

# Homeless Adults Living with Acquired Brain Injuries

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## Acquired Brain Injury

The incidence of ABI in Australia has been reported to range between 100 to 377 people per 100,000 people each year.<sup>1</sup> The exact number of people with an ABI living in Victoria is unknown, but is estimated to be around 72,800 of which 31,000 have some need of personal assistance or supervision.<sup>2</sup> It has been suggested that these estimates are conservative and the actual number of people affected is much greater due to difficulties in differentiation between ABI and other conditions such as dementia. There difficulties are attributable to:

- Imprecise use of terms and definitions;
- Differentiation of ABI from the memory changes associated with normal aging is difficult or impossible;
- The symptoms of normal aging, depression, and mild dementia can be misdiagnosed by a clinician who may misinterpret the signs and symptoms of these disorders.
- Depression often occurs as a complication of dementia, however depression is also frequently accompanied by cognitive problems, especially in older persons;
- The signs and symptoms of neurologic disorders accompanied by dementia (e.g., Alzheimer's, Huntington's, Alcohol related brain injury, and Parkinson's disease) may have some overlap with those of depression;
- No sound method available for testing and demarcating the boundaries between (a) intellectually intact depressed elderly individuals; (b) others who have significant affective symptoms and substantial cognitive impairment, where the intellectual deficits are reversible following vigorous therapeutic intervention; and (c) those who suffer a progressive neurological disease which manifests itself with both behavioural symptoms.<sup>3</sup>

ABI refers to any type of brain damage that occurs after birth. The specific symptoms or losses of functioning depend on which brain areas are affected. There is a wide range of causes of ABI, some of which include:

- **Alcohol or drugs** — alcohol related brain damage (ARBD);
- **Disease** — such as AIDS, Alzheimer's disease, cancer, multiple sclerosis or

Parkinson's disease;

- **Lack of oxygen** — called anoxic brain injury (for example, injury caused by a near drowning);
- **Physical injury** — such as an impact to the head, which may occur in car or sporting accidents, fights or falls;
- **Stroke** — when a blood vessel inside the brain breaks or is blocked, destroying the local brain tissue.<sup>4</sup>

The changes in mental function caused by an ABI are complex. The diversity of symptoms can include impairments in executive functioning, ability to learn (learning difficulty), thought processes and emotional regulation. The terms 'learning impairment' or 'learning difficulty' can incorporate a wide variation of problems with memory, perception, problem-solving, and conceptualising resulting in the person having significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities. The condition is attributed to a heterogeneous group of disorders including,

cerebral palsy, epilepsy, neurological impairment, autism or acquired brain injury. People with ABI are more likely to suffer from mental health problems that may precede the injury or occur as a result of major disruption to their health, functional capacity and lifestyle following the injury. Although the group of people with ABI constitutes only a small proportion of the total number of people with dementia, they pose severe and ongoing challenges for residential aged care facilities. Most problematic is the frequency with which significant problems with impulse control, social skills and self-awareness accompanies the diagnosis of ABI.

Similarly, an ABI can cause symptoms similar to psychosis and dementia as well as to significant problems with impulse control, social skills and self-awareness. These problems may manifest as agitated, difficult, disruptive, inappropriate and/or aggressive behaviour which may or may not be associated with a serious mental illness or disorder.<sup>5</sup> Behavioural disorders can also result from two common syndromes associated with long-term alcohol abuse and ARBD. They are the



Korsakoff Amnesic Syndrome and the Adaptive Behaviour Syndrome:

- The Korsakoff Amnesic Syndrome is characterised by intact immediate memory, a profound difficulty learning new information, poor recall of recent events, confabulation and lack of spontaneity.
- The Adaptive Behaviour Syndrome is characterised by poor planning and organisation, concrete and inflexible thinking, lack of insight, inappropriate behaviour and a lack of self-criticism.<sup>6</sup>

Mental health services receive both Commonwealth and State/Territory funding. Commonwealth funding enables people to access GPs and private psychiatrists, while State funding covers community health services and specialist public mental health services. However, because these services are targeted at people with serious mental illness, people with ABI sometimes encounter difficulty accessing them. This is because the significant cognitive, emotional and behavioural disturbances that can result from an ABI can be difficult to distinguish from those of a co-existing mental illness.

