

CR212

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# Alcohol-related brain damage in Northern Ireland

Treatment, not just care

COLLEGE REPORT

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# Contents

Authors, contributors, acknowledgements	4
Glossary of terms	6
Foreword	7
Executive summary	8
Lay summary	12
Introduction	13
1.1 Alcohol misuse in Northern Ireland	13
1.2 What is alcohol-related brain damage (ARBD)?	13
1.3 What is the treatment for ARBD?	14
Northern Ireland Perspective	16
2.1 ARBD in Northern Ireland	16
2.2 Belfast Health and Social Care Trust	17
2.3 Northern Health and Social Care Trust	23
2.4 South Eastern Health and Social Care Trust	24
2.5 Southern Health and Social Care Trust	25
2.6 Western Health and Social Care Trust	26
2.7 Treatment and Support Advisory Committee	27
Existing Service Provision for ARBD in Northern Ireland	29
3.1 Pilot ARBD service in South Eastern Health and Social Care Trust	29
3.2 Service provision for ARBD in nursing home environments	30
3.3 Service provision for ARBD in supported living environments	31
3.4 Education and training of healthcare staff	33
Proposals for service development	34
4.1 Invest to save strategy	34
4.2 Proposed service model	35
Summary of recommendations	39
Conclusion	41
Appendix 1: Case study of a patient who has completed a psychosocial rehabilitation programme for ARBD	42
Appendix 2: Patient information leaflet	45
References	54

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# Glossary of terms

<b>ACE III</b>	Addenbrooke's Cognitive Examination Version III.
<b>Acquired brain injury</b>	An injury happening to the brain after birth, which is not related to a congenital defect or degenerative disease process. Causes include: infection, stroke, and traumatic brain injury.
<b>Acute bed occupancy</b>	The amount of time spent admitted to a general medical or surgical ward in an acute hospital.
<b>Care pathways</b>	A specified framework by which patients can access the necessary assessment, treatment and continuing care.
<b>Cognitive impairment</b>	Problems with thinking, memory, reasoning and the ability to sequence tasks logically.
<b>Dementia</b>	Dementia describes a set of symptoms which occur when the brain is damaged by disease. The patient may experience difficulties with memory, problem-solving and language. Their mood and behaviour may also be affected. It is a progressive condition.
<b>Dysexecutive syndrome</b>	Damage to the frontal lobes can lead to problems with planning and organisation. This can also give rise to impulsive and/or aggressive behaviour.
<b>Gastroenterology</b>	A medical subspecialty concerned with disorders of the digestive system.
<b>Hepatology</b>	A medical subspecialty concerned with disorders of the liver, gallbladder, biliary tree and pancreas.
<b>Korsakoff's psychosis</b>	This is a chronic cognitive disorder caused by deficiency of thiamine, most commonly as a result of long-term alcohol misuse.
<b>MoCA</b>	Montreal Cognitive Assessment for detection of mild cognitive impairment.
<b>Prevalence</b>	The total number of individuals that have a particular condition in a defined population during a specific time period.
<b>Psychosocial rehabilitation</b>	Psychosocial rehabilitation promotes personal recovery, successful community integration and satisfactory quality of life for people who have a mental illness or cognitive impairment.

<b>Thiamine</b>	Vitamin B1
<b>Traumatic brain injury</b>	A non-degenerative insult to the brain caused by external mechanical force, possibly leading permanent or temporary impairment of the function of the brain.
<b>Transforming Your Care</b>	A review of health and social care services in Northern Ireland commissioned in 2011, with the aim of bringing forward recommendations for the future shape of services and providing and implementation plan.
<b>Wernicke's encephalopathy</b>	An acute neurological disorder, and medical emergency, caused by severe thiamine deficiency.
<b>6CIT</b>	Six item cognitive impairment test.

# Foreword

“

Alcohol misuse and its consequences are one of the most challenging public health issues we are facing. Alcohol is so ingrained in our society that we often overlook the wide range of harm it causes. This report highlights an issue many people will just never think about – the harm alcohol misuse can have on their brain.

This report, drawing on local perspectives and an emerging evidence base across the UK, highlights the impact alcohol misuse can have on brain function, leading potentially to alcohol-related brain damage (ARBD). Given the varying nature of the conditions contained under this umbrella term, and the difficulty in accurately diagnosing them due to the overlap with the symptoms of other conditions such as dementia, it has been challenging to get an accurate picture of the prevalence of ARBD. I believe however this report demonstrates a conservative estimate of the prevalence of ARBD, which may be growing, and worryingly it also demonstrates that increasingly we are seeing people presenting with these conditions at an early time in their life.

The cost of dealing with ARBD is substantial, not just financially to the Health and Social Care Family, but also emotionally and physically to the individuals directly affected and their families.

Fortunately, this report, and also the wider research, provides hope. Where we can identify those with an issue at an early stage, and provide appropriate treatment and support, up to 75% can and do begin to recover. The problem is that currently too many people end up receiving just care – not treatment – and this is something we need to look at and begin to address.

The report aligns with current policy as it is about identifying and supporting those who need help at an early stage, ensuring people can access the right help, in the right place, at the right time, and providing appropriate treatment to help people recover. This specifically supports the approach laid out in Health and Wellbeing 2026: Delivering Together.<sup>1</sup>

I would encourage the wider health and social care family, including those who commission and plan services, as well as service providers, to consider the report and see what practical action they can begin to put in place to tackle this issue.

I would like to thank the Royal College of Psychiatrists, and the report authors and contributors, for investing in this important piece of work shedding light on an important and growing issue that is often hidden from our view.

”

**Dr Michael McBride**  
Chief Medical Officer



# Executive summary

## Introduction

The effects of alcohol misuse in Northern Ireland have been estimated to cost up to £900 million annually, with almost £250 million being attributed to the health and social care sector.<sup>2</sup> As a result, the number of hospital admissions for alcohol-related harm has been increasing steadily. One example of alcohol-related harm is alcohol-related brain damage (ARBD). This report aims to highlight the burden this condition is placing on our health and social care services, and also to call for better provision of services for this group of patients.

ARBD describes the effects of changes to the structure and function of the brain resulting from alcohol toxicity and vitamin deficiencies (principally thiamine). It is a relatively newly-coined umbrella term, which has been introduced to cater for the wide range of individually named conditions, such as Korsakoff's Syndrome, cerebellar syndrome, and the more-subtle frontal lobe dysexecutive syndrome.<sup>3</sup> These conditions rarely present in a classically described way,<sup>4</sup> but they all share common characteristics – the existence of cognitive impairment directly related to chronic alcohol consumption.

There is a very important distinction between ARBD and dementia and it is therefore crucial to distinguish the two conditions. There are implications for the commissioning of services, as dementia is always a progressive condition, but ARBD has a relatively good prognosis in that up to 75% of patients make an improvement with abstinence and appropriate treatment.<sup>5</sup> Patients with ARBD tend to be younger than dementia patients, yet can find themselves placed inappropriately in dementia care homes with long-term cost implications and poor outcomes. There is a strong cost- and outcomes-based argument that patients with ARBD require specific treatment, and not just care.

Key guidance for service development in this area has already been highlighted in a national intercollegiate report published by the Royal College of Psychiatrists in 2013.<sup>6</sup> This document clearly lays out the challenges faced by healthcare professionals when managing these patients, such as the lack of care pathways, no identified roles of responsibility, stigma, and training gaps. It also provides information about newly-developed ARBD services in the UK, all of which have demonstrated excellent patient and cost efficiency outcomes. This report aligns itself to this national document but attempts

to provide a more detailed Northern Ireland perspective. Overall, the aim is to create an argument for investment and service development for patients with ARBD across the region.

### **Northern Ireland perspective**

ARBD is not a new problem in Northern Ireland. Various projects have been carried out across the region in an attempt to gather prevalence data and estimate the burden this condition places on healthcare services, in the full knowledge that the patient group would be difficult to define. There is a widespread understanding amongst healthcare professionals that ARBD is a current and growing problem, and that the gap in service provision is expanding. Patients with ARBD do not currently have their needs met by standard mental and physical health services.

### **Existing service provision for ARBD in Northern Ireland**

As with many other areas of the United Kingdom, there are no clear care pathways in Northern Ireland for managing patients with ARBD. Historically many patients have ended up in dementia care settings with little hope for recovery. There are, however, several facilities in the region with specific ARBD units but there is no standardised or formal approach to the treatment given.

### **Proposals for service development**

This report has identified the need for a designated ARBD multidisciplinary team to be established in each health and social care trust, which would have access to an assessment unit. This unit would be a step-down unit, bridging the gap between acute hospitals and community placements. Such a unit would accept referrals from acute hospitals for a period of assessment. The team would require psychiatry input, as well as from other disciplines, such as mental health nursing, social work, occupational therapy, psychology and support workers.

### **Conclusion**

This report concludes that this patient group is currently being neglected, with few patients having access to any kind of specialised treatment. There are, however, important building blocks already in place that, with further investment, planning and formalisation, could develop into an excellent ARBD service. Despite the lack of dedicated services, patients with ARBD are costly to the health and social care sector due to their acute bed

occupancy, frequent ED (Emergency Department) attendances and, for many, ultimate placement in a costly dementia care setting. Specialist ARBD services elsewhere in the UK are demonstrating positive outcomes in terms of improvements in patients' cognition and functioning, as well as dramatic cost savings.<sup>6</sup> In light of this increasing evidence base, there is a vision that patients with ARBD in Northern Ireland will be provided with **treatment, not just care.**

# Lay summary

Alcohol-related brain damage (ARBD) describes the changes to the structure and function of the brain, as a result of chronic heavy alcohol misuse. It is thought that 35% of alcohol dependent patients<sup>7,8</sup> could have the condition. It can appear like a dementia because the symptoms are often memory loss and difficulty with daily functioning, however, ARBD is not a true dementia because it can improve to some degree, in up to 75% of cases, with abstinence from alcohol and adequate treatment.<sup>5</sup> There is, therefore, a national drive to improve services for patients with ARBD. Those that have been developed have helped turn lives around and there are many examples of recovery emerging. At the same time such services are showing cost savings<sup>6</sup> in what has been referred to as a 'no brainer' move in healthcare development.

ARBD represents a serious public health challenge, yet it remains very much overlooked and misunderstood. A national report published in 2013 has provided much-needed context, describes the condition in detail, highlights the challenges and shortfalls in current service provision and, perhaps most importantly, contains evidence produced from specialist services that have been developed which show impressive outcomes for ARBD when appropriate treatment is made available.<sup>6</sup>

For many years, concerns have been raised by doctors and healthcare professionals in Northern Ireland regarding the lack of services for patients with ARBD. In many cases, these patients are deemed to require institutional care and have found themselves inappropriately placed in dementia care homes. This has been shown to be detrimental to recovery for the condition, and there is an argument that such cases are best managed in a specialised setting with access to rehabilitation and a focus on recovery. In other words, patients with ARBD are thought to require active treatment, rather than just care, to move them forward to live as full and independent a life as possible. In a care-type environment, they may not ever regain skills or recover.

