

Factsheet 438LP June 2020



Alcohol-related brain damage (ARBD) is a brain disorder. It is caused by a person regularly drinking too much alcohol, or binge-drinking, over several years.

There are different types of ARBD, including alcohol-related 'dementia' and Wernicke-Korsakoff syndrome. Although these are not types of dementia, they have similar symptoms and treatments.

ARBD doesn't always get worse over time, unlike common causes of dementia such as Alzheimer's disease. If a person with ARBD stops drinking alcohol and receives good support, they may be able to make a partial or even full recovery. They may regain much of their memory and thinking skills, and their ability to do things independently.

This factsheet explains what ARBD is, including the main types. It outlines the causes, symptoms, diagnosis and treatment. It also includes practical tips about how to support someone who has ARBD.

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

If a person regularly drinks much more than the recommended limit of alcohol, it can damage their brain. It will cause their memory and ability to think clearly to get worse over time, especially if the person drinks too much over many years. This is known as alcohol-related brain damage (ARBD) or alcohol-related brain injury (ARBI).

Some people with ARBD will only have small changes to their thinking and memory, known as mild cognitive impairment (MCI). They are at risk of more serious brain damage unless they stop drinking. For more information see factsheet 470, What is mild cognitive impairment (MCI)?

Other people with ARBD will have more serious problems with their memory and thinking. Alcohol-related 'dementia' or Wernicke-Korsakoff syndrome will cause them to struggle with day-to-day tasks. This is similar to someone living with dementia, such as Alzheimer's disease.

A person who has ARBD won't only have problems caused by damage to their brain. They will usually also be addicted to alcohol. This means that they have become dependent on it. Addiction can make it much more difficult to treat a person with ARBD. This is because professionals need to treat the person's alcohol addiction together with their symptoms related to memory and thinking. See 'Treatment' on page 9.

#### How much is too much alcohol?

A unit is a measure of alcohol. You can find out how many units are in an alcoholic drink by reading the label. The NHS recommends not drinking more than 14 units of alcohol each week. This should ideally be spread over three or more days because 'binge-drinking' is particularly harmful to the brain. When a person starts drinking more than around 25 units per week on a regular basis, it may start to affect their ability to think and function properly.

Drinking a large amount of alcohol in a short space of time (such as a single evening) is known as 'binge-drinking'. It is equivalent to drinking 8 units or more for men and 6 units or more for women. It has been suggested that older people should have lower limits because they are at greater risk of the damaging effects of alcohol.

# Who gets ARBD?

About one in 10 people with dementia have some form of ARBD. In people with young-onset dementia (who are younger than 65 years old) ARBD affects about one in eight people. It is likely – for a wide range of reasons – that the condition is under-diagnosed. This means that the number of people living with ARBD is probably higher.

People who are diagnosed with ARBD are usually aged between about 40 and 50. This is younger than the age when people usually develop the more common types of dementia, such as Alzheimer's disease. It is not clear why some people who drink too much alcohol develop ARBD, while others do not.

ARBD affects men much more often than women. However, women who have ARBD tend to get it at a younger age than men, and after fewer years of alcohol misuse. This is because women are at a greater risk of the damaging effects of alcohol.

#### What causes ARBD?

ARBD is caused by a person regularly drinking or binge-drinking much more alcohol than the recommended limit. Alcohol can damage the brain in several different ways, but the most common are:

- Damage to nerve cells: If a person regularly drinks too much alcohol it can be toxic to their nerve cells. Over time, drinking too much alcohol can cause brain cells to die and a person's brain tissue to shrink. This means there are fewer cells to carry the messages that the brain needs to do different tasks
- Damage to blood vessels: Regularly drinking too much alcohol damages blood vessels in a person's brain and can lead to high blood pressure. Both increase their risk of having a stroke (when the brain does not get enough oxygen and is damaged).
- Low levels of thiamine (vitamin B₁): A lot of the brain damage that is caused by alcohol happens because it prevents the body from getting enough thiamine (vitamin B₁). This is a vitamin that the brain needs to work properly. People who are addicted to alcohol are also much less likely to have a balanced diet. They often get a lot of their energy from alcoholic drinks. This means that over months and years they have a higher risk of malnutrition, including a lack of vitamins such as thiamine (vitamin B₁).
- Increased risk of head injuries: If a person regularly drinks too much alcohol, they also have a higher risk of repeated head injuries. While under the effects of alcohol they may fall and hit their head, or receive blows to the head in fights or as victims of violence. Both can cause lasting damage to the brain.

A person with ARBD may experience all of these types of damage. The different types of damage are linked to different types of ARBD. For example, Wernicke–Korsakoff syndrome is most closely linked with low levels of thiamine (vitamin  $B_1$ ).

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# Types of ARBD

Usually a person is diagnosed with a specific type of ARBD. Depending on their symptoms, they may have one of several conditions, including:

- alcohol-related 'dementia'
- Wernicke–Korsakoff syndrome (also called amnestic syndrome)
- traumatic brain injury
- alcohol-related stroke
- other rarer forms of ARBD.

The two main types of ARBD that can cause symptoms of dementia are alcohol-related 'dementia' and Wernicke-Korsakoff syndrome. Neither of these are actual types of dementia, because you cannot get better from dementia, and there is some chance of recovery in both of these conditions.

#### Alcohol-related 'dementia'

If a person has alcohol-related 'dementia' they will struggle with day-to-day tasks. This is because of the damage to their brain, caused by regularly drinking too much alcohol over many years.

The person may have memory loss and difficulty thinking things through. They may have problems with more complex tasks, such as managing their finances. The symptoms may cause problems with daily life. For example, the person may no longer be able to cook a meal.

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## Symptoms of alcohol-related 'dementia'

The symptoms of alcohol-related 'dementia' can change a lot from person to person.

If a person with the condition has a brain scan, it will often show that some areas of the brain have shrunk much more than others. Alcohol particularly affects the frontal lobes of the brain. If these are damaged, the person may have difficulty with:

- staying focused on a task without becoming distracted
- solving problems, planning and organising
- setting goals, making judgements and making decisions
- being motivated to do tasks or activities (even essential ones like eating or drinking)
- controlling their emotions they may become irritable or have outbursts
- understanding how other people are thinking or feeling (their behaviour may seem insensitive or uncaring).

A person with alcohol-related 'dementia' may also have problems with their memory. They might not be able to understand new information – for example, they may quickly forget the details of a conversation. They may also not be able to recall knowledge and events, such as where they lived previously or places where they have been on holiday.

Alcohol-related 'dementia' can also cause problems with a person's mood, such as apathy, depression or irritability. These can make it even harder for the person to stop drinking – and make it difficult for people close to them to help. For more information see factsheet 444, **Supporting a person with dementia who has depression, anxiety or apathy**.

A person with alcohol-related 'dementia' may be unsteady on their feet and more likely to fall over – even when they are sober. This is because alcohol damages the part of the brain that controls balance, co-ordination and posture.

## Diagnosis of alcohol-related 'dementia'

It can be very difficult to diagnose alcohol-related 'dementia'. If a doctor is unaware of the person drinking too much alcohol over many years, they may not consider alcohol-related 'dementia' as a possible diagnosis. The person may not get the right treatment and support, which is why it is important to tell doctors about drinking too much alcohol.

A person can be diagnosed with alcohol-related 'dementia' if they have problems with memory, thinking or reasoning that severely affect their daily life, and are most likely to have been caused by drinking too much alcohol.

For a clear diagnosis, the person needs to have these symptoms even when they have stopped drinking and are not suffering from the effects of alcohol withdrawal. The doctor will also need to make sure that these symptoms don't indicate another type of dementia, such as Alzheimer's disease or vascular dementia.

In order to make a diagnosis of alcohol-related 'dementia', a doctor may ask the person to do a paper-based test to check for problems with memory and thinking. For more information see factsheet 426, **Assessment and diagnosis**.

The doctor will also do a full physical examination and take a detailed history of the person's symptoms and how they are affecting their life. They should also take an account from someone who knows the person well, as this can help if the person has gaps in their memory. The doctor may also ask about problems with mood, such as anxiety or depression.

It is likely that a person will need a brain scan to rule out other causes of their symptoms. These include a stroke, a bleed caused by physical trauma, or a tumour.

It can be difficult to get an assessment, as some GPs will insist that the person has stopped drinking for several weeks before they can assess the person's memory. Some experts think that a person can be assessed for alcohol-related 'dementia' while they are still drinking too much, as long as they aren't intoxicated at the time of the assessment. The diagnosis

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is less certain than if they had been sober for a long time. If the person is refused an assessment by the GP, they can contact NHS England to make a complaint (for details see 'Other useful organisations' on page 17).

