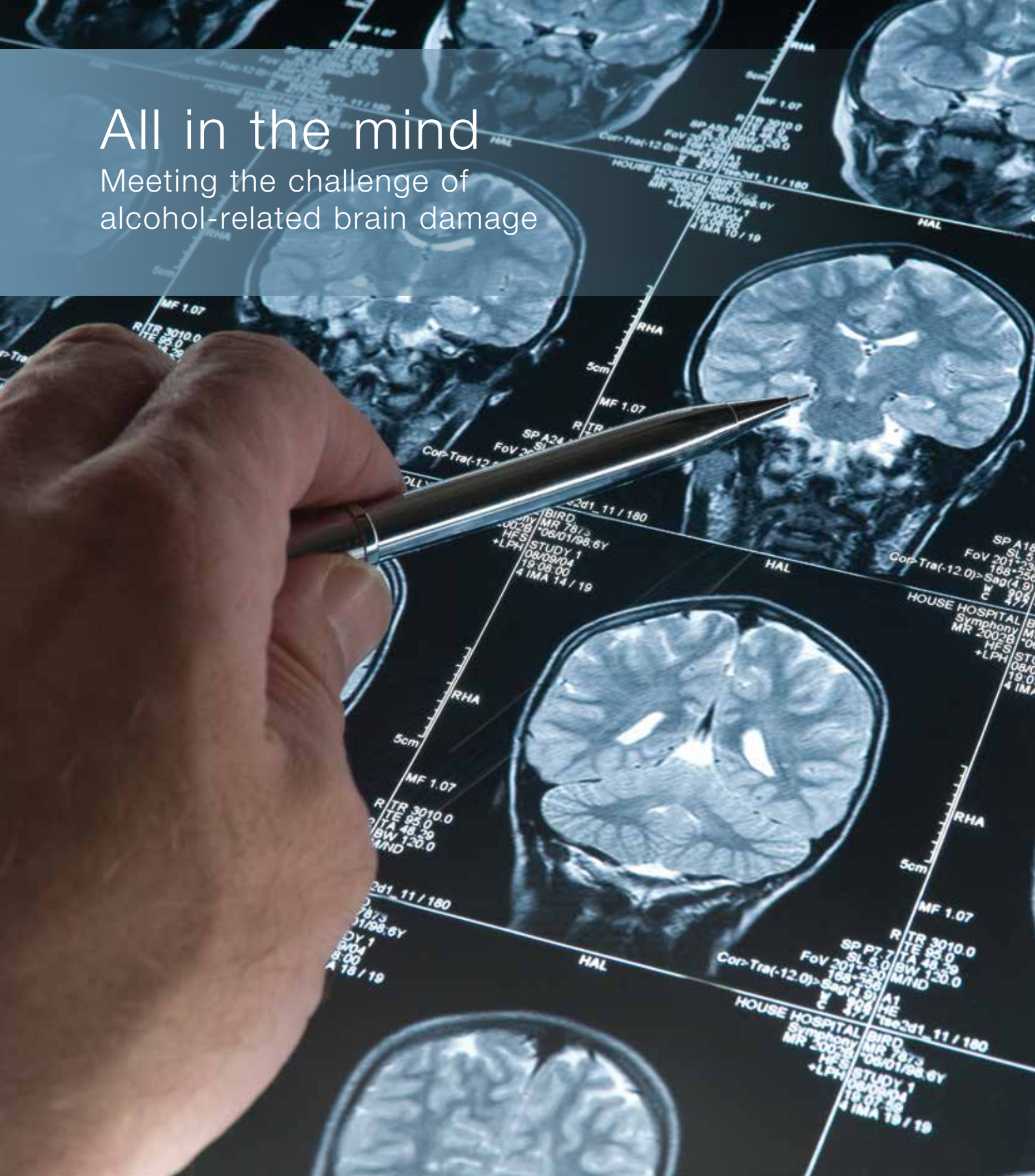


# All in the mind

Meeting the challenge of  
alcohol-related brain damage



Alcohol Concern  
Making Sense of Alcohol



## Alcohol Concern

Alcohol Concern is the national charity on alcohol misuse campaigning for effective alcohol policy and improved services for people whose lives are affected by alcohol-related problems.

## Our work in Wales

Alcohol Concern opened its office in Cardiff in August 2009. Alcohol Concern Cymru is focusing on policy and public health in Wales, acting as a champion for alcohol harm reduction.

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# Introduction

*"If you see an elephant on your doorstep, you know it's there."*

John Morris, 1979<sup>1</sup>

This paper looks at the range of conditions that are grouped under the umbrella of alcohol-related brain damage or impairment (ARBD or ARBI). These conditions have a variety of related symptoms, including confusion, memory loss, and difficulty reasoning and understanding. They are the result of the physical damage that alcohol, as a poison, does to brain tissue, coupled with nutritional deficiencies resulting from heavy drinking.

Although less common than some other alcohol-related conditions, ARBD nevertheless represents a serious public health challenge, and remains very much overlooked and misunderstood. This paper seeks to clear up much of the ignorance around ARBD, and to place it firmly in the context of our drinking society, rather than stereotyping it as an extreme affliction of a distinct group of easily identifiable 'problem drinkers'. It also emphasises the fact that, unlike some other forms of mental impairment, ARBD is not a progressive condition – it does not inevitably worsen, and can be successfully treated. It makes the case for ensuring that appropriate treatment is provided promptly to all who can benefit from it.

