mentalwelfare
commission for scotland

GOOD PRACTICE GUIDE

Alcohol-related brain damage (ARBD)

JANUARY 2019

Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

Contents

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Why we wrote this guidance

Alcohol-related brain damage (ARBD) is a condition where there are changes to the structure and function of the brain as a result of long-term, heavy alcohol use. People with ARBD can have problems with their memory, their judgement, and their ability to live independently. These problems, often compounded by ongoing alcohol use, can make them more likely to develop social and health problems and to present to social services, their GP, or hospital. Working with individuals with ARBD can be challenging for all those involved in their assessment, care, treatment, and rehabilitation.

The brain changes and functional impairments seen in ARBD can be partially or fully reversible if the person stops using alcohol, but they will often progress with ongoing use. People with ARBD can require help managing their alcohol use as well as with their day-to-day living and their healthcare needs. Many people will accept such help voluntarily. However some will refuse help, and in some individuals with ARBD there is so much concern about their judgement and their safety that legal measures are considered in order to maintain their health and well-being.

In Scotland the use of certain legal powers is restricted to those people who are considered to lack capacity for a particular decision or to have significantly impaired decision-making ability due to mental impairment. Establishing whether a person with ARBD lacks capacity is therefore often of great importance. We have heard that practitioners find it difficult to assess capacity in people with ARBD. This may be because the patient is either intoxicated or in withdrawal when they are seen, or it may be because people with ARBD can have preserved verbal abilities which can cause practitioners to underestimate their deficits.

ARBD patients can be a stigmatised group where there is a perception that they are difficult to help and a feeling in some that their problems are self inflicted. A further difficulty can be balancing the rights of individuals to live as they choose with their rights to access potential help to maximise their quality of life.

We answer many questions about our recommendations in this area via our telephone advice line and have heard multiple reports of challenges and problems on our visits.

We have written this guidance principally for professionals working with people with ARBD—medical practitioners (mainly psychiatrists and GPs), social workers, mental health officers (MHOs), mental health support workers, and addictions workers. The guidance is not written specifically for patients, relatives, or carers, but might be useful in describing available resources and approaches.

The guidance considers the diagnosis of ARBD and gives an overview of treatment options, before discussing the assessment of capacity with specific reference to the problems presented by ARBD patients. It goes on to review the legal powers available in Scotland, and the use of those powers in particular settings and situations, illustrated by a variety of case examples.

Part 1 – the nature and treatment of Alcohol-related brain damage (ARBD)

What is ARBD?

ARBD describes a clinical syndrome due to structural and functional brain changes which occur as a result of chronic, heavy alcohol use[1]. Those affected may have problems with their memory, performance, and ability to function. They may also experience difficulties formulating and executing plans, and learning new information. Both the brain changes and the functional impairments are at least partially reversible if the individual stops using alcohol, but will often progress with ongoing use.

While ARBD has been increasingly recognised as a major clinical problem over the last decade and a half, it has long been recognised that excessive alcohol use can lead to both physical and mental impairment. Wernicke-Korsakoff Syndrome (WKS), a condition caused by thiamine deficiency that most commonly occurs in chronic alcohol use, was first described in the 1800s. It is characterised by severe difficulties with short-term memory and learning[2], as well as problems with balance and eye movements. Broader, reversible cognitive difficulties are also routinely observed in heavy alcohol users. The terms "wet brain", alcoholic dementia and alcohol-related brain injury (ARBI) have all been used to refer to this group. ARBD is now the generally preferred term. It encompasses both situations described above as well as the damage caused by the withdrawals and recurrent head injuries often experienced by those who chronically abuse alcohol[3]. Head injuries caused by alcohol will often affect different brain regions and have differing consequences. Treatment teams will often include occupational therapists (OT), speech and language therapists, and physiotherapists.

Most individuals with ARBD will exhibit problems with short-term memory and recall, and changes associated with damage to the frontal lobe of the brain. These changes include difficulty with planning, abstract thinking, cognitive flexibility (the ability to switch between tasks or to adapt to novel or changing situations), and impulse control. Confabulation is another common feature, where an individual creates false memories but without the deliberate intention to deceive. This can be as a result of the individual's need to make sense of their own situation. These memories are often

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[1] Neither of the current major diagnostic classifications of mental disorders, the World Health Organisation's International Classification of Diseases (ICD-10) or the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM-5), uses the term ARBD. In ICD-10 the syndrome is best described using "alcohol-induced amnesic syndrome" (F10.6) or "alcohol-induced residual disorder" (F10.7), and in DSM by "alcohol related major neurocognitive disorder, amnestic-confabulatory type" (291.1).