#### Treatment and support for alcohol-related 'dementia'

Unlike Alzheimer's disease or vascular dementia, alcohol-related 'dementia' is not certain to get worse over time. With the right treatment and support, there is often a good chance that it will stop getting worse or improve. For example, if the person stops drinking alcohol, takes high doses of thiamine and starts eating a balanced diet. However, if the person keeps drinking alcohol and doesn't eat well, alcohol-related 'dementia' is very likely to get worse.

It is not easy to help a person with alcohol addiction to stop drinking. However, it can be even more challenging when the person has alcohol-related 'dementia'. Problems with thinking and reasoning (caused by dementia) can prevent a person from understanding that they need to stop drinking. They may also find it very difficult to stay motivated if they do stop drinking, because losing motivation is a symptom of dementia.

#### **Treatment**

The first part of treatment usually lasts up to several weeks. It aims to stop the person drinking alcohol and make their health more stable. Most people with alcohol-related 'dementia' will need to stay in hospital for this.

Alcohol withdrawal usually causes a person to have delirium, which can make them easily distracted and confused, disorientated, and prone to mood swings. They may also experience intense sweating, anxiety and a high heart rate. They may become agitated or hallucinate. They may be treated with drugs that mimic the effect of alcohol on the brain to reduce withdrawal symptoms. These drugs can be safely reduced slowly. The person will also be given fluids and salts, and high doses of thiamine (vitamin  $B_1$ ) by injection.

Many people with alcohol-related 'dementia' have to wait in hospital for a long time before they can get specialist care. Depending on how serious their condition is, they could be supported in residential care, sheltered accommodation or in their own home – with support in the community.

#### Support

After the first part of treatment, a person with alcohol-related 'dementia' will need support from different kinds of services.

Firstly, the person is likely to need support to help them stop drinking alcohol (see 'Other useful organisations' on page 17). They may be given special prescription drugs to reduce their craving for alcohol. They will also need to take high-dose thiamine (vitamin B<sub>1</sub>) tablets and eat a healthy, balanced diet.

As well as medication, the person will need a lot of non-drug support. This often includes counselling or 'talking therapies' that help them to stay alcohol-free. They may also be encouraged to attend self-help groups. See 'Other useful organisations' on page 17.

Some of the common symptoms of alcohol-related 'dementia' may make it harder for a person to take part in an alcohol treatment programme. These symptoms can include denial, lack of insight and being impulsive. The person may struggle to stay focused during therapy sessions.

Staying alcohol-free can be particularly challenging if the person is homeless or isolated from their family due to drinking too much, or if they have poor physical or mental health. Dealing with all these issues is important for helping the person to stay alcohol-free, and to reduce the symptoms of alcohol-related 'dementia'.

A professional who has experience of supporting people with alcoholrelated 'dementia' should be involved in the person's care. The type of support they get will depend on the person's individual situation and what they need. People with alcohol-related 'dementia' tend to be younger and physically more active than most people who have other types of dementia. They may benefit from services designed for people with youngonset dementia

Supporting a person with alcohol-related 'dementia' can be challenging for their carer, friends and family. They will need different kinds of support, which may not always be easy to access. Most alcohol support services are designed to help people stop drinking and stay sober and there may sometimes be less immediate support available to deal with the dementia-related parts of rehabilitation. However, many support services have a 'complex needs' team which are better equipped to support the different needs of someone with alcohol-related 'dementia'.

#### Rehabilitation

As well as staying alcohol-free, a person with alcohol-related 'dementia' will need help to get better. This is known as rehabilitation and is support that is matched to the person's needs. It works towards goals that the person agrees with a health professional. This could include practising ways to improve their memory, and learning to use memory aids or other supportive technology.

For more information see booklet 1540, The memory handbook and factsheet 437, Using technology to help with everyday life.

Rehabilitation may be provided by a dementia service, community mental health team or rehabilitation service for people with a brain injury (for example, following an accident or stroke). The availability of these local services may be different across the country.

A person should usually see the most improvement in their abilities during the first three months after they stop drinking alcohol. However, for some people this improvement could continue for as much as two or three years.

## Wernicke-Korsakoff syndrome

Wernicke-Korsakoff syndrome is a condition that is similar to dementia and is caused by drinking too much alcohol. Very rarely, it can be caused by factors other than alcohol. The majority of cases are caused by alcohol, and alcohol-related 'dementia' is the focus of this information.

In Wernicke-Korsakoff syndrome the damage to the brain is caused in a very specific way. Alcohol prevents the body from getting enough thiamine (vitamin B<sub>4</sub>), which is vital for brain cells to work properly. This lack of vitamin B, can have severe and long-lasting effects on the brain.

Wernicke-Korsakoff syndrome has two separate stages. First there will be a brief time when a person has intense inflammation (swelling) of their brain. This is known as 'Wernicke's encephalopathy'. If this condition isn't treated quickly, the person may develop a more long-term condition called 'Korsakoff's syndrome'. This has many of the same symptoms of dementia.

About a quarter of the people affected by Wernicke-Korsakoff syndrome who get treatment make a good recovery. About half make a partial recovery and still need support to manage their lives. About a quarter of people with the condition make no recovery and may need long-term care in a specialist residential care home.

# What is Wernicke's encephalopathy?

Wernicke's encephalopathy develops if a person's brain doesn't get enough thiamine (vitamin B<sub>1</sub>). This is almost always caused by a person drinking too much alcohol.

Alcohol prevents thiamine from being absorbed properly in the gut, stops it from being used properly in the body, and increases the amount of thiamine that the body loses in the urine.

# Symptoms of Wernicke's encephalopathy

Wernicke's encephalopathy can be difficult to identify - particularly if a person is still intoxicated with alcohol. The symptoms can sometimes be mistaken for alcohol withdrawal. The symptoms of Wernicke's encephalopathy include:

- being disorientated, confused or having mild memory loss
- having difficulty controlling eye movements
- having poor balance, being unsteady and walking with their legs wide apart
- being undernourished for example, being very underweight or having lost a lot of weight in the previous months.

It is unusual for someone with Wernicke's encephalopathy to have all of these symptoms. However, most people will be disoriented and confused.

# Diagnosis of Wernicke's encephalopathy

Because a person with Wernicke's encephalopathy is in a very serious condition, diagnosis is often carried out in a hospital. The doctor will look for symptoms of the condition and may also carry out a brain scan to confirm their diagnosis.

As with other forms of ARBD, a diagnosis can be more challenging if the doctor doesn't know how much alcohol the person drinks.

## Treatment for Wernicke's encephalopathy

The treatment of Wernicke's encephalopathy is for the person to immediately stop drinking alcohol and be given several injections of high doses of thiamine (and other B vitamins).

After a person has had this treatment, they may be referred to a service that can help them to stop drinking alcohol. See 'Support' on page 10, 'Rehabilitation' on page 11 and 'Other useful organisations' on page 17.

## What is Korsakoff's syndrome?

Korsakoff's syndrome is a long-term condition that develops when Wernicke's encephalopathy is left untreated, or is not treated soon enough. Over time, the damage to the brain becomes more difficult to recover from.

Because Korsakoff's syndrome often follows on from untreated Wernicke's encephalopathy, many people refer to it as Wernicke-Korsakoff syndrome.

#### Symptoms of Korsakoff's syndrome

The main symptoms of Korsakoff's syndrome are confusion and memory loss – particularly memory of events that happened after the person developed the condition. Because the person is less able to form new memories, they may also repeat the same question several times. For some people with the condition, memories of the more distant past can also become lost or distorted.

Other symptoms of Korsakoff's syndrome can include:

- difficulty understanding new information or learning new skills
- changes in personality the person may become apathetic (lacking) emotional reactions), become very talkative, or do the same things over and over
- lack of insight into the condition even a person with large gaps in their memory may believe their memory is working normally
- confabulation a person's brain may fill in the gaps in their memory with things that didn't happen. For example, a person who has been in hospital for several weeks may talk about having just visited a person or a place earlier that day (this is more common in the early stages of the condition). It is important to remember that the person thinks this is a real memory. It may seem as if they are purposefully lying - but often this isn't the case
- problems with concentration, planning, making decisions or solving problems.

# Diagnosis of Korsakoff's syndrome

A person may be diagnosed with Korsakoff's syndrome if they show some of the symptoms and have a history of drinking too much. A brain scan can be helpful but is not always necessary. People with Korsakoff's syndrome are often diagnosed in hospital after they have been admitted for other medical reasons.

## Treatment for Korsakoff's syndrome

As with Wernicke's encephalopathy, the main treatment for Korsakoff's syndrome is to give the person high doses of thiamine immediately. They may also need to be given other types of nutrition and hydration to get their body working properly.

