

Alcohol Related Brain Damage

A report of the learning captured from Carenza Care in North
Wales

This report was commissioned by the
CSIP/Alzheimer's Society ARBD Working Group
June 2007

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3:11:1951 - 8:11:2007

**This report is dedicated to the memory of Lynda Boughey whose
compassion and pioneering work to support and care for people
with alcohol related brain damage was the inspiration for this study.**

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Executive Summary

This report was commissioned by the CSIP Alcohol Related Brain Damage (ARBD) Working Group in an attempt to capture the learning within Carenza Care, a service aimed specifically at people with ARBD in Rhyl, North Wales. The purpose of the report is to raise awareness of ARBD and its management, and to explore statistical

data for emerging trends regarding

ARBD. Aims of the report

This report aims to:

- Give an overview of ARBD, its causes and features
- Present the experiences/stories of people with ARBD in North Wales
- Present the recommended core elements of a care pathway for ARBD
- Analyse available quantitative data from Carenza to identify emerging themes
- Highlight key messages emerging from this work
- Identify areas for further work

Key findings

The journey of people with ARBD

The emerging themes of the experiences of people with ARBD seem to be:

- Being passed from pillar to post between services both before and after diagnosis.
- Not being given information about Korsakoff's disease
- A perception of Health Professionals that ARBD is self-inflicted and therefore not worthy of an empathic approach
- A general view that recovery is not possible with ARBD
- The only option for care for someone with ARBD is an Older People's Mental Health Nursing Care Home

Key emerging messages

- People can recover their abilities if they stop drinking and adopt a healthy lifestyle.
- People don't have to be completely recovered to live independently.
- Everybody is different and has different circumstances that have led them to this point.

- Happiness is really important
- Reducing anxiety is really important
- Need to manage risk - encourage positive risk taking and balance this with individual wishes.
- Self awareness is key "if I'd known that if I stopped I would get better, I might have stopped sooner."

Recommendations for current practice

- There appear to be significant issues around who should take responsibility for the clinical management of someone with ARBD. This needs to be seen as a multi-agency issue due to the complex needs of individuals.
- The pathway of care for ARBD appears to be unclear with many barriers to accessing appropriate services. It is recommended that this is an area for future work.
- There is a perception that ARBD is a self-inflicted disability and is therefore not seen as a priority. People with ARBD are also subject to double stigma of dementia and alcohol misuse. This stigma needs to be challenged by increasing awareness of ARBD.
- There is a need to ensure that the community (particularly young people and children) are educated and informed about ARBD and the dangers of excessive drinking of alcohol.
- Health Professionals and commissioners also need to be educated about ARBD and its management. For example, professionals tend to think that individuals are unable to recover if they stop drinking and that it is a waste of time trying to rehabilitate such individuals. Commissioners should be encouraged to ensure that judgemental attitudes within services are challenged. This could be assisted by the production of a Toolkit which includes awareness raising materials, baseline audit, signposting to other resources, etc for health professionals

Recommendations for Future Research

It is recommended that the following areas for future research are considered:

- Building a national epidemiological picture of the needs of people with ARBD. This should include OPMH, prisons, homeless organisations, PCTs, general medicine etc.
- Exploring the links between ethnicity and ARBD.
- Exploring possible links between ARBD and post traumatic stress/loss.

N.B All the names used in case studies in this report are fictitious.

Introduction

The Older People's Mental Health Programme within CSIP's Older People's programme has been leading a working group on alcohol related brain damage (ARBD). Among the members of the Working Group is Carenza Care, a provider organisation, based in Rhyl in North Wales, which has been providing specialist care for people with ARBD since 1996. The ARBD Working Group commissioned this report in an attempt to capture the learning within Carenza Care in order to raise awareness of ARBD and its management, and to explore statistical data for emerging trends regarding ARBD.

Aims of the report

This report aims to:

- Give an overview of ARBD, its causes and features
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- Identify areas for further work

Methodology

This report has been compiled from data gathered from:

- Face to face interviews with the Director of Carenza Care
- A two-hour Focus Group with 13 clients of Carenza Care
- A visit to one man with ARBD at home in an adult placement scheme environment and interviews with the landlords/carers
- Individual interviews lasting 1 -1 1/2 hours with 2 residents of a supported living scheme.
- Individual interviews lasting 30 - 45 minutes with X clients of Carenza Care Day Club.
- Quantitative data provided by Carenza Care
- Reading relevant literature provided by carenza Care from other countries re: ARBD.

All clients consented to be involved in this work and all signed a Consent Form to this effect (see appendix A)

What is ARBD?

Wernicke -Korsakoff syndrome is a well recognised syndrome, associated with thiamine deficiency and excessive alcohol ingestion. However, classical presentation of the syndrome is rare as presentation is frequently complex and varied (Victor et al 1989).

The variable long term effects of alcohol abuse have promoted the concept of alcohol related dementia (Victor 1994). More recently, a more pragmatic, approach has emerged with development of the concept of alcohol related brain damage (ARBD). This concept has the advantage in that it facilitates differentiation from 'dementia' which is usually understood to be a defined as a progressive condition. As most patients with alcohol related brain damage do not deteriorate without further exposure to alcohol, this is an important distinction with potential implications for the commissioning of services (Smith & Atkinson 1995).

ARBD is a clinical syndrome characterised by two seminal features; prolonged intellectual impairment and a causative link to excessive alcohol ingestion. Its presentation is frequently complicated by physical problems, including a high prevalence of traumatic brain damage and sub acute and acute confusional states associated with physical illness or alcohol withdrawal. In order to establish the degree of sustained cognitive damage it is important to assess a patient after a significant period of abstinence in order to allow transient brain damage to recover and the physical state of the patient to stabilise

ARBD covers a wide range of alcohol related intellectual and neurological syndromes, including Wernicke's encephalopathy, Korsakoffs syndrome, alcohol dementia, and other disorders affecting many structures in the brain (Schmidt et al 2005).

ARBD is a physical injury sustained by a part or parts of the brain, as a result of excessive consumption of alcohol.

ARBD is not the same as dementia.

Excessive alcohol consumption can cause dehydration, which leads to shrinkage and in some cases, permanent death of cells. Alcohol interferes with the absorption of thiamine, and this coupled with poor nutritional status, can lead to lesions in parts of the brain.

The extent of injury to the brain through alcohol abuse and the resulting effects range from mild to severe and can vary from person to person.

In the early stages of ARBD, cognitive impairment may mean a decrease in the performance of certain functions and a person may find ways to compensate for these deficits. In later stages the person may be unable to care for him/herself and be severely disabled.

Arbias 1995

Diagnosis of ARBD

Harvey's study (1998) found that 12.5% of younger people (<65 years old) identified as suffering from 'dementia' in secondary service settings had alcohol related cognitive impairment.

Ferran et al (1996) found a similar distribution attending a specialist memory clinic, with seven percent suffering from alcohol related brain damage. As most cases of significant cognitive impairment are first recognised within acute hospital settings or through critical situations within the community, (Smith and Hillman 1999, Elleswei 2000), the implications for acute hospital Trusts are of considerable significance.

The impact is likely to be even greater in that many cases are not recognised and go undetected (Thomson et al 2002). This is reflected in the findings of other studies which have indicated that heavy alcohol abuse may be a contributing factor to as many as 21-24% of all cases of cognitive impairment in mid adulthood (Smith & Atkinson 1995).

Establishment of diagnosis is confounded by general ignorance concerning the effects of excessive alcohol ingestion the related lack of expertise (Anderson 1999, Hillman et al 2001) , high levels of stigmatisation (Cox et al 2004), the variable presentation of intellectual damage (Jacques & Stevenson 2000) and the complicating factors of acute withdrawal syndrome, associated physical ill health and frequently associated traumatic brain damage (Cox et al 2004).

Epidemiology of ARBD

Irrespective of variability in prevalence within acute hospital settings, recent evidence suggests that prevalence is increasing (Smith & Flanigan 2000, Ramayya & Jauhar 1997). The prevalence is likely to be higher in areas of socio-economic deprivation (Cox et al 2004) with the highest prevalence between the ages of 50 and 60 years (MacRae & Cox 2003)

The epidemiology of ARBD is an undeveloped area and it is strongly recommended that an area of future research is focused on building a national picture of the needs of people with ARBD.

Appendix B highlights an analysis of available quantitative data for Carencia Care in North Wales.

Features of ARBD

Alcohol related intellectual impairment presents with variable psychosocial problems. Sufferers are likely to be relatively younger and experience variable degrees of brain damage (Woodburn & Johnstone 1999), often associated with head trauma. They are physically active and prone to high levels of fire hazard, agitation, disinhibition, delusional experiences (Ferran et al 1996) and aggression (Harvey et al 1998) when compared with younger patients suffering from dementia syndrome.

Cognitive impairments that can result from ARBD

- Difficulties in planning and organising
- Problem solving difficulties

- Not learning from mistakes
 - Lack of ability to see consequences of one's own behaviour
 - Difficulties in abstract thinking
 - Rigid behaviour or lack of flexibility
 - Doing things the same way - constant repetition of actions
 - Short term memory loss - e.g. thinking they have performed tasks of daily living - washing, cleaning teeth, changing clothes etc

However, I realised she had a continuing problem with memory loss. She could remember things from years ago, with one or two hazy areas, but she seemed to have great difficulty with her short term memory. Each time I visited or spoke to her on the phone, she would have forgotten what we had spoken about the previous time or forgotten a day out she might have had recently. (Family carer)

- Problems with retrieval (recall)

Another challenge / was faced with was, every time J spoke to her or visited her, at some point she would ask me 'why am I here?' and 'when can I have a flat of my own?' Each time I would explain, quite truthfully, that as a result of drinking heavily for many years she has developed a condition called Korsakoffs, which I would then explain in more detail. And as to the question 'when can I have a flat of my own?' I would remind her that in each of her last two flats there had been a fire and at one point, she was on the verge of being homeless. (Family carer)

- Difficulty learning new information
- Confabulation (fabrication of memory)

"When they are unable to remember an incident or happening they use this way to cover up the deficiencies in their memory to protect their fragile self esteem and confidence. Although it seems that they are unaware that they are doing this, a client explained to me how frightening this situation is and that as they begin to recover some abilities they are unsure whether to say what comes to mind as they are unsure what is true and what they have made up.

Director- Carenza Care

- Denial

1 didn't drink because I needed it, I drank because I enjoyed it - I never got drunk. I don't need any help.

- Lack of insight

Eliza's story

I'm not sure how long I've lived here - I think about twelve months.

Its very nice but I want my own place. I want to be independent - and just get on with my own life. I keep my place very tidy.

I have never drank too much alcohol - I never got drunk - I just drank normally. I

think my daughter is too protective. She doesn't drink or smoke.

I Lived in Warrington until I was 17 years old. Then moved to London and lived in Bayswater. I worked as a shop assistant in Whitley's. I met my husband after twelve months and we got married and bought a house in Richmond. He was a schizophrenic and would get drunk and kicked me in the stomach when I was pregnant causing my daughter to be born early. I divorced him on the grounds of cruelty.

I then returned to Warrington and then moved back to London a little later.

I met new boyfriend and married him. We bought a chip shop and then bought a restaurant and a pottery shop. He was a compulsive gambler so I left him and kept the chip shop and bought a bungalow in Llandudno.

I used to make hand painted white satin outfits but I was burgled and the bungalow was burnt down and all my white satin was burned too.

I haven't been seen by a doctor and have never been given a diagnosis of korsakoff's Disease. On the way to the pub I went between two cars and one car drove off and hurt my leg and that is why I went to hospital.

Eliza's daughters story

My mum, Eliza, is 60 years old and has had a problem with alcohol ever since I can remember. We have been faced with many challenges over the years, to say the least, however, I am happy to say that we have now arrived at a calm place. I could tell you 101 stories of what we have been through over the years, but I won't, I'm just going to tell you from the time that things finally took a turn for the better.

It started in December 2001 - My mum's best friend died suddenly, they had been friends for many years, and something made my mum finally admit that she was an alcoholic and she wanted help.

Before we could arrange to get help for my mum, there was a fire in my mum's flat in

early January 2002. She wasn't hurt, but she was taken to hospital and put in the psychiatric ward, where she stayed for about two months.

One day I received a phone call from the hospital saying `we're not sure how to tell you this, but we don't feel that your mum is able to look after herself.' 'Oh right' I said, (what I really wanted to say was `yes I have known that for years, but there has never been the right kind of help for my mum and it has taken her to burn down two flats for someone to cotton on'!!) - but ! Just agreed and asked what happens next. There was only one answer - old peoples home - my mum was 56!

I was working full time in London and on my days off I would travel to North Wales and drive around various nursing homes, sometimes with my mum, sometimes by myself. But all the time, I felt uncomfortable and unhappy that this was not the answer for my mum, but it seemed as though we had no choice.