In Australia, community-based clients with an ABI requiring treatment for mental illness are referred to the Specialist Mental Health Service System. This service provides clinical services managed through public hospitals and psychiatric rehabilitation services managed through non-government community organisations. The Brain Disorder and Injury service at Royal Talbot Rehabilitation Centre is the major ABI-specific service funded by the Mental Health Branch of the Victorian Government. It provides specialist assessments, treatment, rehabilitation and extended care for traumatic brain injury and /or organic brain disorders. Other services include:

- The Royal Melbourne Hospital Neuropsychiatry Service — providing in/outpatient assessments and treatment; and
- The Bouverie Centre at the Victorian Family Institute — providing state-wide specialist services to families and professional health carers.

Treatment for an ABI can include a combination of interventions including cognitive/behavioural remediation, psychotherapy; and pharmacotherapy. Current research suggests that alternative intervention treatments may be as effective as antipsychotics or other drug treatments for some conditions. These may potentially be less expensive and have fewer side effects than medication; however they rely on a greater degree of expertise and training of support staff as well as careful planning and execution of care plans. Behaviour management therapy involves a process of understanding what reinforces and sustains maladaptive behaviours and designing methods or teaching skills that reduce or eliminate them.<sup>7</sup> These therapies are being investigated for use in many different disability groups including the treatment of socially unwanted behaviours or antisocial behaviours (ASB) that commonly accompany acquired brain injuries.

## Alcohol Related Brain Damage

The consumption of alcohol is intrinsic to the Australian culture yet it has been demonstrated that beyond the aspect public awareness campaigns such as 'drink-driving', Australians have limited understanding of the extent of alcohol-related harm through its chronic abuse.<sup>8</sup> The consumption of alcohol has been estimated to have resulted in 31,133 deaths in Australia between 1992 and 2001 through associated disease or injury. Alcohol misuse in older people is of particular concern as this population group is particularly vulnerable due to limited access to opportunities or appropriate services. The misuse of alcohol among older people is often described as a 'hidden' or 'neglected' area of research.<sup>9</sup>

At present the most frequent drug of abuse among the elderly is alcohol. However, there is an emerging population group who has experienced greater exposure to illicit drugs and therefore may influence the incidence of drug-induced ABI over the next decade. The majority of drugs that are abused act on the brain to produce euphoric effects; however some of them also have severe negative consequences in the brain such as seizures, stroke, and widespread brain damage that can impact all aspects of daily life. Drug use can also cause brain changes that lead to problems with memory, attention and decision-making. Drugs that can cause neurological problems include: cocaine, GHB, inhalants, marijuana, MDMA, methamphetamine, nicotine, prescription stimulants and Rohypnol.<sup>10</sup>

Alcohol problems in older people are increasingly common.<sup>11,12</sup> It has been found that significant numbers of people over 65 exceed recommended drinking limits.<sup>13</sup> These limits are usually set for the general population representing adults of all ages and therefore represent excessive amounts for older people. Although generally, the amount individuals' drink decreases with age, in USA it has been found that up to 15% of older people had problems associated with alcohol and in the UK, it was found that between 3–9% of older people drink to excess.<sup>14</sup> The frequency of under-diagnosis of alcohol problems and ARBD in older people is considered to be significant. The principal cause of this under-diagnosis is thought to be due to the awareness of ARBD being low among frontline workers in health and social care.<sup>15</sup> Alcohol problems may not be identified by GPs or other primary care and frontline staff and older people rarely access specialist alcohol services. Alcohol use by older people is often found to be associated with cognitive impairment caused by ARBD.

When the effects of excessive or inappropriate alcohol consumption is considered in an aging population, alcohol-related ill health is a compounding factor. The physiological changes that occur with aging result in increased vulnerability to the effects of alcohol and increased risk associated with mixing alcohol with

prescribed medication. The negative health effects of chronic alcohol misuse for older people are well documented. Traditionally alcohol treatment services have not been available for older people and there has been a lack of appreciation of the problems associated with alcohol for older people.

Alcohol related brain damage (ARBD) is caused by a combination of Thiamine (vitamin B1) deficiency, general cerebral shrinkage (secondary to alcohol consumption), and a range of other insults to the brain including repeated head injury or assault. The process of metabolising alcohol increases the metabolic demand for Thiamine, which plays an important role in ensuring that the brain receives a steady supply of sugar. In addition alcohol dependence also decreases the absorption of Thiamine from the gut. And because alcohol-dependent people are prone to deprivation their nutritional status is generally poor increasing their vulnerability to ARBD.

Although varying degrees of recovery from an ABI can occur, there is typically some degree of permanent impairment. For people recovering alcohol-related brain damage (ARBD) however, there is evidence of improved cognitive functioning over the first two weeks of abstinence but conflicting evidence as to the possibility of further improvement over a longer period of time.

Estimates of the incidence and prevalence of ARBD are particularly difficult to obtain because of under-diagnosis, and the estimates that are available are difficult to compare because of different methodologies and different study populations. Autopsy studies in Australia have produced estimates of the prevalence of Wernicke-Korsakoff syndrome (a type of alcohol-related brain injury associated with thiamine malnutrition) of around 2% for the adult population. The early identification of ARBD is difficult due to the diversity, complexity and variability of individual symptoms. The resulting diversity of individual needs has led to the recommendation that ARBD requires a person-centred approach.<sup>16</sup> However, the social stigma attached to ARBD, resulting from its association with alcohol, mental health problems and dementia, needs to be addressed beyond the individual to institutional and societal levels. It has been suggested that future strategic development of information, advice and health promotion services would go a long way to addressing these issues.

There is a growing body of research examining the effects of aging in association with long-term alcohol abuse; however the increased complexity of these two factors in the homeless population has received little attention. In study in Melbourne 43% of an elderly homeless population reported having issues with alcohol.<sup>17</sup> Problems were more commonly reported by men (48%) than women (28%) with nearly half the men admitting to heavy drinking or alcohol dependence. However, when case workers were questioned as to their client's level of alcohol consumption, there is evidence of significant underreporting with alcohol-related problems being reported in 77% of

the male population and 44% of the female population. Similarly, in the UK it was found that the number of women with reportedly high levels of alcohol consumption decreased as their socioeconomic position decreased, however for men there was an upturn in consumption levels (particularly in relation to excessive drinking) among the poorest income groups and unskilled social class. However, much of this research stems from population groups known to demonstrate a high incidence of excessive alcohol consumption, such as the homeless.

More recent evidence suggests that the problem is much more wide spread and that alcohol abuse among the older population is being grossly under diagnosed. This may be due to such factors as a lack of acknowledgment of alcohol problems among staff working with older people, a lack of accurate screening or assessment tools and the social stigma associated with alcohol abuse. Older people who have the financial means to afford private residential aged care and those with family who may fear the "labelling" of their aged relative can, and do, enter mainstream aged care residential services provided that they are over 65 years of age. However, as discussed earlier many people with ARBD often experience premature aging and are younger than 65. They commonly have issues around their alcohol problems which generic services may not be designed to cope with. Therefore it has been acknowledged that some specialist aged-care service providers such as Wintringham allow younger people in target populations to access their older peoples' services.

## **Acquired Brain Injury Amongst Older People who are Homeless**

There are currently some 105,000 homeless Australians on any given night, of which approximately 30% are entrenched in a cycle of homelessness. 17% of homeless Australians are aged over 55 (approximately 185,000 people) and people in this age group are also overrepresented among those living in temporary and insecure housing and at risk of homelessness.<sup>18</sup>

The presence of dementia is highly prevalent within the older homeless population and is usually multi-factorial in aetiology. Research has found that approximately 50% of homeless service users (58% of homeless men and 42% of homeless women) have a history of traumatic brain injury.<sup>19</sup> The most common of which are acquired brain injuries (ABI) arising from long-term exposure to the harmful levels of alcohol intoxication and/or head trauma. People with multiple diagnosis including mental illness, substance abuse and ABI often find it difficult to access appropriate services. These individuals may have trouble negotiating complex systems due to cognitive or behavioural problems. Even with help, barriers exist. The multiply diagnosed are often unable to get assistance because of their co-morbid diagnosis. When a multiply diagnosed patient is homeless these barriers are magnified. Commonly

accompanying these injuries is an overlay of challenging behaviours that may further alienate the individual from social inclusion and accessing mainstream aged care support.

The relationship of alcohol and drug use to homelessness is interactive and iterative in that it can be both a cause and an effect of homelessness.<sup>20</sup> When significant proportions of already limited financial resources are spent by someone who is alcohol-dependent on alcohol or other substances, the maintenance of stable housing becomes increasingly difficult. It is also difficult for an individual to focus on substance misuse treatment when their basic survival needs for food and shelter are threatened. The stress and danger associated with homelessness also may feed back into the cycle of relying on alcohol or other substances as a coping strategy. With the added complication of alcohol-related ill health, the complexity of the individuals' care needs increases exponentially. In particular, problems associated with behavioural disorders make the ability to maintain stable accommodation more difficult.

Traditional treatment options with detoxification and abstinence, although recognised as the best option from a health perspective, are not generally as effective with the homeless population compared with the general population.<sup>21, 22, 23</sup> 'Mainstream providers' are generally reluctant to accept referrals for homeless alcohol abusers because of their frequent unpredictable behaviour, high-risk medical problems, poor compliance with discharge care plans and extensive, complex needs.

Over the last two decades, in Australian and international literature, there has been an increasing use of terms such as 'complex needs'<sup>24</sup> or clients with 'high complex behaviours'.<sup>25</sup> However these terms more often are used to refer to people whose needs and behaviours present significant, sometimes intractable challenges to all health, human service and criminal justice systems. Representing a very small proportion of the population but requiring considerable resources, a significant proportion of these people also frequently experience homelessness.<sup>26</sup>

People with coexisting mental health and ongoing substance abuse are known to have a poorer prognosis than those with exclusive substance addiction, with a higher incidence of hospitalisation, medication non-compliance, criminality, homelessness, and suicide.<sup>27</sup> Because of such complicated diagnostic and morbidity issues, patients identified as having a dual diagnosis require specialised treatment for a successful outcome.

The difficulty in case management and providing appropriate accommodation for older homeless persons with high and complex needs has posed a problem for health care providers, social support agencies and housing agencies for decades, especially since the introduction of social policies involving deinstitutionalisation and the promotion of community-based living.

The people to whom we refer somehow fall in the jurisdictional cracks created by division and structure of funding for health and social care.

These people tend to transiently shuffle between organisations that cannot provide long-term care management solutions. Their mental well-being and chronic health status incrementally deteriorates to such a point that the increased reliance on hospital and emergency services reaches crisis level at which stage institutionalisation remains as the only viable option. All too often these people become part of a cyclic pattern that commences when their self-neglect deteriorates to such a point that they lose the capacity to care for themselves. At this stage they usually enter the hospital service where an assessment is made and a guardian and trustee is appointed. Their care is managed, the alcoholics 'dry out', psychiatric conditions are treated and their cognitive ability improves.

The unfortunate consequence of this cyclic pattern of care and neglect is the progressive deterioration in psyche and physical health. There is evidence that older people with multiple needs may be particularly unwilling to use specialist or mainstream services. Outreach services provided on the streets; need to be maintained for this client group, however there remains a difficult balance between human rights and intervening where the client is unable to make a "rational" decision about their own welfare or poses a risk to others.