The aim of this report, therefore, is to gain a closer perspective which is specific to Northern Ireland, and to make a case for local service development for ARBD, ensuring that appropriate treatment is provided for all who can benefit from it.

# Introduction

## 1.1 Alcohol misuse in Northern Ireland

“Alcohol misuse has a devastating impact on our society – first and foremost to the individuals directly affected, and their families and communities.”<sup>9</sup>

In stark contrast with the rest of the United Kingdom, there has been a marked increase, over the last twenty years, in the number of people who regularly consume alcohol in Northern Ireland.<sup>10</sup> More than seven in ten people now consume alcohol<sup>11</sup> and it is estimated that 81% of those individuals exceed their daily recommended limit.<sup>12</sup> There are approximately 217,000 people drinking at hazardous or harmful levels, which is almost 17% of those who consume alcohol.<sup>13</sup>

The effects of alcohol misuse in Northern Ireland have been estimated to cost up to £900 million annually, with almost £250 million of these costs being picked up by the health and social care sector.<sup>2</sup> From as far back as the 1970s, cases of alcohol-related harm have been steadily rising, resulting in a year-on-year increase in alcohol-related hospital admissions between 2000/01 and 2009/10.<sup>13</sup>

Patients with a history of chronic and heavy alcohol consumption utilise healthcare resources for a wide variety of reasons, such as alcoholic liver disease and trauma. One such group of patients using significant healthcare resources are those who have developed alcohol-related brain damage (ARBD).

## 1.2 What is alcohol-related brain damage (ARBD)?

ARBD describes the effects of changes to the structure and function of the brain resulting from alcohol toxicity and vitamin deficiencies (principally thiamine). Increasingly, the more accessible umbrella term ‘ARBD’ has replaced the use of individually named conditions such as Korsakoff’s psychosis, cerebellar syndrome, and the more subtle frontal lobe dysexecutive syndrome.<sup>3</sup> These all, particularly Korsakoff’s psychosis, rarely present in a classically described way.<sup>4</sup> Moreover, the term ARBD allows for other concomitant conditions, which are often overlapping, such as, encephalopathy and traumatic brain injury, provided alcohol is the primary causative factor.<sup>3</sup> It is important to note that a three-month period of abstinence is required before a diagnosis of ARBD can be made definitively.<sup>14</sup>

Although ARBD can often be mistaken for dementia, it is crucial to distinguish the two conditions. Patients with ARBD tend to be younger than dementia patients, and a significant proportion present with frontal lobe damage,<sup>15</sup> which can lead to disinhibited and aggressive behaviours in this patient group.<sup>16</sup> Due to the lack of available options for treatment, patients with ARBD can find themselves inappropriately placed in dementia care homes. This has important implications not only for patients with ARBD, but also for the vulnerable, and often older, population with whom they reside. Dementia is always a progressive condition, but ARBD can have a relatively good prognosis: up to 75% of patients improve to some degree with abstinence and appropriate treatment. Indeed, 25% can make a full recovery.<sup>5</sup> It is clear, therefore, that patients with ARBD require specific treatment aimed at recovery and re-enablement, rather than just care provision.

### 1.3 What is the treatment for ARBD?

As mentioned above, the literature suggests that 75% of patients with ARBD will make some degree of recovery, with 25% having the potential to make a full recovery.<sup>5</sup> Alongside abstinence from alcohol and good nutrition, early physical stabilisation and active treatment are essential. The evidence behind this is summarised in the intercollegiate document published by the Royal College of Psychiatrists in 2013.<sup>6</sup>

Over recent years, there is an increasing body of evidence suggesting rehabilitation is required to improve patient outcomes, and the techniques used are akin to those used in treating acquired brain injury. This improvement is enhanced further if rehabilitation takes place in a specialised ARBD unit, rather than in a generic dementia care setting,<sup>17,18,19</sup> with a multidisciplinary approach.

There is no prescribed model for how rehabilitation should be delivered, and the services that currently exist in the UK all differ from each other. There are, however, some common themes running through these services, which include:

- specialist ARBD multidisciplinary teams
- in-reach into district general hospitals to reduce the burden on acute medical beds
- a three-month period of assessment prior to giving a diagnosis
- active rehabilitation
- community placements with assertive follow-up.

There is a current drive in Northern Ireland, and elsewhere in the United Kingdom, to address the service needs for patients with ARBD. There is also lack of national guidelines, but recommendations for service development in this area have been highlighted in the intercollegiate report published by the Royal College of Psychiatrists. This document clearly lays out the challenges faced by healthcare professionals when managing these patients, such as, the lack of care pathways and there being no identified roles of responsibility. It also provides a summary of the few existing services in the UK, all of which have demonstrated significant patient and cost efficiency outcomes.<sup>6</sup> Some of the existing ARBD services have won prestigious awards for their innovative practice, and the outcomes from these services have justified their existence, enabling them to secure recurrent funding. All the services have demonstrated cost savings and improved patient outcomes.<sup>6</sup> The ARBD service in the Wirral, for example, has resulted in an 85% reduction in the use of acute hospital bed days by the patients under their care. Following intervention by this team, the majority of their caseload remains in community, non-institutional settings.<sup>20</sup> Other services have demonstrated a reduced frequency of ED (Emergency Department) attendances, as well as improvements in patients' quality of life and cognitive functioning.<sup>6</sup>

# Northern Ireland perspective

## 2.1 ARBD in Northern Ireland

ARBD is not a new problem for Northern Ireland. The Bamford Review of Mental Health and Learning Disability Services called for action:

“A report should be commissioned to establish the extent of ARBD in Northern Ireland.”

It stated there is a lack of information on the prevalence of ARBD, and that health and social care trusts can mostly only identify cases of ARBD in terms of hospital bed occupancy and nursing home placements. It was acknowledged that this population is likely to be interspersed throughout several programmes of care, often without a formal diagnosis.<sup>21</sup>

More recently, The Royal College of Psychiatrists in Northern Ireland published a report: ‘Recovery for People with Severe and Complex Mental Health Problems in Northern Ireland – A Guide for Trusts and Commissioners of Rehabilitation Services’. This report stated that despite the developments in mental health service delivery over the past 30 years, there remains a small group of patients whose needs cannot be met by standard services. Due to the severity and complexity of their illness, they need longer timeframes, and more intensive interventions to recover.<sup>22</sup> While the report does not specifically discuss this patient group, it is clear that patients with ARBD do not currently have their needs met by standard mental or physical health services.

Clinicians from a variety of disciplines have the unanimous opinion that patients with ARBD in Northern Ireland are currently being neglected, but demonstrating the need for a dedicated service is difficult due to underdiagnosis of the condition. This is clearly highlighted in a statement from the Southern Health and Social Care Trust:

“Patients with ARBD become hidden within a number of service delivery programmes due in the main, to funding issues and a lack of any form of dedicated discrete service or programme delivery. As such, the nature and extent of this issue is hard to determine within the Trust as those services which deliver care do not directly identify these patients as suffering from ARBD...We have no clear idea of numbers, demand or need because of the complexities outlined above, though colloquially we are aware of the need our CMHTs are outlining in terms of seeking placements and providing support to patients and families”.

It should be noted that existing research confirms the difficulties



in grasping the true scale of the problem,<sup>5,23</sup> and the most useful epidemiological data is based on post-mortem studies. From these studies it has been estimated that alcohol-related brain changes are present in 35% of those with alcohol dependence<sup>7,8</sup> and in up to 1.5% of the general population.<sup>24</sup> Any attempts to estimate the prevalence of ARBD in real time has likely been a gross underestimation due to a number of factors:

- Only a small minority of cases are diagnosed with the condition during life
- Patients are unlikely to present to services<sup>25</sup>
- There is a relative lack of expertise in this area<sup>26,27</sup>
- There are high levels of associated stigma<sup>28</sup>
- There are variable presentations of the condition.<sup>3</sup>

Projects in Northern Ireland have been carried out to estimate the burden that ARBD places on healthcare services, in the full knowledge that the patient group would be difficult to define. Attempts have been made to be as comprehensive as possible, and what follows describes these projects.

## 2.2 Belfast Health and Social Care Trust (BHSCCT)

### Acute hospital admissions

An observational study was carried out across the three main Belfast hospital sites in 2013. Medical and surgical teams referred patients to the study if they met the inclusion criteria, which were adopted from the Wirral ARBD service referral criteria, as this would indicate a possible diagnosis of ARBD. All three criteria were to be met as follows:

- 1 A history of drinking more than 35 standard alcoholic units per week (more than 28 for women) for at least five years, with associated nutritional deficiency.
- 2 Evidence of confusion, memory problems or doubts about capacity after alcohol withdrawal and physical stabilisation.
- 3 Three or more admissions into hospital in the last year associated with alcohol ingestion, or one or more delayed discharges from a hospital ward in the last year.<sup>20</sup>

Data was collected by alcohol liaison nurses and included demographic information, reason for hospital admission, alcohol history and any documented concerns about cognition or capacity within the medical notes. The results from any cognitive tests performed were also recorded. When the patients were medically fit, and at the point of discharge, they were cognitively tested by the alcohol liaison nurses for the purposes of the study.

In an eight-month period, 105 patients with a likely diagnosis of ARBD were identified. A definitive diagnosis of ARBD cannot be made unless there has been a minimum of 12 weeks' abstinence from alcohol,<sup>14</sup> and so the term 'likely' was used to cater for this limitation. The patients were aged between 38 years and 83 years, with a mean age of 58 years, reflecting this patient group are likely to be younger than those diagnosed with dementia. Of those identified, 73% were male.

Accidents and seizures were the most common reason for admission, occurring in 52% of cases. Six per cent of the patients were consuming extremely high quantities of alcohol, between 300 and 420 units, per week. In addition, 31% were consuming more than 200 units per week, and 60% over 100 units per week.

Medical staff had documented concerns about cognition in 53% of patients' notes, but only 22% had cognitive testing performed by ward staff. When tested for the purposes of the study, 74% had significant cognitive impairment at the point of discharge. There were also documented concerns in 28% of these patients' notes about their capacity to make decisions regarding discharge living arrangements.

88% had three or more admissions to a general hospital for alcohol related complaints in the preceding 12 months, and 97% had one or more delayed discharges in that time. One of the patients included in the study spent six months in an acute medical bed awaiting an appropriate placement.

A random sample of 50 of these patients was selected to gain a more in depth understanding of their frequency and duration of admissions over the previous twelve months. In-patient databases from the three hospital sites were used to retrieve the required information. The number of separate stays in hospital ranged from one to sixteen, with a mean of just over three admissions per patient. On reviewing discharge letters, 95% of these admissions were recorded as alcohol-related. The length of hospital admission ranged from one to 67 days, with a mean of 8 days. The total number of bed days for this group of 50 patients was 1279, at a cost of £464,967.00 over the one-year period, as calculated by the Trust finance department. If this sample is representative of the larger group of 105 patients, then the estimated cost of acute hospital admissions over the previous year would have been £976,430.00.<sup>29</sup>

The results of this study very much chime with other research in this area, which describes a 'revolving door' pattern of hospital admissions, along with high delayed discharge rates.