[2] Kopelman MD "Disorders of memory," *Brain* 125, no. 10 (2002): 2152–90.

[3] Lishman WA *Organic Psychiatry: The Psychological Consequences of Cerebral Disorder (3rd edition)* (Chichester: Blackwell Science, 1998)

bizarre, but can be more plausible. Visuospatial problems are commonly observed later, while general intellect and verbal skills often remain relatively unaffected.

Prevalence of ARBD

It is believed that ARBD is often not recognised and is underdiagnosed. This is important as contact with general hospitals for these patients often results in prolonged admissions[4].

ARBD is present in 1.5 per cent of the general population and almost 30 per cent of alcohol dependent individuals[5]. The number of hospital admissions for ARBD has been described as 'comparatively low'[6]. The mean age of those referred to specialist ARBD services is 55 years with three quarters being male[7]. In the general hospital, referrals to liaison psychiatry with ARBD make up about 3 per cent of total referrals. In this setting, 70 per cent of those referred were male, and the mean age was 59.5 years with a range of 28 to 91 years[8].

Making a diagnosis

The diagnosis of ARBD requires a good clinical history from the individual when not under the influence of, or withdrawing from, alcohol. The assessor should gather reliable information about the patient's alcohol use over time. They should ensure that an objective test of the individual's cognition is undertaken.

Some commonly used examinations do not include tests of executive function. We would recommend the use of either the Addenbrooke's Cognitive Examination (ACE-III) or the Montreal Cognitive Assessment (MoCA), as opposed to the Mini Mental State Examination (MMSE) which does not include any test of frontal lobe functioning.

In individual cases, where it is available, specialist neuropsychological testing of executive functions, e.g. with the Hayling Sentence Completion Test and the Brixton Spatial Awareness Test, can provide a more detailed view of any deficits.

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[4] Popoola A, Keating A, Cassidy E "Alcohol, cognitive impairment and hard to discharge acute hospital inpatients," *Irish Journal of Medical Science* 177 (2008): 141–5.

[5] Cook C, Hallwood P, Thomson A "B Vitamin deficiency and neuropsychiatric syndromes in alcohol misuse," *Alcohol and Alcoholism* 33 (1998): 317–36.

[6] NHS Information Services Division "Alcohol-related Hospital Statistics Scotland 2017/18" (2018): 20. This sets out that the stay rate in the general acute setting has increased since 1997/98 from 12.3 per 100,000 to 17.0 per 100,000. In contrast the stay rate in psychiatric hospitals was 6.4 per 100,000 in 1998/9, falling to 2.7 per 100,000 in 2016/17.

[7] Smith, I. (2012) "Alcohol-Related Brain Damage in the Longer Term: Scottish Initiatives to Maximize Recovery". *Alcohol and Alcoholism* Vol. 47, No. 2, p. 84.

[8] Smyth R; Department of Psychological Medicine, Royal Infirmary of Edinburgh. Unpublished data via correspondence, 02/11/18.

Neuropsychological testing may also be of value in identifying areas of preserved function which can aid rehabilitation efforts.

Preserved verbal abilities and the presence of plausible confabulation means that clinicians can often be 'taken in' and overestimate an individual's abilities. These individuals are also likely to be younger and fitter. A further difficulty is that often people with ARBD have a narrowed social network, so attempts to gain accurate collateral information which may challenge confabulation and good social façade is often not available. Together, this can mean that their cognition and capacity are over-estimated and they are assumed to maintain capacity. To reduce the possibility of clinicians being 'taken in' it is recommended that an occupational therapy (OT) functional assessment is undertaken. The most standard tool is the Assessment of Motor and Process Skills (AMPS). This provides a 'real-life' assessment of an individual's skills and deficits in respect of their activities of daily living (ADL) tasks, thereby giving a more comprehensive picture of functioning which informs treatment planning and capacity formulation.

Oslin[9] proposed criteria for the diagnosis of probable "alcohol-related dementia" that have been adapted and are commonly used clinically. These criteria include:

- Documented evidence of cognitive impairment.
- Significant alcohol use (35 standard units per week for women and 50 for men) for a period of at least 5 years.
- The period of significant alcohol use must have occurred within three years of onset of the cognitive deficits.
- The absence of a better explanation e.g. acute alcohol intoxication/withdrawal or progressive mental disorder.

In addition, the presence of a lack of co-ordination or evidence of alcohol-related damage to other organs would add weight to a clinical suspicion of ARBD.

