IDENTIYING AND ADDRESSING COGNITIVE IMPAIRMENT IN DEPENDENT DRINKERS

A guide for staff in Westminster and Kensington & Chelsea

ALCOHOL CHANGE UK
Change Communication
City of Westminster
Groundswell
Out of homelessness

Contents

Introduction

After drinking heavily for 17 years, Alice finally engaged with treatment and despite the inevitable challenges reached one year sober. At that point sobriety was still a struggle; however, she began to rediscover a love of dressmaking and this passion now supports her recovery and she is thriving.

Barry drank heavily throughout his adult life, he regularly engaged with treatment but never managed to achieve any lasting change. He died by dropping a cigarette onto his bedding and burning himself to death.

Some people find it much harder to recover from alcohol misuse than others. Some seem able to engage with treatment, turn their lives around and achieve permanent change. Others, however, relapse many times, cause huge damage to themselves and those around them and sadly die because of their drinking. It is vital, therefore, to understand what differentiates those who achieve recovery and those who do not.

It is unlikely that there is one simple answer. Factors such as family support, having a job and other forms of social capital will be vital. However, **it is likely that cognitive impairment, in the widest sense of the term, is a key factor.**

We know that:

- People are more likely to drink problematically because of traumatic brain injuries or other brain damage experienced in utero, in childhood or in early adult life.
- As a drinking career progresses alcohol related brain damage accumulates, impairing impulse control, executive function, and the ability to regulate cognition, emotion, and behaviour and, therefore, making it harder and harder to engage with recovery.
- Physical damage to the brain from falls, fights and fits accumulates to similar effect.
- The drinking lifestyle may generate other forms of cognitive impairment e.g., the damage from strokes, chronic poor sleeping patterns or the “brain fog” associated with hepatitis C.

This accumulating damage generates a downward spiral. As the cognitive impairment increases, impulse control decreases, consequently drinking may increase and the risk of further head injury also increases. Those head injuries then further impair impulse control leading to the risk of more drinking.

The aim of this guidance

This brief guidance aims to:

- Raise awareness generally about cognitive impairment in drinkers
- Set out the wide range of cognitive impairments experienced by drinkers
- Describe the effects of those impairments
- Comment on screening and assessment
- Provide guidance on communication techniques with people with cognitive impairment
- Describe interventions and model pathways for use in both specialist alcohol services and non-alcohol specialist settings such as safeguarding and adult social care
- Describe how best to engage with existing brain injury services
- Comment on the impact of cognitive impairment on mental capacity and the use of legislative frameworks.

This guidance will be supported by a training course which disseminates the material in the document.

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The complex nature of cognitive impairment in dependent drinkers

Cognition refers to skills including attention and focus, processing information, solving problems, memory, and communication. These are all controlled by the brain.

Our cognitive abilities can be affected by lots of different things some of which are temporary e.g., being very tired, angry, or intoxicated. However, some things either cause our cognition to change permanently e.g., traumatic brain injury (TBI), or as in dementia, cause cognitive skills to worsen over time.

Chronic alcohol misuse is particularly associated with a specific form of cognitive impairment. Consuming high levels of alcohol over time deprives the brain of important vitamins such as B1 which can cause the brain cells to stop working properly and result in cognitive impairment. If a person stops drinking and improves their nutrition the brain cells may recover and their cognitive abilities may improve, but sadly sometimes the damage is permanent, and the person remains cognitively impaired. In its extreme form this is called Wernicke Korsakoff's Syndrome (WKS). Wernicke being the acute form, Korsakoff being the chronic form.

While cognitive impairment in drinkers tends to be associated with WKS, it may be caused by a range of other factors. The table below highlights the many types of cognitive damage that might be associated with someone with a history of chronic dependent drinking.

