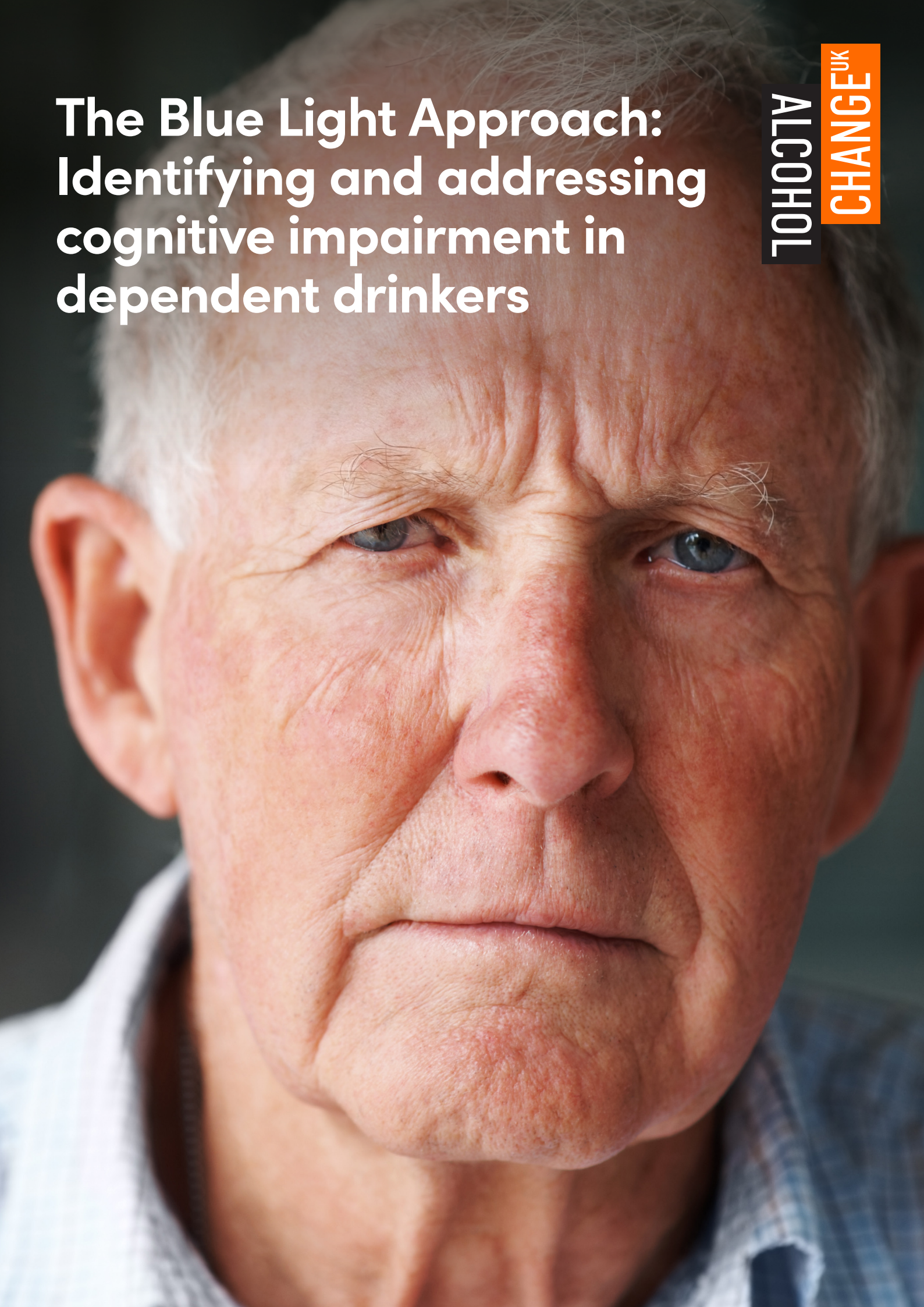


A close-up portrait of an elderly man with light skin, blue eyes, and white hair. He has a serious, somewhat somber expression. The background is dark and out of focus.

The Blue Light Approach: Identifying and addressing cognitive impairment in dependent drinkers

ALCOHOL
CHANGE^{UK}

Contents

	Page
Section 1. Introduction	3
Section 2. The nature and extent of cognitive impairment in dependent drinkers	7
Section 3. Addressing cognitive impairment – primary and secondary interventions	12
Section 4. Addressing cognitive impairment – initial identification	14
Section 5. Addressing cognitive impairment – adjusting how services work with an individual	17
Section 6. Addressing cognitive impairment – attempting to secure a diagnosis and further help	19
Section 7. Referring to and understanding the services that work with cognitive impairment	21
Section 8. Addressing cognitive impairment – tertiary interventions	26
Section 9. Addressing cognitive impairment – living with the impairment	33
Section 10. Recommendations	39
Appendices	40

Acknowledgements

This work is the result of a partnership between Alcohol Change UK, 25 local authorities, alcohol treatment and other services, national experts and people with lived experience. The contributors are listed in appendix 2. However, the authors would particularly like to acknowledge that they have drawn on two key documents:

Turning Point Australia – Managing Cognitive impairment in AOD treatment – 2021

Alcohol Forum Ireland – Alcohol Related Brain Injury: A guide for professionals – 2015

These have been especially useful in tips on identification and on day-to-day management of people with alcohol-related cognitive impairment. We are also very grateful for the input of [Change Communication](#) who are doing powerful work with this group.

All images within this report are stock photos used for illustrative purposes only, and posed by models.

Introduction

1.1 Setting the scene

Cognitive impairment is very common in dependent drinkers.

- People are more likely to drink problematically because of traumatic brain injuries (TBI) or other brain damage experienced before birth, in childhood or in early adult life.
- As a drinking career progresses brain damage caused by alcohol and poor nutrition and vitamin deficiency accumulates.
- Physical damage to the brain from falls, fights, fits and impulsive self-harm accumulates to similar effect.
- This damage impairs memory but also impulse control, executive function and the ability to regulate cognition, emotion, and behaviour, therefore, making it harder to engage with recovery.
- The drinking lifestyle may generate other forms of cognitive impairment e.g. the damage from strokes, 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 and the risk of further head injury may also increase. Those head injuries then further impair impulse control leading to the risk of more drinking.

Therefore, anyone working with dependent drinkers needs to be aware of the impact of cognitive impairment.

However, most practitioners will not meet dependent drinkers with a diagnosis of cognitive impairment; they will meet dependent drinkers who are confused, impulsive and possibly self-destructive and who they *suspect* may have a cognitive impairment. The problem is that the next steps can be very difficult.

Therefore, anyone working with dependent drinkers needs to be aware of the impact of cognitive impairment.

Securing a diagnosis may be a challenge. Memory and brain injury services may require someone to be alcohol-free for three months before they can be assessed. The dependent drinkers themselves may be hard to engage into constructive interventions and may struggle to engage in traditional ways of assessing cognitive impairment. Their behaviour may be dismissed as a 'lifestyle choice' or attributed to intoxication rather than brain damage.

It is this situation that is the focus of this guidance. Its target audience is the practitioner struggling with an individual who finds it difficult to move forward because of cognitive impairments or the challenging requirements of other services.

1.2 Real people

Case studies from the development stage of this guide highlight the challenges presented by individuals with both alcohol-related brain damage because of their harmful drinking as well as patterns of traumatic brain injury.

Case study – Steve

Steve is 49 years old and had a traumatic brain injury three years ago because of his harmful drinking. Since then, he has had further falls and was recently admitted to hospital with a significant head injury. He has a background of social phobia, anxiety and depression and lives with a partner who doesn't understand, or appear concerned about, these cognitive deficits. There may be coercion from the partner. On discharge from hospital his mental capacity was questioned, particularly regarding his safety at home and his high falls risk. He refused ongoing community services to support him (probably because of pressure from his partner). No action was taken by the hospital, he was just discharged when the head injury was stabilised. He is now a frequent A&E attender, and it is assumed that this will continue.

Case study – Natalie

Natalie is 28 and is drinking up to a bottle of vodka daily. She started drinking in her teens and her health is already very poor, with high levels of damage to her liver. She had a very problematic relationship with her mother and makes poor decisions when intoxicated. She has been in hospital via A&E on multiple occasions. She may suffer from the negative effect (kindling) of having multiple unplanned detoxes and there is a regular risk of injury when intoxicated. She presents at hospital with impaired cognition but once alcohol-free she is deemed to have capacity. However, she needs much more help in the community than simply being assessed as having capacity. There is significant concern about possible further illness or death and no pathway is in place to address her cognitive impairment.

Case study – David

David is a 63-year-old, single man living on benefits. He has an acquired brain injury because of a significant suicide attempt 22 years ago. This led to a relationship breakdown and the loss of a well-paid job. He was referred to the council as street homeless seven years ago but is thought to have been in insecure accommodation or rough sleeping ever since the suicide attempt. He is well known to police who are not seen as being particularly sympathetic. His sister and mother try and support him, but both have their own health problems, as well as concerns about the risk he poses when drinking. He has significant memory loss, is very aggressive to family, doesn't understand social cues and is assaulted because of this. There is also self-neglect and anti-social behaviour. His mobility is impacted, he can't walk far, and has a poor diet leading to vitamin deficiency. Services often refuse to see him because of historic abuse towards them.

These are just three of the examples collected in our development work. However, case studies can be found in other settings. Serious case reviews such as Safeguarding Adult Reviews can provide very clear pictures of the impact of cognitive impairment on people who are alcohol dependent.

The [Alan Safeguarding Adult Review](#) (SAR) provides a powerful picture of a man with a chronic alcohol problem and an extensive history of head injury. In just the last 14 months of his life he had at least 15 head injuries from falls, fits and other impacts. The report highlights the complex challenges that he presented because of his impulsive and disorganised lifestyle.¹ Other relevant SARs include the [James SAR Brighton](#), [Adult N SAR Newcastle](#) or the [Tom SAR Somerset](#).^{2,3,4} From Scotland, the Mental Welfare Commission report [Mr H](#) is another powerful case study.⁵



1.3 The key messages

This guidance contains an array of information about the impact of, and the response to, cognitive impairment in dependent drinkers. Nonetheless, at its heart are 12 key points. These serve as a summary of the messages in this document.

- | | |
|---------------------|--|
| Key point 1 | Cognitive impairment is very common in dependent drinkers and can have a very wide range of causes. |
| Key point 2 | Anyone working with a chronic dependent drinker, especially in substance misuse services should assume that the person will have a degree of cognitive impairment unless assessed otherwise. Interventions should start from this basic assumption. |
| Key point 3 | Cognitive impairment in dependent drinkers may not manifest itself as poor memory, lower IQ or poor communication skills. Many of these individuals, particularly those with frontal lobe damage, can perform well in interview and memory tests, but will have marked impairments in everyday life in particular, impulsivity and executive function. |
| Key point 4 | The actual effects of cognitive impairment, e.g. poor impulse control or poor executive function may be mistakenly seen as 'self-inflicted' or a 'personal choice'. This can impact on the help dependent drinkers receive from services including alcohol treatment services. |
| Key point 5 | Consideration must be given to pharmaceutical interventions, essentially a high-potency vitamin injection (Pabrinex). |
| Key point 6 | Relevant services should be screening and identifying cognitive impairment, including using a screening tool such as mini-ACE or ACE-III when needed. |
| Key point 7 | Practitioners working with dependent drinkers with cognitive impairment must give careful consideration to how they communicate with them. |
| Key point 8 | Any work with cognitively impaired dependent drinkers should be built on a multi-agency approach. |
| Key point 9 | At points, practitioners may have to 'fight' to secure the help they need for cognitively impaired dependent drinkers. This may include professional challenge and escalation to more senior staff or to multi-agency groups. |
| Key point 10 | Clear and agreed local pathways are required describing how chronic dependent drinkers with suspected cognitive impairment can access neuropsychiatry and memory services. |
| Key point 11 | At times, practitioners will need to consider the use of legal frameworks such as The Care Act (England) 2014 / Social Services and Wellbeing Act (Wales) 2014, Mental Capacity Act (2005) or Mental Health Act (1983 & 2007). |
| Key point 12 | In many cases, the immediate and long-term response to cognitively impaired dependent drinkers will be built around a harm reduction approach – helping them to live as safely as possible in the community. |

1.4 The aim of this guidance

This guidance is one of a series of documents published under Alcohol Change UK's Blue Light initiative. These focus on change resistant or change ambivalent dependent drinkers. The first of these guides was the Blue Light manual on [Working with change resistant drinkers](#). Most recently, Alcohol Change UK published [guidance on safeguarding vulnerable dependent drinkers](#). Both are accompanied by training programmes. This guidance adds another strand to the Blue Light approach.