In Australia, there is a distinct lack of statutory provision for the older homeless population and there continues to be a lack of higher level supportive accommodation for people such as those living with acquired brain injury i.e: 24 hour staffed hostel. Most rehabilitative projects within the community have an emphasis that can overlook the needs of homeless people, particularly with coexisting complex mental health issues resulting from ARBD.

## **The Wicking Project**

Wintringham is a not-for-profit welfare company that provides aged care services specifically targeted at elderly homeless men and women (50 years and older) in Melbourne. The company delivers services to approximately 800 clients each night through a range of programs including residential aged care, rooming houses, independent living units, community care packages, extended aged care at home packages for those with dementia (Extended Aged Care in the Home — Dementia EACHD) and outreach services.

Wintringham is nearing completion of a four year research project called The Wicking Project.<sup>28</sup> The project, fully titled '*Older People with Acquired Brain Injury and Associated Complex Behaviours: A Psychosocial Model of Care That Supports Long-term Residential Care Needs: (The Wicking Project)*', commenced in October 2006 and was funded by a Major Strategic Initiative Grant from The JO & JR Wicking Trust which is managed by ANZ Trustees.

The funding of this project by the JO & JR Wicking Trust has provided the homeless and aged care service industries with the opportunity to develop and trial a much needed specialised service which would otherwise not have been possible due to the prohibitive costs associated with the delivery of such an intensive service model. The Wicking Project was advised by a highly regarded and esteemed committee of representatives from academic and key service industries.

The focus of The Wicking Project reflected the population of older people who had a history of homelessness, financial disadvantage and complex care needs as a result of moderate to severe levels of acquired alcohol-related brain injury (ARBI). The project aims to influence government and policy makers with a view to changing systemic responses to the needs of older people with ARBI. This will be achieved by increasing the awareness among policy makers of the gaps that exist within the current service system in the delivery of appropriately specialised services to meet the needs of these people, and by offering a solution in the form of a validated model of long-term care and support.

The Wicking Project centred on a research trial that investigated the effectiveness of a specialised model of residential care in improving the life quality and wellbeing of individuals with extremely challenging behaviours resulting from ARBI. The 18-month trial commenced in March 2008 with 16 participants selectively recruited with a history of severely affected behaviours associated with moderate to severe levels of ARBI and a history of unsuccessful tenancies arising from these behaviours. Household participants received individualised specialised care support, recreation and behaviour management plan implementation. These initiatives were supported by a team of highly trained and skilled personnel including specialist neuropsychological case management. The Waitlist/Control Participants continued to live their usual lifestyles while receiving traditional service support without additional intervention from the researchers beyond their participation in trial assessments.

Pre-trial participant demographic data showed the prevalence of co-existing mental illnesses was 78%, aggression 100%, severe impairment of executive functions 93%, ongoing excessive drinking 100% of which only 29% considered themselves to have a drinking problem. Preliminary outcome data conservatively estimates a greater than 70% success in transitioning participants into mainstream specialist aged care services and approximately 68% increase in the health and wellbeing of household participants in the trial. Alcohol consumption reduced by approximately 65%.

The Wicking specialised model of residential care has reframed challenging behaviour among the homeless to be interpreted as self-protective/defensive or responsive behaviour that occurs as a result of unmet needs. Primarily these behaviours are stimulated by the presence of an acquired

brain injury. Irrespective of the presence of brain injury or their anti-social behaviours these individuals are entitled to receive care and support that is appropriate to their needs, many of which are exacerbated by the effects of premature aging.

Essentially these successful outcomes have led to greater understanding of what is achievable through a highly supportive model of residential care. It has also led to a shift in emphasis and direction from traditional models that aim to provide long-term residential care to a small number of individuals to a more innovative intensive transitional model that could potentially support many individuals for as long as is needed to make a successful step-down transition to mainstream specialist care. ■

#### Footnotes

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