Type of impairment ↓	Condition
Prolonged excessive alcohol use	• Wernicke (acute) • Korsakoff (chronic)
Traumatic brain injury	• Physical damage to the head / brain through falls, abuse, fights, and fits • Occupational risks in e.g., construction / farming, or military service • Being strangled (e.g., as part of domestic violence) • Contact sports • Serious electrical shock
Progressive brain injury	• Stroke • Kindling (the potential for cognitive impairment to develop as a result of from repeated alcohol detoxification)[i] • Smoking • Diabetes • Chronic poor sleep patterns
Pre-birth	• Foetal alcohol damage • Genetic factors that pre-dispose someone to cognitive damage
Other	• Hepatitis C • Confusion due to a build-up of toxins in the body • Urine infections • Drinking slowing down or stopping recovery from a TBI.[ii]

Things to think about 1 – People with ADHD and Autism are not cognitively impaired. Rather, their brains work in a different way to most people. Therefore, these conditions are not covered in this guidance, but they may, nonetheless, be having an impact on clients in this group.

[i] Alcohol misuse - Risks - NHS (www.nhs.uk)
[ii] Alcohol Use After Traumatic Brain Injury | Model Systems Knowledge Translation Center (MSKTC)

The scale of the problem

A wide range of cognitive impairments may be associated with dependent drinkers. However, the statistics on the scale of the problem are even more striking and do not seem to be having the impact on the management and treatment of dependent drinkers that would be expected. Somewhere between 35-40% of dependent drinkers have damage related to the effects of alcohol on the brain. But this is not the only form of impact.

Brain injuries affect about 8.5% of the general population; however, among drinkers the impact is far greater.[iii]

- Alcohol and traumatic brain injury (TBI) are closely related. Up to 50% of adults with TBI were drinking more alcohol than is recommended before they were injured.[iv]
- A collection of American studies over the last 20 years suggests that the number of individuals receiving treatment for substance abuse problems who have incurred traumatic brain injuries may be as high as 50%.[v]
- People who have an alcohol related TBI are more than four times as likely to have another TBI. This may be because both TBI and alcohol can cause problems with vision, coordination, and balance.[vi]
- A study of prisoners and probationers with traumatic brain injuries in Colorado found that around 96% had problems with substance abuse.[vii]
- Above all people with brain injuries are more likely to develop addictions. [viii]

Beyond alcohol related brain damage and TBI, conditions such as Foetal Alcohol Damage may also be having an impact. For example, around 30% of people with FASD go on to develop their own substance misuse problems.[ix]

The Alan Safeguarding Adult Review (SAR) provides a powerful picture of a man with a chronic lifelong alcohol problem and an extensive history of head injury. In the last fourteen months of his life he has at least 15 head injuries from falls, fits and other impacts. The report highlights the complex challenges that he presented to professionals because of his impulsive and disorganised lifestyle.

From whichever angle the issue is examined, cognitive impairment is having a significant impact on dependent drinkers. Therefore, practitioners need to be able to work with these conditions.

[iii] Brain injuries are startlingly common among those who have committed crimes | The Economist
[iv] Alcohol Use After Traumatic Brain Injury | Model Systems Knowledge Translation Center (MSKTC)
[v] Substance Abuse and Traumatic Brain Injury | BrainLine
[vi] Alcohol Use After Traumatic Brain Injury | Model Systems Knowledge Translation Center (MSKTC)
[vii] Brain injuries are startlingly common among those who have committed crimes | The Economist
[viii] Brain injuries are startlingly common among those who have committed crimes | The Economist
[ix] Data supplied by Dr. Raja Mukherjee at the National FASD Clinic

The impact on the drinkers

In the wake of these statistics, it is easy to focus on the headline that *dependent drinkers are very likely to have cognitive impairment* and lose sight of what this actually means for them. It is not simply a matter of poor memory. It will cause a range of other problems:

- Poor impulse control
- Poor executive function
- Poor self-management
- Poor self-care
- Poor emotional regulation

All of these will be further worsened by ongoing intoxication and mean that the client finds it harder and harder to move forward and is very difficult to manage in mainstream alcohol services.

They may experience a range of negative responses. For example:

- The difficulties they have in daily living maybe attributed to intoxication rather than cognitive impairment
- They may receive the wrong intervention or no intervention e.g., their poor balance is not addressed, or they are not provided with walking aids.
- They may experience bias and discrimination that others with cognitive impairment would not suffer because their symptoms are attributed to alcohol use.
- They are offered inappropriate housing or support which fails to meet their needs.
- Staff may become burnt out or frustrated working with them.

However, above all:

- The associated deficits will impair the effectiveness of their substance misuse treatment.

Things to think about 2 – All professionals should ensure that they do not assume that someone is intoxicated without checking that what they are looking at is not actually a head injury or even a stroke.

The choice paradigm

The needs of dependent drinkers are often mistakenly seen as "self-inflicted" or a "personal choice". The recognition of the significant cognitive impairment experienced by these individuals challenges these viewpoints. In particular, it helps us to understand that chronic dependent drinkers are not choosing to live like this, they are rather at the centre of an almost perfect storm of physiological factors which make it harder and harder to organise themselves, manage themselves, motivate themselves and engage with cognitive behavioural processes.

It is also important to recognise that this group are also likely, for want of other support, to be drinking to deal with deep distress. In the Ms. H and Ms. I SAR, the partner of a woman who had

died having experienced multiple exclusion homelessness[x], commented that she had been unable to maintain abstinence from substance misuse because past traumas and adverse life experiences "kept bubbling up." This captures quite graphically how individuals can be governed by impulses to distance themselves from emotional distress. She was caught in a life-threatening double-bind, driven to avoid suffering through ways that only deepened her suffering.[xi]

Identifying cognitive impairment

1.1 Screening and identification
The starting point for work with cognitive impairment is the simple recognition of the risk. Substance misuse practitioners should routinely ask about lifetime exposure to TBI. However, at some point professionals, especially those in substance misuse services, will need to screen or assess using a validated tool.

The following three cognition questionnaires can be used by anyone who follows the guidance and instructions, you do not need to have specific qualifications to carry out the screening, but the results are best interpretated by health professionals:

Addenbrookes Cognitive Evaluation (ACEIII) assesses for Mild Cognitive Impairment and dementia (https://www.sydney.edu.au/brain-mind/resources-for-clinicians/dementia-test.html)
The Montreal Cognitive Assessment (MoCA) can assess for Mild Cognitive Impairment (https://www.mocatest.org/)
The Mini Mental State Examination can screen for dementia, but the current copyright does not permit a link to the form.

We suggest that the ACEIII is the most appropriate tool for this client group because a clinician can differentiate between dementia and mood disorders when interpreting the results, it is produced in several languages, there are versions for people who are hearing impaired and the assessment is freely available.

The results of these screens are not robust if the person is intoxicated so ascertain what they have drunk and eaten prior to the test as far as possible. Think about the time of day that you will conduct the test and when the person is most likely to be as sober as is practically possible.

1.2 Blood tests and brain scans

Ultimately, if there are indications of cognitive impairment, someone will require blood tests and possibly a brain scan.

[x] "Multiple exclusion homelessness" comprises extreme marginalisation that includes childhood trauma, physical and mental ill-health, substance misuse and experiences of institutional care.
[xi] Preston-Shoot, M. (2020) Ms H and Ms I: Thematic Safeguarding Adults Review. Tower Hamlets SAB - MsHandIExecutiveSummary.docx (live.com)

- Blood tests will be important because cognitive impairment can be caused by infections and tests will help a doctor decide if further investigation is necessary.

Should the doctor request a brain scan it is likely to be either a CT scan or an MRI scan. These scans are different and are good at finding different things.

- A CT scan is a computerised x-ray image that provides more detail of organs, bone and tissue than a traditional x-ray can. The machine looks like a doughnut and the patient passes through to create the image. The patient can see outside the machine and is never entirely enclosed by the machine.
- An MRI scan provides even more detail than a CT scan particularly of soft tissue in the brain. The machine is large with an opening which allows a flatbed to enter the machine. The machine can be noisy, and the patient is enclosed in the machine. Not everyone can have an MRI scan and the medical staff will check it is feasible for the patient before starting the procedure.

Again, it is important to note that these scans are good at different things. The CT scan is effective at looking for bleeding on the brain from recent injuries and is quicker and easier for a hospital to provide. The MRI scan is better at looking at soft tissue damage and is more detailed. An MRI scan may show damage that the CT scan does not detect.

Responding to cognitive impairment

If you know or suspect that someone has cognitive impairment, they will need specialist help. However, you will also need to think about:

- How you communicate with them
- What you can do to improve their immediate wellbeing

In particular, substance misuse services will need to think about how they adjust interventions to accommodate these clients.

General advice on working with change resistant dependent drinkers is included in Alcohol Change UK's Blue Light Manual. In some cases, it may be necessary to refer to the local self-neglect and hoarding pathway which is available from the local authorities. Referral to a relevant multi-agency group (such as the EVF forum) may also need to be considered.

Communicating with the person with cognitive impairment

Cognitive impairment can affect communication. Attention, listening to and processing information, understanding concepts, planning what to say, keeping track of a conversation, telling a story, and finding the right words at the right time can all be affected by cognitive impairment.

Therefore, skilled sensitive communication will be needed to support a person to engage constructively, explain their needs and express their wishes in a way that supports their health and wellbeing. Speech and Language Therapists can help with communication difficulties and more information about their work can be found here.

But anyone can support communication by being aware of the issue and trying simple strategies that can be easily implemented:

- Communicate in a calm, quiet space
- Use everyday words and short sentences
- Talk about one thing at a time
- Ask one question at a time
- Write down key words or use pictures to keep on track and support memory
- Give the person time and silence to process what you have said
- If the person is stuck trying to remember a word, ask what sound the word starts with or ask them to describe what it is like
- Try not to interrupt unless necessary
- In a group conversation just have one person speaking at a time.

Remember

- On the phone we lose visual clues so it's particularly important to use these strategies.
- A person with cognitive impairment may be able to read but may not remember earlier paragraphs or be able to grasp the full meaning of a longer letter.

Improving their wellbeing

People with cognitive impairment need practical support. There are several useful things that can be done quickly by non-specialist services. Before reading these ideas take a moment to consider how it may feel to not be sure of the day and date, to not be able to find the right word, or to be easily lost in the place you may call home. Have a look at the suggestions below and think about whether they could help:

Orientation: Providing a clock, watch, calendar, and diary to the person can help them keep track of time and plan for future activities and appointments.

Reminders: Many clocks can be programmed with reminders and a mobile phone can usually be set up to deliver reminders of appointments and tasks. There are apps and smart speakers that can help with this too, but low-tech approaches can also be effective such as using post-its or a white board.

Nutrition: The brain needs adequate nutrition and hydration. Eating a healthy diet and drinking soft drinks throughout the day will support this.

Activity: The brain responds to stimulation. Being physically and mentally active support brain health. Walking, chair exercises, gardening etc. all help to get blood to the brain. Mental activities

that include an aspect of learning or challenge stimulate the brain e.g., puzzles, hobbies, trying new things etc.

Wayfinding If you provide place-based services to people with cognitive impairment think about whether you have clearly marked routes around the building. Some buildings use colours for certain areas, big signs with large clear text and images and some even have volunteers that can take people to the right area.

Referring to specialist help

2.1 Model pathways

London has a non-Dementia pathway outlined in guidance from the London Dementia Clinical Network. A presentation by the London Dementia Clinical Network about this pathway and others is available here.

For cognitive concerns in the context of alcohol misuse they recommend:

- A session of structured brief advice on alcohol
- Explanation of the effects that alcohol has on memory
- Vitamin treatment for people with significant liver disease, at risk of malnutrition, those with physical frailty and additional conditions
- Referral for specialist treatment for those dependent on alcohol
- Consideration of support for carers and or relatives
- A referral to the memory service should be made if there are concerns that the person has dementia.

The guidance also recommends that if cognitive decline is more than can be explained by significant alcohol use, then the memory service should assess the patient.

2.2 What specialist services are out there to help?

The good news is there are several services that can provide useful help; however, none specifically cater for people affected by cognitive impairments arising from alcohol use. You will therefore find you need to do some research, build contacts, and understand the priorities and realities of working with these services to find out who can be useful.

Voluntary and charitable organisations

Headway West London provides information and advice about brain injury. They also provide direct services to the person and carers. This can include support groups, learning events and social support.

Alzheimer's Society has a detailed information sheet about Alcohol Related 'Dementia', but does not provide direct services itself for this group. Nonetheless, the factsheet has lots of tips and suggestions for helping the person and finding additional support:

Age UK run some dementia and memory loss services for people over 55 living in Kensington and Chelsea. These include Memory Cafes, exercise sessions, and one to one support.

Statutory organisations

The Memory Service is an NHS service with qualified clinical staff such as Occupational Therapists, Psychologists, Nurses and Psychiatrists. People in Westminster and Kensington and Chelsea can request a referral from their GP or refer themselves. They offer a full assessment of the memory difficulties, followed by treatment and strategies to address the difficulties a memory problem can cause.

The Adult Community Neuro-Rehabilitation Service works with people in Westminster, Hammersmith and Fulham and Kensington and Chelsea who have a confirmed neurological diagnosis. Referrals are only accepted from health care professionals including GPs and social workers. The Team comprises Speech and Language Therapists, Occupational Therapists, Psychologists, Physiotherapists, and support workers. They will work with the person to identify rehabilitation goals and create a support plan to achieve them. As with the Memory Service this may involve treatment, therapy, and strategies to address the emotional, social and physical difficulties caused by the neurological condition. The Service has previously confirmed that they are able to work with people experiencing mental ill health and / or alcohol / substance use where this does not cause an intrusive impact on the work they do.

2.3 Preparing to refer to specialist services

If the person you are working with does need specialist help for their difficulties (including support for mental illness, managing day to day living, or accessing rehabilitation services), it is important to provide the right information to the specialist service to help them make an appropriate decision. Helpful information will include:

- Accurate personal details
- Accurate medical information
- Results of any cognitive screens carried out and level of intoxication if present at time of screen
- An overview of the difficulties with cognition
- Examples of the difficulties and how long they have been experienced and whether they are increasing
- The risks associated with the difficulties and impact of dangers encountered
- Whether the difficulties appear present both when intoxicated or not
- Whether the extent of the difficulties changes when intoxicated

- The level and type of alcohol and substance use and whether this is increasing, decreasing or stable.

You may find information that helps you fully describe the situation in your client records, case notes, medical information, and CHAIN. Of course, you will want to speak to the person themselves and perhaps, if safe to do so, people who know them well and have known them over time. It can be helpful to ask about school and work history and any accidents and illness from the past – these are not always recorded in more recent medical records.

Implications for the use of legal frameworks

Dependent drinkers with cognitive impairment may become so vulnerable or risky that they require action under one of three key legal frameworks: The Care Act (2014), Mental Capacity Act (2005) or Mental Health Act (1983 & 2007).

Alcohol Change UK has published national guidance on "Safeguarding Vulnerable Dependent Drinkers" which provides more detailed guidance on using these powers with this client group. However, in the context of cognitively impaired dependent drinkers the following specific points should be considered.

The Care Act (2014) – this should be the starting point for the management of vulnerable dependent drinkers with cognitive impairment via legal powers. A safeguarding referral can focus attention on complex clients and initiate a multi-agency discussion which can focus on the use of other powers. Local safeguarding teams can advise on the appropriateness of a referral.

Mental Capacity Act (2005) - the impact of cognitive impairment on drinkers must be carefully considered when assessing their capacity. In particular, frontal lobe damage may mean that individuals have poor impulse control – therefore, they can appear to have capacity during an assessment but in the real world will find it very hard to act in ways that were indicated during the assessment. This will leave clients vulnerable and will not be in their "best interest".

Mental Health Act (1983 & 2007) – the Act applies to people with mental and behavioural disorders. The 2015 Code of Practice is clear (p.26) that this includes:
Organic mental disorders such as dementia and delirium (however caused)
Personality and behavioural changes caused by brain injury or damage (however acquired)
Mental and behavioural disorders caused by psychoactive substance use.
Therefore, in some cases it would be possible to argue for the use of the Mental Health Act with this client group.

The organisation *Pathway* in association with the Greater London Authority and other partners have produced a short practical MCA guide including templates to complete when considering whether to make a referral to statutory services under the Mental Capacity Act and the Mental Health Act.

Other useful guidance includes:
BASW guidance for social workers on assessing and working with people with brain injury.

Carers

It will be vital to ensure that family members and informal carers who are caring for a dependent drinker are also familiar with the information in this guidance. This will help them identify cognitive problems, provide relevant support and help build a pathway into services.

Moving forward

This guidance cannot exist in isolation. Improving the response to this client group will require more than just a document. This needs to be supported by:

- Widespread training to disseminate and embed this guidance
- Support from managers to help staff follow the guidance; &
- Good multi-agency management structures to provide a framework for identifying and discussion clients who need such support.

In addition

- We believe that this client group would benefit from specific NICE guidance on the management of people with alcohol-related cognitive impairment.