Alcohol Related Brain Damage

Information for Patients & Carers

GIG CYMRU NHS WALES | Bwrdd Iechyd Aneurin Bevan Health Board

In this leaflet you will discover:

What ARBD is

What Causes it

What the damage is

What the treatment is

What is ARBD?

Alcohol Related Brain Damage is an umbrella term covering a number of different brain conditions directly linked to excessive drinking. Most of these conditions impact on the sufferer's memory and thinking. Conditions include:

- **Korsakoff's Syndrome**
- **Frontal Dementia**
- **Alcohol Related Head Injury**
- **Non-specific Memory Disorder**

The good news is that, if recognised early and appropriate measures are put in place, most people will experience some degree of improvement.

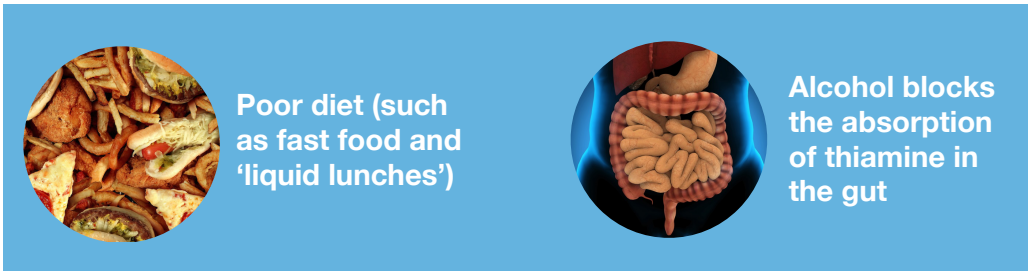
What Causes It?

Some of the conditions under the umbrella have an obvious cause outlined in the name (e.g. alcohol-related head injury clearly describes a situation where an individual experiences traumatic injury to the brain as a result of intoxication). The others, especially the form that most clinicians know as Korsakoff's Syndrome occur because of 2 factors:

Too much alcohol

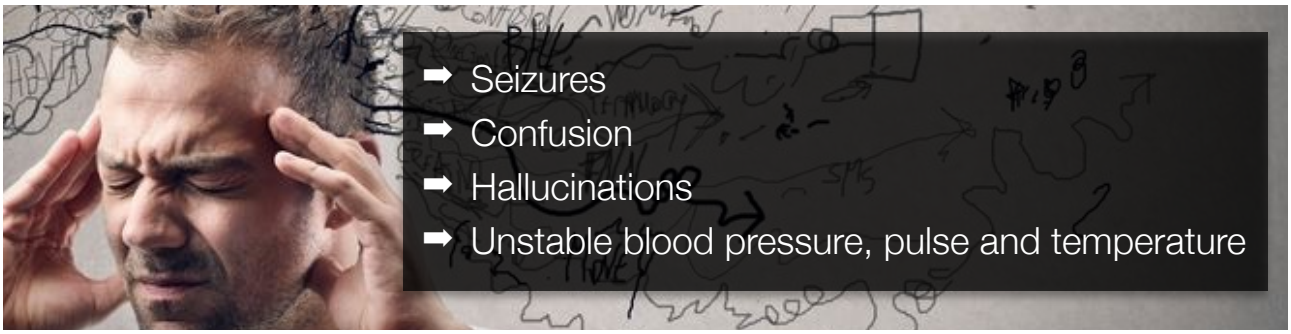
Not enough thiamine (Vit B1)

Thiamine is a vitamin found in vegetables such as cauliflower and asparagus, whole grains and yeast extract. It has a number of important roles in the body but the one we're interested in is the way it helps repair brain cells. Heavy alcohol intake lowers thiamine stores. Research shows that individuals who drink heavily have low body stores of thiamine. Why is this?



The result is that alcohol dependent individuals have very low thiamine stores in their bodies. The other thing we know is that alcohol itself causes direct damage to the brain cells. So, combine the damage alcohol causes to the brain, with a poor ability to repair that damage, and the result is **ARBD**.