In the longer term, the person will most likely need the same kinds of support as a person with alcohol-related 'dementia' (see page 10). They may also benefit from learning ways to help them cope with their memory problems. See 'Rehabilitation' on page 11.

# Tips for supporting a person with ARBD

- Support the person to stop drinking alcohol. This will give them the best chance of recovery.
- Support the person do things that will help them to keep and improve their skills. For example, if they are struggling with shopping, aim to do it with them, not for them. You could give them responsibility for the parts of the shopping trip they enjoy and can manage, such as planning the meals or ticking items off the shopping list.
- Ask professionals who are involved in the person's care how you can best help them.
- Encourage the person to keep a diary. They will benefit from having a structure and a daily routine.
- Break down complex tasks into smaller steps to make them easier to follow, such as cooking a meal.
- When you are talking to the person, be patient, use short sentences and summarise what you have said. Give them time to respond, and encourage them when they are speaking. For more information see factsheet 500, Communicating.
- Support the person at home by labelling cupboards and arranging rooms so that things are easy to find. For information on helping the person to live independently, see booklet 819, Making your home dementia friendly.
- Encourage the person to eat a balanced diet. It's important to eat healthy meals every day to make sure they are getting enough vitamins to help their brain to function. An alcohol treatment service should be able to make suggestions about healthy eating.
- Help the person to look after their general wellbeing, such as getting enough sleep.
- Support the person to go to a self-help group for addiction. Carers, friends and family can also join one (see 'Other useful organisations' on page 17).

# Other useful organisations

#### Adfam

020 3817 9410 admin@adfam.org.uk www.adfam.org.uk

Adfam is a national charity that works with families who are affected by someone's use of drugs and alcohol. It has an online message board and a database of local support groups.

#### Alcohol Change UK

020 3907 8480 contact@alcoholchange.org.uk www.alcoholchange.org.uk

Alcohol Change UK is a national charity. It works on alcohol issues in England and Wales, campaigning for effective alcohol policy and better services for people whose lives are affected by alcohol-related problems.

# Alcoholics Anonymous Great Britain

0800 9177 650 help@aamail.org www.alcoholics-anonymous.org.uk

Alcoholics Anonymous provides support for people to recover from alcoholism. You can use the website to find a meeting in your area.

#### Al-Anon

0800 0086 811 (helpline, 10am-10pm every day) helpline@al-anonuk.org.uk www.al-anonuk.org.uk

Al-Anon provides support for family members and friends of people who are addicted to alcohol. At regular Al-Anon Family Groups people can share their experiences of living with alcoholism.

#### **Drinkline**

0300 123 1110 (9am-8pm Monday-Friday, 11am-4pm Saturday and Sunday)

Drinkline is the national alcohol helpline. Calls to the helpline are free and confidential.

## National Association for Children of Alcoholics (Nacoa)

0800 358 3456 (helpline 12am-9pm Tuesday, Wednesday, Thursday, 12am-7pm Monday, Friday, Saturday, ) helpline@nacoa.org.uk www.nacoa.org.uk

The National Association for Children of Alcoholics (Nacoa) has a free and confidential telephone and email helpline for children of parents who are addicted to alcohol.

#### **NHS England Complaints**

0300 311 22 33 (8am-6pm Monday, Tuesday, Thursday, Friday, 9.30am-6pm Wednesdays) england.contactus@nhs.net www.england.nhs.uk/contact-us/complaint/complaining-to-nhse

NHS England welcomes concerns, compliments and complaints as valuable feedback that will help them learn from your experiences and make improvements to services they commission.

# **SMART Recovery**

0330 053 6022 www.smartrecovery.org.uk

At SMART Recovery meetings people can get help to decide whether they have a problem, build up their motivation to change, and learn about proven tools and techniques to support their recovery.

#### We Are With You

www.wearewithyou.org.uk

We Are With You (previously called Addaction) is a drug and alcohol treatment charity that has local services across England. It helps individuals, families and communities to manage the effects of drug and alcohol misuse.

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Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

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This factsheet has also been reviewed by people affected by dementia. To give feedback on this factsheet, or for a list of sources, please contact publications@alzheimers.org.uk

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need. To make a single or monthly donation, please call us on 0330 333 0804 or go to alzheimers.org.uk/donate

Alzheimer's Society is the UK's leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

For support and advice, call us on **0333 150 3456** or visit **alzheimers.org.uk** 