**A large number of patients with a likely diagnosis of ARBD are being discharged from hospital without cognitive screening, and with severe cognitive impairment going undetected. This patient group is using acute hospital beds frequently and for lengthy periods, conferring huge cost to healthcare services.**

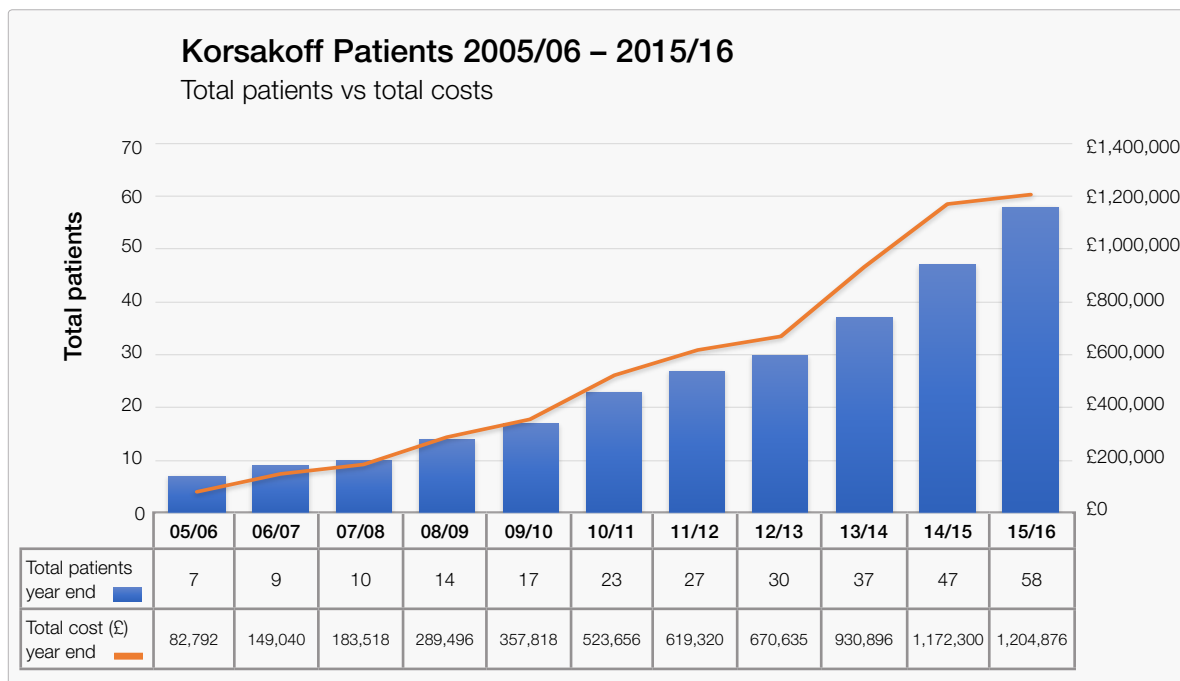
### **Physical disability social work service**

Patients with ARBD are dispersed across many services in the BHSCT, and there are no clear pathways of care or defined roles of clinical responsibility. As time has passed, however, a group of social workers within the Trust have developed skills in managing patients with ARBD. The physical disability social work service has been responsible for the placement of some patients with ARBD in the community. They have expressed an appetite to further develop their service, and increase their level of expertise.

In January 2014, a project was developed to attempt to identify patients with a diagnosis of Korsakoff's, who were under the care of the physical disability and mental health services at that time. The exercise detected 67 patients with such a diagnosis, aged between 44 and 64 years. This represented a 13% increase on the figure identified in the previous exercise in August 2013. In 2005, a similar project found that there were 43 patients with a diagnosis of Korsakoff's under the care of these services, meaning the 2014 figure represents a 36% increase over an almost 10-year-period. This study was limited to patients with Korsakoff's, and there are likely to be many more patients with less specific alcohol-related cognitive impairments which have not been picked up.

Of these 67 patients, 43 (64%) were managed under the physical disability service and only 24 (36%) were managed under mental health services, despite having a clear diagnosis of Korsakoff's psychosis. 62% were in a nursing home placement, and it was found that 27% of these patients would have been capable of living in supported accommodation. A further 15% could have been living in their own homes with peripatetic support.

The cost of a nursing home placement for these patients is, on average, £624 per week, and it should be noted that it is difficult to secure placements for patients with ARBD without paying top-up charges. The annual cost of placements for the identified patients with Korsakoff's is increasing year on year. This data is outlined overleaf.



The physical disability social work service has presented these figures to the Health and Social Care Board, and they have highlighted that these figures are forecast to increase. The Service has stated that there is an urgent need to address the lack of care pathways for this patient cohort. As a result, they have secured additional funding for service development on a recurrent basis.<sup>30</sup>

**Patients with ARBD are dispersed across many services in the BHSCT, and a relatively small proportion is looked after by mental health services. The physical disability social work service has demonstrated there are increasing numbers of patients with alcohol-related cognitive impairments requiring costly placements, which are unable to be reviewed on a regular enough basis.**

### Hepatology service

The BHSCT hepatology service regularly encounters patients with ARBD, and they have expressed support for service development in this area. A survey of the clinical staff (mainly from nursing and social work backgrounds), working on ward 6D at the Royal Victoria Hospital, was carried out in order to identify some of the challenges faced by staff when managing this patient group. All the staff reported they have daily contact with patients who have a diagnosis of ARBD, yet none of them had received any formal training. The knowledge and skills they had developed was acquired 'on the ground'.

The majority of staff felt that that the condition was underdiagnosed, but that through experience, their team was more becoming more proactive in giving a diagnosis of ARBD. The challenges faced when treating patients with the condition included limited treatment options and adequate facilities to refer patients on to. Many staff commented on the difficulties finding appropriate placements for those aged under 65. Multiple staff members commented that patients with ARBD spend long periods of time inappropriately on medical wards. Often other patients are neglected, due to the time-consuming nature of managing patients with ARBD.

“At ward level, some patients with ARBD are not nursed in an appropriate environment. The environment is too busy and noisy and staff may not have the adequate time to spend with these patients managing behaviours etc.”

All of the staff expressed concern that patients with ARBD have the potential to become impulsive and aggressive due to frontal lobe difficulties. The ARBD step-down units that exist elsewhere in the UK report few aggressive episodes presumably due, at least in part, to the impact on patients of being placed in a less stimulating environment than a busy hospital ward. Many staff expressed the need for a specialist ARBD service and an appropriate unit for ongoing assessment of the condition.

“We need a dedicated unit in Northern Ireland so that treatment and care can be continued out of the ward when the patient is able to move on.”

“The provision of somewhere for 3–6 months would be helpful for ongoing treatment and assessment.”

The hepatology service has also provided a case study, described below, which demonstrates the benefits expected from a specialised ARBD team. Their input may have seen ‘Brian’ spend less time in hospital, given him the opportunity to undergo psychosocial rehabilitation, and potentially the ability to go on to live in a less supported environment. These outcomes would not only have obvious benefits to the quality of life of people like Brian’, but also significant cost savings to health and social care services.

### Case study: Brian

Brian is a 45-year-old man with a 25-year history of chronic, heavy alcohol consumption. He developed alcohol dependence as a 21-year-old undergraduate student. Over the course of the subsequent 25 years, Brian's life entered a downward spiral as he struggled with alcohol dependence, becoming socially isolated and estranged from his family. His alcohol misuse resulted in the development of ARBD and alcohol-related liver disease.

In the last five years alone, Brian has had 26 hospital admissions (155 bed days in total) as a result of alcohol-related morbidity, including seizures, traumatic injuries and decompensated liver cirrhosis. Over this time, he has had 25 X-rays and 15 CT scans, reflecting the toll on healthcare resources when managing patients with ARBD. As a result of a progressive decline in Brian's cognitive function, at the age of 45 he was deemed no longer capable of independent living and was placed in a nursing home. He now requires 24-hour supervision and is largely dependent in his activities of daily living, requiring constant nursing care.

### Liaison psychiatry

The BSHCT liaison service has received referrals for patients with ARBD for many years, and strongly supports the need to develop ARBD services in Northern Ireland. Dr Catherine Taggart, Consultant Liaison Psychiatrist, has contributed the following statement:

“Liaison psychiatrists are often asked to see patients in general hospitals who have alcohol-related brain damage (ARBD). These patients are frequently admitted to general hospital wards, often with concomitant physical problems. ARBD covers a wide spectrum from quite subtle, to very severe and disabling symptoms. Liaison psychiatrists usually see those at the more severe end of the spectrum, the most common reasons being to advise about management of aggressive behaviour, and to help with the process of placing someone who can no longer live at home.

“Typical symptoms include disorientation and memory loss. In some patients this can lead to severe agitation and aggression. This is particularly problematic when the patient is a relatively young, physically strong male. In extreme cases there is a risk of injury to staff and to other patients, many of whom are physically frail. Staff in general wards may not have specific training in management of aggression and these patients can present a considerable challenge to manage.

“Patients with ARBD often end up in hospital because community supports have broken down and their level of disability means they are unable to return home. Cognitive impairment often means patients are unable to engage in a decision-making

process about their future care, and liaison psychiatrists are sometimes involved in assessing this. Problems may then arise in trying to find a suitable placement resulting in delayed discharge.

“A lack of specialist community placements and treatment means that hospital stays can be prolonged while a placement is sought, and that on following discharge patients are unlikely to receive specialized support.

“As a liaison psychiatrist, it is frustrating to treat ARBD patients in the general hospital but I know that when they are discharged, specialist community services are not available.

“In summary, ARBD has a high personal cost for patients in terms of cognitive disability, and for Health and Social Care in terms of resource use. Investment in better services is required for this group who represent a significant unmet need in Northern Ireland.”

## **2.3 Northern Health and Social Care Trust (NHSCT)**

As in other trusts, there have been no specific ARBD services commissioned within the NHSCT. There are also no current guidelines or care pathways in place for health professionals relating to screening, assessment and treatment of this disorder. There also are no reliable figures on the incidence and prevalence of ARBD within the Trust, but they are unlikely to differ significantly from other areas of the region. There are particular difficulties in finding suitable placements for those individuals with ARBD who are under 65 years old, and who may also have behavioural, as well as cognitive, difficulties.

The NHSCT convened a working group to look further at this issue and have submitted the following contribution:

“The importance of recognising individuals who have, or are at risk of developing, ARBD, who present to acute hospitals needs to be emphasised to health professionals. Parenteral thiamine should be prescribed in line with best practice for prophylaxis and treatment of known or suspected Wernicke’s encephalopathy.

“Collaborative working and agreed clear pathways of care are vital to improve services for individuals with known or suspected ARBD. The interface between Acquired Brain Injury (ABI) Services and ARBD should be reviewed.

“More emphasis needs to be placed on providing an extended period of active treatment and recovery over a period of two

years, or longer, rather than on a relatively short period of treatment within an acute hospital setting which can result in a placement with limited ongoing rehabilitation.

“As the severity of ARBD ranges from mild to severe it requires a range of services matched to individual clinical needs. The NHSCT would support the establishment of a specialist in-patient/residential service organised regionally for the most severely affected, with local capacity built up in each trust to provide specialist evidence-based treatments in conjunction with other services based on a needs assessment.