# As their heads boil with drink and confusion’ – what alcohol does to our brains

*“By this door were various pots and flagons.  
These were the remnants of the good  
companions, who freeze their feet under  
benches, as their heads boil with drink and  
confusion.”*

Ellis Wynne, 1703<sup>2</sup>

*“What we are seeing here is the capacity of a  
simple molecule to interfere with, or in some  
way hijack, the functioning of very complex  
brain systems.”*

Griffith Edwards, 2000<sup>3</sup>

Alcohol has been described as “the ambiguous molecule”.<sup>4</sup> Although commonly used to enhance mood and liven up social gatherings, it actually depresses the central nervous system, slowing our mental and physical reactions and reducing our co-ordination and cognitive function.<sup>5</sup> Alcohol acts upon the chemical messaging systems within the brain, producing on the one hand sensations of pleasure, and on the other a sedative effect.<sup>6</sup> Immediate symptoms include reduced inhibitions, talkativeness, impaired judgement and slurred speech.<sup>7</sup>

The long term effects of alcohol on the brain can be both psychological (mental health problems) and physiological (damage to brain tissue). People who drink heavily are particularly vulnerable to developing mental health problems,<sup>8</sup> and alcohol has a role in a number of conditions, including anxiety and depression, psychotic disorders, and suicide.<sup>9</sup> Over a long period of time, however, heavy drinkers may also develop various types of physical brain damage. These are due in part to the toxic effects of alcohol itself, but long term alcohol misuse can also lead to vitamin deficiencies that exacerbate the damage. The body uses Vitamin B1 (thiamine) in particular to build blood vessels, including those in the brain. If B1 is deficient, the blood vessels will leak. As any leaked blood clots, it also damages brain tissue around it.<sup>10</sup> There are various reasons this vitamin deficiency occurs:

- Alcohol can impede the metabolism of vitamins, most crucially of Vitamin B1
- Alcohol can inflame the stomach lining (gastritis) leading to vomiting of food before it is digested, and so making it difficult for the body to absorb the vitamins from it
- Alcohol also impedes the liver from storing vitamins
- Many very heavy drinkers eat little or eat badly, leaving them malnourished.<sup>11</sup>

The damage done by alcohol itself and by vitamin deficiency may be further compounded by physical injuries to the brain resulting from falls and/or fights during drunkenness.

# Clearing up the confusion – what is ARBD?

*"We might like to joke about killing off a few brain cells during a good night out, but the reality is that long term heavy drinking can do real damage to how well our brains work."*

Andrew Misell, 2013<sup>12</sup>

Alcohol related brain damage or impairment (ARBD or ARBI) is the umbrella term used to describe the effects of long term alcohol consumption on the function and structure of the brain. It can be divided into a number of categories:

- Wernicke-Korsakoff's Syndrome – first identified in the 1880s, and encompassing two separate but related disorders: Wernicke's Encephalopathy and Korsakoff's Psychosis.<sup>13</sup>
- Alcohol-related dementia or alcoholic dementia – the symptoms of which are broader and more numerous than those of Wernicke-Korsakoff's Syndrome, and are similar to those of Alzheimer's Disease<sup>14</sup>
- Alcohol amnesic syndrome – involving short term memory loss, difficulty concentrating, and confabulation (filling gaps in memories with irrelevant or inaccurate information).

Some researchers have argued, however, that ARBD is really a spectrum of disorders (including the three above) that merge into each other and overlap.<sup>15</sup> One crucial common factor to note about all forms of ARBD is that in spite of their similarity to conditions like Alzheimer's Disease, ARBD is not an inherently progressive condition – it does not inevitably worsen over the course of time, and given the right treatment, it can often be halted and reversed.

The physical and mental symptoms of ARBD are set out in the table below. Some of these are a direct result of the condition, and others are co-morbidities resulting from alcohol consumption and/or malnutrition.<sup>16 17</sup>

## Cognitive and memory problems

- Confusion about time and place
- Poor concentration
- Difficulty processing new information
- Inability to screen out irrelevant information
- Confabulation
- Apathy – loss of motivation, spontaneity and initiative
- Depression
- Irritability

## Physical problems

- Ataxia – poor balance and a shambling gait
- Damage to the liver, stomach and pancreas
- Hepatic encephalopathy – damage to the brain by toxins normally removed by the liver
- Cerebellar degeneration – damage the area of the brain that controls coordination and balance
- Traumatic brain injury – as result of falls and/or fights
- Peripheral neuropathy – numbness, pins and needles or pains in hands, feet and legs
- Nystagmus – involuntary eye movement, sometimes called 'dancing eyes'
- Ophthalmoplegia – weakness or paralysis of the eye muscles

People with ARBD often also show damage to the frontal lobe of the brain, leading to impaired reasoning skills and difficulties with:

- Planning
- Understanding the implications of decisions, e.g. decisions about whether to drink alcohol or abstain, and how this will hinder or help their recovery
- Problem solving
- Adapting and inhibiting behaviours, potentially leading to disruptive or inappropriate behaviour<sup>18</sup>

# Myths and reality – who gets ARBD?

*“The stereotypical image of someone with ARBD as being a troublesome street drinker may be inaccurate, with many having worked for years and having experience family life at some point.”*

Dr Pamela Roberts, 2012<sup>19</sup>

*“Even heavy social drinkers who have no specific neurological or hepatic problems show signs of regional brain damage and cognitive dysfunction.”*

Dr Clive Harper, 2009<sup>20</sup>

Whilst the traditional image of someone whose mental capacity has been eroded by alcohol is of a hardened street drinker, the reality is somewhat different. In 2004, the Scottish Executive’s expert committee on the subject concluded that “people affected by ARBD are a diverse group in terms of age, gender, lifestyle, family structure, social networks, drinking history, age of onset of ARBD, the presence of other mental health problems, physical or learning disabilities, neurological or medical conditions, employment history, cultural and spiritual background”.<sup>21</sup>