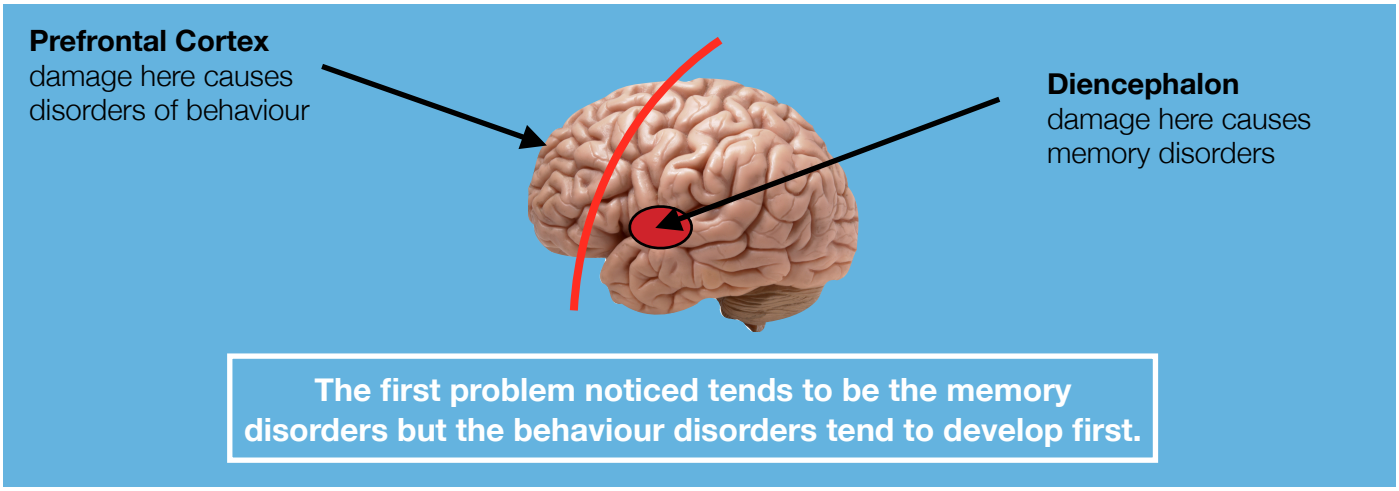
The biggest time of risk for this brain damage to occur is during withdrawal from alcohol. Alcohol withdrawal is not an easy process – in fact the body finds it quite stressful. A number of different chemicals responsible for passing messages in the brain are affected by alcohol. Drinking on a regular basis (in a dependent manner) leads to an internal readjustment where the brain tries to counteract the changes. If alcohol is suddenly withdrawn these counteracting changes are then unopposed and this is what causes the symptoms of alcohol withdrawal. We can minimise the damaging effects of withdrawal by medical treatment (detoxification). However, if withdrawal remains untreated the potential complications include:



What Causes It?

Classically the problems seen in ARBD affect particular issues with behaviour and memory function. (These are the features seen with the main form of ARBD – Korsakoff's Syndrome – but other damage can occur as a result of injury etc). We will concentrate on these two areas of functioning.

The two areas concerned are the **Prefrontal Cortex** and the **Diencephalon.**



Behaviour Change

The proper term for the behaviour change seen as a result of Prefrontal Cortex damage is Dysexecutive Syndrome. This leaves people with difficulties in the following areas:

- **Planning and decision making**
- **Impulse control**
- **Motivation**
- **Controlling irritability/ aggression**

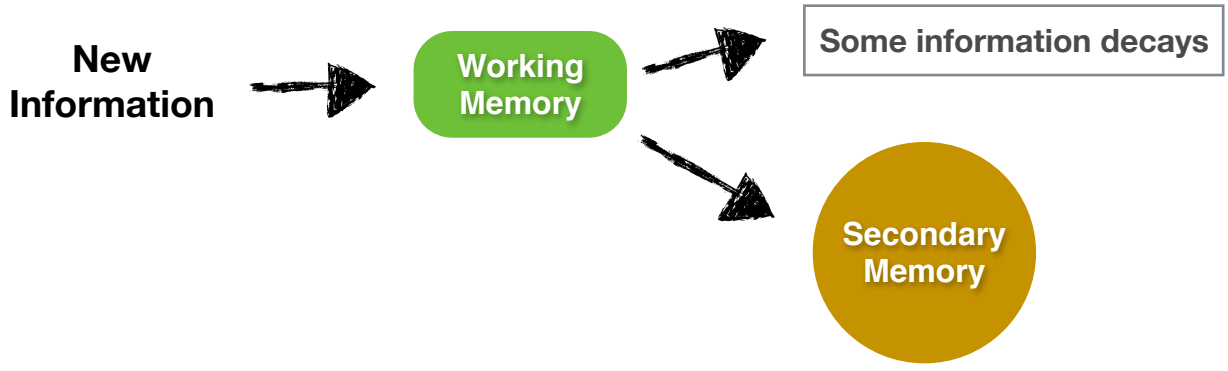
Memory Disorder

The problem here is mainly of short term memory. Sufferers may notice difficulties remembering shopping lists or appointments and learning new things becomes difficult. As the condition worsens (because of continued drinking) the memory impairment starts to stretch back into memories for up to 25 years prior to the condition developing.

The end result of this damage to the brain is that the sufferer can end up unable to care for themselves and requiring admission to a care home.

Another problem associated with this memory impairment is something called confabulation. This is where the brain selects the wrong memory. The person isn't 'lying' - they have just grabbed the wrong memory from their memory banks.

One interesting feature is that so called working memory appears intact. In all of us, new information goes into working memory initially where it lasts for minutes.