One day, after showing us around a home, the member of staff asked me if my mum had a drinking problem - a little surprised, I answered yes. This lady then said she thought my mum maybe suffering from a condition called Korsakoffs. I had no idea what she was talking about, but she suggested I pay a visit to a lady who lived in Llandudno and cared for people with Korsakoffs.

I took my mum back to the hospital and arranged to see this lady that afternoon. As I sat in her front room and she explained to me the signs and symptoms of Korsakoffs, tears just rolled down my cheeks uncontrollably, I had finally found someone who would understand my mum and our situation and may be able to help us.

After approximately 30 years of anxiety, upset, and worry we had finally arrived at a different place. A place of hope and relief. I took my mum to live at the unit in a wheelchair - within weeks she progressed to a zimmer frame and shortly after she was able to get around the house with minimal assistance. Within months my mum showed many signs of improvement, in her walking, talking, taking pride in her appearance, eating well and generally looking very healthy.

The last time my mum asked me `why am I here?" and `when can I have my own flat?' was yesterday!!!! And before that pretty much every day this week!!! My mum is a wonderful person, she is very talented, when she was younger she could play the piano, competed in ballroom dancing competitions, she did some modelling, was a fantastic cook and made all her own clothes and even sold them in her own boutique, she has a heart of gold and a great sense of humour.

My mum is a 60 year old woman, although she doesn't look it, and has the same needs as any other. She craves her independence and would like to meet a nice man! My mum and I, together with the staff team, work together to give my mum a certain amount of independence and keep her safe and well. The main challenge is, that although we can remind her every single day, my mum forgets all the bad things that have happened over the years and forgets that she has a problem with alcohol.

- Attitude of unconcern

<p>You're supposed to be close to your brother. When I was young I used to lend my money to him. He is looking after my children because I've been in hospital. I don't know why. He said he would phone me and let me see them but I've not heard from him. None of them bother with me -!m not bothered really. (Brenda)</p>
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- Lack of motivation

David would not or could not find the motivation to do anything for himself, but if he was asked to do something for someone else, he would do it with enthusiasm. Judith was a lady wit poor mobility, on Millennium Eve David pushed her to watch the fireworks at the prom. He also taught the Director's daughters to tie their shoelaces, learn their timetables. They in turn helped his memory by reading to him and doing jigsaws and playing other games. David was a man who had been told by medical staff that he had 'wet brain' and the Centre were told they were wasting their time trying to rehabilitate him. They were advised to take him home until he deteriorated enough to go into an EMI home. Over the years David has been involved in voluntary work with horses, birds and adults with learning disabilities.

- Confusion
- Frustration
- Suspiciousness or paranoid behaviour
 - Anger

Who does ARBD affect?

On considering the experience of Carenza Care, it seems that ARBD is very unpredictable and affects people of all professional backgrounds. Occupations of clients of Carenza Care include: -

- Bank manager
- Accountants
- C.I.D
- Postman
- Security
- Nurses
- Business Women
- Housewives

Within the constraints of this report it is not possible to explore the links between ethnicity and ARBD. It is recommended that this is an area for future research.

It is the view of *staff* at Carenza care that there is possibly a link between ARBD and significant stress or loss. Indeed all those interviewed had experienced traumatic distress in some way.

An example of this can be seen below:

Stella's story

I was brought up in Bolton and had a very good education at a Grammar school. I had known my husband since I was 11 years old. He was a dentist and we had

four children in four years.

My eldest son died at the age of 3 years with a brain tumour which was very hard to deal with.

My husband insisted on buying a house in Prestatyn against my wishes. There was nothing there, no shops it was far too quiet!

He then joined the army and we were sent to Hong Kong for three years. We had a very active social life there and there was a heavy drinking culture. My husband didn't like socialising too much but I did.

After three years we moved back to Prestatyn which was awful. I stayed there but I didn't want to. My husband was a workaholic and I was so lonely. My husband cut down his drinking but I didn't, I couldn't, I just didn't have the willpower. We separated eventually although this was never formalised.

Unfortunately he died a few years ago.

I never saw my drinking as a problem. People were telling me there was a problem but I couldn't see it.

I was admitted to hospital a few times to dry out but unfortunately, they send you back to the same situation - nothing changes.

I suffered physical effects that I am sure were due to my drinking, such as losing body hair, and going through the menopause in my early 40's.

My husband said my memory was poor - but I don't know - I've always had a poor memory.

Eventually, I knew I had to do something. I went to a private nursing home for alcoholics and made contact with Carenza Care whilst I was there.

I don't know what I will do in the future. A part of me would like to go home but I would get very lonely again.

Another example is Ryan who was in the British Army and served in Iraq. On return to North Wales, he discovered that his father had died of cancer and his brother had died in a car accident on the same day.

It is recommended that the link between stress and loss and ARBD is an area for future research.

Traditionally, there has been a higher incidence of ARBD in men than women but it is reported by Carenza Care that this trend currently appears to be reversing, similarly, referrals are tending to be for younger adults than previously. ARBD may now be affecting more people due to:

- More accessible and cheaper alcohol
- Drinking culture
- Drinking younger
- Chemical drinks
- Prescribing of thiamine to people with alcohol disorders

- Social isolation of people with alcohol disorders
- Poorer diet

Can people recover from ARBD?

There can be some improvement if a person remains abstinent and maintains a balanced diet and a healthy lifestyle. It is recommended that individuals take a multivitamin supplement containing a high level of thiamine together with vitamin C.

Cox et al (2004) derive information from clinical reports and suggest that 25% of patients with ARBD make a full recovery. A further 25% make a partial recovery, with another 25% making minor recovery and the remainder showing no improvement at all.

At least two studies report follow-up data on patients diagnosed with ARBD and Korsakoffs syndrome. Price et al (1988) followed up 37 patients for one year following discharge into the community. Ten of these patients (27%) were known to be successfully placed, a further 20 (54.1 %) were described as dysfunctional and the remaining seven were dead.

Two years earlier, Lennane (1986) followed up 104 patients for between eight months and two years. Fifty three of these patients were classified as successful placements, 11 (10.6%) had been re-admitted into hospital and the remainder were lost to follow-up or presumed dead. Both these studies took place in Australia, in the context of access to community services designed to cater for this patient population.

The journey of people with ARBD

The emerging themes of the experiences of people with ARBD seem to be:

- Being passed from pillar to post between services both before and after diagnosis.
- Not being given information about Korsakoffs disease
- A perception of Health Professionals that ARBD is self-inflicted and therefore not worthy of an empathic approach
- A general view that recovery is not possible with ARBD
- The only option for care for someone with ARBD is an Older People's Mental Health Nursing Care Home

Whose problem?

There appear to be significant issues around who should take responsibility for the clinical management of someone with ARBD. Smith and Atkinson (1995) draw attention to the difficulties in accessing appropriate services and the need for research in this area. As a consequence patients are frequently passed between services and lack access to expert care (Jaques 2006b).

ARBD needs to be seen as a multi-agency issue due to the complex needs of

individuals. The following services all have a part to play in the assessment and care of an individual with ARBD:

- Dementia
- Brain injury
- Younger adults with dementia
- Mental illness
Alcohol team
- Older people

An individual's presenting problem may appear to be dementia, with memory problems and confusion to time and place. The older people's mental health service may have the appropriate expertise to assist the individual in managing these. However, there is a growing recognition that such services do not have the skills or the capacity to care for this patient group (MacRae and Cox 2003)_

For a more in depth assessment, the brain injury team have knowledge of brain function and rehabilitation.

Social Work may need to be involved due to the need for aids and adaptations, or the need for the Protection of Vulnerable Adults

The expertise of Mental Health services may be needed for the management of anxiety, depression or post-traumatic stress disorder.

The Alcohol team may help the individual with abstinence and support in the future

An example of good practice

A client with ARBD who was assessed for the small unit could not be accepted as he was non-weight bearing. It was agreed that he should go into a local nursing home for young physically disabled people and that Carezza Care would provide rehabilitation care and local statutory services would provide social and nursing care. This is reported to have been successful.

The elements of a Care Pathway for ARBD

The pathway of care for ARBD appears to be unclear with many barriers to accessing appropriate services. It is recommended that this is an area for future work.

However, within the confines of this work, the core elements of a care pathway for people with ARBD have been reported to include:

- Assessment and care planning
- Nursing Home care
- Rehabilitation
- Post rehabilitation support

Assessment and Care Planning

It is important that a holistic approach is adopted in assessing the needs of an individual with ARBD. This must include a thorough exploration of the context and causes of

excessive drinking. Failure to do this is reported to be one of the reasons why people do not tend to get help until they reach physical collapse.

Care Plans should be developed with the individual (and his/her carer if appropriate), need to be tailored to individual needs and should include their aspirations, wishes and expectations. The ultimate aim of the care plan is for the individual to achieve and maintain independence.

The components of a comprehensive assessment process will include:

- Psychological aspects
 - Cognitive aspects including memory
 - Neurological assessment
 - Physical aspects
 - Emotional aspects
 - Social aspects
 - Financial aspects
 - The extent and impact of presenting challenging behaviours
 - The possibility of dual diagnosis
 - The extent and impact of night time disturbances
 - The extent and impact of any difficulties in settling
 - The possibility of fatigue resulting in an inability to walk
-
- Determination of existing services already in place
 - Accommodation,
 - Availability of natural support -family, friends
 - Current coping strategies
 - Personal skills
 - Life experiences
 - Beliefs and values
 - Effectiveness of problem solving skills

Nursing Home care

Nursing home care may be appropriate initially for clients who are physically unwell and in the first stages of ARBD, from which they might recover. It is important that they have access to well trained and supported staff. They need careful assessment and an appropriate key worker who can be trained to observe for improvement, offer help, encouragement and support, develop the relationship required to allow stress free conversations and be able to relieve any stress appropriately.

Nursing home environments are also required for clients who, due to physical damage to organs, need to be in general nursing environments with support from mental health services as required.

Rehabilitation

Rehabilitation is important to help the client understand the need for abstinence and to help them in a safe environment with others who understand the problems and can help each other.

Most clients wish to return to their own house or flat and rehabilitation must aim to help them achieve this.

Rehabilitation Unit

There is a strong view that, for rehabilitation to be successful, there is a need to ensure that units are small with no more than 6 - 8 people with ARBD. Such units might be within Residential Care Homes but with designated age appropriate space that is separate from the main living area.

The Unit was part of a large building, and the Unit itself was spread over two entire floors, with the use of other parts of the building as well and there were a lot of clients living there. What I am trying to say is that I felt my mum was getting lost in a large group of people and may not be getting the individual care and attention that I felt she needed. There also seemed to be quite a steady turn over of staff, which bothered me in as far as my mum getting to know members of staff and having familiarity and security and then the staff member would leave. (Family carer)

Interventions

People should have an individual key worker who works closely and responsively with him/her.

Interventions may include:

- A Behavioural approach - individuals need ideas and concepts to be presented very simply and concretely.
- Provision of 'step by step' information, perhaps writing it down or repeating it in the same format several times as decision-making can be difficult for people with ARBD because of the complexity of taking in new information and shifting between concepts.
- Use of a diary, lists, signs or other prompts, as people often have difficulty remembering information discussed previously, when to take medication, appointments etc, due to memory impairment.
- Frequent summing up and checking with the person about their retention of information and understanding.
- Development of coping strategies for dealing with stress as a person with ARBD may find it very difficult to deal with stress due to the need for planning and organising abilities to reduce or manage stress. They may become confused, angry or overreact if asked to do something they are unable to do, or if too much is expected of them. Noise, clutter or being hurried can also cause stress.
- Diversion of attention by changing the subject during conversations if the person with ARBD becomes confused or frustrated during a conversation
- Establishment of routines and structured days as people with ARBD lose their organisational skills and find it difficult to plan.
- Activities such as quizzes etc to assist in maintaining skills and enable individuals to feel useful and valued. Support should be provided initially to

the individual to pursue the activity and this should be gradually withdrawn when it is no longer needed. It is also important to carry out old activities that individuals have retained the knowledge of how to do

"Then we developed a small unit with an emphasis on reablement. As clients improved, they helped with the preparation of meals and took cooking courses and healthy eating lessons. The self-catering accommodation was developed in preparation for returning people to the community. Everything was about growing/restoring confidence in catering, housekeeping and budgeting; as well as being part of the community through employment education, volunteering, leisure, creativity. and spiritual growth." Director - Carenza Care

Emotional support

It is important to recognise that rehabilitation depends on appropriate support being available to individuals for the avoidance/management of loneliness and depression. Services that combine practical and emotional support will help to bridge the gaps in functioning and help to deal with the feelings of self worth.

Work

Carenza Care has a shop, which has the purpose of providing a safe environment for people to relearn a work ethos and provides people with normality, activity, status and companionship. Many people are reported to feel worthless without this. People need to feel they have a purpose. The service is also exploring providing NVQ accredited training for clients.

Post rehabilitation support Accommodation

There should be a range of options for accommodation available to individuals. Sadly, this is very often not the case. Options might include:

- Supported Living environment
- Adult Placement Scheme
- Extra Care Housing

Carenza Care provides high quality supported living accommodation. All the current tenants interviewed were very satisfied with this.

Individuals have their own bedroom and key. They share responsibility for the running of the house and gain experience of activities of daily living in a safe environment, e.g. budgeting, shopping, cooking, etc. There are also daytime activities and community involvement, which assist people in establishing and maintaining relationships.

She has her own flat, which consists of a lounge with kitchenette and small dining area, bedroom and bathroom. The flat is part of a house that consists of 4 separate flats and the downstairs is a communal lounge, dining room, kitchen and back garden. The house is staffed 24 hours a day, there is a separate bedroom and bathroom downstairs for the member of staff.

My mum is safe and being well cared for, with the right care. It was my mums 60th birthday last September- Lynda arranged a party and my mums two sisters came along. Pat, who had got back in touch, only within the last couple of years, and Kath who she had not seen for about 20 years. (Family carer)

An example of an adult placement scheme was also visited which was reported to be working successfully both by the receiving family and the individual.

Support

Support, such as help and advocacy, needs to be flexible and available when needed so that people have the confidence of knowing they can call on it as needed and can gradually build up independence and coping strategies.

It is essential that, once an individual has moved on from rehabilitation, on-going support and socialisation mechanisms are established such as:

- Community support
- Coffee Club - peer support
- Respite

Carenza Care works with individuals to enable them to socialise without alcohol, e.g. coffee club, . This enables continuing support (including peer support) in a friendly atmosphere

It is also crucial that arrangements for care in the event of a relapse are secured. Unfortunately, due to the nature of the condition, relapse is likely.

Workforce issues **Culture of the facility**

The culture within a unit/service seems to be crucial. Carenza Care place a lot of emphasis on staff having excellent interpersonal skills, e an understanding and appreciation of individual differences and an enabling style of working.

When asked what they liked about the service, comments from clients included:

"Everyone is very friendly"

"You are able to be yourself."

"You are not embarrassed (which I was before and didn't talk to anyone at all)"

"You have your own independence and privacy here. It is not forced on you."

"Other services tried to force it on me - I needed it but didn't want that. Here they take it slowly."

When the focus group was asked what people with ARBD needed from a service, suggestions included:

- One-to-one time
- Friendship
- Support
- No restrictions
- Keep independence

Staff skills

Staff working with people with ARBD need to have a wide range of skills ranging across a broad spectrum of specialties such as:

- Brain Injury
- Alcohol
- Dementia
- Mental health (especially the management of depression and anxiety)
- Physical health
- Rehabilitation
- Behavioural approach

They will need to be skilled in holistic assessment and monitoring the effectiveness of care plans. Further, staff will need to be non-judgemental with high levels of personal effectiveness and excellent interpersonal and analytical thinking skills as well as possessing a very practical and methodical style of working.

It is important that staff demonstrate empathy and understanding to individuals with ARBD to enable the development of a relationship based on trust.

I am amazed how many people are unaware of Korsakoffs Syndrome, especially people connected to alcoholics and people in the medical profession. / strongly feel that people in general need to be educated and given information on this condition, as alcohol is such a widely accepted and accessible drink. (Family carer)

"One day when I was sad and reflecting on my 3-year-old son's death, a member of staff told me to stop wallowing in it"

Carenza Care recommends the following elements to be included in any training plan for staff working with people with ARBD:

- Alcohol
 - Wernickes Encephalopathy
 - Korsakoffs syndrome
 - Rehabilitation in Alcohol related brain damage
 - Care planning
 - Memory Aids and Activities
 - The importance of activity
 - Good Health
-
- Communication problems in Alcohol Related Brain Damage

- Difficulties in managing behaviours in people with A.R.B.D.
- Managing challenging behaviour
- Development of service and appropriate care Pathways
- The Service
- Quality of life
- A Future With Korsakoffs
- Alcohol Related Brain Damage

Raising awareness and fighting stigma

There is a perception that ARBD is a self-inflicted disability and is therefore not seen as a priority. People with ARBD are also subject to double stigma of dementia and alcohol misuse. This stigma needs to be challenged by increasing awareness of ARBD.

There is a need to ensure that the community (particularly young people and children) are educated and informed about ARBD and the dangers of excessive drinking of alcohol.

Health Professionals and commissioners also need to be educated about ARBD and its management. For example, professionals tend to think that individuals are unable to recover if they stop drinking and that it is a waste of time trying to rehabilitate such individuals. Commissioners should be encouraged to ensure that judgemental attitudes within services are challenged.

GP's have a crucial role to play in the detection and subsequent care of those with ARBD and consideration should be given to providing training and education for G.Ps and other primary care professionals.

Recommendations for current practice

- There appear to be significant issues around who should take responsibility for the clinical management of someone with ARBD. This needs to be seen as a multi-agency issue due to the complex needs of individuals.
- The pathway of care for ARBD appears to be unclear with many barriers to accessing appropriate services. It is recommended that this is an area for future work.
- There is a perception that ARBD is a self-inflicted disability and is therefore not seen as a priority. People with ARBD are also subject to double stigma of dementia and alcohol misuse. This stigma needs to be challenged by increasing awareness of ARBD.
- There is a need to ensure that the community (particularly young people and children) are educated and informed about ARBD and the dangers of excessive drinking of alcohol.

- Health Professionals and commissioners also need to be educated about ARBD and its management. For example, professionals tend to think that individuals are unable to recover if they stop drinking and that it is a waste of time trying to rehabilitate such individuals. Commissioners should be encouraged to ensure that judgemental attitudes within services are challenged. This could be assisted by the production of a Toolkit which includes awareness raising materials, baseline audit, signposting to other resources, etc for health professionals

Recommendations for Future Research:

- Building a national epidemiological picture of the needs of people with ARBD. This should include OPMH, prisons, homeless organisations, PCTs, general medicine etc.
- Exploring the links between ethnicity and ARBD.
- Exploring possible links between ARBD and post traumatic stress/loss.

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Appendix A

Referrals to Carenza Care

Number of Referrals to Carenza Care since 1996

	Male	Female	
	78	41	
Total			119

Age of referrals to Carenza Care since 1996

Youngest referral aged 32 years (male)

Oldest referral aged 64 years (female)

Age group	Male	Female	Total
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30 - 35 years	4	0	4
36 - 40 years	5	1	6
41 - 45 years	10	9	19
46 - 50 years	25	15	40
51 - 55 years	14	8	22
56 - 60 years	17	6	23
61 - 65 years		2	5
Total	78	41	119

Numbers of individuals currently in rehabilitation

Year of contact with Carezza	~	Male	Female	Total
2003		1	0	1
2004		2	0	2
2005		6	4	10
2006		15	2	17
2007		3	0	3
	Total	27	6	33

Move on Destination for past and present clients (1996 - 2007)

Length of stay	Total Number of individuals	Home	Nursing Home	Currently in rehab	Awaiting supported living acc	Adult placement	Deceased
Less than 1 year	11	7	0	4	0	0	0
1- 2 years	36	13	2	17	2	1	1
2- 3 years	15	4	1	9	0	0	1
3- 4 years	14	2	0	2	9	0	1
4- 5 years	5	2	0	1	2	0	0
5-6 years	1	0	0	0	1	0	0
6-7 years	2	0	1	0	1	0	0
7-8 years	1	0	0	0	1	0	0
	85	28	4	33	16	1	3

Referrals/Enquiries - Area of residence

Area	Number of enquiries	Referral accepted	Advice only
Wales			
Wales	1		1
Rhyl	12	12	
Conwy	7	5	2
Wrexham	2	2	
Ruthin	1	1	
Holywell	2	1	
Sub total	25	21	4
North of England			
North	5	1	4
Lakes	8	8	
Blackpool	1	1	
Manchester	1		1



Area	Number of enquiries	Referral accepted	Advice only
Leeds	4	2	2
York	1		1
Wirral	2	2	
Sub total	22	14	8
North East			
Tyneside	3	2	1
Notts	2	1	1
Humber	1	1	
Sub total	6	4	2
Midlands			
Shropshire	7	5	2
Coventry	1	1	
Birmingham	1		1
Sub total	9	6	3
South England			
South	15	5	10
West Sussex	1	1	
Sub total	16	6	10
Other			
Scotland	1		1
USA	2		2
Germany	1		1
France	1		1
Denmark	1		1
Sub total	6	0	6
Unknown	34	33	1
Grand total	119	85	34