Research has found the highest prevalence of ARBD between the ages of 50 and 60.<sup>22</sup> However, we cannot ignore the potential implications of current high levels of alcohol consumption amongst many young people, already seen in earlier presentations at hospital with alcoholic liver disease.<sup>23</sup> As Prof Kenneth Wilson has noted, as early as 2003 the Australian acquired brain injury service ARBIAS reported that more than half of its patients were aged between 35 and 54.<sup>24</sup> Similarly, the Scottish Executive’s expert committee noted that “overall in Scotland it appears that the age of presentation to services is lower than it used to be” and that “services should note the increased presentation of men at a younger age. Assessment and ongoing care will have to take account of the needs of this younger client group”.<sup>25</sup> It is also worth noting that women have been found to have a shorter drinking history prior to developing ARBD,

and on average present with ARBD 10 to 20 years younger than men.<sup>26</sup>

One reason for the continued stereotyping of those with ARBD as being of a certain age and background – typically an elderly, homeless male – is our more general reluctance to recognise that ‘problem drinkers’ are not bizarre outliers, but rather members of a drinking society that includes the vast majority of us. There is paradox here, in that whilst alcohol use (and certain forms of drunkenness) have become more normal and acceptable, alcohol problems remain shrouded in mystery and shame. This situation is in part perpetuated by the drinks industry’s insistence that alcohol is a neutral commodity that helps us “celebrate life”<sup>27</sup> and that only causes problems in the hands of irresponsible or weak willed consumers,<sup>28</sup> an alleged “mindless minority [that] does not understand how to drink sensibly”.<sup>29</sup> The implication that people with ARBD have brought the condition upon themselves by irresponsibility has led to concerns that those with ARBD are not seen as suitably deserving of support.

Alcohol Concern seeks very much to challenge this attitude, given the body of evidence that alcohol is an intrinsically dangerous substance and that its marketing, distribution and use therefore require careful regulation and management.<sup>30</sup> Once we recognise that alcohol, whilst being an established part of most of our social lives, is also a toxic and addictive drug with a number of intrinsic dangers,<sup>31</sup> we will be in a better position to deal in an evidence-based manner with the prevention and management of conditions like ARBD.

# Overlooked and undercounted – how we miss ARBD

*“For a condition that is treatable, there are a lot of people who are being misdiagnosed or not diagnosed at all.”*

Prof Simon Moore, 2013<sup>32</sup>

The exact prevalence of ARBD in the population of Wales, and the UK as a whole, is hard to pin down. A number of studies from around the world give us some indication of the size of the problem:

A meta-analysis of nearly 40,000 post mortems in America and Europe found signs of Wernicke-Korsakoff's Syndrome in around 1.5% of the brains examined<sup>33</sup>

- A similar study also including Australia found a range of prevalence rates from 0.4% in France and 0.5% in the UK to 2.8% in Australia<sup>34</sup>
- Studies in Scotland have found prevalence rates of 0.07% in Argyle and Clyde<sup>35</sup> and 0.14% in Inverclyde<sup>36</sup>
- Unsurprisingly, studies have shown a much higher prevalence in people who are dependent on alcohol – around 35%.<sup>37 38</sup>

ARBD, however, remains very much overlooked and underdiagnosed. One post mortem study of around 2,000 brains found 25 cases of Wernicke-Korsakoff's Syndrome, only 4 of which had been diagnosed during life.<sup>39</sup>

A number of assessment tools for ARBD do exist, the most usual being ACE-R (Addenbrooke's Cognitive Examination – Revised Version),<sup>40</sup> a short test taking around 15 minutes to administer. However, there are various reasons why ARBD is often not diagnosed, nor even considered as a possible diagnosis:

- Ignorance of ARBD amongst clinicians, leading to patients with the condition being misdiagnosed as having other forms of dementia or mental illness
- Stigma around the condition and people with it
- Commonly used assessment tests such as the Mini Mental State Examination<sup>41</sup> are not necessarily well suited to identifying ARBD
- Difficulty differentiating between the prolonged or permanent effects on the brain of excess alcohol, and the short term states associated with intoxication, alcohol withdrawal and physical illness. In short, when a person is drunk, or withdrawing from alcohol, it is not always clear if their confused condition will improve when sober, or is more permanent
- People with ARBD are often alienated from their families and friends, and generally socially isolated, meaning they will often not have people around them who know their history and can explain it to clinicians.<sup>42 43</sup>

Epidemiological studies may also underestimate the prevalence of ARBD for various reasons:

- A reliance on medical records, which, given the frequent failure to diagnose ARBD, are undercounting prevalence
- A tendency to concentrate on the classic presentations of Wernicke's Encephalopathy and Korsakoff's Psychosis, thereby overlooking other forms of ARBD and other symptoms.<sup>44</sup>



# 'Difficult patients' – managing ARBD in our health and social care system

*"One common experience of all the service users assessed is that they tended to come to the attention of statutory services as a result of a crisis in their lives."*

Dr Pamela Roberts, 2012<sup>45</sup>

*"They are frequently difficult to discharge due to the absence of support services for them in the community. Mainstream mental health services have limited expertise in this area."*

Prof Kenneth Wilson, 2010<sup>46</sup>

One obvious consequence of the lack of awareness of ARBD, and the lack of specialist provision for it, is that people with the condition often access services that are not set up to meet their particular needs. Their inability to care for themselves and maintain a stable home may mean they come to the attention of local authority social services or housing departments. Their erratic behaviour may lead to involvement with the police. They may arrive in hospital via A&E or be admitted for other alcohol related conditions, such as gastric disorders. They may then remain on acute medical wards for long periods of time, requiring considerable supervision.<sup>47</sup> Given the frequent lack of rehabilitation and follow-up after discharge, there is often a 'revolving door' of readmissions to hospital.<sup>48</sup>

When they are received by a service, a number of the symptoms of ARBD can make working with people with the condition very challenging:

- They often lack insight into their own condition, making them reluctant to engage with a programme of treatment
- They may be unable to recall their own history and also unable to retain information given by staff – typically, patients with advanced ARBD will retain information for up to half an hour, and may respond lucidly to questioning during this time, but gradually forget what has been discussed
- They may have difficulty reasoning and making decisions, making it hard for them to manage

their alcohol consumption or think through the implications of continuing to drink

- They may also be disorientated and behave erratically and/or aggressively.<sup>49</sup>

Given all these factors, it is hardly surprising that there is considerable anecdotal evidence of patients with ARBD being passed between services who feel reluctant or ill-equipped to take them on. For example, of the 30 patients with ARBD recorded by Cardiff's Community Addictions Unit between 2008 and 2012:

- 5 are known to have been placed in specialist units in England
- 2 have been placed locally in older people's residential homes
- 5 have returned to hostels for the homeless
- The remainder are receiving limited support from local authority services within their own homes, and several have resumed drinking after detox.<sup>50</sup>

Similarly, the Cardiff and Vale of Glamorgan substance misuse charity Pen yr Enfyfys has described a number of scenarios that may play out with people with ARBD:

- Some are placed in care homes for the elderly, which are recognised as unsuitable, and where they often move from one place to another as their behaviour becomes difficult to cope with. They often end up in homes that are willing to cope but do not offer rehabilitation nor very good living conditions
- Others end up in hospital beds, awaiting decisions about their future
- Some remain in the family home, sometimes undiagnosed and deteriorating
- Some, due to the problems above, end up homeless
- Some meet an early death due to unchecked deteriorating health.<sup>51</sup>

It is also worth noting that some providers actively exclude clients with a diagnosis of ARBD from their services, because of the difficulties that can come with them.<sup>52</sup>

# Can we fix it?

## – preventing and treating ARBD

### Prevention

Whilst it may be regarded as an extreme and unusual condition, ARBD is simply one of many indicators of our unhealthy relationship with alcohol in the UK. As Prof Kenneth Wilson has noted, the available evidence indicates that the prevalence of Wernicke-Korsakoff's Syndrome is related not just to levels of alcohol dependency but also to national alcohol consumption indices.<sup>53</sup> It therefore follows that the single simplest and most obvious method for preventing ARBD is moderating alcohol consumption in the population. Alcohol Concern has noted previously that alcohol misuse is a spectrum and that the boundary between healthy alcohol use and alcohol misuse is not always clear. Many of us will alternate between healthy and unhealthy patterns of use over time, and for this reason it is not helpful or honest to attribute problematic drinking and alcohol-related illnesses to a discrete group of 'problem drinkers'.<sup>54</sup> There is a strong preventative case for whole population interventions to reduce overall consumption – the most effective of which are those to increase the price and reduce the availability of alcohol.<sup>55</sup>

As noted above, vitamin deficiency is a major factor in ARBD. For this reason, it has been occasionally suggested that increasing intake of Vitamin B1 by the general population would be a valuable tool for ARBD prevention. In 1998, researchers found that there had been a significant decrease in the prevalence of Wernicke-Korsakoff's Syndrome in Australia since extra thiamine began being added to bread flour in 1991. They advised, however, that "further research is needed before adding thiamine to alcoholic beverages can be recommended".<sup>56</sup> There has been a legal requirement to add thiamine to white and brown flour in the UK since the 1950s (although wholemeal flour contains sufficient natural thiamine).<sup>57</sup> In 2012, the UK Government's Scientific Advisory Committee on Nutrition (SACN) concluded that the "evidence to continue the mandatory addition of thiamine to wheat flour is much weaker" than the case for adding other nutrients such as calcium and iron.<sup>58</sup> It is also questionable to what extent extra thiamine in foodstuffs will benefit heavy drinkers, as they may absorb very little of it.

### Treatment and recovery


*"It is important to note that Korsakoff's psychosis is not inherently progressive in the same way that an organic cause of dementia such as Alzheimer's Disease is. Overall, Wernicke-Korsakoff's Syndrome should be viewed as a treatable condition."*

Alcohol Concern, 2001<sup>59</sup>

Once ARBD is established, the prognosis for recovery can be split broadly into quarters:

- 25% make a complete recovery
- 25% make a significant recovery
- 25% make slight recovery
- 25% make no recovery.<sup>60</sup>

This means that, overall, 75% can make some recovery if they are identified at an early stage and offered appropriate treatment – a remarkably positive prognosis that has to encourage us to treat the condition more effectively. As in the case of any medical condition, there is no absolute guarantee of long term good health, and there are certain preconditions for recovery. As Prof Kenneth Wilson has noted, patients with ARBD can achieve "varying degrees of recovery, provided they are abstinent, physically well and their nutritional support is maintained".<sup>61</sup> It is also important to note the evidence that there is a two year window for recovery after an initial diagnosis of ARBD,<sup>62</sup> and so whilst treatment needs to be provided in a measured and evidence based fashion, it also needs to be provided promptly.



*"If people with Wernicke's encephalopathy are given treatment early, their symptoms will improve and they may make a complete recovery. However, if treatment is not given, or is not given in time, their condition may become life-threatening and irreversible brain damage can occur, severely affecting short-term memory."*

National Institute for Healthcare and Clinical Excellence, 2010<sup>63</sup>

Improved nutrition is a key component of any treatment regime. As with anyone else, it is generally beneficial to encourage and support people with ARBD to maintain a broad and balanced diet – both for their general health, and to aid recovery from the condition. However, for the reasons noted above, my heavy drinkers are unable to absorb nutrients well via the gut, and so are best treated with high doses of B vitamins given intravenously or intramuscularly – a treatment sometimes referred to as a 'banana bag' on account of the yellow colour of the liquid supplement, and marketed under the brand name Pabrinex. In spite of the effectiveness of this treatment, in 2001, Alcohol Concern noted "a trend away from prescribing this vital treatment".<sup>64</sup> Information gathered by Alcohol Concern at various forums indicates that knowledge of Pabrinex and rates of prescribing vary greatly in primary and secondary care in Wales and England.


One reason for this inconsistency has been concerns about the risk of anaphylaxis – a strong allergic reaction that can cause death. Problems with such reactions to Parentrovite – a mixture of B and C vitamins in use at the time – were noted by the Committee on the Safety of Medicines in 1989.<sup>65</sup> The Committee, however, revised its guidance following the replacement of Parentrovite with Pabrinex in 1993,<sup>66</sup> concluding in 2007 "that rare occurrence of serious allergic reactions should not preclude use in patients who need treatment by this route of administration – particularly those at risk of Wernicke-Korsakoff[s] Syndrome, for whom treatment with thiamine is essential."<sup>67</sup> In 2004, the British Association for Psychopharmacology

had stated that "given the nature of W[ernicke's] E[ncephalopathy], the benefit to risk ratio still favours parenteral thiamine".<sup>68</sup> Similarly, in 2009 a team at the National Addiction Centre at King's College, London, concluded that "it is better to give too much thiamine too soon than to give too little too late".<sup>69</sup> In 2010, NICE stated that thiamine should be offered to patients suspected Wernicke's encephalopathy, and that it should be given "in doses toward the upper end of the British national formulary range".<sup>70</sup>

Alongside nutritional and pharmaceutical interventions, a number of other therapeutic approaches have been shown to have benefits for people with ARBD. Neuropsychological approaches to the treatment of ARBD that have been tried successfully include:

- Errorless learning – A teaching method that is designed so that the learner does not have to make mistakes as he or she learns new information, giving the learning process a very positive feel
- Assistive technology – Use of an electronic diary has been shown to improve the ability to recall information, and improve attendance at therapy sessions
- Executive functioning – Using a clear set of rules to improve problem solving skills, with potential for applying this to everyday problems like meal planning and budgeting
- Mood modification – An adapted form of Cognitive Behavioural Therapy (CBT), with motivational elements and visual and written memory aids, has been used to improve mood and challenge negative automatic thoughts.<sup>71</sup>

In all cases, research suggests that recovery is enhanced by developing a rehabilitation programme specific and relevant to each patient, helping them to acquire (or regain) the skills they need to manage their own lives and their own environment.<sup>72</sup>



*"People are intrinsically active and creative, needing to engage in a balanced range of activities in their daily lives in order to maintain health and wellbeing...They create identity and meaning through what they do and have the capacity to transform themselves through premeditated and autonomous action."*

British Association of Occupational Therapists,  
2013<sup>73</sup>

There is also anecdotal evidence for what may be termed 'softer' interventions focussing on quality of life. In his 1985 volume of 'clinical tales' *The man who mistook his wife for a hat*, neurologist Dr Oliver Sacks described the history of a retired navy man 'Jimmie' with Korsakoff's Syndrome. Although this man showed no neuropsychological changes in 9 years, Sacks noted how 'Jimmie's' sense of wellbeing and his connection to the world around him was greatly improved by what could be described as occupational therapy:

- Appreciation of music – "He had no difficulty following music, for every moment in music and art refers to, contains, other moments"
- Gardening – "At first he greeted the garden each day as new, but for some reason this had become more familiar to him than the inside of the Home. He almost never got lost or disorientated in the garden now"
- Taking an active part in the Catholic Eucharist – "I saw here an intensity and steadiness of attention and concentration that I had never seen before in him or conceived him capable of".<sup>74</sup>

Clearly, these are examples of activities particular to one person, but the scope for equivalent interventions is certainly worth exploring. Whatever approach is taken, it is clear that improved care, support and treatment structures are very much needed. Whilst care of people with ARBD is often fragmented, where coordinated action is taken, real gains can be made. A review in 2011 of a new service in the Wirral found that bed occupancy by patients with ARBD had been reduced by 80% in terms of bed days per year.<sup>75</sup> As noted by the Welsh Government in 2005 with regard to management of chronic conditions more generally,<sup>76</sup> to properly support people with ARBD there is a need for:

- Early assessment
- Accurate and timely diagnosis
- An appropriate level of specialist service provision by a multidisciplinary team
- Self-management training schemes
- Active multidisciplinary rehabilitation programmes to reduce patient re-admission.

To this list, in the specific case of ARBD, should be added the need for appropriate and timely medication, specifically high doses of B vitamins.



# Under one roof – the role of residential care

Whilst support for people with ARBD can be provided in community settings, a number of studies have shown that patients with ARBD who are referred to residential facilities that specialise in the condition show greater improvements than those living in non-specialised accommodation.<sup>77</sup> Such specialist provision is scarce in Wales. The privately owned Arbennig Unit in Colwyn Bay includes 2 self contained homes for 6 to 7 residents each, with en-suite bedrooms, and shared cooking, socialising and eating areas. The unit has a strong focus on life skills and reintegration into the community.<sup>78 79</sup> There are no similar facilities in south Wales, and a number of people with ARBD from the area are placed in specialist accommodation in England, raising concerns not only about costs but also about disconnecting them from both their own families and friends and their healthcare professionals.

The Care and Social Services Inspectorate for Wales (CSSIW) has noted that identifying care homes prepared to accept residents with ARBD is not straightforward. The CSSIW is, however, able to provide figures for the number of care homes accepting adults under 65 with brain injuries (which are likely to offer a more appropriate care model for ARBD than residential services for older adults with Alzheimer's disease). The Inspectorate has identified 19 such care homes, unevenly distributed across Wales, providing a total of 244 places.<sup>80</sup> It is fair to conclude that this number is likely to be insufficient to meet the current and growing need for care of people with ARBD. It is also not clear what, if any, routes to recovery and rehabilitation each of these 19 facilities offers.

In 2012, an expert working group convened by Pen yr Enfyys and Alcohol Concern examined the need for specialist accommodation for 20 to 25 people with ARBD in south Wales. The group looked in particular at research by the Dementia Services Development Centre at the University of Stirling<sup>81</sup> into memory aids and cognitive rehabilitation, and how this research had been incorporated into specialist designs such as the development of 22 studio flats for people with ARBD at Tollcross Road, Glasgow.<sup>82</sup> Building on this work in Scotland, the group agreed the following basic principles for any new residential facility:

- The service should be developed with the idea that service users will remain in the unit for up to 2 years, this being the optimal length of time to benefit from a period of intense rehabilitation following a diagnosis of ARBD
- The emphasis should be very much on rehabilitation and reintegration into society, rather than simply providing somewhere to stay
- Consideration should be given to the need for subsequent accommodation when the period of intense rehabilitation has come to an end. Currently, when clients with ARBD are discharged from residential settings or hospital, they are often left to return to inadequate settings such as homelessness services, where many begin drinking alcohol again
- The provision of end of life care should also be considered within this service.<sup>83</sup>

# Conclusions and recommendations

It is clear that alcohol-related brain damage, in its various forms, is poorly understood by the public and many professionals, and that it is underdiagnosed and undertreated. This is in spite of a good prognosis for at least partial recovery, and the availability of a range of care and treatment approaches. To address the current issues relating to ARBD in Wales, Alcohol Concern recommends the following in relation to prevention, diagnosis and treatment:

## Recommendation 1

Work is needed to raise awareness amongst the general population, as well as health and social care professionals, of ARBD, its risk factors and symptoms, and the preventative measures that can be taken.

## Recommendation 2

Evidence-based whole population interventions – such as a minimum price per unit of alcohol, and control of the availability of alcohol – should be undertaken to reduce the prevalence over time of ARBD and other illnesses caused by alcohol overuse.

## Recommendation 3

Standardised accredited training should be developed on the early identification and diagnosis of ARBD. This training should be provided to all relevant health and social care professionals.

Alongside this, the expertise of local alcohol treatment service staff should be developed to better support and manage individuals with ARBD in the community.

## Recommendation 4

Where they do not already exist, links should be established and formalised between local alcohol treatment services (both statutory and voluntary sector) and specialist psychiatric and psychological services for ARBD, to ensure ready access to appropriate expertise.

## Recommendation 5

A clear care pathway from diagnosis to ongoing assessment and treatment for ARBD should be drawn up, and included within the Welsh Government's Substance Misuse Treatment Framework.

## Recommendation 6

Clinical guidance regarding the use of injected B vitamins (Pabrinex) for the prevention and treatment of ARBD should be reviewed, and additional training provided to clinicians, with the aim of ensuring optimal uptake on the basis of clinical need. In addition, a review should be undertaken of the evidence regarding the provision of injected B vitamins in community settings, and clinical guidance developed for these.

## Recommendation 7

Consideration should be given to the need for, and viability of, additional specialist residential rehabilitation facilities for the treatment of ARBD in Wales.

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# References

1. Lord Morris of Aberavon (2011) *Fifty years in politics and the law*, Cardiff, University of Wales Press.
2. Wynne, E. (1703) *Gweledigaethu y bardd cwsc*, University of Cambridge: A Historical Corpus of the Welsh Language 1500-1850, on-line, available at: [http://people.pwf.cam.ac.uk/dwew2/hcwl/gbc/gbc\\_frames.htm](http://people.pwf.cam.ac.uk/dwew2/hcwl/gbc/gbc_frames.htm) [accessed 29 November 2013].
3. Edwards, G. (2000) *Alcohol: The ambiguous molecule*, London, Penguin Books, p.9.
4. *ibid.*
5. Alcohol Concern (2010) *What's the damage? Negative health consequences of alcohol misuse in Wales*, London, Alcohol Concern.
6. *op. cit.* Edwards, G. (2000).
7. *op. cit.* Alcohol Concern (2010) *What's the damage?*
8. Mental Health Foundation (2008) *Alcohol and mental health*, London, Mental Health Foundation.
9. *op. cit.* Alcohol Concern (2010) *What's the damage?*
10. Alcohol Concern (2001) *Factsheet: Wernicke-Korsakoff's syndrome*, London, Alcohol Concern.
11. Alzheimer's Society (2013) *What is Korsakoff's syndrome?*, London, Alzheimer's Society
12. Sanders, A. (2013) *Symptoms of alcohol-induced brain damage being missed*, Western Mail, 28 October 2013.
13. Alcohol Concern (2001) *Factsheet: Wernicke-Korsakoff's syndrome*, London, Alcohol Concern.
14. Alzheimer's Society (2013) *What is Korsakoff's syndrome?*, London, Alzheimer's Society
15. Jacques, A. and Stevenson, G. (2000) *Korsakoff's Syndrome and other chronic alcohol related brain damage*, Stirling, Stirling Dementia Services development Centre.
16. Chiang, C.P.C. (2002) *Wernicke Korsakoff's Syndrome in Argyll and Clyde: A literature review needs assessment and recommendation for the prevention, treatment and provision of Wernicke Korsakoff's Syndrome*, Part II. Unpublished submission to the faculty of Public Health Medicine.
17. Smith, I. and Hillman, A. (1999) *Management of alcohol-Korsakoff's syndrome*. *Advances in Psychiatric Treatment*, 5, 271-278.
18. Roberts, P. (2013) *Neuropsychological assessment and approaches to treatment for ARBD*, presentation to Alcohol Concern and Cardiff University ARBD seminar.
19. Roberts, P. (2012) *Alcohol related brain damage – A diagnosis of exclusion in Wales?*, presentation to the Pen yr Enfyfys ARBD working group, Newport and Cardiff.
20. Harper, C. (2009) *The neuropathology of alcohol-related brain damage*, *Alcohol & Alcoholism*, Vol. 44, No. 2, pp. 136–140. Clive Harper
21. Cox, S. et al. (2004) *A fuller life – report of the expert committee on alcohol related brain damage*, Stirling, Dementia Services Development Centre on behalf of the Scottish Executive.
22. Rhoda MacRae, R. and Sylvia, S. (2003) *Meeting the needs of people with alcohol related brain damage: A literature review on the existing and recommended service provision and models of care*, Stirling, University of Stirling.
23. Campbell, D. (2011) *Alcohol-induced liver problems soar among young adults*, *Guardian*, 1 December 2011, online, available at: <http://www.theguardian.com/society/2011/dec/01/liver-problems-alcohol-young-adults> [accessed 5 December 2013].
24. Wilson, K. et al. (undated) *Alcohol related brain damage (ARBD) epidemiology*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 5 December 2013].
25. Cox, S. et al. (2004) *A fuller life – report of the expert committee on alcohol related brain damage*, Stirling, Dementia Services Development Centre on behalf of the Scottish Executive.
26. Cox, S. et al. (2004) *A fuller life – report of the expert committee on alcohol related brain damage*, Stirling, Dementia Services Development Centre on behalf of the Scottish Executive.
27. Diageo website (2011) <http://www.diageo.com/en-sc/ourbrands/categories/pages/default.aspx> [accessed 4 December 2013].
28. Bailey, J. et al. (2011) *Achieving positive change in the drinking culture of Wales*, London, Alcohol Concern.
29. Wine and Spirits Trade Association press release (2010) *Drinkaware host industry seminar with 50 drinks industry companies*, online, available from: <http://www.wsta.co.uk/Press/drinkaware-host-industry-seminar-with-50-drinks-industry-companies.html> [accessed 4 December 2013].
30. *op. cit.* Bailey, J. et al. (2011).
31. Babor, T. et al (2010) *Alcohol: no ordinary commodity*, Oxford, Oxford University Press.
32. Sanders, A. (2013) *Symptoms of alcohol-induced brain damage being missed*, Western Mail, 28 October 2013.
33. Cook, C. et al. (1998) *B Vitamin deficiency and neuropsychiatric syndromes in alcohol misuse*, *Alcohol & Alcoholism* Vol. 33, No. 4, pp. 317-336.





34. Harper, C. et al. (1995) *An international perspective on the prevalence of the Wernicke-Korsakoff Syndrome*. *Metabolic Brain Disease* 10, pp. 17-24.
35. Chiang, C.C.P. (2002) *Wernicke Korsakoff's Syndrome in Argyll and Clyde: A literature review, needs assessment and recommendation for the prevention, treatment and provision of Wernicke Korsakoff's Syndrome*. Part II, Submission to the Faculty of Public Health Medicine.
36. MacRae, S. and Cox, S. (2003) *Meeting the needs of people with alcohol related brain damage: a literature review on the existing and recommended service provision and models of care*, Dementia Services Development Centre, University of Stirling.
37. Torvik, A. et al. (1982) *Brain lesions in alcoholics. A neuropathological study with clinical correlations*. *Journal of Neurological Sciences* 56, pp. 233-248.
38. Victor, M. et al. (1989) *The Wernicke-Korsakoff Syndrome and related neurological disorders due to alcoholism and malnutrition*, 2nd edn. FA Davis, Philadelphia.
39. Harper, C.G. et al. (1998) *Prevalence of Wernicke-Korsakoff syndrome in Australia: has thiamine fortification made a difference?*, *Medical Journal of Australia* 168(11):542-5, online, available at: <https://www.mja.com.au/journal/1998/168/11/prevalence-wernicke-korsakoff-syndrome-australia-has-thiamine-fortification-made> [accessed 9 December 2013].
40. ACE-R (2005), online, available at: <http://www.cornwallandislesofscilly.nhs.uk/DocumentsLibrary/CornwallAndIslesOfScillyPCT/WebDocuments/Internet/InformationForPatients/SelfCareInCornwall/HealthCareProfessionals/AddenbrookesCognitiveExamACER.pdf> [accessed 3 December 2013].
41. Alzheimer's Society (2013) *The Mini Mental State Examination (MMSE)*, online, available at: [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=121](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=121) [accessed 12 December 2013].
42. Wilson, K. et al. (undated) *Alcohol related brain damage (ARBD) – Clinical definition and diagnosis of alcohol related cognitive impairment*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 4 December 2013].
43. Wilson, K. et al. (undated) *Alcohol related brain damage (ARBD) – Barriers to care*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 4 December 2013].
44. Wilson, K. et al. (undated) *Alcohol related brain damage (ARBD) epidemiology*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 4 December 2013].
45. Roberts, P. (2012) *Alcohol related brain damage – A diagnosis of exclusion in Wales?*, presentation to the Pen yr Enfyfys ARBD working group, Newport and Cardiff.
46. Wilson, K. (2010) *Assessment and intervention for alcohol-related brain damage*, online, available at: [http://217.33.237.40/document\\_uploads/Case\\_Studies/Rehab%20of%20ARBD%20-%20Kenneth%20Wilson%20Case%20Study%20\(Bursary\).pdf](http://217.33.237.40/document_uploads/Case_Studies/Rehab%20of%20ARBD%20-%20Kenneth%20Wilson%20Case%20Study%20(Bursary).pdf) [accessed 9 December 2013].
47. Wilson, K. et al. (undated) *Alcohol related brain damage (ARBD) – Presentation and outcome*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 9 December 2013].
48. Roberts, P. (2012) *Alcohol related brain damage – A diagnosis of exclusion in Wales?*, presentation to Pen yr Enfyfys ARBD working group, Cardiff.
49. Wilson, K. et al. (undated) *Alcohol related brain damage (ARBD) – Presentation and outcome*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 9 December 2013].
50. Roberts, P. (2012) *Alcohol related brain damage – A diagnosis of exclusion in Wales?*, presentation to the Pen yr Enfyfys ARBD working group, Newport and Cardiff.
51. Pen yr Enfyfys (2012) *Steering group to establish need and design for accommodation and rehabilitation services for people with alcohol related brain damage*, presentation to the Pen yr Enfyfys ARBD working group, Newport and Cardiff.
52. Roberts, P. (2012) *Alcohol related brain damage – A diagnosis of exclusion in Wales?*, presentation to the Pen yr Enfyfys ARBD working group, Newport and Cardiff.
53. Wilson, K. et al. (undated) *Alcohol related brain damage (ARBD) epidemiology*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 4 December 2013].
54. Alcohol Concern (2012) *Everyone's problem – The role of local alcohol services in tackling Wales' unhealthy relationship with alcohol*, London, Alcohol Concern.



55. Bailey, J. et al. (2011) *Achieving positive change in the drinking culture of Wales*, London, Alcohol Concern.
56. Harper, C.G. et al. (1998) *Prevalence of Wernicke-Korsakoff syndrome in Australia: has thiamine fortification made a difference?*, Medical Journal of Australia 168(11):542-5, online, available at: <https://www.mja.com.au/journal/1998/168/11/prevalence-wernicke-korsakoff-syndrome-australia-has-thiamine-fortification-made> [accessed 9 December 2013].
57. Scientific Advisory Committee on Nutrition (2012), *Nutritional implications of repealing the UK Bread and Flour Regulations*, online, available at: [http://www.sacn.gov.uk/pdfs/sacn\\_uk\\_bread\\_and\\_flour\\_regulations\\_position\\_statement.pdf](http://www.sacn.gov.uk/pdfs/sacn_uk_bread_and_flour_regulations_position_statement.pdf) [accessed 20 December 2013].
58. Scientific Advisory Committee on Nutrition (2012), *Nutritional implications of repealing the UK Bread and Flour Regulations*, online, available at: [http://www.sacn.gov.uk/pdfs/sacn\\_uk\\_bread\\_and\\_flour\\_regulations\\_position\\_statement.pdf](http://www.sacn.gov.uk/pdfs/sacn_uk_bread_and_flour_regulations_position_statement.pdf) [accessed 20 December 2013].
59. Alcohol Concern (2001) *Factsheet: Wernicke-Korsakoff's syndrome*, London, Alcohol Concern.
60. Smith, I. and Hillman, A. (1999) *Management of Alcohol Korsakoff Syndrome*, Advances in Psychiatric Treatment, Vol. 5, pp. 271-278.
61. Wilson, K. et al. (undated) *Alcohol Related Brain Damage (ARBD) – The case for Intervention*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 4 December 2013].
62. Cox, S. et al. (2004) *A fuller life – report of the expert committee on alcohol related brain damage*, Stirling, Dementia Services Development Centre on behalf of the Scottish Executive.
63. NICE (2010) *Information for the public: Physical health problems caused by drinking alcohol*, online, available from: <http://publications.nice.org.uk/physical-health-problems-caused-by-drinking-alcohol-ifp100/thiamine-deficiency> [accessed 19 February 2014].
64. Alcohol Concern (2001) *Factsheet: Wernicke-Korsakoff's syndrome*, London, Alcohol Concern.
65. Committee on the Safety of Medicines, (1989) *Current problems*, Number 24, online, available at: <http://www.mhra.gov.uk/home/groups/pl-p/documents/websitesresources/con2024431.pdf> [accessed 3 December 2013].
66. Sussex Partnership NHS Foundation Trust (2012) *Pabrinex*, online, .available at: <http://www.sussexpartnership.nhs.uk/component/jdownloads/finish/2303/8684?Itemid=0> [accessed 3 December 2013].
67. Medicines and Healthcare Products Regulatory Authority (2007) *Pabrinex: allergic reactions*, online, available at: <http://www.mhra.gov.uk/Safetyinformation/DrugSafetyUpdate/CON079169> [accessed 12 December 2013].
68. Lingford-Hughes, A.R. (2004) *Evidence-based guidelines for the pharmacological management of substance misuse, addiction and comorbidity: recommendations from the British Association for Psychopharmacology*, Journal of Psychopharmacology 18(3) (2004) pp. 293–335.
69. Thomson, A.D. et al. (2009) *Wernicke's encephalopathy: Role of thiamine*, Practical Gastroenterology, June 2009, pp. 21-30.
70. NICE (2010) *Quick reference guide: Alcohol-use disorders – Diagnosis and clinical management of alcohol-related physical complications*, online, available from: <http://www.nice.org.uk/nicemedia/live/12995/49004/49004.pdf> [accessed 19 February 2014].
71. Svanberg, J and Evans, J.J. (2013) *Neuropsychological rehabilitation in alcohol-related brain damage: A systematic review*, Alcohol and Alcoholism Vol. 48, No. 6, pp. 704–711.
72. Wilson, K. et al. (undated) *Alcohol Related Brain Damage (ARBD) – The case for Intervention*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 4 December 2013].
73. British Association of Occupational Therapists (2013) *Occupational therapy: definition, values and beliefs*, <http://www.cot.co.uk/ot-helps-your-client/definition-occupational-therapy-its-values-and-beliefs>, online, available at: [accessed 6 December 2013].
74. Sacks, O. (1985) *The man who mistook his wife for a hat, and other clinical tales*, New York, Touchstone, pp. 37-39.
75. Wilson, K. et al. (undated) *Alcohol Related Brain Damage (ARBD) – The case for Intervention*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 10 December 2013].
76. Welsh Assembly Government (2005) *Designed for life – creating world class health and social care for Wales in the 21<sup>st</sup> century*, Welsh Assembly Government, Cardiff.



77. Wilson, K. et al. (undated) *Alcohol Related Brain Damage (ARBD) – The case for Intervention*, Liverpool, Cheshire and Wirral Partnership Trust and University of Liverpool, online, available at: <http://www.alcoholrelatedbraindamage.com/Pages/Welcome.aspx> [accessed 10 December 2013].
78. Cox, S. et al. (2004) *A fuller life – report of the expert committee on alcohol related brain damage*, Stirling, Dementia Services Development Centre on behalf of the Scottish Executive.
79. Potens website (2013) <http://www.potensial.co.uk/locations/arbennig-unit-old-colwyn> [accessed 10 December 2013].
80. Information provided by the Care Standards Inspectorate for Wales via Public Health Wales in December 2013.
81. Dementia Services Development Centre, University of Stirling, website: <http://dementia.stir.ac.uk/> [accessed 11 December 2013].
82. Collective Architecture website: <http://www.collectivearchitecture.com/projects/arbd-care-home> [accessed 11 December 2013].
83. Roberts, P. (2012) *Alcohol related brain damage – A diagnosis of exclusion in Wales?*, presentation to the Pen yr Enrys ARBD working group, Newport and Cardiff.

# All in the mind

Meeting the challenge of  
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Alcohol Concern  
Making Sense of Alcohol