So, a brief conversation may not necessarily reveal the difficulties the individual has. This is important when considering whether the person can give consent for certain things.

Practical Effects

So, putting those deficits in brain function all together, what practical difficulties might someone with ARBD have?

Ultimately they may not be able to make decisions about important things such as where they live. This is because they are unable to keep the information they need to make the decision in their memories and then weigh up the pros and cons to arrive at a decision. People who are unable to do this are said to 'lack capacity' so, if important decisions need to be made, professionals may need to carry out a capacity assessment. This will need to comply with the Mental Capacity Act 2005. If the person with ARBD is deemed to lack capacity to make a specific decision (and there is a set way of testing this), professionals will then act in the person's best interests. As part of deciding what this might be, they will take into account what the person's relatives and friends think is best, but the decision ultimately rests with the professional. There are Independent Mental Capacity Advocates (IMCAs) who may be brought in to the discussion to advocate on behalf of the individual.

What You Might Notice

- **Low levels of motivation.**
- **Difficulty remembering appointments.**
- **Shying away from activities requiring planning.**
- **Getting irritable quite easily - especially when frustrated as a result of the other difficulties.**
- **Turning to aggression more easily than in the past.**
- **Taking a long time to get used to changes in the environment.**
- **Not being able to remember which cupboards things are kept in.**
- **Not being able to remember when to take medication.**
- **Difficulties in problem solving.**

Prognosis

This may all sound quite distressing but let's go back to what was said right at the beginning. If the condition is **identified early**, the individual **stops drinking alcohol**, takes a **good diet** (especially thiamine) and has some degree of **supportive interventions** not only will the condition not progress but in up to **75%** people some sort of **improvement** will occur. This is in contrast to Alzheimer's dementia which progresses no matter what we do.

So, the important thing is to recognise it and respond appropriately. For those with established ARBD there is a lot that can be done to enable them to live with their deficits and enhance their intact areas of brain function.

Preventing ARBD

Getting help for dependent drinking as soon as possible is very important. People who experience physical withdrawal symptoms should never be told to stop drinking suddenly as poorly treated alcohol withdrawal is one of the major triggers for ARBD. Detox should always be carried out in a planned, controlled way with an alcohol treatment agency.

Emergency withdrawal is not as safe as planned, well prepared withdrawal. It can be very tempting when waiting for a planned detox to present to the Emergency Department in withdrawal in the hope that they will admit you as an emergency but this is much riskier.

Sometimes individuals end up in unplanned withdrawal accidentally when they get admitted for other reasons. It is important that medical and nursing staff are told clearly that the individual is a dependent drinker and at risk of alcohol withdrawal. This is vital so that signs of withdrawal can be recognised early and the correct treatment started. Part of that treatment includes thiamine, either by intravenous infusion (in a drip) or intramuscular injection. This is so that those important thiamine stores can be boosted and it is of no use to give this by tablet as only a tiny amount will be absorbed.

Dependent drinkers in the community should be prescribed thiamine tablet (100mg) three times a day.

For those who do experience one of the complicated forms of alcohol withdrawal, it is important that it is recognised as early as possible and treated appropriately.

Full Assessment

Once the clinicians are happy that the patient is abstinent from alcohol they may arrange for a psychologist to carry out a range of more in depth cognitive assessments. This will then enable the team to properly pin down the diagnosis and identify the exact areas of affected brain function. This will enable them to design an individualised treatment plan for that patient – building on the intact areas of function and assisting the affected areas. This is particularly important once the initial period of improvement is over.

Treatment of ARBD

The first thing that is needed is a diagnosis. Current diagnostic criteria need patients to be abstinent from alcohol for several months. If they are still actively drinking at the time of assessment, it may be possible to suggest this is a likely diagnosis but a full diagnosis can only be make once they have undertaken alcohol detoxification.

To make a diagnosis the doctor will use the following:

- **A full clinical history including information from family/ carers.**
- **Use of a test of cognitive function (questions to test memory, concentration, language etc). This can be done in shortened form in clinic but ideally a psychologist will carry out a more in depth series of tests (see later).**
- **MRI brain scan**
- **Tests of daily function (e.g. cooking, hygiene etc)**

If a diagnosis of ARBD (or suggestive ARBD) is made, the most important treatment elements are:

- **Abstinence from alcohol (possibly via medically treated detoxification)**
- **Good nutrition, especially thiamine**

The clinic may suggest a short course of thiamine injections followed up by thiamine by tablet.