It aims to:

- raise awareness generally about the wide range of cognitive impairments experienced by dependent drinkers
- help practitioners understand the effects of those impairments
- support the use of screening and assessment tools
- describe interventions and pathways for use in both specialist alcohol services and non-alcohol specialist settings
- provide guidance on working with dependent drinkers with cognitive impairment
- comment on the impact of cognitive impairment on mental capacity and the use of other legislative frameworks.

This guidance will also be supported by a training course which disseminates this material.



1.5 Who is this guidance for?

Alcohol-related cognitive impairment is likely to be found across the health, social care, housing and criminal justice system. Its impact will be felt in prisons, homelessness services, hospitals (e.g. A&E, gastroenterology), custody, adult safeguarding, primary care as well as substance misuse, brain injury or memory services. Therefore, this guidance will be relevant to people in all of those, and similar, settings.

1.6 Terminology

Several potentially confusing descriptive terms can be used with these individuals. An agreed language for this area of work will be useful: that needs a separate piece of work. In this document we have chosen to use the following definitions:

Alcohol-related brain damage – the damage caused to the brain by the consumption of alcohol either through the direct effect of alcohol on the brain or alcohol's effect on other mechanisms crucial for brain function e.g. the absorption of key vitamins.

Alcohol-related brain injury – the damage to the brain caused by lifestyle factors such as falls and fights, or the physical consequences of seizures.

Cognitive impairment – a general term to describe the range of damage to cognitive function because of heavy drinking or the associated lifestyle.

Dependent drinker – someone who would be classified as dependent on diagnostic tools such as the Severity of Alcohol Dependence Questionnaire (SADQ) or who fulfils the established diagnostic criteria for dependence.

Chronic dependent drinkers – someone with a long-term pattern of such dependency, probably characterised by repeated unsuccessful efforts to change, which is having serious impacts on their wellbeing, those around them and, very likely, public services.

Traumatic brain injury – damage resulting from a blow to the head or other part of the body. Mild injury may affect the brain temporarily. More serious traumatic brain injury can result in long-term complications.⁶

Alcohol-related cognitive impairment is likely to be found across the health, social care, housing and criminal justice system.

The nature and extent of cognitive impairment in dependent drinkers

- | | |
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| Key point 4 | The actual effects of cognitive impairment, e.g. poor impulse control or poor executive function may be mistakenly seen as 'self-inflicted' or a 'personal choice'. This can impact on the help they receive from services including alcohol treatment services. |

2.1 The complex nature of cognitive impairment in dependent drinkers

Cognition refers to skills controlled by the brain. These include memory and communication, but also cover attention and focus, impulse control, processing information and solving problems: i.e. 'executive function'. At its simplest, cognitive impairment is problems with these various functions.⁷

Chronic alcohol misuse is particularly associated with Wernicke Korsakoff's Syndrome. This consists of two phases:

- **Wernicke's Encephalopathy** a brain disorder caused by a severe lack of vitamin B1. It is characterised by abnormal eye movements, ataxia (walking with a wide based gait), changes in mental functioning and dietary deficiencies. Not all these features may be present, and

the most consistent feature is confusion. Treatment involves intravenous thiamine (vitamin B1).⁸

- **Korsakoff's Syndrome** is a condition of short-term memory impairment (progressing to longer term impairment if drinking continues) as well as confusion, confabulationⁱ and with the appearance of delusion. There will also be some signs of frontal lobe damage such as impulsivity. 85% of those with Wernicke's Encephalopathy will develop Korsakoff's if not treated. However, not all of those who develop Korsakoff's Syndrome will have experienced an episode of Wernicke's. Some cases will have a more gradual onset which may not be identified until the condition has advanced.⁹

ⁱ Confabulation is when the brain creates false or distorted memories, usually to fill in gaps in memory.

The cognitive impairment experienced by dependent drinkers is not just about Wernicke Korsakoff's Syndrome. Cognitive abilities can be affected in many ways. Some of these are temporary e.g. being very tired, angry, or intoxicated. However, our focus is on those problems which

cause longer term changes to cognition or cause cognitive skills to worsen over time. The table below highlights the many types of cognitive damage that might be associated with someone with a history of chronic dependent drinking. Even this list is not exhaustive.

Type of impairment ▼	Condition
Prolonged excessive alcohol use	▶ Wernicke (acute) ▶ Korsakoff's (chronic) ▶ Alcohol interferes with the brain's metabolism of thiamine ▶ Liver damage leads to hepatic encephalopathy – confusion due to a build-up of toxins in the body because of liver damage. It may be short-term or long-term and is usually treatable¹⁰ ▶ Dehydration caused by alcohol use may cause brain cell death¹¹ ▶ Vomiting and diarrhoea are linked with alcohol misuse and reduce the number of vitamins and minerals being kept in the body. This can disrupt how the brain functions¹² ▶ Alcohol can damage the gastrointestinal tract (stomach and intestines) and this can impair absorption of essential nutrients for normal brain function.¹³
Traumatic brain injury	▶ Physical damage to the head / brain through falls, abuse, fights and fits ▶ Stroke ▶ Occupational risks in e.g. construction or military service ▶ Drug overdose starving the brain of oxygen¹⁴ ▶ Being strangled (e.g. as part of domestic violence) ▶ Contact sports ▶ Serious electrical shock.
Progressive brain injury	▶ Kindling (the potential for cognitive impairment to develop because of repeated alcohol detoxification)¹⁵ ▶ Smoking ▶ Diabetes ▶ Chronic poor sleep patterns ▶ Ageing – harmful drinking may worsen cognitive changes associated with normal ageing.¹⁶
Pre-birth	▶ Foetal alcohol spectrum disorder ▶ Genetic factors that pre-dispose someone to cognitive damage – did their parents have Alzheimer's?
Other	▶ Hepatitis C ▶ Urine infections ▶ Drinking slows down or stops recovery from a traumatic brain injury (TBI).¹⁷

Even this list is not exhaustive. Many other factors can impact on cognition, some of which are rare; however, two other noteworthy conditions that cause cognitive impairment are eating disorders (poor nutrition) and chronic obstructive pulmonary disease (the impact on oxygen uptake which is needed for thinking).

Things to think about 1 (Prolonged excessive alcohol use) – In most cases people with ADHD and Autism are not cognitively impaired. They have a developmental disability that affects the way in which they communicate and interact with the world, and they are conditions that affect everyone differently. Therefore, these conditions are not covered by this guidance, but they may, nonetheless, impact dependent drinkers.

Things to think about 2 (Traumatic brain injury) – Evidence exists that emotional trauma, especially in childhood, may lead to cognitive impairment in adulthood. Again, this is not covered here.¹⁸

2.2 The scale and breadth of the problem

The statistics on the scale of the problem are striking. A much-repeated statistic has suggested that 50–80% of individuals with a substance-use disorder experience at least mild cognitive impairment.^{19,20} Other data confirms the impact.

- Approximately 50–70% of people with alcohol-use disorders have cognitive deficits on neuropsychological testing. These can range from time-limited mild to moderate impairments to more severe and persistent disorders²¹
- Somewhere between 35–40% of dependent drinkers have damage related to the effects of alcohol on the brain²²
- 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 (TBI) may be as high as 50%²³
- Up to 50% of adults with TBI were drinking more alcohol than is recommended before they were injured²⁴
- 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, balance and risk-taking.²⁵

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 foetal alcohol spectrum disorder (FASD) go on to develop their own substance misuse problems.²⁶

Nonetheless, these statistics on the scale of the problem do not seem to be having the impact on the management and treatment of dependent drinkers that would be expected. In one study, up to 80% of people with alcohol-related cognitive impairment were missed by medical practitioners and allied professionals.²⁷

Evidence exists that emotional trauma, especially in childhood, may lead to cognitive impairment in adulthood.

Things to think about 3 (Progressive brain injury)

– The raised levels of alcohol consumption associated with the “baby boomer” generation who are now in their sixties may suggest an increased level of alcohol related cognitive damage in the near future.²⁸

2.3 The impact on the drinkers

In the light of this data, it is easy to focus on the headline that *dependent drinkers are very likely to have cognitive impairment* and lose sight of what it means for them.

Cognitive impairment in dependent drinkers may not manifest itself as poor memory, lower IQ or poor communication skills. For many it will present as:

- Poor impulse control (in one study 38% of alcohol dependent patients presented with an Impulse Control Disorder)
- Poor executive function (e.g. Flexible Thinking, Working Memory, Self-Monitoring, Planning and Prioritising, Task Initiation, and Organisation)
- Poor self-management
- Poor self-care
- Poor emotional regulation and loss of empathy.

Many of these individuals, particularly those with frontal lobe damage due to head injuries, can perform well in interviews and memory tests, but will have marked impairments in everyday life due to impulsivity and poor executive function. This is very well described by University of Kent academics Melanie George and Sam Gilbert: *“Patients with frontal lobe damage can perform well in interview and test settings, despite marked impairments in everyday life. This is known as the ‘frontal lobe paradox’. Failing to take account of this when conducting Mental Capacity Act assessments can result in disastrous consequences for patients.”*²⁹

These impairments can be misinterpreted as the typical characteristics of a chronic dependent drinker. Difficulties in daily living may be attributed to intoxication or ‘client choice’ rather than cognitive impairment.ⁱⁱ A House of Lords Select Committee Report on acquired brain injury described the general problem: *“Acquired brain injury is not visible and is widely misunderstood; therefore, its symptoms can easily be misinterpreted as wilful behaviour, unwise decisions or lifestyle choice.”*^{30, 31}

Above all, these deficits will impair the effectiveness of alcohol treatment. Individuals with cognitive impairment can be viewed by treatment providers as less attentive, having lower motivation and greater ‘denial’ compared to unimpaired individuals and may be more frequently removed from treatment for rule violations.^{32, 33}

ⁱⁱ This can be called diagnostic overshadowing – where everything gets blamed on the alcohol.

In reality, they may be unable to:

- identify the problematic consequences associated with alcohol use
- identify possible sources of support
- initiate help-seeking behaviours
- remember appointments
- make arrangements to attend
- navigate to a new environment
- follow and remember a detailed conversation
- bring important information to mind and communicate this in a logical way
- learn new strategies
- implement advice/strategies and follow-through with actions
- self-monitor and apply new behaviours in key contexts
- reflect on what is working, what is not working, and make changes as necessary.³⁴

As a result, they may experience a range of negative responses:

- 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 unconscious bias and discrimination that others with cognitive impairment would not suffer because their symptoms are attributed to alcohol use.
- They may be banned from services because of their behaviour.
- They may be offered inappropriate housing or support which fails to meet their needs.
- Staff may become burnt out or frustrated working with them.
- Families may be left to cope without access to adequate support and information.

Things to think about 4 (Pre-birth) – All practitioners 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. A couple of examples highlight this:

'Drunk' mother ignored by Morrisons staff actually had a stroke | Daily Mail Online

'Drunk' woman suffered a stroke – Daily Star

2.4 Cost

Alcohol Change UK's [Blue Light manual](#) has commented on the significant cost burden associated with change resistant and dependent drinkers. This was estimated at an average of £48,000 per person per year. The impact of people with alcohol related cognitive damage on health and other services will be even greater. In many cases, the cost of providing care would easily be met by savings to the system. In Nottinghamshire, hospital admissions in relation to just four such patients cost £286,922.³⁵

Positive interventions with individuals with alcohol-related cognitive impairment have been estimated to deliver an 85% reduction in bed usage in that group.³⁶

Professionals do not need to act solely because of sympathy for these individuals' situation. There are very powerful economic arguments for action.

2.5 Specific groups

2.5.1 Gender

Although men are more likely to drink heavily, women are more susceptible to the physical effects of alcohol. Body size may impact, but women also tend to break alcohol down more slowly than men. Both will increase the risk of physical and cognitive damage. Research has shown that women develop alcohol-related brain damage about 10 years earlier than men and as a result of shorter drinking histories.³⁷

In addition, the gendered nature of domestic violence means that women are more susceptible to brain injury as a result. Four in five female prisoners in Scotland have a history of significant head injury, with sustained domestic abuse the most likely cause.³⁸ There is also evidence that many women may not seek medical care after they are injured in this way, and hence there may be limited data.³⁹

2.5.2 People with a pre-existing traumatic brain injury

In many cases the cognitive impairment is a consequence of the drinking and the drinking lifestyle. However, for a smaller group, the traumatic brain injury may come first with the alcohol problem developing as a result. Evidence suggests that people with pre-existing TBI or cognitive impairment are at increased risk of subsequently developing a substance use disorder, particularly when injury is sustained during childhood or young adulthood.

Among those who sustain a TBI, alcohol consumption can also undermine rehabilitation, increase the risk of seizures (including alcohol withdrawal seizures) and the likelihood of further TBIs. This information is important generally, but specifically highlights that alcohol advice and intervention in the first six months after an injury are crucial to managing future alcohol use.⁴⁰

2.6 Reversibility – Will they get better?

Some cognitive impairment experienced by dependent drinkers is reversible. In those with ARBD, if a person stops drinking and improves nutrition the brain cells may recover, and their cognitive abilities may improve. It has been estimated that 25% of people will make a full recovery. Up to 25% will make a significant recovery. Another 25% will make a partial recovery. Unfortunately, 25% of people will make no recovery and will have permanent difficulties. Younger people seem to have a better chance of recovery. Earlier identification of the signs and symptoms can also improve the chances of recovery.^{41, 42}

However, other studies have found more permanent impairment. The implication is that the degree of permanence will vary from person to person and from causal factor to causal factor. The main way to determine reversibility is to help the person achieve abstinence and determine whether change occurs.⁴³

The voice of lived experience

"From my perspective I didn't even know I was struggling. I didn't really know about how the drink can cause brain damage. I did notice my memory was going. When I was stressed, like if was late for work, I would think - what are we doing here? So, my brain it gets kind of confused with times and places. Not like when you have lapses in memory, but I really couldn't remember...I didn't seek help as I didn't know where to go...Things escalated, and people noticed I was having problems when I began to turn up to a past house I used to live in and try and get in the door. I feel sorry for the people who lived there. They used to have to call the police as I thought it was where I lived. They used to find me sometimes asleep on the porch."

I didn't really know about how the drink can cause brain damage. I did notice my memory was going. When I was stressed, like if was late for work, I would think - what are we doing here?



Addressing cognitive impairment – primary and secondary interventions

Key point 5

Consideration must be given to pharmaceutical interventions, essentially, Pabrinex – a high-potency vitamin injection.

3.1 Primary interventions – prevention

It would be far better to prevent alcohol-related cognitive impairment developing in the first place. This will require a range of measures from the widespread use of alcohol screening tools through to alcohol awareness work with the victims of brain injuries. However, the focus of this guidance is secondary and tertiary interventions. Identifying and intervening with people who are at risk of, or suffering from, alcohol-related cognitive impairment. For this group, the starting point is nutrition.

3.2 Pabrinex

The key pharmaceutical intervention for cognitive impairment in dependent drinkers is Pabrinex. Pabrinex is the brand name for an injection that contains vitamins B (thiamine, riboflavin, pyridoxine, nicotinamide) and C (ascorbic acid). **This is not just important for those with suspected cognitive impairment but for all those who are alcohol dependent (especially the malnourished).**

Vitamin B (especially thiamine) deficiency is common in people who are alcohol dependent. This is due to their poor diet, the presence of gastritisⁱⁱⁱ which can affect its absorption and storage in the liver, increased demand by the body for B1 due to co-occurring conditions such as liver disease and its role in the breakdown of alcohol. As B vitamins are water soluble, they need to be topped up daily. Deficiency can cause Wernicke's Encephalopathy (see above), which if left untreated, can lead to further cognitive impairment.

Oral thiamine (tablets) is poorly absorbed in dependent drinkers. For this reason, all those undergoing detoxification, and showing the risk of developing Wernicke's, whether as an inpatient or in the community, should be considered for Pabrinex. In addition, prophylactic (preventative) treatment with thiamine is routinely recommended for those clients with a high risk of developing thiamine deficiency i.e. those with severe alcohol dependence, a history of seizures/delirium tremens, a pattern of diarrhoea, vomiting and physical illness, and those who are malnourished, have a poor diet and are experiencing weight loss.

It can be given as an inpatient via intravenous injection (into the vein) or in the community as an injection into the muscle. Most hospitals will have protocols / pathways for the management of intravenous Pabrinex. The injection can be given as part of a detoxification regime, but it can also be given preventatively as an injection every three to six months. These are prescribed by doctors or nurse prescribers, and it will be given by a healthcare professional.

There is a very small risk of anaphylaxis (a serious allergic reaction) with a Pabrinex injection. However, the incidence of anaphylactic reactions has been estimated as one in 5 million pairs of intramuscular ampoules sold in the UK.⁴⁴ This is much lower than other medications: for example, the incidence of anaphylaxis to penicillin is 0.02% to 0.04%. However, facilities for treating anaphylaxis should be available when Pabrinex is administered. This essentially requires access to adrenaline into the muscle (1:1000 strength).

ⁱⁱⁱ Inflammation of the stomach lining.

If the patient is healthy and well-nourished, and alcohol dependence is uncomplicated, then oral thiamine is an alternative. Oral thiamine should also be given after injected thiamine as ongoing treatment or prevention.

Good practice

In Glasgow the ARBD team runs a Pabrinex clinic in the community which helps people to access the drug and nutritional support without attending a specialist alcohol service.

3.3 Nutrition

Most readers will be aware of the importance of nutrition in preventing and addressing cognitive impairment. The same is also true of hydration. The brain needs adequate nutrition and eating a healthy diet and drinking some non-alcoholic drinks throughout the day will support this.

Eating regularly will also help to provide this group with a routine, improve sleep, provide energy for exercise, fill the stomach (slowing the absorption of alcohol) and stimulate the continued desire for food.

This is not the place to provide detailed information on good nutrition for dependent drinkers. The Blue Light manual already provides a significant section on nutrition. However, even better sources of information are:

- A guide from Alcohol Forum Ireland '[Thiamine, Healthy Eating and You – You can help to prevent Alcohol-Related Brain Injury](#)'
- [Nutrition for Substance Misuse](#) (a guide from Northern Ireland).

Some services will want to include nutritional assessment in their work with dependent drinkers. Two possible tools are:

- [MUST – Malnutrition Universal Screening Tool](#) a five-step screening tool to identify adults who are malnourished, at risk of malnutrition or obese.^{45, 46}
- [Mini-Nutritional Assessment Short-Form](#) (MNA®-SF) a screening tool used to identify older adults who are malnourished or at risk of malnutrition. It consists of six questions on food intake, weight loss, mobility, psychological stress or acute disease, presence of cognitive impairment or depression, and body mass index.^{47, 48}



Addressing cognitive impairment – initial identification

Key point 6

Relevant services should be screening and identifying cognitive impairment, including using a screening tool such as mini-ACE or ACE-III when needed.

4.1 Identifying the risk of cognitive impairment

Intervention begins by identifying the possibility of cognitive impairment in an individual. Staff in all services that come into contact with dependent drinkers should:

- be aware of alcohol-related cognitive impairment
- be able to identify and flag the possibility of this risk in a dependent drinker to relevant colleagues
- understand the potential next steps.

Alcohol Forum Ireland has published a good list of indicators of cognitive impairment in dependent drinkers which can remind practitioners what to look out for.

Indicators of cognitive impairment

People affected by cognitive impairment can present in a variety of ways. A cluster of indicators should be noted before beginning to attribute a person's behaviour to cognitive impairment.

- Vague responses to questions – struggles with specifics and details
- Poor day-to-day memory – general forgetfulness
- Overly descriptive or tangential answers
- Does not pick up on social cues to allow others to talk or end a conversation
- Has difficulty remembering recent events
- Only discusses events from the past
- Has trouble keeping track of what is being said

- Takes longer to answer questions or bring information to mind
- Difficulties with flexible thinking e.g. thinking about things from 'different angles'
- Difficulties remembering when it was that things happened
- Difficulties solving problems
- Poor self-awareness
- Changes in levels of interest and motivation – the person seems to have 'lost their spark', appears apathetic, lacks initiative or spontaneous behaviour
- Confabulation (although not "lying deliberately" someone provides false or invented information).

It is also worth considering:

- Can the person remember events/conversations following a delay?
- Is there a complete loss of information, are only elements retained, is information confused or merged with other information so that it is recalled inaccurately? After what amount of time is the information forgotten – after hours or days?
- Does the person tell the same story or ask the same questions repeatedly?
- Do they frequently misplace or lose things?
- Do they frequently forget daily routines e.g. taking medications?
- Would they be able to find their way around in an unfamiliar environment or would they get lost easily? Is it better in a familiar environment?⁴⁹

Many cognitively impaired dependent drinkers can present with relatively unimpaired memory. They may be able to communicate, remember autobiographical details, undertake activities of daily living, and remember specific facts. Instead, they will have problems with their impulse control and executive function. Alcohol Forum Ireland has also published a useful set of questions that explore executive function, a few other indicators have been added to this list:

Indicators of executive function deficits

- Can they initiate/begin activities on their own or do they need to be prompted/told to do something?
- Can they think flexibly about things e.g. change their mind when provided with reasons or do they appear to have a very rigid thinking style e.g. quite stubborn?
- Are they socially appropriate with other people e.g. can they respect boundaries? Do they make jokes offensively or at the wrong time? Can they take appropriate turns in a conversation?
- Have they become more irritable than they have been in the past? Do they react to stress or frustration as they always have or are they more short tempered?
- Do they seem aware of the difficulties they have been experiencing in their life? Does their account of their life match the reality of their situation? Are their personal goals perceived to be realistic and in line with capabilities?
- Can the person implement feedback from others consistently, or does it need to be reinforced regularly through repetition?
- Are they interested in doing things? Do they seek out activities or do they need to be prompted to engage in events?
- Do they make impulsive decisions without thinking things through? Do they act in good judgement when making decisions?
- Do they have an interest in their personal affairs – e.g. finances. Can they attend to these on a daily/ weekly basis?⁵⁰

Other potential questions include:

- Do they have trouble regulating emotions?
- Have their reactions to things changed?
- Are their emotions more intense (or more changeable)?
- Has the way they relate to other people changed?
- Have their views about the world changed?
- Do they have trouble with self-care, managing bills, cleaning, mobility?
- Do they have trouble stopping themselves from doing things that are illegal?⁵¹

4.2 Further screening

Once the possible risk has been identified, this will need to be explored in more depth.

In alcohol treatment and other services such as adult social care, homelessness / rough sleeping services and probation there should be practitioners who can move beyond simply identifying the risk and be able to carry out a more formal screening. (It is assumed that health and mental health services will routinely have these skills).

Observation, assessment and re-assessment of the possibility should continue over time. It should not just be a 'yes or no' check box in an assessment. Cognition needs to be an ongoing consideration with chronic dependent drinkers.

More detailed screening starts with a good history and good recording. Beyond exploring alcohol use, this will ask questions such as:

- Has there been lifetime exposure to traumatic brain injury?
- Are there any diagnoses of cognitive impairment?
- Do referral documents or other notes provide any indicators or diagnoses of cognitive impairment?
- What are current and past medical diagnoses?
- Have they had any blood borne viruses such as HIV, Hepatitis B or C?
- Have they had their liver function tested? If yes, what were the results?
- Have they ever experienced an overdose? If yes, how long were they unconscious?
- Can family and carers contribute relevant information?
- Can other services contribute relevant information?
- What kinds of serious disorders or illnesses (physical or psychological) have other family members experienced?^{52,53}

Such questions should be asked with appropriate sensitivity to the individual and their situation.

It will also be important to gather practical, observational evidence about their cognitive impairment, for instance:

- Can they complete simple tasks such as making a cup of tea?
- Are they dressed appropriately?
- Can they maintain their hygiene?

Practitioners need to be aware that people can become adept at masking cognitive impairment. They may laugh the problem off as a joke, assert clearly that they can do something or become aggressive when an issue is highlighted. Again this emphasises the importance of seeking information from other sources such as the family or other agencies.⁵⁴

4.3 Next steps

Once the possibility of cognitive impairment is recognised, services will need to:

- adjust how they work with the individual
- attempt to secure a diagnosis and further help.

These themes will be considered in subsequent sections.



Addressing cognitive impairment – adjusting how services work with an individual

Key point 7

Practitioners working with dependent drinkers with cognitive impairment must give careful consideration to how they communicate with individuals.

If there is a suspicion that someone is cognitively impaired, services will need to consider how they relate to that person. They will need to:

- review how they communicate with them
- adapt the service's expectations of them.

5.1 Communicating with a person with cognitive impairment

Many of the skills people require to successfully engage with services can be affected by cognitive damage. 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. 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.

Many of the skills people require to successfully engage with services can be affected by cognitive damage.

Speech and Language Therapists can help with communication difficulties. 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. Reduce environmental distractions (i.e. noise) and consider where the person sits so they are not distracted by posters or people walking past the office
- cognitive impairment can cause sensitivity to light, so consider low lighting
- use everyday words and short sentences
- ask simple yes/no questions
- present key information slowly, focus on only one key area/theme per session to avoid confusion
- talk about one thing at a time. Ask one question at a time, do not ask compound questions
- try not to interrupt unless necessary
- write down key words or use visual aids or other means of communication to keep people on track and support memory
- give the person time and silence to process what has been 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
- ensure key messages and strategies are presented on multiple occasions



- link new information back to information or ideas already discussed
- recognition is easier than recall: make it easier to recall information by using cues and prompts
- in a group conversation, just have one person speaking at a time
- schedule important assessments at a time when they are usually most alert
- check the person understands questions and instructions, ask them to explain what has been said
- show the person what to do as well as tell them
- give specific examples to illustrate abstract words or phrases such as 'abstinent'
- frequently orient the person (note the time, place, what is happening and why)
- take breaks if needed

And

- Remember that on the phone visual clues are absent so it is particularly important to use these strategies
- Remember, a person with cognitive impairment may be able to read something but may not recall earlier paragraphs or be able to grasp its full meaning.⁵⁵

5.2 Adjusting expectations

Within services, it will be necessary to adjust expectations about what people with cognitive impairment will be able to achieve:

- progress will be slower
- flexibility will be required over time frames
- reminders of appointments and assertive follow up for non-attendance will be necessary
- groupwork will probably not be an appropriate intervention
- interventions that require reading and writing will be much more challenging.

Expecting people with possible cognitive impairment to pursue the same pathway as more able individuals is a process that is doomed to fail both the individuals and the service. If someone does not comply with treatment it is not safe to assume that the non-compliance is the result of an informed decision; it may be a consequence of cognitive problems.

Addressing cognitive impairment – attempting to secure a diagnosis and further help

Securing a diagnosis of alcohol-related cognitive impairment is an important and useful step on the journey but it is not the end of the journey. It is not the solution. It may not lead to new treatment; however, it will make other aspects of the care simpler. It will make it easier for the person to be assessed as requiring safeguarding or as having eligible care and support needs. It may help with mental capacity decisions and ultimately use of the Mental Health Act.

Securing a diagnosis will require referral to specialist memory and brain injury services and that will be facilitated by providing:

- the results of a screening with a validated screening tool
- information from blood tests and brain scans.

These are the focus of this section. The engagement with specialist services is considered in the next section.

6.1 Use a validated screening tool

Relying on the person's own reporting will probably not give an accurate picture of their cognition. They may not appreciate the extent of their impairment.⁵⁶ Information from other agencies may also be inadequate. Therefore, at some point practitioners will need to screen for cognitive impairment using a validated tool.

Remember – this process will need to be explained to the individual because the results will need to be fed back.

Many screening tools exist e.g.:

- [Addenbrookes Cognitive Evaluation \(ACEIII\) or \(the shorter\) mini-ACE⁵⁷](#)
- The Montreal Cognitive Assessment (MOCA)
- The Mini Mental State Examination (MMSE)

It is suggested that ACE-III or the mini-ACE (a shorter version of ACEIII) are most appropriate for this group. The tool can identify both mild cognitive impairment and dementia, it is produced in several languages, there are versions for people who are hearing impaired, and the assessment is freely available. The ACEIII tools also have some items that screen for executive function deficits. It can be administered within 10–15 minutes and provides a total score of overall cognitive functioning. Importantly, the tool has had some validation for use with alcohol and drug treatment populations e.g. in Australian treatment settings.⁵⁸

NB This is not a diagnostic tool. It is simply giving an indication of the level of harm that may be associated with this person.

Relying on the person's own reporting will probably not give an accurate picture of their cognition.

6.2 Screening intoxicated individuals

The challenge with all these tools is that the results are not reliable if the person is intoxicated. Therefore, try and find out what they have drunk and eaten prior to the test. Think about the time of day that the test will be conducted and when the person is most likely to be as sober as is practically possible. Over time, better opportunities to use the test should be sought, e.g. a period in hospital or prison, and these should be taken when they arise.

It can be useful to repeat the test over time, either to demonstrate to someone still drinking that they are becoming worse or to show someone who is abstinent that they are improving. However, this is probably only valid with a three-month interval between tests.

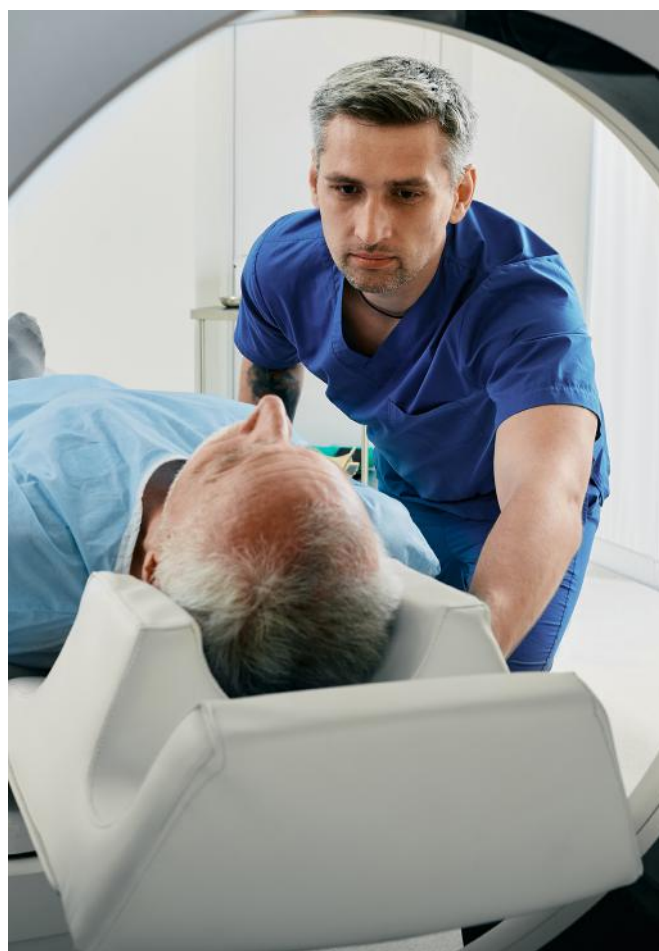
6.3 Blood tests and brain scans

If there are indications of cognitive impairment, the next step may be blood tests and possibly a brain scan. This will need to be organised via a GP or other doctor. Blood tests will be important because apparent cognitive impairment can be caused by infections.

At this point, the quality of the assessment work undertaken will be of great help. The more practitioners can evidence their concerns about the potential cognitive impairment, whether from notes, observations of behaviour or the results of screening tools, the more powerful will be the argument for further diagnostic work.

Should the doctor request a brain scan it is likely to be either a [CT](#) scan or an [MRI](#) scan.

- 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. It is one of the most readily available and quick neuroimaging techniques and is typically used to detect bleeding and structural changes in the brain, often immediately following a suspected stroke or brain injury.⁵⁹
- 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 by the machine. Not everyone can have an MRI scan and medical staff will check it is feasible for the patient before starting the procedure. MRI offers a more sophisticated and high-resolution image of the brain and is often used for more detailed investigation once damage has already been detected through a CT scan.



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. Neither of these scans can be used to precisely predict what clinical problems or changes a person may experience after an injury. Consequently, to evaluate the severity and impact of brain injury on a person's functioning, further assessment is required from more specialist services.

Good practice

People attending brain injury, cognitive impairment and memory services should be routinely screened for alcohol problems using an alcohol screening tool such as the [AUDIT](#) tool.⁶⁰

Referring to and understanding the services that work with cognitive impairment

7.1 Referral to specialist memory, brain injury and neuropsychiatry services

At some point, a referral to specialist cognitive impairment or memory services may be required. For many practitioners, this is the most challenging step.

At the outset, it will be important to provide good referral information to the specialist service. Helpful information will include:

- accurate personal details
- accurate medical information / medical history
- results of any cognitive screens carried out and level of intoxication if present at the time of screening
- 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 impairment
- whether the difficulties appear present both when intoxicated and sober
- whether the extent of the difficulties changes when intoxicated
- the level and type of alcohol and other substance use and whether this is increasing, decreasing or stable.

Much of this information will already be in individual records. Information from the person will be essential and, perhaps, if appropriate, 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 records.

NB In making a referral, it will be important to make it clear where the service should send their appointment letters: sending them direct to the individual may be either impossible or inappropriate.

The rest of this section describes the range of services that can work with this group and what they may offer. This section is for information and people may choose to ignore it if they are familiar with these services. Section 8 looks in more detail at overcoming blockages in the pathways between services.

A diagnosis from a memory service will be very useful in justifying and supporting access to other elements of a care package.

7.2 Specialist clinical services

The two main clinical services that can work with this group are memory services and neuropsychiatry services.

Memory services (memory clinics) are operated by medical staff, specialist dementia nurses, psychologists, and occupational therapists. The team at the memory service run comprehensive cognitive assessments on people of any age who have or are suspected to have memory problems, to determine whether they should be diagnosed with dementia or not. Once a diagnosis is given the service can provide ongoing support and information to people with memory problems and their carers.⁶¹

A diagnosis from a memory service will be very useful in justifying and supporting access to other elements of a care package. However, it is unlikely that these services will provide long term care for dependent drinkers, especially if they are continuing to drink.

Neuropsychiatry services are focused on mental disorders in patients with damage to the nervous system. This includes neurological diseases such as Parkinson's and cerebral palsy; but it also includes mental disorders that develop following brain injuries.

Their assessment will probably involve the following and occur over several sessions and, if possible, across multiple settings:

- a review of the person's personal social and medical history based on interview or medical notes
- face-to-face interview with the person using interview schedules and screening tools for cognition, mood and mental state
- interviews with significant others e.g. family members and people involved in their care
- the use of selected psychometric assessment tools as a means of answering specific referral questions
- the interpretation of these psychometric tools in the context of the individual's clinical history, presentation and current functioning.⁶²

This assessment may lead to a helpful diagnosis but may also, following consultation, lead to the development of a rehabilitation plan.

The challenge with both these services is to access their help. Practitioners across the country have highlighted that there may be an expectation of three months sobriety before dependent drinkers can access an assessment. This is a real barrier to accessing help. This issue is explored in section 8.

7.3 Specialist voluntary and charitable organisations

Several specialist voluntary and charitable sector organisations can offer information, advice and, more importantly, support. These include [Headway](#), [Alzheimer's Society](#) and [Age UK](#). Other specific local third sector agencies can also help. Those working with cognitively impaired drinkers could benefit from finding out what these organisations offer in their area.

7.4 Adult social care (England and Wales)

In England, practitioners can refer to adult social care for support under two main sections of the Care Act (2014):

Section 9 – under this section a person may have their care and support needs assessed and if identified as having such needs they may receive help to meet those needs e.g. a package of home care.

Section 42 – if a local authority *believes an adult* (with care and support needs) *is experiencing, or is at risk of, abuse or neglect* (including self-neglect), then it must *make enquiries, or ensure others do so... An enquiry should establish whether any action needs to be taken to stop or prevent abuse or neglect, and if so, by whom.* This may again result in a series of steps to tackle the problem.

In Wales, practitioners can similarly refer to adult social care for support under the Social Services and Wellbeing (Wales) Act (2014): e.g. Section 19 is the equivalent of section 9; Section 126(1) is the equivalent to section 42.

The challenge is that local authority staff may not view this group as qualifying for support. At the crudest level, they may feel that they are making a 'lifestyle choice'. It may be

suggested that 'all they need to do is to sort their drinking out' or that the answer is simply a referral to specialist alcohol services.

These responses need to be challenged whether they are from Local Authority or other agencies' staff. This will be facilitated by practitioners following the steps identified in section 6: developing and providing the best possible evidence of the individual's cognitive damage, perhaps through diagnosis, perhaps through test results and observations, perhaps through the outcomes of discussions in a multi-agency meeting.

It will also be important to highlight that providing a package of care built around, for example, a regular cleaning input may well not work for this group. People who find it difficult to organise themselves to engage with services and are driven by a compulsion to drink and access alcohol are going to find it hard to engage with a regular cleaning appointment. They will need care that helps them to build up their ability to engage with services and to care for themselves.

Good practice

Manchester City Council has a Statutory Substance Misuse Team which has 17 social workers, of which five are senior social worker posts. The Seniors focus on the most complex cases and high-risk cases. Their aim is to achieve better outcomes and better lives. This will involve understanding why a person is behaving in particular ways and will inevitably identify many dependent drinkers with cognitive impairment.

Practitioners across the country have highlighted that there may be an expectation of three months sobriety before dependent drinkers can access an assessment.

7.5 Occupational Therapy

Occupational therapy involves the use of assessment and intervention to develop, recover, or maintain the meaningful activities, or *occupations*, of individuals. This may include help with:

- daily living skills e.g. self-care, meal preparation, managing finances
- providing modifications or adaptations to address physical difficulties
- vocational rehabilitation
- developing coping skills
- goal setting.

It, therefore, encompasses a set of skills which will be very useful for people experiencing cognitive impairment.



Several specialist voluntary and charitable sector organisations can offer information, advice and, more importantly, support.

7.6 Speech and language therapists

Many aspects of communication are controlled by the brain. Communication requires several demanding brain activities which may be temporarily unavailable or permanently damaged by heavy alcohol use. Therefore, speech and language therapists could be useful in working with cognitively impaired drinkers. However, they are not usually part of the multi-disciplinary team (MDT) working with this group.

Nonetheless, speech and language therapists could be considered as a potential ally in assessing and working with this group. More information about their work can be found [here](#). However, the box below provides an example of especially good practice from Westminster.

Good practice

Change Communication in Westminster uses Speech and Language Therapy (SLT) to work with those in homelessness, mental health and substance misuse services. Their perspective is:

- A person consistently drinking alcohol is at their baseline (usual skills and abilities) when they are drinking. These are the circumstances which the family, loved ones and practitioners are working with most of the time.
- Asking a person to stop drinking to attend an SLT appointment may cause a medical emergency through alcohol withdrawal symptoms – these can be fatal.
- The presenting behaviour may be a result of alcohol related brain damage or other factors not current levels of intoxication. There is a risk that dangerous medical conditions may not be noticed if we exclude people drinking from services.
- The person may be less intoxicated than believed.
- Observing where communication is challenging can help identify what environmental changes can be made *by others* to support communication.
- Meeting with people with alcohol use disorders, recognising that their use usually stems from a desire to manage difficult feelings, and approaching contact in trauma-informed ways builds helpful relationships and knowledge of the person over time. Both will be extremely important should the person wish to stop drinking in future.

In practice this means Change Communication:

- ✓ Prioritises referrals from change resistant drinkers
- ✓ Meets people early in the day
- ✓ Keeps appointments short
- ✓ Uses pictures and key words to support communication
- ✓ Checks with the person and those who know them well what they have eaten and drunk that day
- ✓ Allows people to drink alcohol in their appointments

- ✓ Creates an environment that minimises shame and stigma
- ✓ Works with people on something they want help with
- ✓ Carefully plans sessions and materials for the individual
- ✓ Provides people (for free) with things that help them to keep appointments e.g. clocks
- ✓ Works closely with the team around the person to share communication ideas, assess risk and support health treatment.

They find that generally people are happy to meet with them and the team around the person finds their practical suggestions helpful for their area of work too. Of course, should a person stop drinking they can then carry out formal clinical assessments and provide concrete data that may support requests for social care, housing or health treatment.

7.7 Hospital Alcohol Care Teams

The 2019 NHS Long-term Plan advocated the development of hospital based Alcohol Care Teams (ACTs). These teams are highly skilled and can have an important role in supporting those with cognitive impairment due to drinking. They can:

- be the 'alcohol champions' within the hospital and advocate for this group
- support the design and implementation of pathways or protocols such as the prevention and management of Wernicke's Encephalopathy and alcohol withdrawal
- educate staff in early identification through to treatment and recovery
- be involved in the medical and behavioural management of presentations through prevention, acute support and longer-term intervention. This may include promoting effective verbal and non-verbal communication and reducing environmental stimulus
- support ward staff where necessary
- be used for their input on legal powers such as the Mental Capacity Act
- support people's journey into and through the treatment system.

The ACT may also meet family and carers. Therefore, they are in an ideal place for support and education about, for example, the need for good nutrition or adherence to nutritional supplementation.

ACTs can also be a valuable resource for the management of those with cognitive impairment in the community. They can access physical and mental health records that provide admission summaries, assessments, blood test and scan results. They may also be the team that assess, engage, and build up rapport with treatment resistant populations. They may get to know them over many years noting deterioration (or improvement). As a result they can be key players within the MDT approach; often leading on high intensity user meetings.

Good practice – Royal Cornwall Hospital ACT

RCH ACT developed a *Guideline for Patients Diagnosed with Alcohol Related Brain Injury* in January 2019. This defined their Pabrinex prescription and treatment protocol as well as a patient pathway for identifying Alcohol Related Brain Injury (ARBI) and appropriate referrals. They provide training and education to medical staff and RCH inpatient social workers regarding ARBI identification, management and potential recovery which has improved appropriate diagnosis and allowed extended time in hospital for patients to improve cognitively with the correct assessment and support. They are also actively involved in setting up the ARBI working group to enhance connections between the hospital and community with the aim of improving the patient journey and reducing delays in discharge. Over time, they have developed connections with two specialist ARBI rehabilitation units which have attended the hospital for assessment and planned admissions of patients.

7.8 Dietetics

Dietitians are qualified and regulated health professionals who assess, diagnose and treat dietary and nutritional problems. The importance of diet and nutrition and, in particular, the role of poor nutrition in the development of cognitive impairment has already been mentioned

(3.3). Therefore, dietitians can be an important source of support. Dietetics services are available via the NHS and both primary and secondary health services will be able to facilitate referrals. In some areas, it may be possible to refer directly to a dietitian.

7.9 Residential and nursing care

Some cognitively impaired dependent drinkers will require long term residential and / or nursing care. This is an important part of the pathway and is dealt with in section 8.15.

Some cognitively impaired dependent drinkers will require long term residential and/or nursing care.

7.10 Prison mental health inreach teams

Each prison in England and Wales has a mental health inreach team. Many cognitively impaired dependent drinkers will spend time in prison. Therefore, these teams will provide an opportunity for assessment of a prisoner's cognition during a period in which they are likely to be abstinent. Practitioners will need to make contact with the team if they are aware that a person of concern has been imprisoned.



Addressing cognitive impairment – tertiary interventions

- | | |
|---------------------|--|
| Key point 8 | Any work with cognitively impaired dependent drinkers will be built on a multi-agency approach. |
| Key point 9 | At points, practitioners may have to 'fight' to secure the help they need for cognitively impaired drinkers. This may include professional challenge and escalation to more senior staff or to multi-agency groups. |
| Key point 10 | Clear and agreed local pathways are required describing how chronic dependent drinkers with suspected cognitive impairment can access neuropsychiatry and memory services. |
| Key point 11 | At times, practitioners will need to consider the use of legal frameworks such as The Care Act (England) 2014 / Social Services and Wellbeing Act (Wales) 2014, Mental Capacity Act (2005) or Mental Health Act (1983 and 2007). |

8.1 Tertiary interventions

This guidance has described a pathway in which cognitive impairment is identified and assessed, vitamin therapy is provided, adjustments are made by agencies to how they work with an individual and consideration is given to referral to specialist memory, neuropsychiatry or other services.

The question is how are individuals managed from this point forward?

The answer is that, as in all work with alcohol and drug dependency, the choice is either:

- change focused interventions, or
- maintenance focused interventions.

Helping the person to move forward or helping them to live safely with their condition.

This section focuses on rehabilitation and change, section 9 focuses on maintenance and support in the community.

8.2 Principles

Describing a rehabilitative pathway is relatively straightforward. The challenge is delivering it in a local context. How do agencies overcome the barriers or gaps they may encounter?

This will not necessarily be easy and four principles are likely to apply:

- Workers may have to 'fight like a tiger'^{iv} to secure the help they need. They will need a persistent approach that involves appropriately challenging other practitioners.
- Care pathways will require multi-agency planning and interventions.
- Legal frameworks such as the Mental Capacity Act, the Care Act or the Human Rights Act may be required.
- Workers will need to be prepared to escalate concerns to more senior staff or more senior forums if they cannot secure the help they need.

^{iv} This phrase was used by one worker to describe her struggle to secure help for a chronic dependent drinker.

Section 8.3 describes a model intervention. However, for many practitioners this may feel a long way from their current situation. Therefore, sections 8.4 – 8.15 consider practical steps to help practitioners achieve these positive interventions.

8.3 Prof. Wilson's Five Stages of Rehabilitation

Best practice with this group was described very simply by one doctor as: 'stabilisation and rehabilitation'. Professor Ken Wilson's *Five Stage Model of Rehabilitation* takes this a step further.⁶³

Stage One: Acute Physical Care

The person receives the medical treatment they require to stabilise physical and mental health conditions. This will usually involve detoxification and thiamine supplementation. Their level of vulnerability or risk may be assessed. An MRI or a CT scan may be completed. The person may also be seen by a psychiatrist, social worker and occupational therapist. The most appropriate discharge destination to facilitate abstinence and recovery is identified.

Stage Two: Stabilisation

The person is transferred to an environment where their ongoing rehabilitation and abstinence can be supported and maintained. This could be at home, within an alcohol treatment service or in a hospital or care home. The priorities are to develop a consistent daily routine: improving nutrition and sleep patterns is important. The person is continually monitored to see if they are improving. Cognitive screenings and regular multi-disciplinary reviews are required. Some people will make a full recovery within three months. Others will have longer term support needs.

Stage Three: Functional Rehabilitation

At this active stage of rehabilitation the person begins to redevelop key life skills which may have been impaired. They are gradually introduced to key activities. They may begin keeping a diary or using other methods to improve their memory. They may also have full occupational therapy and neuropsychological assessments. Importantly, they may begin rebuilding relationships with family: developing a social network which will be important at Stage Five.

Stage Four: Adaption and Generalisation

Following a full occupational therapy and neuropsychological assessment, the person is introduced (in a planned manner) to an environment that is most suited to them in the long term. This may be a supported living accommodation or at home with additional support. For a small minority, long term care with high support may be required.

Stage Five: Socialisation and Relapse Prevention

They are encouraged to maintain their daily routine, support systems and abstinence in the long term and develop a wider network of supportive relationships.⁶⁴ From this stage forward there is unlikely to be further improvement in cognitive function, therefore, ongoing work will be about helping the person to live as independently as possible.

8.4 The challenge

The question is how can these interventions, or elements of them, be delivered in a local area? A range of problems can impede the care of this group. The rest of this section sets out the problems and offers thinking about how to negotiate them.

The most common problem is the challenge of securing a diagnosis.

Memory services and neuropsychiatry services may say that a full assessment of people with alcohol problems is impossible unless they have stopped or greatly reduced their drinking.⁶⁵ Some services have suggested the need for three or six months abstinence before an assessment can occur.^{66, 67}

Memory services and neuropsychiatry services may say that a full assessment of people with alcohol problems is impossible unless they have stopped or greatly reduced their drinking.

This is a classic 'catch 22' situation – the individual may find it hard to stop drinking because of poor impulse control due to cognitive impairment, but they can't have that impairment assessed without stopping drinking. There is a rationale for agencies seeking sobriety; however, this requirement does perpetuate the problems of a vulnerable group. Indeed, one doctor argued that it was inappropriate because if the damage is actually a degenerative brain condition such as Alzheimer's any wait will allow the situation to worsen.

However, this is not the only problem:

- Individuals may fail to turn up for appointments, engage with interventions, discharge themselves from care or be challenging and aggressive.
- Even if they have been assessed by memory services, there may be limited options in terms of support and care from services that work primarily with people with dementias such as Alzheimer's.
- The lack of detoxification beds in England and Wales will pose a problem for the management of this group. (This is not a problem this guide can address).

The rest of this section outlines a number of approaches that will improve the response. This starts with commissioning but continues with more operational approaches. All of them will require multi-agency working.

8.5 Commissioning services for cognitively impaired dependent drinkers

The most direct approach to improving care for this group will be the commissioning of a specialist clinic (e.g. Dr Julia Lewis's clinic in South Wales). In the absence of this, the next best approach is for commissioners and service managers to clarify care pathways.

The person receives the medical treatment they require to stabilise physical and mental health conditions.



This pathway development process should focus on:

- Which agency will hold lead responsibility for this group at which stage of their care?
- Whether a period of sobriety is required before assessment by memory or neuropsychiatry services?
- What flexibility there is around that timeframe and under what circumstances this can be waived or changed?
- What information do other services need to provide about someone referred to memory and neuropsychiatry services?
- What are the indicators that action may be required under the Care Act or Social Services and Wellbeing (Wales) Act?
- How and where can residential and nursing care be accessed for this group?
- How can legislation such as the Mental Capacity Act, Mental Health Act or Human Rights Act be used with this group?
- What other support can be provided to those working with cognitive impairment?
- How can an open and ongoing dialogue between the various services involved in this pathway be facilitated?
- How and where will any problems be escalated?

In the absence of a clear local pathway, practitioners will need to identify answers to some of these questions themselves. Sections 8.6 to 8.15 provide guidance on meeting some of the elements of this pathway.

8.6 Clear leadership

It will be important to be clear about who is leading any rehabilitative pathway. No national guidance exists on who should take on this role. It could arguably be substance misuse services, adult social care, neuropsychiatry, memory services, primary care or the mental health trust. In reality, either substance misuse services or adult social care will probably take the lead role.

Substance misuse services can arrange an inpatient detoxification followed by a period in a residential or nursing setting. This will allow someone to be cognitively assessed and for a longer term package of support to be arranged.

On the other hand, many cognitively impaired dependent drinkers will be identified by adult social care via safeguarding concerns or via assessments of care and support needs. Either could provide a very good framework for beginning to develop a multi-agency response.

The lead agency will then need to ensure that there is:

- an assertive response to individuals who are likely to be difficult to engage in services
- multi-agency planning
- thinking about a long-term care package before the detoxification occurs

- a willingness to use the Mental Capacity Act, in particular Deprivation of Liberty Safeguards (or the Liberty Protection Safeguards^v which were still to be introduced at the time of publication), to keep someone in a detoxification or a residential setting for sufficient time for decisions to be made about the way forward.

Good practice – The Glasgow ARBD Service

Glasgow City Health and Social Care Partnership has a specialist ARBD service. This consists of a Team Leader, two Addiction Nurses, four Social Care Officers, a Specialist Occupational Therapist, a Psychologist, half time Psychiatry input and admin support.

The Team has an open referral system and contact for advice, support and recommendations is also encouraged. Once referred the team will gather collateral information e.g. speak to relatives / carers / friends or significant others to assemble a history. They will undertake a preliminary investigative assessment – based on records / service history / details of scans. They will use the ACE-III cognitive screening. There will also be Psychiatric, Occupational Therapy and Neuropsychological assessment.

This will lead to the development of a rehabilitative care plan which considers the individual's goals and wishes, their support networks, the appropriate level of placement (e.g. home, supported living, supported accommodation, care home). However, the plan ultimately may need to consider use of legislation.

The team also has access to a range of nursing and residential placements and supported accommodation which will be used as required.

8.7 Engaging with memory and neuropsychiatry services

Experience across the country has shown that specialist memory and neuropsychiatry services can exercise some flexibility on referral criteria. This may require contact with more senior staff who can agree that flexibility is needed in a particular case. This will be helped by clear evidence of the reasons for the concern and the level of risk and vulnerability.

8.8 A regular multi-disciplinary meeting

A simple starting point, and one that is being set up in at least one local authority, is to have a regular consultation meeting to discuss this client group involving: memory services, neuropsychiatry services, adult social care, substance misuse services and an approved mental health professional. This provides a forum for determining the best care plan for each individual, e.g. access to cognitive assessment, detoxification, residential care, use of legal frameworks and support in the community.

^v Liberty Protection Safeguards are a new framework which are designed to replace and enhance the existing Deprivation of Liberty Safeguards.



8.9 Escalation

If practitioners cannot secure the help they need for a particular individual, they may need to escalate the concern through:

- existing agency management structures
- existing complaints procedures
- a local multi-agency problem-solving group
- Patient Advice and Liaison Service

If there is concern about a pattern of individuals who are being left vulnerable in the community this could require escalation to the Safeguarding Adult Board. Ultimately, if a person has suffered very serious harm as a result of inadequate care – there could be a referral for a Safeguarding Adult Review under section 44 of the Care Act in England, or an Adult Practice Review under The Safeguarding Boards (Functions and Procedures) (Wales) Regulations 2015.

8.10 Using legal frameworks

At times, it will be necessary to use legal frameworks such as: The Care Act (England) 2014 / Social Services and Wellbeing Act (Wales) 2014, Mental Capacity Act (2005), Mental Health Act (1983 & 2007) or the Human Rights Act 1998.

Alcohol Change UK has published '[How to use legal powers to safeguard highly vulnerable dependent drinkers](#)' which provides detailed guidance on using these powers. The organisation *Pathway*, in association with the Greater London Authority, has produced another useful tool:

a short practical guide including templates to complete when considering whether to make a referral under the Mental Capacity Act and the Mental Health Act. Their guidance can be found [here](#).⁶⁸

Sections 8.11 to 8.14 set out the key legal frameworks that may need to be considered.

8.11 The Care Act 2014 (England) or Social Services and Wellbeing Act (Wales) 2014

These are likely to be the starting point for managing vulnerable and cognitively impaired dependent drinkers through legal powers.

- Under Section 9 of the Care Act and Section 19 of the Welsh legislation local authorities must ensure that any adult with an appearance of care and support needs, (and any carer with an appearance of need for support), can receive an assessment which identifies their level of need. If care and support needs are identified this could lead to the development of a package of support.⁶⁹
- Practitioners (but also the public) can submit safeguarding concerns about people who they believe to be vulnerable and at risk of abuse, neglect or self-neglect. A safeguarding referral can be a useful way to focus attention on complex individuals.
- In response to such referrals, local authorities have a duty to make inquiries and determine what action needs to be taken (Care Act Section 42 / Social Services and Wellbeing Act Section 126). This is a useful way of initiating a multi-agency discussion about meeting the needs of an individual.

8.12 Mental Capacity Act (2005)

Consideration of mental capacity will be important with many cognitively impaired dependent drinkers. They may, for example, be unable to care for themselves, keep themselves safe or manage their finances. Decisions may need to be taken on their behalf by someone else.

Arguably the most useful approach to this group is to consider *executive function* or *executive capacity*. It is vital to consider both their ability to take a decision and their ability to execute that decision. "Show me you can do something, don't just tell me". This group may be able to talk about what they will do but will be unable to put that into effect (to execute it). The repeated inability to execute decisions should raise question about capacity. The updated Code of Practice on the Mental Capacity Act has given more specific support to this approach.

In particular, use may need to be made of Deprivation of Liberty Safeguards / Liberty Protection Safeguards (see above), in order to detain people in inpatient or residential care in order to enable detoxification, assessment and the development of a long-term programme of care.

The consensus in the development of this guidance is that more assertive and confident use of these powers is needed. As one senior doctor said: *"I do put them on a DoLS [Deprivation of Liberty Safeguards] – I have a conversation with them about why I am putting them on a DoLS – sometimes they are relieved that they are no longer having to think about whether they are going to stay.... You keep them until there is a good plan in place that they can buy in. By the time they are off the DoLS there is a need to have a plan and if the person can see that, it will help them."*

It is vital that practitioners are educated about assessing mental capacity with dependent drinkers, especially those with cognitive impairment.

Consideration of mental capacity will be important with many cognitively impaired dependent drinkers.

8.13 Mental Health Act (1983 and 2007)

This Act applies to people with mental and behavioural disorders (and who also pose a significant risk to themselves or others). The 2015 Code of Practice is clear (p.26) that disorders include:

- 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
- organic mental disorders associated with prolonged abuse of drugs or alcohol.

All of these, the latter particularly, suggest that some people with alcohol related cognitive impairment could

be protected and supported by use of the powers in one of the sections of the Act e.g. Section 2 (assessment) or Section 3 (treatment).

The voice of lived experience

"I was sectioned under the Mental Health Act. I can't remember the section. My mum said when they fetched me, I was crying, shaking and screaming. I was grabbing onto things...I didn't remember much of my three months there; I weighed about six and a half stone and lost all my fingernails, toenails due to poor nutrition. My skin was yellow and had blood blisters. The things I do remember are the hallucinations at night. I thought people were running round and there were people in the room. There were people coming out the walls, she says. I also remember the big bleed I had. The most vivid thing I remember was the nurse, Milly: her patience and kindness. When I was scared, she would sit with me and calm me down. It is weird how I remember that the most."

8.14 Other powers: Environmental Health and The Human Rights Act 1998

The Alcohol Change UK safeguarding guidance also highlights two other areas of legislation. First, environmental health legislation which will help with people living in insanitary homes.

Second, the Human Rights Act 1998 which incorporated the European Convention on Human Rights into UK law and includes:

Article 2 – The right to life

Article 3 – The right to freedom from inhuman or degrading treatment

Article 8 – The right to privacy including the maintenance of physical integrity.⁷⁰

A case could be built that leaving someone to drink in a fashion that leads to their physical decline or which leaves them open to abuse and exploitation is a breach of Article 2 or Article 3. Therefore, consideration could be given to building a case for action under e.g. Article 2 of the Human Rights Act 1998 for action to preserve someone's right to life. This might seek to require a local authority or health service to take particular steps to preserve those rights.⁷¹ Social workers in Manchester City Council's Statutory Substance Misuse Team use the Human Rights Act to build a case for action where other frameworks, e.g. the Mental Capacity Act, have not driven intervention.

8.15 Inpatient / residential rehabilitation

For many individuals, particularly the most complex presentations, a period as an inpatient or in residential rehabilitation may be the best approach, if not a necessity. It is impossible to be specific about what is required because this will depend on the individual, however, this might include:

- medically managed inpatient alcohol withdrawal followed by residential rehabilitation in a dry house
- a long-term placement in a residential care home for people with significant cognitive impairment
- a stay in a neuro-rehabilitation unit followed by specialist residential care
- a short-term treatment placement in a residential setting that provides specific cognitive rehabilitation for ARBD
- placement in a 'wet house' for people who are continuing to drink.

This may be hard to achieve because of a lack of appropriate facilities (locally or nationally). This requires action at three levels:

- action needs to be taken to identify local, regional or national facilities that can work with this group
- providers need to identify gaps in the availability of services and feed this information into commissioners
- commissioners need to encourage the development of services that will meet these needs.

The latter, in particular, may require action at a regional or even national level to develop the range of services for what may be a small group of people in any one area.



For many individuals, particularly the most complex presentations, a period as an inpatient or in residential rehabilitation may be the best approach, if not a necessity.

8.16 The family

At every point in this process it will be necessary to consider the needs of the family and other carers. Where possible and appropriate, practitioners should:

- involve a person's family or carers (if the person agrees) in developing and reviewing the care plan to ensure it is tailored to meet their needs
- ensure the care plan takes into account the concerns of the person's family or carers
- share a copy of the care plan with the person's family or carers (if the person agrees).

It should also be recognised that:

- family and carers have needs in their own right
- they should be offered an assessment of their needs
- the caring role may have a significant impact on their mental health
- family and carers can easily be unaware of, or excluded from, any plans or decisions being taken by/for the person
- any assumptions the patient has made about the level of support that their carer will provide will need to be checked with the potential carer.⁷²

In particular, practitioners need to be aware that cognitively impaired individuals may make statements about family support or family relationships that are not based in reality. For example, "I will go and stay with my daughter when I leave hospital", when they have not seen her for many years.

The national charity, Adfam, has developed guidance and resources on working with the families of substance users with mental disorders. These can be very useful in this context.

- [Toolkit-for-practitioners-co-occurring-conditions.pdf \(adfam.org.uk\)](https://adfam.org.uk/toolkit-for-practitioners-co-occurring-conditions.pdf)
- [Toolkit-co-occurring-conditions.pdf \(adfam.org.uk\)](https://adfam.org.uk/toolkit-co-occurring-conditions.pdf)

The voice of lived experience

"Getting back with the family was important. I had to relearn my family networks. The rehab re-established links and eventually my mum and dad come out to visit. It was emotional; emotional for them too. And when they left, it was kind of, like upsetting, you know. But they came, eventually on a regular basis, and then I had a visit home and stayed at mum and dad's."

Addressing cognitive impairment – living with the impairment

Key point 12

In some cases the immediate and long-term response to cognitively impaired dependent drinkers will be built around a harm reduction approach – helping them to live as safely as possible in the community.

The ideal pathway is that someone is identified with cognitive impairment and, as a result of specialist input, then enters a process of treatment and rehabilitation. However, many will not engage with this approach. For this group, the main goal will be harm reduction: helping them to live with their impairment in the community.⁷³

General advice on working with change resistant dependent drinkers is included in Alcohol Change UK's [Blue Light Manual](#) and our guide on [Alcohol assertive outreach](#). The manuals emphasise the importance of:

- an assertive outreach approach
- relationship building
- a person-centred approach
- multi-agency management
- risk assessment and risk management
- harm reduction.

These provide a structure for the relationship with the dependent drinker. However, this section explores several areas that need to be considered in developing the content of an intervention that will support individuals to live in the community:

- building an effective relationship
- nutrition
- thinking about the environment
- improving memory
- building structure
- physical activity
- sleep

- managing medications
- managing impulsivity
- family and carer involvement.

9.1 Building an effective relationship

If cognitively impaired dependent drinkers are to manage in the community, they will need good relationships with those who are supporting them. This will require practitioners to think about how they relate to, and work with, these individuals. Much of the information in section 5.1 on communication will be relevant here. In addition:

- provide structure – devise and use a daily routine avoiding long periods of inactivity
- plan tasks in advance. Break them into small steps. Teach the person to approach a new activity/task in a systematic manner e.g. break the task into small parts or steps and tick them off as completed
- use alarms or other reminders to prompt these activities throughout the day
- avoid changes to routine but if disruptions are inevitable, remind the person of any changes several times, send text message reminders, and explain why it has occurred
- adapt any interventions to the person's pace. Set very small goals and only one at each session
- encourage the person to rehearse strategies; practice skills in different situations to encourage use in new environments
- use role play to practise strategies for coping with triggers or high-risk situations

- reduce demands – do not expect open ended decision making but give solutions from which to choose
- avoid giving open ended tasks
- when teaching problem-solving skills, provide specific, concrete examples of a strategy
- monitor what times during the day their attention seems best
- schedule more demanding tasks for when attention is at its best or when the environment is at its calmest
- if some activities are too demanding, try something less demanding first and build up over time to more demanding tasks
- build in regular breaks to every task
- when a person is distracted, gently interrupt and bring them back to the task
- change activities, if necessary, to keep their interest
- encourage staying on the task for a little longer each time
- people who experience difficulties thinking abstractly and responding to open-ended questions may do better with a more directive therapeutic style
- help develop a script or strategies that can be used to let others know they have difficulties e.g. “I’m more likely to remember what you are saying if you speak more slowly”.⁷⁴

9.2 Nutrition

Good nutrition (and hydration) is vital with dependent drinkers. However, this point has already been made, and it will be helpful to refer to the information and, particularly, the links in section 3.

9.3 Thinking about the environment

A person’s living environment needs to support their wellbeing. It may be necessary to:

- provide assistance when introducing them to a new place
- change their living space to allow more room to move around objects
- put personal belongings in easily accessed places
- provide special adaptations e.g. a handrail
- use clear fronted drawers so that it is easy to see the contents
- consider safety when cooking or using tools and discuss the need for support with this
- organise for bills to be paid automatically
- provide a clock, watch, calendar or diary to help them keep track of time and plan future activities and appointments
- programme clocks and mobile phones with reminders of appointments and tasks. Apps and smart speakers can help with this too, but low tech approaches can also be effective such as using post-its or a white board
- set-up contingency plans in case someone gets lost when out and about.⁷⁵

Memory stations

A ‘memory station’ can be set up within the person’s home/room. Memory stations usually include a white board or pin board, a small table to keep important items (e.g. keys, medications, wallet, watch or glasses), and other things that need to be taken with the person the following day (e.g. a phone, important documents), a calendar for appointments, important dates, bills that need to be paid, and tasks that have to be completed. It could also include photos of practitioners to be met or places to be visited.⁷⁶

If people with cognitive impairment are coming to a service, it may be necessary to think about whether they will find their way through large and complex buildings.

The environmental issues may be more basic: they may be living in cluttered, unsafe or even insanitary premises. In such cases consideration will need to be given to:

- an assessment using the [clutter image ratings](#), these provides a series of pictures of rooms in various stages of clutter so that practitioners can describe the degree of clutter on a standard scale⁷⁷
- a home safety check from the fire service
- a referral into the local hoarding or self-neglect pathway
- action under the Care Act or Social Services and Wellbeing (Wales) Act
- use of the range of available environmental health legislation (see ‘[How to use legal powers to safeguard highly vulnerable dependent drinkers](#)’ for more detailed guidance).

9.4 Improving memory

Help the person to improve their memory:

- encourage the use of a notebook to log daily events and tasks to be completed. Encourage the person, and everyone involved in their care to contribute to it and refer to it for daily events. It can take a person a long time to get used to doing this: approximately three months. It is important that everybody works together to remind the person to use it until it becomes an established behaviour
- encourage them to review and rehearse information in the diary at key parts of the day (e.g. every hour or at breakfast, lunch etc.). Set an alarm to remind them
- put a sign on their door to remind them to take their diary with them if they go out
- assist them in setting regular alarms for key tasks (e.g. an alarm reminder to put the bins out on a specific day each week, or take medication)
- teach the person to keep important things (e.g. things they need to take with them to their next appointment) in a designated place – see the ‘memory station’ above⁷⁸
- put large and visible notes in their home (e.g. on a fridge or wall), reminding them in their own words of what they had agreed to do before the next session



- put a whiteboard in their home for messages about visits and goals
- record sessions (on a piece of paper, phone or other device) for the person to have access to later; or allow them to take notes
- repeat important information as much as possible and give regular reminders
- encourage the person to rehearse this information out loud. Ask them to repeat important information before the end of the conversation
- keep belongings in the same place – a place for everything and everything in its place!
- association: ask the person to think about the unique features associated with a piece of information. For example, to remember a person's name, someone can associate that name with a characteristic or something they have previously learned (e.g. her name is Susan, and my sister's name is Susan). associating context-based cues with the central piece of information (what they were doing, where they were, when it was learned etc.). This is a good method to use when trying to retrieve a piece of information such as where they left their keys, or what happened several days before. Ask the person to retrace their steps i.e. what room were you in when you learned that information? Who were you with?
- acronyms are helpful in recalling key information and reduce the load on the memory. For example: WHO for 'World Health Organisation'. People may like to generate their own useful acronyms
- acrostics are like acronyms, but instead of forming a 'word', they generate a sentence that helps to recall information (e.g. *Eat An Apple After A Night-time Snack* stands for the continents: *Europe, Antarctica, Asia, Africa, Australia, North America, South America*)
- ask the person to develop a short story out of important information (e.g. all the items they need to take with them, like glasses, trainers, lunch, medication). For example, they may generate a story about *their glasses running away with their trainers to have a nice lunch but then they had to come back because the shoes needed their medication*⁷⁹
- gently remind the person of the correct details if they get it wrong⁸⁰
- encourage the person to do puzzles which require concentration – e.g. word-finding puzzles, jigsaws. Start with the most basic level and build up in difficulty⁸¹
- use telephone calls to remind them of appointments.

Good practice

Life Story Books are an activity in which the person with cognitive impairment is supported by staff and family members to gather and review their past life events and build a personal biography. It is used to help the person understand their past experiences and how they have coped with events in their life.⁸²

For more on this approach see:
[Life Story Work – Dementia UK](#)

The voice of lived experience

"My Top tips for helping people like me:

- Be nice. Be patient. I am a person with an illness
- Repetition
- Get yourself into a routine. Stick to that routine
- Exercise the brain at different levels depending on where you are at, e.g. I used to look at the papers. Scrabble helped
- I used to always take a pad and pen in in my pocket, and I used to write down the date and the year because I forgot what month it was
- When I was improving, I used to keep a journal of who I spoke to, and I used to write down emotions too. If somebody spoke to me inappropriately, I used to write that down too (it helped me manage anger)
- An activity board
- For me learning to cook in the home's kitchen was very helpful. I really enjoyed it and eventually progressed to an NVQ level three in cooking and counter service."

Life Story Books are an activity in which the person with cognitive impairment is supported by staff and family members to gather and review their past life events and build a personal biography.

9.5 Building structure

It will be important to help people structure their day and develop routines (people with cognitive impairment often find it difficult to organise and make productive use of their time).⁸³

- establish a structured routine of daily tasks
- limit changes in daily routine as much as possible
- provide detailed explanations of even the most basic changes in daily routines.

9.6 Physical activity

The brain responds to stimulation. It is well evidenced that physical activity, especially cardio intensive activities such as brisk walking, running, dancing, yoga or pilates, is associated with improved cognitive functioning. Physical exercise can also improve daily functioning, wellbeing and sleep quality.

For some, vigorous exercise will be inappropriate. However, walking, chair exercises or gardening can all help to get blood to the brain and improve functioning.

9.7 Sleep

Improving sleep can improve cognitive functioning:⁸⁴

- have a stable sleep pattern – go to bed and get up at a similar time each day
- cut down on using caffeine and other stimulants in the afternoon or evening
- keep away from bright screens/lights in the last two hours before bed
- try to keep electronics out of the bedroom (e.g. TV or phone, use an analogue alarm clock instead)
- ensure the bedroom is dark and relatively cool before attempting sleep
- exercise may help improve sleep
- wind down and relax before bed (e.g. music, bath, reading, meditation)
- if not asleep within about 20 minutes of trying to sleep, get up and do something quiet and calming for a short time
- avoid spending too much time in bed before attempting sleep.⁸⁵

9.8 Managing medications

Practitioners will need to find ways to ensure that drug regimens are followed:

- linking taking medications to regular events (e.g. taking medications after brushing teeth or eating dinner (something they are unlikely to forget to do)
- keep medications in a prominent, designated place that is difficult to miss (but out of the reach of children)
- a 'dosette box' may be helpful (i.e. a pill organiser in which medications are deposited into seven daily segmented containers)
- for people who really need to take medications on specific days at specific times, and cannot manage using a dosette box, a 'Webster-pak' from the pharmacy may be useful. A multi-dose Webster-pak is a sealed weekly calendar pack designed to assist people in taking their medications as prescribed.

9.9 Managing impulsivity

Impulsivity is a key effect of cognitive impairment. Management strategies can help.

- set clear boundaries and behavioural expectations and ensure the consequences of a breach are understood
- encourage self-monitoring techniques such as 'stop, think, check'
- coach people in strategies that will allow them more time to decide what to do/actions to take – this may include asking others to repeat questions, speak more slowly to give them more time to think⁸⁶
- ask someone to explain their feelings (perhaps using an emotion wheel), and identify what upset them
- do role-play exercises and teach the person to recognise which behaviours are problematic, which scenarios may trigger certain behaviours and when to apply compensatory strategies

- if agitated by the presence of others, schedule appointments at quiet times when fewer people are around
- use neutral language where possible, assume a calm and sympathetic tone
- if the person becomes frustrated, distract them with neutral questions, change the subject, or take a break
- it may be appropriate to return to a problem behaviour either later or at another session
- for people who see a number of different practitioners it can be helpful to have a team meeting to discuss a consistent approach to managing behaviour
- sometimes ignoring behaviours will be appropriate as long as they do not place someone at risk. Peer support or supervision can be a good place for discussing the impact of any behaviours.

Always follow organisational specific health and safety guidelines.

9.10 Involving family members and carers

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

- The Adfam family guides mentioned above (8.16) will be useful
- The Alcohol Forum in Ireland have a [Family Guide](#) which could be useful.

9.11 Other support

A number of other ideas are worth consideration:

- develop a 'This Is Me' document or "health passport". This is a document that a person (and their carers) completes that explains their condition and how it affects them so that they can give it to health and social care professionals when they meet
- link people with local services such as day centres or befriending services to deal with the social isolation of individuals with cognitive impairment
- give a photo of relevant practitioners with the worker's name, job and contact details
- ask a family member or friend to accompany the individual to appointments or provide other support
- provide a wearable GPS Tracker or ensure they are carrying identity and health information in case they become lost or collapse in public
- if relevant, consider issues related to driving (or other machinery). Reinforce that they should not drive unless this has been approved by their doctor. Refer to the DVLA for a driver's licence assessment
- ensure guardianship or financial management structures are in place.⁸⁷

It may be that for some in this group, the goal is a 'good enough intervention'. Death is a real outcome for this group and ensuring a good death can be a step forward for some. In others, simply stopping them smelling of urine may be a good outcome.

The voice of lived experience

"The rehab promoted structured work. It might be just a games day or going out for a day. I learned to read and write again. There was a day care coordinator there and he helped me with reading. We started with nursery books like Ladybird Books. We started off with reading like 'the cat and the dog' and stringing the words together. And that was frustrating as well because I choose to burst into tears and go: "I feel like there's something wrong with my brain" ...And we'd read paragraphs. And then he said what I want you to do is tell me about the paragraph you've just read. Yeah, I remember crying, saying I can't remember anything I read. I got there in the end, eventually I progressed, and I played Scrabble every day.

"When I was first there I used to be like, oh, I don't want to do this all the time. But it was explained that I needed initial structure. They clearly explained 'the thing is you forget about times. You forget when its mealtimes. You forget when it's medication time.' I worked with them and then I come up with a plan of my own. I listed prompts on a chart on the wall and I had to do it on a day-to-day basis because that's the structure I needed.

"I would write: tomorrow morning I need to get up, go to breakfast, then I need to go to that group at 10 and then

I need to go to lunch at 12. So, every day I added structure like that until I got into a pattern where I didn't need the paperwork anymore. Eventually I remembered. After the first year I was there and had a daily structure, I remember I was going somewhere in the building, and I began remembering the way back to my room. I used to take a piece of paper and pen with me and draw a direction that I had gone to get back because I was afraid that I wouldn't find my way back. Almost like drawn a map. It was only a short little journey, but I used to forget.

"I used to get frustrated, and I used to cry because I didn't know what was wrong. I became angry and I was crying myself to sleep because I thought I was never going to be normal again. It was very frustrating. The staff were very good at giving me emotional support. Eventually as they saw I was recovering a support worker at the rehab supported me in starting work in a charity shop. I remember her saying "it will do you a world of good, to work in there". I relearned tools to get numeracy skills to prevent me becoming institutionalised, to get used to the public again. It was mega benefit. I also extended my social circle as I got to meet people. It was like going back to school again."



Recommendations

This guidance cannot exist in isolation. Improving the response to this group will require more than just a document. Therefore, this guidance concludes with recommendations for action at both the commissioning and practitioner level.

10.1 Commissioning

Those who commission and plan substance misuse services, mental health services, brain injury and memory services as well as senior managers in adult social care will need to ensure that the needs of this group are considered in relevant plans and strategies. This will require ensuring that:

- the needs of this group are reviewed in needs assessments and other local research
- key performance indicators do not, at the least, dissuade services from working with this group and, at best, encourage work with these individuals
- a local champion is identified to lead this work
- wherever possible the voices of people who have lived experience of alcohol-related cognitive impairment are heard in planning
- clear pathways are mapped, and this includes pathways for people who will find it hard to engage with services
- clarity exists on who commissions and leads on which aspect of the needs of this group
- multi-agency management groups are identified to which this group can be referred
- funding is available for inpatient and residential / nursing care as required.

10.2 Practice

Those providing services that will encounter these individuals, at whatever level, should:

- ensure widespread training to disseminate and embed this guidance
- ensure managers support staff to follow the guidance
- ensure good multi-agency management structures are in place to provide a framework for identifying and discussing people who need such support
- develop a virtual team in the community for the management of this group
- ensure that a lead worker providing a focal point for this work is identified in specific services, e.g. substance misuse services. Memory and cognitive impairment services could equally identify someone who specialises in work with dependent drinkers.

10.3 National

- Much more research is needed into what works with this group
- This group would benefit from specific NICE or other governmental guidance on the management of people with alcohol related cognitive impairment
- Government guidance is required on the key legal powers that are relevant to this group and how they apply.

10.4 Training and support to workers

Both practitioners and commissioners will require appropriate training to support this complex group. This will require a range of training on basic good practice such as care planning, engagement skills and motivational interventions. However, working with cognitively impaired dependent drinkers will encompass training in:

- identifying and responding to alcohol related cognitive impairment for all relevant agencies (including commissioners)
- alcohol awareness and intervention training for staff in neuro psychiatry, memory and related services
- harm reduction training including e.g. fire safety training
- using cognitive impairment screening tools
- effective interventions with complex change resistant and dependent drinkers
- using legal frameworks such as the Mental Capacity Act to protect vulnerable dependent drinkers.

This training should be built into agency and partnership training programmes.

Both practitioners and commissioners will require appropriate training to support this complex group.

Appendix 1

Useful resources

Professor Ken Wilson and Dr Julia Lewis have set up a network to raise awareness of alcohol related brain damage (ARBD) amongst healthcare practitioners and the public through education and information to improve clinical outcomes. At the heart of this is a [website](http://www.ARBD.net) (www.ARBD.net) which contains a wealth of information about issues such as diagnosis, prevalence and mental capacity as well as hosting useful resources. This is an invaluable aid to supporting work with this complex client group.

Two documents, produced from outside the UK, have been particularly helpful in the development of this guidance:

[Turning Point Australia – Managing Cognitive impairment in AOD treatment – 2021](#)

[Alcohol Forum Ireland – Alcohol Related Brain Injury: A guide for professionals – 2015](#)

In addition, the [ACE programme](#) from New South Wales in Australia has developed a range of interesting materials.

Important documents from the UK include:

- [‘Alcohol and Brain Damage in Adults’](#) (Royal College of Psychiatrists, 2014),
- Welsh Government – Substance Misuse Treatment Framework: [Prevention, Diagnosis, Treatment and Support for Alcohol-Related Brain Damage](#) – 2021
- [Headway’s Alcohol After Brain Injury Factsheet](#)
- [BASW guidance for social workers on assessing and working with people with brain injury](#)
- [Alcohol-related brain damage – signs and symptoms, Alcohol Change UK](#)

Appendix 2

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Shropshire Council
Staffordshire County Council
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- Dr. Phillipa Griffiths – Neuropsychiatrist
- Andrew Misell – ACUK Wales
- Prof. Michael Preston-Shoot – National expert on safeguarding
- Dr. Sebastian Yuen
- Susan Laurie – Lived experience
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- Mark Holmes – ACUK
- Jane Gardiner – ACUK
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- Dr Fiona Robinson – Addictions Psychiatrist
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Interviewees (other than steering group members)

Ellie Atkins – Manchester City Council
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