“Support and information for carers and family members of individuals with ARBD should be readily available within each trust.”

## **2.4 South Eastern Health and Social Care Trust (SEHSCT)**

In the SEHSCT, there has been a recognised and growing problem with ARBD within medical wards, particularly gastroenterology. These services are experiencing problems, such as, frequent re-admissions of patients with ARBD who invariably utilise bed days well beyond a point of medical fitness. Normally, the reason for the delayed discharge is due to a lack of options for onward referral or appropriate placement.

In 2016, the gastroenterology service carried out a retrospective review of ARBD cases encountered by their service over the previous five years. A random sample of 19 patients was selected. The average age of patients was 66 years, and 65% were male. It was found that four of the patients had subsequently died.

For this group, the number of hospital admissions over five years ranged from one to 37, with an average of 14.7 admissions per patient. The length of the most recent hospital stay ranged from two to 98 days, with an average length of 21.2 days. This compares to the average length of stay for a typical alcohol-related hospital admission, which is estimated as 5.6 days.<sup>31</sup> In terms of cost, the team was supported by the finance department to estimate that the average stay cost £7,165. This equates to £105,334 per person over a five-year period, and a total cost of £2,001,184.50 for the 19 patients sampled.<sup>32</sup>

A staff survey, similar to that conducted in the BHSCT hepatology ward, revealed comparable opinions from staff in the gastroenterology wards in SEHCT. Each responder had regular contact with patients with ARBD, and approximately half described difficulties with the detection and diagnosis of ARBD. One third believed there were unnecessary delays in diagnosing patients with ARBD, while two thirds felt there was a lack of formal training on the condition. Half felt that the current facilities for management of ARBD required



improvement, and they reported specific problems such as no official policy or pathway, the lack of both a specialised unit and specialised community support on discharge.

## 2.5 Southern Health and Social Care Trust (SHSCT)

The SHSCT has made the following statement in relation to ARBD in their catchment area:

“The Southern Health and Social Care Trust (Mental Health and Learning Disability) welcome the opportunity to provide comments... in respect of the needs of a particularly vulnerable and often forgotten group of patients. Those patients, who suffer as a result of alcohol-related brain damage, become hidden within a number of service delivery programmes, mainly due to funding issues and a lack of any form of dedicated discrete service or programme delivery.

“As such the nature and extent of this issue is hard to determine within the Trust as those services which deliver care do not directly identify these patients as suffering from ARBD, as this may not meet funding criteria etc. This care, however, does not always meet the needs of the individual and treatment approaches which may help to optimise the patient’s functioning are not provided as a routine, more as an exception.

“The need to work closely with services for older people, dementia, neurology and brain injury is reflected in the above, as well as gathering this type of diagnostic information in a different way.

“In the SHSCT, we acknowledge the issues presented by those suffering from ARBD. Addiction services, physical disability and memory services have developed joint working arrangements to try and streamline the pathways available for this patient group, however these arrangements are not comprehensive and need to be developed for areas such as old persons services and neurology. Ideally a discrete service with all levels of care provisions is required. The SHSCT does have a discrete independent sector provider of a small residential centre; this resource is limited and throughputs in this sector are problematic.

“There is no doubt this remains an area of significant need – especially as this is often a relatively young population with multiple co-morbidities. There is no real specific resource we could identify for this group – other than that provided through any generic services provided as outlined above.

“We have no clear idea of numbers, demand or need because of the complexities outlined above, though colloquially we are

aware of the need our mental health teams are outlining in terms of seeking placements and providing support to patients and families.”

## 2.6 Western Health and Social Care Trust (WHSCT)

Due to anticipated local issues with regards to the understanding, identification, and care of patients with ARBD in the WHSCT, a successful application was made to the Big Lottery for funding to establish a working group to explore this area further. Representatives from concerned disciplines gathered regularly to look at ways to understand more about the challenges faced when managing patients with ARBD in the Trust, and to make recommendations to improve service delivery. There were five main pieces of work undertaken by the project group:

- 1 A scoping exercise to estimate the prevalence of ARBD or suspected ARBD in the WHSCT area (identified from both in-patient and community sources).
- 2 The preparation of a comprehensive report exploring the issues that services are currently experiencing, highlighting the key strengths and weaknesses in current service provision, and making specific recommendations for future service provision based on examples of best practice and the available research evidence.
- 3 The proposal of a local service model to improve the management of ARBD in the WHSCT.
- 4 The development of care pathways for both community and in-patients with a potential or actual diagnosis of ARBD.
- 5 The financial and staffing investment required for a proposed ARBD team.

The overall prevalence rate of ARBD in the WHSCT was found to be 9.4/10,000, which lies at the higher end of prevalence estimates across the UK. This was not entirely unexpected, however, due to the high levels of both alcohol consumption and social deprivation in the region.

As well as the already recognised problems with delayed discharges and the associated patient care and financial costs, several other challenges were identified by WHSCT staff who manage patients with ARBD. It was felt that patient access to care, and delivery of evidence-based treatment, are compromised by the current informal

nature of service provision. Specifically, there was an identified need for specialist services, facilities and clinical practitioners, as well as ARBD assessment beds and timely, accurate diagnosis. There was also a recognised need for appropriate training and education about ARBD.

Taking into consideration best practice models, alongside the local data gathered, the working group identified that changes towards a more integrated model of care provision are required to comprehensively meet the needs of those with ARBD within the WHSCT. It was concluded that mobilising resources to establish a specialist ARBD team, and implementing dedicated care pathways, would be fundamental to help ensure a more consistent delivery of a quality service. Two new care pathways were proposed capturing referral routes for patients from in-patient hospital admissions, ED attendances and those in, or outside of, treatment services in the community.

To go alongside this, a suggestion for a new ARBD team was outlined. Establishing a specialist ARBD team, applying a dedicated care pathway, and the commissioning of specialised accommodation that would enable the optimal assessment, treatment, and rehabilitation for those affected with ARBD, would of course require funding. Evidence suggests that this can be an ‘invest to save’ strategy, supporting the delivery of cost effective quality care consistent with the vision described in Transforming Your Care.<sup>33,34</sup>

**In the WHSCT area, the prevalence of ARBD was estimated to be 9.4/10,000, which is higher than many other areas of the UK. The delivery of evidence-based treatment is compromised by the current informal nature of service provision and the lack of education and training in this area.**

## 2.7 Treatment and Support Advisory Committee (TSAC)

TSAC provides advice and guidance on a range of issues relating to the New Strategy Direction for Alcohol and Drugs Phase 2,<sup>35</sup> and has provided a statement of support for the development of specialised ARBD services in Northern Ireland:

“TSAC is aware of the impact of ARBD on a range of services across Northern Ireland – with many patients being dealt with in inappropriate settings leading to delayed discharges from services such as hepatology. Not only is this costly in terms of managing the patients, it also means the patients are not receiving the treatment and care they require to recover. TSAC believes that by developing appropriate care pathways and services, and recognising and building capacity in this area, not only will we reduce costs to the HSC, we will also greatly

improve the quality of care provided to those dealing with this issue. TSAC therefore recommends that commissioners and providers consider this work in detail and seek to put in place appropriate services and supports.”

# Existing service provision for ARBD in Northern Ireland

In Northern Ireland, as with many other areas of the UK, there are no care pathways for managing patients with ARBD, and no clearly defined roles of responsibility. Patients themselves have reported feeling as though they are passed from 'pillar to post'.<sup>36</sup> Healthcare professionals working on medical, gastroenterology and hepatology wards have reported that patients with ARBD cause significant problems for them in terms of inappropriate bed usage. There is a current drive to develop alcohol care teams within the acute hospitals, and as part of the care pathway, cognitive screening will be performed to improve detection of ARBD.

Historically, many patients with ARBD in Northern Ireland have ended up in dementia care settings, at a relatively young age, with little hope for recovery. With increasing evidence suggesting good potential for at least some degree of recovery from ARBD, there are care providers who have recognised the distinction between dementia and ARBD. There are now several facilities in the region which have specific ARBD units, and they use a 're-enablement and recovery' programme to provide rehabilitation for patients. A recent scoping exercise has demonstrated, however, that there is no standardised or formal approach to treatment, but the very existence reflects a strong willingness to provide these services. There is currently a provider offering supported accommodation for patients with ARBD, without the provision of any active treatment, but they are seeking to expand their service by developing a rehabilitation package. There is a need, not only for the expansion of available beds within these facilities, but also for the delivery of more standardised approaches to the treatment of ARBD across Northern Ireland. Some of these services are outlined in more detail below.

## 3.1 Pilot ARBD service in the South Eastern Health and Social Care Trust (SEHSCT)

Within the SEHSCT addictions service, two in-patient beds have been set aside to pilot an ARBD treatment pathway. Due to the ward setting, only mild cases of the condition are accepted directly from the Ulster Hospital gastroenterology wards. This pilot will aim to develop over time, with staff gaining knowledge and expertise in the process of stepping patients down from the acute medical setting. Outcome measures will be gathered to further demonstrate the need for ARBD service development. It is expected that there will only be modest

gains in terms of cost savings amongst this patient group, as patients at the more severe end of the spectrum are likely to confer greater financial savings.

### **3.2 Service provision for ARBD in nursing home environments**

#### **Greenville Manor, Four Seasons Health Care, Belfast**

Greenville Manor in Belfast is a nursing home facility that has an ARBD unit located next to, yet kept separate from, an Elderly Mentally Infirm (EMI) dementia care home. They have 15 ARBD beds, and had 14 resident patients with a diagnosis of ARBD when visited for the purpose of this exercise. The age range was 47 to 65 years, with 12 being male and two being female. There had been 17 admissions of patients with ARBD in the preceding year. Four of those 17 had since been discharged back to their own homes or to a supported living facility, because of recovery. They had one re-admission due to relapse in alcohol consumption.

Staff working at Greenville Manor have had no formal training in the psychosocial rehabilitation principles for treating ARBD, but have expressed a keen interest in having more guidance and access to a structured programme. They have, however, downloaded material from an American-based ARBD service as a resource for training their staff. The unit manager trains staff using this resource, and staff deliver the 'activity plans'. There is a weekly staff meeting to discuss patient progress.

The manager has identified that the ARBD unit should be very distinct from the dementia unit. In the dementia unit, patients are cared for by staff as they are unable to attend to their activities of daily living. In the ARBD unit, however, there is a focus on recovery. The patient is expected perform the activities of daily living where they are able, with support from the staff. For example, patients are encouraged to make simple snacks for themselves and do laundry. The difficulty of the tasks increases with progress, and the steps are taken on a 'trial and error' basis.

'The focus in ARBD is recovery and activity. We have seen patients do less well when placed in a dementia unit.'

#### Case study: John

John is a 62-year-old man. He was admitted to the dementia unit, but over time staff felt his diagnosis was more likely to be ARBD given his alcohol history and age. He was very cognitively impaired and unable to carry out any of his activities of daily living independently. He became depressed, was isolating himself in his bedroom, and told staff he did not belong there with the elderly people. He reported feeling hopeless that he would spend the rest of his life in an old people's home.

John noticed a maintenance worker, and asked if he could help as he had previously worked in the plumbing trade. He assisted with small tasks, with support from staff, and began to show signs of improvement. His diagnosis was reviewed by a psychiatrist and he was subsequently placed in the ARBD wing of the home. He has continued to improve, and staff are clear that rehabilitation, as well as abstinence and good nutrition, is vital when it comes to the treatment of ARBD.

### 3.3 Service provision for ARBD in supported living environments

#### Connaught House, Praxis Care, Newry

Connaught House was originally a five-bed supported living unit for patients with ARBD, but there has been subsequent funding for three more beds. When visited for the purposes of the scoping exercise there were five patients in residence, all male, and all with a diagnosis of ARBD. These five patients had been resident there for more than one year. Connaught House receives referrals from acute hospitals but insists on a three-month period of abstinence before accepting the patient. This is to allow for an accurate diagnosis of ARBD.

Staff were aware of other specialised ARBD services within the UK and had been to visit one to obtain first-hand information about rehabilitation. They then returned and developed their own rehabilitation package, which is individualised for each patient. They have access to an occupational therapist, but not to a psychologist. They provide skills training, using formal techniques such as chaining, and cognitive rehabilitation. The focus of the skills training is on activities of daily living and completion of tasks and chores.

All five patients' cognitive function improved, as measured by the six monthly cognitive assessments that are performed. As Connaught House is a supported living facility, there is no locked door, and so staff take an assertive approach to maintain an alcohol-free environment. One of the residents was going into the town independently, but did not buy alcohol, and two of the patients had access to their bank accounts.

The manager of the unit stated that he believed:

“Many patients with ARBD are inappropriately placed in generic care homes and this instantly decreases potential for recovery.”

Staff from Connaught House felt that the main priorities for ARBD service provision in Northern Ireland include:

- the need for more specialised units in each trust area
- the availability of an assessment facility so that patients do not have to wait in acute hospital beds for a diagnosis, and therefore admission to a unit such as theirs. A proportion of patients would likely be able to return home from such a facility and not require rehabilitation in a costly placement
- education and training for staff, with more standardised rehabilitation packages across the region
- the need for psychology input into rehabilitation processes.

### **Leonard Cheshire Disability (LCD) NI Group**

LCD have begun to tailor their services in a specialised way to facilitate patients with ARBD, who require supported living. LCD provides a range of supported living and community-based outreach services across the region. In recent years, a number of the supported living services have experienced a significant increase in the number of referrals for people with ARBD, namely:

- **Cheshire House, Derry/Londonderry:**  
Cheshire House is a well-established purpose-built development of 18 apartments in the heart of the Waterside area of the city. Six of these apartments have been adapted to provide specialist support for people with acquired brain injury.
- **The Maples, Belfast:**  
The Maples consists of 14 enhanced support sheltered housing and 17 supported living homes for people with physical disabilities. Five of these have been completely refurbished and future-proofed with the latest assistive technology.

These supported living services support disabled people, including those with ARBD, to develop essential daily living skills. Person-centered support is tailored around each individual to identify and achieve their goals, with the aim of improving quality of life outcomes.

The organisation has plans to develop their ARBD services significantly, and is keen to engage in multi-agency working, including with



the health and social care trusts. In terms of service development needs regarding ARBD, LCD NI have reported that the following is required:

- Awareness of this issue needs to be promoted, and training should be rolled out across the health and social care sector.
- Clear pathways need to be established to prevent the 'revolving door' pattern of acute hospital admissions that people with an ARBD experience.
- A number of ARBD services need to be developed and established, such as floating support, supported living, residential, day opportunities,
- The potential opportunities offered through assistive technologies should be strongly considered to enhance the quality of service provision for patients with ARBD.
- Knowledge transfer partnerships should be established with groups and organisations that possess an expertise in the field, to enhance learning and inform models of good practice.

### **3.4 Education and training of healthcare staff**

The authors of this report have developed a training package for staff who manage patients with ARBD. This training covers topics such as the nature of the condition, epidemiology, assessment and treatment of the condition. The training has been delivered to social work staff in the Belfast Health and Social Care Trust, and there are plans to roll this training out elsewhere in Northern Ireland. An ARBD eLearning module has also been developed by the authors for the Royal College of Psychiatrists' CPD online programme, and this covers similar topics.

# Proposals for service development

## 4.1 Invest to save strategy

This report has aimed to highlight that investing in ARBD service development would lead to significant cost savings, whilst improving patient outcomes, a finding which has been demonstrated by other services such as the specialised ARBD service in The Wirral, England.<sup>20</sup> This is one of the most experienced services in the UK, and they have produced data for patients who have completed the rehabilitation programme, showing a significant reduction in the cost of care packages for patients with ARBD. For a patient with ARBD, without co-morbid severe mental illness, and who completes the three- to four-year programme, the average care package cost is reduced by 71% as the patient recovers.<sup>37</sup> This reflects the active process of rehabilitation, resulting in the majority of these patients ending up in non-institutional settings, such as supported living accommodation or in their own home, by the end of the rehabilitation. The majority of these patients do not incur alcohol-related cost on health service provision once they have completed the rehabilitation, due to low rates of relapse into uncontrolled alcohol consumption.<sup>20</sup> The few that remain in institutions often have significant mental health problems, in addition to ARBD, and have ongoing problems unrelated to alcohol. Even when considering these complex patients, the team demonstrated a 48% reduction in care package costs overall.<sup>37</sup>

Currently in Northern Ireland, many patients with ARBD remain in institutional settings for the rest of their lives. With the availability of specialist treatment, a majority of these patients would recover sufficiently to enable them to be transferred to less supported, and ultimately less costly, placements, possibly even their own homes. This is already occurring for patients fortunate enough to be placed in one of the few ARBD specific units that exist in Northern Ireland.

The service in The Wirral also demonstrated an 85% reduction in acute hospital bed occupancy as a result of the in-reach nature of their service.<sup>20</sup> Another ARBD service, in Edinburgh, found that in 2011, patients with ARBD used 4772 acute hospital bed days at an estimated cost of £2 million.<sup>38</sup> Funding was approved in 2013 for a two year pilot scheme, at a cost of approximately £650,000 per year, where patients were discharged early from acute hospitals to spend a planned 12 weeks in a designated step-down unit. This is a registered care home, managed by a third sector organization, with part-time in-reach provided by NHS Lothian and the City of Edinburgh

Council. This includes input from disciplines such as general medicine, psychiatry, clinical psychology, occupational therapy, physiotherapy and social work. There is also a service-level agreement with a local GP practice. Between August 2014 and December 2015, 59 patients were admitted to the unit. This was found to release an average of 27 acute bed days per patient, saving the acute trust £1 million per annum. This takes into account the costs incurred by running the service on a yearly basis. Alongside this were improvements in cognitive function and indicators of wellbeing.<sup>39</sup>

As mentioned previously in this report, an observational study in the Belfast Health and Social Care Trust estimated that 105 patients with likely ARBD cost £1 million in one year in terms of acute hospital bed occupancy.<sup>29</sup> A sample of 19 patients from the South Eastern Health and Social Care Trust, admitted with alcohol-related problems and found to have ARBD, were estimated to have cost £2 million over a five-year period through lengthy acute hospital admissions.<sup>32</sup> It would be expected that providing specialised ARBD services, with in-reach into acute hospital wards, would accrue similar savings for healthcare services in Northern Ireland as have been shown elsewhere.

**Health and social care services in Northern Ireland have a significant financial burden placed on them by patients with ARBD. As with elsewhere in the UK, specialised ARBD services can reduce acute hospital bed occupancy and the cost of community care packages.**

## 4.2 Proposed service model

### ARBD step-down assessment unit

There are currently no clear care pathways to facilitate early discharge from acute hospital beds, and there is also no step-down unit available to provide a 12-week period of abstinence to allow for specialist assessment and initial rehabilitation for patients with suspected ARBD. Patients are currently being transferred to care home settings unnecessarily as a result.

Having an alcohol-free period of assessment is vital to the overall pathway, and should not be overlooked, despite the current focus on community treatment in healthcare reform. Such a period of assessment will allow for a reduction in acute hospital bed occupancy, accurate diagnosis, and more appropriate community placements.

There are several options by which to provide this service:

- Assessment units in each trust – These could sit within either statutory services or the third sector. A model similar to that in Edinburgh could be adopted so that step-down beds would be located within a registered care facility. The provider would deliver the staff for day-to-day running of the unit, and a statutory team would provide specialist ARBD input. This would be the preferred model given there are ARBD units already in existence, and there is an appetite for the development of more facilities catering for this group of patients.
- Sub-regional assessment units –This option, however, would also require the development of specialised community teams within each trust.

Essential to the design of the step-down units is the provision of a specialist multidisciplinary team. The exact composition of the team would be determined by the model chosen, but would include staff from:

- Psychiatry – there is no absolute consensus as to which sub-speciality is desirable. Some services have a consultant addictions psychiatrist, whereas others have input from a consultant later life psychiatrist.
- General practice
- Mental health nursing
- Occupational therapy
- Social work
- Neuropsychology
- Care management
- Support work staff.

This team would provide an in-reach service to the acute hospitals in the trust. Referrals would be screened and an initial assessment provided. Patients may be referred to the step-down unit for assessment and diagnosis, or it may be appropriate at this stage to commence rehabilitation in the patient's own home, a supported living environment, or another care facility, particularly if they have already been abstinent for at least three months. Patients would initially only be accepted from acute hospital wards, as this is where significant cost savings can be made. However, in time it may become appropriate

to accept referrals from primary care, addictions services, homeless services and other sources.

The team would provide multidisciplinary assessment and after completion of this phase, patients would continue to be followed up in the community if they have been given a diagnosis of ARBD. Rehabilitation packages would be designed for each patient, which may be of three to five years' duration, and largely delivered by staff in the care facility where the patient is residing. The team would also provide education and training to care home staff, and ensure the treatment being offered is according to the rehabilitation programme drawn up. There would be an element of assertive outreach in order to keep the patients engaged with the team. The level of care required would be continually monitored, so that patients can be transferred to less supportive, and therefore less costly, environments when appropriate.

### **Specialist ARBD community teams**

Should a sub-regional unit model be chosen, additional ARBD community teams would be required in each trust. The overall team specification would have a similar profile to that required by the assessment unit. The team would accept patients, with a diagnosis of ARBD, discharged from the step-down unit, and supervise rehabilitation programmes tailored to each patient's individual needs, as outlined above.

### **Proposed criteria for referral**

These have been adapted from the Wirral ARBD service referral criteria.<sup>20</sup> The criteria are:

- 1 The patient should be drinking more than 35 standard units of alcohol per week (more than 28 for women) for at least five years. The patient may be currently abstinent but drinking at this level within three years of the onset of cognitive deficits.
- 2 There should be documented concerns in the medical notes about cognitive function, and the relevant test score is to be included in the referral. For example, as per the regional alcohol withdrawal guidelines, a 6CIT is to be performed on all patients presenting to an acute hospital with alcohol dependence syndrome. If impairment is detected, a MoCA or ACE III should be performed for a more detailed assessment.

AND/OR

There should be documented concerns in the medical notes about the patient's capacity to make specific decisions about, for example, discharge living arrangements.

- 3 The patient should have had three or more alcohol-related admissions to hospital in the last year.

AND/OR

The patient should have had one, or more, delayed discharges in the last year. A delayed discharge being defined as a delay in discharge from hospital because of psychosocial reasons, beyond the time when they are declared medically fit.

For a referral to be accepted by the service, all three criteria should be met. All other medical or reversible causes of cognitive impairment should also be ruled out.

# Summary of recommendations

- 1 Patients with ARBD in Northern Ireland would greatly benefit from the provision of specialist services that can adequately respond to their needs. The Health and Social Care Board and Local Commissioning Groups should ensure the delivery of such services to meet the local needs in each of the five geographical areas.
- 2 Each health and social care trust should determine the speciality in which the service will sit. There are some specialist services in other areas of the United Kingdom but they fall under the auspices of various specialities, for example: addictions psychiatry and young onset dementia services.
- 3 An ARBD specialist service should take the lead in the assessment and treatment of patients, whereas care pathways for such a service need to be developed by each health and social care trust. There must be a move away from simply placing these patients in care facilities, without active treatment, given the potential for at least some degree of improvement in the condition with treatment.
- 4 Each health and social care trust should ensure that an ARBD specialist service is multidisciplinary in nature and be comprised of clinicians with specialist knowledge. Required disciplines include psychiatry, mental health nursing, neuropsychology, occupational therapy, care management, support workers and general practice.
- 5 Each health and social care trust should ensure that the ARBD service will in-reach into acute medical and surgical wards so that there can be early identification of patients suspected of having ARBD. Early discharge can then be facilitated to reduce acute hospital bed stays and provide a short-term period of psycho-social assessment for up to three months.
- 6 The Health and Social Care Board and Local Commissioning Groups should facilitate each health and social care trust to have access to an assessment unit which would allow for an alcohol-free period of assessment. Not all patients would require an assessment in this unit, but it would be primarily used for behaviourally challenging patients and those who are severely impaired. Such units could be either be statutory in nature, or

sit within the third sector having input from the above described multidisciplinary team.

- 7 Each health and social care trust should ensure that the service delivers an education programme to other healthcare professionals looking after patients with ARBD, in a variety of settings, to address such issues as: assessment, diagnosis, stigma and potential for treatment. Such a programme has already been developed and could be rolled out to a wider audience.
- 8 Each health and social care trust would be required to ensure the service provides training, including the training of care home staff to enable them to deliver patient-centred rehabilitation programmes. The team would also share expertise with colleagues who are looking after patients at the milder end of the ARBD spectrum.
- 9 Assertive outreach is a key principle for the ongoing follow-up of patients under the care of community ARBD services. This should be taken into account by each health and social care trust when planning services, particularly acknowledging the significant input support work staff can have in providing practical help and making regular contact.
- 10 Each health and social care trust should set up services which actively encourage carers, family members and friends to become involved where possible.



# Conclusion

There is a resounding message from healthcare professionals across Northern Ireland that development of ARBD services needs to be a priority. This patient group is currently being neglected, with few patients having access to any kind of specialised rehabilitation. Despite this neglect, patients with ARBD are costly to health and social care services by virtue of their acute bed occupancy, frequent ED attendances and for many, ultimate placement in a costly dementia care setting. Specialist ARBD services elsewhere in the UK are demonstrating positive outcomes in terms of improvements in patients' cognition and functioning, as well as significant cost savings.

There is a need for more joined-up working between existing and proposed services. With the already planned development of alcohol care teams, more cases of ARBD will be detected. Existing care providers in Northern Ireland are planning expansion of placements for patients with ARBD. The development of specialised multidisciplinary ARBD teams, with access to an assessment unit, would bridge the gap between the acute hospitals and the community placements. Acute hospital bed occupancy by these patients will, therefore, be reduced. Following assessment, patients would then be placed appropriately in a community setting and have the quality of their treatment monitored regularly, with the potential for prompt step-down to the least supportive, and therefore the least costly, setting as soon as possible.

With investment in ARBD service provision, cost savings by the health and social care sector could be made in the longer term, and patients with ARBD in Northern Ireland would be provided with **treatment, not just care.**

# Appendix 1

## Case study of a patient who has completed a psychosocial rehabilitation programme for ARBD<sup>40</sup>

A patient, and her carer, were interviewed following completion of a rehabilitation programme, delivered by the specialised ARBD service in The Wirral.

### Patient

**Q: Tell me about your memories of the last three or four years**

A: They don't seem very good.

**Q: Can you tell me what your problems were?**

A: I forgot what was going on.

**Q: Do you remember the issues you had with alcohol?**

A: Even though John [husband and carer] told me I was drinking too much, I would not remember drinking the day before, and I was sure I had not even though everybody told me. I cannot remember drinking every day, but now I know I was.

**Q: Did you think you were drinking less than you were because you could not remember?**

A: Yes.

**Q: What happened next? Did you end up in hospital?**

A: All I can remember is somebody else was looking after me. I was in a care home or something.

**Q: Do you remember anything about that experience when you were in that home?**

A: People were pleasant to me and people made me do things like look after myself, learn to clean and cook again. I was trying to fit in with things.

**Q: Do you remember when you started visiting your own home again?**

A: I only remember my family were pleased to see me, and I was pleased to see them

**Q: What role do you think alcohol has played in your problems?**

A: It made me go doolally. Since it was over with, I have not had a drink. I've learned my lesson. I have wine or lager that has got 'alcohol-free' on the front of the bottle.

## Carer

**Q: When you look back five or six years, can you give me a little background on what your life with your partner was like?**

A: It was at the stage where I was frightened to come home as I was scared of what I was going to be confronted by.

**Q: And was that due to alcohol?**

A: Oh yes.

**Q: How long had she been drinking for?**

A: Since I met her.

**Q: And what sort of quantity was she drinking?**

A: Certainly a bottle of rocket fuel cider or white wine. It was hard to tell. She had it hidden all over the house. It was less and less as time went on. She just couldn't handle it.

**Q: How did things come to reaching breaking point?**

A: I think it was just like a sponge filling up and filling up and filling up, eventually just can't take anymore. She had a couple of falls, banged her head a couple of times, and we ended up regularly at the hospital. That is where her memory trouble was really picked up.

**Q: That's when the alcohol-related brain damage service got involved. What happened then?**

A: She stayed in hospital to have her physical health sorted and then she was moved to a rehab unit, which was like a care home.

**Q: And what's your view looking back at it, about the purpose of the rehabilitation? Did they seem to be doing anything active with her?**

A: Yes.

**Q: Could you describe a little bit of that to me?**

A: Just getting back to day-to-day things. I mean, as silly as it sounds, putting the kettle on, hygiene, making the bed, but in a structured way. It helped her get confident again.

**Q: And how long was she in the rehabilitation home before she started coming home?**

A: Only about six months.

**Q: Did you have any fears or worries about that?**

A: Only whether she was going to start drinking again.

**Q: How is she now?**

A: On a day-to-day basis there is still a problem with short term memory, but she is living at home independently.

**Q: Has alcohol been a problem since?**

A: No.

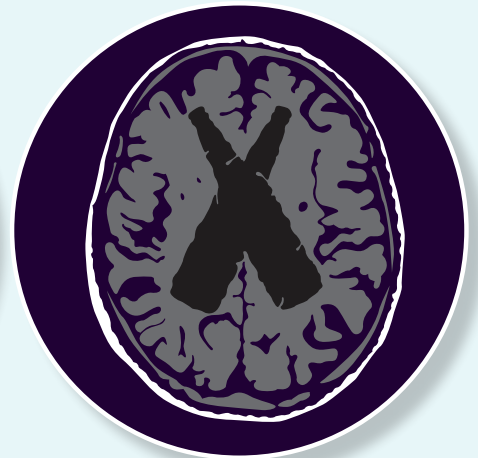
**Q: Does your wife, from your point of view, crave alcohol?**

A: No. She knows now she has too much to lose.

# | Appendix 2

## Patient information leaflet<sup>41</sup>

(Shown on the following eight pages.)



ALCOHOL  
and you

# ALCOHOL RELATED BRAIN DAMAGE (ARBD)

This fact sheet will help you get a better understanding of Alcohol Related Brain Damage, how it can present, what causes it and how someone with ARBD can be helped. There is also information for family members.

## → What is Alcohol Related Brain Damage (ARBD)

Alcohol Related Brain Damage (ARBD) describes actual damage to the structure and function of the brain due to long-term heavy drinking and poor nutrition. It is an umbrella term which includes many different syndromes.

## → How does alcohol damage the brain?

- Alcohol itself is toxic in large amounts
- Long-term heavy drinking damages brain cells

### Depletion of vitamin B1:

Vitamin B1 (thiamine) is essential for the brain to function normally. A combination of heavy drinking and poor diet can lead to a deficiency in Vitamin B1. When levels of Vitamin B1 are too low, serious damage to the brain can occur. A severe lack of Vitamin B1 can lead to a medical emergency called Wernicke's-Encephalopathy (see page 3).

### Heavy drinkers often don't eat very well:

Heavy drinkers often swap food for alcohol and don't eat well. At the same time alcohol itself has carbohydrates in it which needs B1 to break it down. Alcohol can also cause inflammation of the guts (gastritis) and vomiting, both of which mean that heavy drinkers may not be able to absorb B1. All of these things mean B1 can be at very low levels.



### Liver damage:

Alcohol can damage the liver, which breaks down toxins in the body. If the liver is not working properly, toxins stay in the body for longer and this can damage the brain.

### Drunkenness can lead to falls and fights:

Many heavy drinkers have frequent falls or other head injuries. The medical term for this is traumatic brain injury, and around 25% of people with ARBD have this kind of injury.

### Alcohol withdrawal can also damage the brain:

When someone is dependent on alcohol and suddenly stops drinking without medical supervision, it can cause damage to the brain as the body's chemistry tries to re-adjust to not having alcohol.



All these causes of Alcohol Related Brain Damage are related to heavy and regular drinking.



## → Who is at risk of developing ARBD? →

Research shows that in some cases, men who regularly drink more than 35 units of alcohol a week and women who drink more than 28 units of alcohol a week for a period of five years or more are at risk.

**This equates to around 3½ BOTTLES OF WINE or 14 PINTS OF LAGER in a week for a man, and just less than 3 BOTTLES OF WINE or about 11 PINTS OF LAGER for a woman.**

The recommended maximum alcohol use for adults (men or women) in the UK is 14 units per week, spread over three or more days and with several alcohol free days each week.

### People may be particularly at risk if they:

- Have frequent 'memory blackouts' while drinking.
- Have alcohol-related liver damage.
- Have had a lot of withdrawals or detoxes.
- Binge drink regularly.
- Don't eat enough while drinking.
- Have been admitted to hospital because of their drinking.

**Because a woman's brain and body is more vulnerable to the effects of alcohol, women develop ARBD earlier than men.**

Some cases reported as early in the 20's

## Specific ARBD Syndromes

### Wernicke-Korsakoff's Syndrome

Wernicke's Encephalopathy is a deterioration of brain tissue, and the symptoms include confusion and disorientation, abnormal eye movements, blurred vision, and poor balance (walking unsteadily). It should be treated as a medical emergency which can be life threatening. It can be effectively treated with large doses of Thiamine, if caught early. People with Wernicke's Encephalopathy often appear drunk, even if they've had very little to drink. This is why it can often go undiagnosed and can easily be missed. Therefore it is important that for every case where the condition is remotely suspected, treatment with Thiamine should be given, the treatment itself has very few side effects and is cheap yet can be life-saving.

Some patients who experience Wernicke's Encephalopathy go on to develop Korsakoff's Psychosis. The symptoms of this include more permanent memory loss, apathy, and confusion about where they are and about the passage of time. Sometimes patients with Korsakoff's will have such severe memory loss that they can no longer cope with living independently.

### Frontal Lobe Syndrome

Damage to the frontal lobe leads to problems controlling impulses, making decisions, discussing goals, planning, problem solving, assessing risk and prioritising activities. This means a person may struggle to engage with services or make their appointments.

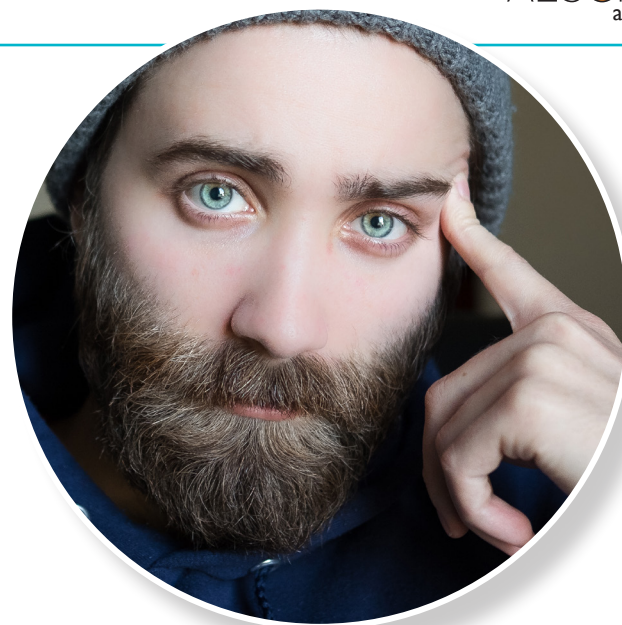
### Cerebellar Syndrome

The cerebellum is at the back of the brain and controls co-ordination. Damage to this area can mean poor coordination, unsteady and broad based walking as well as tremor and other associated symptoms.

Quite often a person doesn't fit neatly into a definite syndrome and has symptoms from many different areas. This is why the broader term "Alcohol Related Brain Damage" is used.



# → What are the signs and symptoms



## Cognitive and memory symptoms

### Memory loss

– a person is unable to remember things.

### Difficulty with familiar tasks

– a person may struggle with everyday tasks.

### Difficulty in processing new information

– not being able to recall times, dates or to remember people they've just met.

### Depression and irritability

– this can include apathy, a lack of interest and a lack of spontaneity or motivation.

### Poor judgement and loss of inhibition

– a person may be too trusting of strangers or respond inappropriately, for example by removing their clothes in public.

### Problems with language

– there may be difficulties in remembering words, people's names, or forgetting the end of a sentence halfway through.

### Erratic behaviour

– carers of people with ARBD often find this the most difficult thing to cope with. A person may have rapid mood swings, become aggressive or even violent, or behave out of character.

They may also have no insight into how they're behaving and the effect it is having on themselves or others.

### Difficulty concentrating

– it can be hard for people with ARBD to focus on one thing for more than a few minutes.

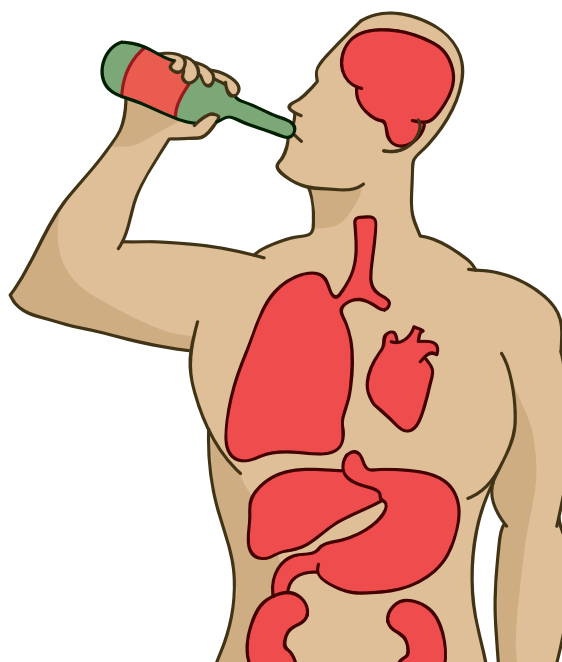
### Poor choices and decision-making

- they may have difficulty in weighing up options or making sensible decisions. They may also be vulnerable to manipulation and abuse.

## Physical problems

There may also be physical signs of the damage to the body such as:

- Damage to the liver, stomach and pancreas can affect brain function.
- Pins and needles and numbness or burning sensation in arms and legs- can increase the risk of falls and accidents.
- Slow, wide, stumbling gait (ataxia) – this can make walking difficult.
- Poor temperature control, muscle weakness and disturbed sleep patterns – caused by shrinkage of the brain and by tissue damage.



**One reason ARBD may not be diagnosed in a drinker is that its symptoms can appear very much like drunkenness.**

## → Can ARBD be prevented?

### Vitamin B1/Thiamine

Given that lack of Thiamine is one of the causes of ARBD it is important for it to be replaced. This is especially important during an alcohol detox, which can be a vulnerable time for the brain.

Doctors use a solution called Pabrinex® which is given as a drip. Thiamine can also be prescribed by your GP in tablet form. These tablets are important but when stores of Thiamine are really low they would not be enough to replace it and that's when the drip or injection is required.

It is also important to seek advice from your doctor if you do not have a good diet. Adequate nutrition is a key factor in preventing ARBD.



It is important to seek help for alcohol dependence. A good first step would be to discuss this with your GP and they can direct you to the appropriate alcohol services.

It is important to remember that you should never stop drinking suddenly as this can lead to severe alcohol withdrawal which is dangerous. It is best to seek support and advice to guide you on how to reduce and stop drinking.

## → What is the Treatment for ARBD?

The mainstay of treatment involves maintaining total abstinence from alcohol. Good nutrition is also essential and Thiamine should be replaced.

There is also new research to show that re-learning skills of everyday life that may have been lost through ARBD can be achieved by re-training your brain (Rehabilitation). This is similar to how people recover from traumatic brain injuries.

This requires input from professional services that have developed in the UK and have shown good outcomes. It is hoped that services in Northern Ireland will improve so that more patients with ARBD can be diagnosed and receive appropriate treatment.



By remaining abstinent and maintaining a balanced diet, a person may recover their brain functions over a period of several months or years.

**It is estimated that:**

- 25% of people will make a full recovery.
  - 25% will make a significant recovery.
  - 25% will make a partial recovery.
  - 25% of people unfortunately, will make no recovery and will have permanent difficulties.
- Younger people seem to have a better chance of recovery.
- If the signs and symptoms of ARBD are identified earlier, this can improve a person's chances of recovery.

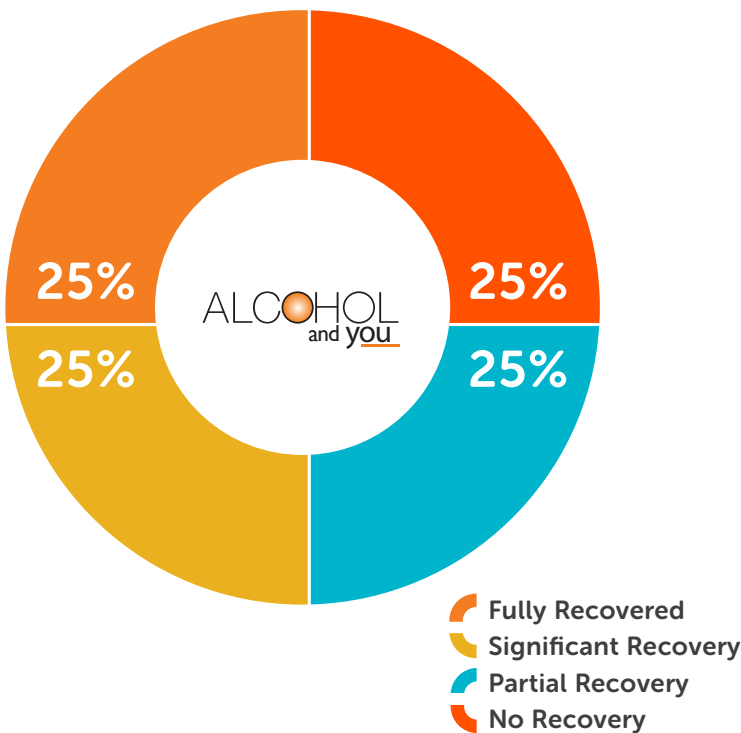
# Can ARBD improve?

Some labelled ARBD a "Dementia" in the past for which there is no cure. It can be very similar in presentation to Dementia.

But very importantly, it is now known not to be a true Dementia. ARBD can get better if a person stops drinking and avails of the correct treatment.

In fact, up to 75% of people will make a full or partial recovery.

## Recovery following ARBD



**In the majority of cases, ARBD is reversible (to different degrees) if a person remains alcohol free**







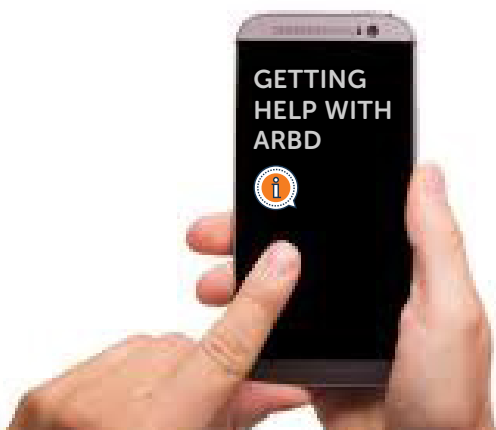
## → A note for family members

One of the greatest impacts of an Alcohol-Related Brain Damage is the devastating effect it can have on the family.

By the time the person receives their diagnosis, the family will already have been through many difficulties with their loved one.

### The family members may have:

- A partner/spouse/father/mother who was physically or emotionally unavailable to them because of their drinking
- Struggled to cope financially due to the person's drinking
- Taken on all of the caretaking roles for the family leading to exhaustion and resentment
- Tried to protect the loved one or hide the problem from other people
- Experienced verbal or physical abuse as a result of alcohol use
- Watched someone they love physically and psychologically deteriorate over many years
- Always expected the 'unexpected' - waiting for the phone to ring to hear something has happened to the person
- Left the family home due to concerns over personal and children's safety



For the children of the family, the development of this condition may have followed them through their childhood, into their teenage years and may be with them for much of their adult lives.

# → Getting support

It is important to say there is support for you in your own right.

Each of the five Health Trust areas has a community based service (step 2) that provides individual family support.

For a directory of services for family members and how to contact them see.

[www.drugsandalcoholni.info](http://www.drugsandalcoholni.info)

For young people Steps to Cope is an intervention for 11-18 year olds

[www.stepstocope.co.uk](http://www.stepstocope.co.uk)

T: 0800 2545 123

Developed by:

Ed Sipler (Health Development Specialist, South Eastern Trust) and Dr. Joy Watson (Consultant Psychiatrist South Eastern Trust).

ARBD is a serious condition that if addressed early can be successfully treated.

- 2 in 100 people in the general public may develop Alcohol-Related Brain Damage
- 1 in 8 people who are dependent on alcohol may develop Alcohol-Related Brain Damage

The good news is that it can improve if the person can successfully achieve abstinence from alcohol.

If you are worried about your drinking see your GP or use the alcohol and drug services in your area which can be found at;

[www.drugsandalcoholni.info](http://www.drugsandalcoholni.info)

or see the Alcohol and You website that has self-help and a range of information and resources.

[www.alcoholandyouni.com](http://www.alcoholandyouni.com)

ALCOHOL  
and you



Download the KNOW UNITS APP:  
[alcoholandyouni.com](http://alcoholandyouni.com)

T: 0800 2545 123



# References

1. Department of Health. *Health and Wellbeing – Delivering Together 2026*. Available from: <https://www.health-ni.gov.uk/publications/health-and-wellbeing-2026-delivering-together> [Accessed 29 July 2017].
2. North South Inter-Parliamentary Association. *Substance Misuse*. [http://www.niassembly.gov.uk/globalassets/Documents/RalSe/Publications/2014/north\\_south/4314.pdf](http://www.niassembly.gov.uk/globalassets/Documents/RalSe/Publications/2014/north_south/4314.pdf) [Accessed 29 July 2017].
3. Jacques A, Stevenson G. *Korsakoff's Syndrome and Other Chronic Alcohol Related Brain Damage: A Review of the Literature*. Stirling: Dementia Services Development Centre, **University of Stirling; 2000**.
4. Harper C, Gold J, Rodriguez M. *The prevalence of the Wernicke-Korsakoff syndrome in Sydney, Australia: a prospective necropsy study*. *Journal of Neurology, Neurosurgery and Psychiatry*. 1989; 52: 282–5.
5. MacRae R, Cox S. *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, **Scotland; 2003**
6. Wilson K, Afghan S, Bowden-Jones H, et al. *Alcohol and Brain Damage in Adults (with reference to high risk groups)*. London: Working Group of the Royal College of Psychiatrists, **The Royal College of Physicians (London), The Royal College of General Practitioners and The Association of British Neurologists; 2014**.
7. Torvik A, Lindboe CF, Rogde S. *Brain lesions in alcoholics. A neuropathological study with clinical correlations*. *Journal of Neurological Sciences*. 1982; 56: 233-248.
8. Victor M, Adams RD and Collins GH (eds). *The Wernicke Korsakoff Syndrome and Related Neurological disorders Due to Alcoholism and Malnutrition*. Philadelphia: FA Davis, **Philadelphia; 1989**.
9. Western Health and Social Care Trust. *Working with the Community to Tackle Alcohol Misuse Together*. Available from: <http://www.westeritrust.hscni.net/about/2830.htm> [Accessed 28 July 2017].
10. Public Health Agency. *Health intelligence briefing: Alcohol use and alcohol related harm in Northern Ireland - April 2011*. Available from: [http://www.northerntrust.hscni.net/images/Health\\_Intelligence\\_Briefing\\_Alcohol\\_use\\_and\\_alcohol\\_related\\_harm\\_April\\_2011.pdf](http://www.northerntrust.hscni.net/images/Health_Intelligence_Briefing_Alcohol_use_and_alcohol_related_harm_April_2011.pdf) [Accessed 27 July 2017].
11. Department of Health, Social Services and Public Safety. *Adult Drinking Patterns in Northern Ireland 2013*. Available from: <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/adps-2013.pdf> [Accessed 30 July 2017].
12. The Royal College of Psychiatrists in Northern Ireland. *Alcohol. What does it really cost?* Available from: <http://www.rcpsych.ac.uk/pdf/NI%20Alcohol%20%20What%20does%20it%20really%20cost%2010%2011.pdf> [Accessed 29th July 2017].
13. Public Health Agency, Health and Social Care Board. *Alcohol and Drug Commissioning Framework for Northern Ireland 2013-16 (Consultation Document)*. Available from: <http://www.publichealth.hscni.net/sites/default/files/Drug%20and%20Alcohol%20Commissioning%20Framework%20Consultation%20Document.pdf> [Accessed 31 July 2017].
14. Oslin DW, Cary MS. *Alcohol-related dementia: validation of diagnostic criteria*. *American Journal of Geriatric Psychiatry*. 2003; 11: 441-7.

15. Ihara H, Berrios GE, London M. *Group and case study of the dysexecutive syndrome in alcoholism without amnesia. Journal of Neurology, Neurosurgery and Psychiatry.* 2000; 68: 731-7.
16. Ferran J, Wilson K, Doran M. *The early onset dementias: a study of clinical and service need. International Journal of Geriatric Psychiatry.* 1996; 11: 863–9.
17. Ganzelvels PGJ, Geus BWJ, Wester AJ. *Cognitive and behavioural aspects of Korsakoff's syndrome: the effect of special Korsakoff wards in a general hospital. Tijdschrift voor Alcohol Drugs en Andere Psychotrope Stoffen.* 1994; 20: 20-31.
18. North L, Gillard-Owen L, Bannigan D, et al. *The development of a multi-disciplinary programme for the treatment of alcohol related brain injury. Advances in Dual Diagnosis.* 2010; 3: 5–12.
19. Fals-Stewart W, Lucente S. *The Effect of Cognitive Rehabilitation on the Neuropsychological Status of Patients in Drug Abuse Treatment Who Display Neurocognitive Impairment. Rehabilitation Psychology.* 1994; 39: 75-94.
20. Wilson K, Halsey A, Macpherson H, et al. *The psycho-social rehabilitation of patients with alcohol related brain damage in the community. Alcohol and Alcoholism.* 2012; 47: 304-11.
21. Department of Health. *The Bamford Review of Mental Health and Learning Disability (Northern Ireland): Living Fuller Lives.* Available from: [https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/Living%20Fuller%20Lives\\_3.pdf](https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/Living%20Fuller%20Lives_3.pdf) [Accessed 31 July 2017].
22. Babington D, Bell P, Boyle J, et al. *Recovery for people with severe and complex mental health problems in Northern Ireland. A guide for trusts and commissioners of rehabilitation services. London: Royal College of Psychiatrists; 2014.*
23. Chiang CCP. *Wernicke Korsakoff Syndrome in Argyll and Clyde: A Literature Review, needs assessment and recommendation for the prevention, treatment and provision of Wernicke Korsakoff Syndrome.* Edinburgh: Faculty of Public Health Medicine; 2002.
24. Cook CCH, Hallwood PM, Thomson AD. *B Vitamin deficiency and neuropsychiatric syndromes in alcohol misuse. Alcohol & Alcoholism.* 1998; 33, 317-336.
25. Thomson A, Cook C, Torquet R. *The Royal College of Physicians report on alcohol: Guidelines for managing Wernicke's encephalopathy in the accident and emergency department. Alcohol and Alcoholism.* 2002; 37:513-21.
26. Anderson JJM, Flanigan C, Jauher PJ. *Knowledge of alcohol related problems in clinical staff in psychiatric community resource centres in Glasgow. Health Bulletin.* 1999; 57: 162.
27. Hillman A, McCann B, Walker NP. *Specialist alcohol liaison services in general hospital improve engagement in alcohol rehabilitation and treatment outcome. Health Bulletin.* 2001; 59: 420–3.
28. Cox S, Anderson I, McCabe L. *A Fuller Life: Report of the Expert Group on Alcohol Related Brain Damage. Stirling: Dementia Services Development Centre, University of Stirling; 2004.*
29. Bell J, Craig V. *The recognition of patients with alcohol-related brain damage (ARBD) in medical and surgical units – an observational study. Belfast Health and Social Care Trust; 2013. (Unpublished)*
30. Kelly B. *A project to attempt to identify patients, with a diagnosis of Korsakoff's, who are under the care of physical and/or mental health services. Physical Disability Social Work Service, Belfast Health and Social Care Trust; 2014. (Unpublished)*
31. Blunt I, Ariti C, Bardsley M, et al. *Alcohol-specific activity in hospitals in England. Research report. London: Nuffield Trust; 2015.*



32. Addley J, Eccles J. *Retrospective review of hospital admissions for patients with ARBD. Gastroenterology, South Eastern Health and Social Care Trust; 2016. (Unpublished)*
33. Divin B, Owens M, Payne S. *ARBD in The West (Northern Ireland): A report from the Western Health and Social Care Trust's ARBD Project Team. Londonderry: Western Health and Social Care Trust; 2015. (Unpublished)*
34. Department of Health. *Transforming Your Care: A Review of Health and Social Care in Northern Ireland. An overarching road map for change in the provision of health and social care services in Northern Ireland. Available from: <https://www.health-ni.gov.uk/topics/health-policy/transforming-your-care> [Accessed 31 July 2017].*
35. Department of Health, Social Services and Public Safety. *New strategic Direction for alcohol and drugs. Phase 2. 2011-2016. Available from: <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/alcohol-and-drug-new-strategic-direction-phase-2-2011-16.pdf> [Accessed 31 July 2017].*
36. Boughy L. *Alcohol-related Brain Damage: A Report of the Learning Captured from Carezza Care in North Wales. London: Care Services Improvement Partnership/Alzheimer's Society ARBD Working Group; 2007.*
37. Wilson K. *Comparative expenditure – total costs of patients that have completed treatment (sum of all patients), comparing initial per week cost (when taken on by the service) with final per week cost. Wirral Memory Assessment Service, Cheshire and Wirral Partnership; 2016. (Unpublished)*
38. Brown K, Douglas H, Duncan J, et al. *Alcohol Related Brain Damage: An example of a health and social care collaborative. Available from: <http://nhsscotlandevent.com/sites/default/files/2015%20-%20NHSScotland%20Event%20-%20Posters%20-%20PDF%20-%20HPO2%20-%20Lynn%20McCallum.pdf> [Accessed 31 July 2017].*
39. Hume F, Simpson M. *The business case for the alcohol related brain damage (ARBD) service. Edinburgh: NHS Lothian; 2016. (Unpublished)*
40. Wilson K, Bell J, Craig V. *Alcohol-related brain damage. Available from: <http://www.psychiatrycpd.co.uk/learningmodules/alcohol-relatedbrain-damage.aspx> [Accessed 31 July 2017].*
41. Sipler E, Watson J. *Alcohol Related Brain Damage. Belfast: Alcohol and You; 2017.*