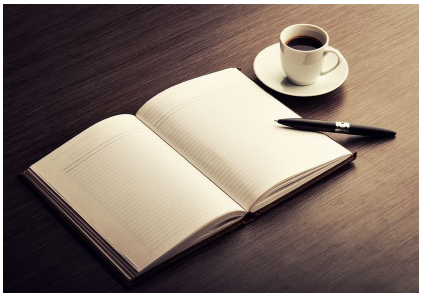
The supportive treatment depends on the level of cognitive damage the patient has. For those with significant impairment who are unable to live independently, a long term placement in a suitable care home may be required. For those with established ARBD who are able to live in the community with support, there are some practical steps that can help them live with their ongoing impairments (see next section).

In individuals with a relatively early diagnosis it is possible to put in place a programme of rehabilitation that can increase recovery of function. Ideally this is done in a residential setting but currently few of these placements exist in the UK. This programme is termed ‘cognitive rehabilitation’.

Practical Help

Remember those practical effects we considered earlier? They can make life extremely difficult. Also, consider how it feels to have short term memory impairment. You can’t remember what happened yesterday and you’re not sure what’s happening tomorrow (because you can’t remember what your carer told you). The only moment you are certain of is now. The rest is uncertain – and, therefore, quite anxiety provoking.

So, what practical things can be done to help people with ARBD?



Diaries

A diary can be helpful in reducing uncertainty about the future. The individual should be encouraged to keep it with them and if they have any queries about what is due to happen in the future, they can check. In addition they can record the day’s events so that, when having a conversation about something that happened a few days earlier, they can look over what they wrote and this may help jog their memories. One of the most difficult

aspects of ARBD is the fear of not remembering what happened yesterday and not being clear about what is due to happen tomorrow. A diary can help to reduce that fear.

Whiteboard

It can be helpful to have a whiteboard in a prominent place (such as the kitchen or on the bedroom wall) where you can display the timetable for the coming week as well as recording the current day and date. Again, this will help to orientate the person with ARBD. In the beginning it may be useful for the carer to complete this but, with time, the responsibility can be transferred over to the individual themselves.

Electronic Reminders

For the more technically minded there are a whole range of electronic reminder systems from smart phones through to medication boxes that remind you when you need to take your tablets. It is worth exploring what is available. Remember, however, that if the individual isn't already used to this sort of system, the ARBD can make it difficult for them to learn something new.

Label Cupboards/ GlassFronts

Take the guess work out of finding things around the home by either labelling cupboards or by changing to glass fronted cupboard doors so that the contents can be seen. As will be explained in the next point, encouraging the person with ARBD to guess can do more harm than good.

Errorless Learning

If the person with ARBD asks you about something they can't remember, give them the right answer straight away and get them to repeat it. This helps to reinforce the correct answer. By making them guess (and probably pick several wrong answers) you can end up reinforcing incorrect information. Remember, making them guess does not improve their memory; if anything it can make it worse.

Abstinence

The most important thing though is supporting the individual to remain abstinent from alcohol. Some will need a medically treated alcohol detox and then there are a variety of ways to help them stay off (medication, counselling*, appropriate environment). As each person is different it is important that their individual needs are assessed and a package of care drawn up that is tailored to those needs. As things progress, they will need to be reassessed and the care adapted as necessary.

standard alcohol counselling can be adapted by experienced clinicians for people with memory, planning and motivation problems but it is not easy.

Time Frames

Some clinicians divide the progression of ARBD into certain distinct time frames.

If the condition develops suddenly as a result of an illness or complicated alcohol withdrawal, the initial phase is an acute medical stage where the priority is the management of the alcohol withdrawal and any other physical problems.

The sufferer may then enter an acute confusional stage where they may be uncertain where they are and what is going on. As a result they can seem quite frightened and behaviourally can be difficult to manage. The priority here is keeping them safe and ensuring that they do not drink and to help them rebuild their thiamine stores. This stage typically lasts around 3 months.

The next phase is that of non-permanent cognitive impairment. Here the individual has lost their confusion but their short term memory and frontal lobe problems become evident. Obviously abstinence and thiamine remain important but in this phase a comprehensive assessment is needed to inform a personal treatment plan. This phase can last up to 3 years or so.

Finally there is the phase of permanent cognitive impairment. From here there is no further scope for improvement and an in depth assessment will allow for the development of a care plan that takes into account the permanent deficits.

Some individuals do not seem to develop the condition suddenly but instead the condition becomes obvious slowly in the community. A full assessment can allow the clinician to identify which of the above stages they are in.

Remember the good news though – improvement can occur during any of the first 3 stages as long as the individual does not drink alcohol and takes a good diet (especially thiamine). So, not everyone progresses through all the stages and not everyone will have the same degree of impairment.

Because of the nature of ARBD it is really important that you discuss things fully with the clinicians you have seen. The pattern and degree of damage in any one individual can be extremely variable and so it is important to have a personalised plan for treatment.

In the space below record the contact details of the professionals involved in your/ your loved one's care and keep this booklet safe

Professional	Name	Contact number
Consultant		
Nurse		
Keyworker		
Social Worker		
Residential Placement		

Notes: