 78

Commonwealth Respite and Carelink Centre
1800 052 222
www.health.gov.au/ccsd CRS

Commonwealth Rehabilitation Services
1800 277 277
www.crsaustralia.gov.au

Cultural Diversity Resource
www.multicultural.vic.gov.au

Directline (Alcohol and drugs)
1800 888 236

Disability Online
www.disability.vic.gov.au

Gambler's Help
1800 858 858

Infoxchange
9418 7400
www.infoxchange.net.au

Interpreter
Translating and Interpreting Services
(TIS) 131 450
www.immi.gov.au

Kids Helpline
1800 55 1800

Legal Aid
www.nla.aust.net.au

Lifeline
13 11 14

Mensline Australia
1300 789 978

NSW Public Guardian
www.lawlink.nsw.gov.au/opg

Nurse-On-Call (Health Advice)
1300 606 024

Office of the Public Advocate (VIC)
1300 309 337
www.publicadvocate.vic.gov.au

Parentline
13 22 89

Poison's Information Centre
13 11 26

Relationships Australia
1300 364 277
www.relationships.com.au

SEWBMH
Social and emotional wellbeing and mental health services in Aboriginal Australia
www.sewbmh.org.au

NOTES

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