Co-morbidity is common in this patient group, and this may complicate assessment. Approximately one quarter of people with ARBD will have evidence of vascular or traumatic brain changes[10]. Some specific features might suggest significant or complicating co-morbidity. These may include a difficulty with language or word finding, prominent neurological signs, or brain imaging that shows microvascular or traumatic injuries. They may also have educational deficits.

[9] Oslin D, Atkinson R, Smith D, Hendrie H "Alcohol related dementia: Proposed clinical criteria," *International Journal of Geriatric Psychiatry* 13, no. 4 (1998): 203-212; Royal College of Psychiatrists Alcohol and brain damage in adults with reference to high-risk groups (2014)

[10] Wilson K, Halsey A, Macpherson H, et al "The psycho-social rehabilitation of patients with alcohol-related brain damage in the community," *Alcohol and Alcoholism* 47 (2012): 304–11.

Professionals often meet individuals with suspected ARBD whilst they are either acutely intoxicated with, or withdrawing from, alcohol. These states may be the presumed explanation for subtle changes in memory or functioning. Many will also have liver damage and the associated brain dysfunction, known as encephalopathy. This too can obscure symptoms of ARBD and complicate the clinical picture.

Given the change in presentation over time and with alcohol status, the best time to assess an individual can be difficult to determine. The patient should be free from alcohol intoxication and withdrawal. Practically, this would typically mean at least seven to 10 days after the patient's last drink. It may be possible to complete only *cognitive screening* rather than a *full diagnostic assessment* while the individual is in an acute setting due to the pressures on hospital beds. This may mean that some individuals with a concerning cognitive screen and a planned diagnostic assessment may be discharged from hospital and the planned assessment does not happen because the individual has resumed drinking. Finding a suitable, alcohol-free environment for the individual therefore becomes a consideration if time allows for a full assessment. Ideally clinicians should allow plenty of time, and it is often useful to repeat cognitive testing after three to six months. ARBD is a diagnosis of exclusion, and ruling out all other causes of cognitive impairment is time consuming.

Clinical course

ARBD typically develops as a result of many years of heavy alcohol use and the early signs can be subtle. As a result, it is common for the definitive diagnosis of ARBD to be made several years after the first signs and symptoms begin. The earliest stages of impairment in ARBD begin with executive problems, including the loss of social inhibitions. If the use of alcohol continues, memory deficits and finally broader cognitive and functional difficulties follow[11].

These impairments are likely to recover with abstinence from alcohol. For many, the most substantial gains occur within the first six to 12 weeks. After this, progress often flattens off, although more gradual changes can continue for up to three years[12]. Complete lack of improvement with abstinence might indicate an alternative condition, such as vascular dementia.

With abstinence and support, studies have suggested that an estimated 25 per cent of people with ARBD will recover completely. A further 25 per cent will recover partially, 25 per cent will make minor improvements and the rest will not recover[13].

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[11] Ihara H, Berrios GE, London M "Group and case study of the dysexecutive syndrome in alcoholism with-out amnesia," *Journal of Neurology, Neurosurgery and Psychiatry* 68 (2000): 731–7.

[12] Wilson K, Halsey A, Macpherson H, Billington J, Hill S, Johnson G, Raju K, Abbott P "The psycho-social rehabilitation of patients with alcohol-related brain damage in the community" *Alcohol and Alcoholism* 47, no. 3 (2012): 304-311

[13] Emmerson C and Smith J,. (2015) *Evidence-based profile of alcohol related brain damage in Wales*. Public Health Wales. p9.

However, some of these studies are old, and a number of the specialist Scottish services we have consulted promote a more positive view. Clearer definitions on what is meant by 'recovery', and further research in this area, are needed.

Treatment of ARBD

The prevention of new cases of ARBD is an important goal. This may be achieved by reducing the risk of detoxifications, through the use of medications such as benzodiazepines. Experiencing more or unnecessary detoxes will increase the overall toxic burden to the brain, and should be avoided. Administering prophylactic thiamine minimises the risk of developing WKS. In the event that WKS is suspected, thiamine should be given intravenously or intramuscularly. Long-term excessive alcohol use causes damage to bowel, kidneys, pancreas and the mucosal lining of the GI tract. Hence storage and absorption of vitamins is impaired, so intravenous and intramuscular Pabrinex are important. The organs of the body are not fully recovered after three to five days, and the British National Formulary (BNF) stresses the importance of administration of thiamine during this period. Keeping individuals on long-term vitamins might be helpful in some cases.

Recognising and identifying patients with ARBD early may reduce morbidity. Screening those referred for treatment of alcohol problems with simple cognitive tests is likely to increase detection. Many patients will present acutely to general hospitals, so consideration should be given to assessing the cognition of patients undergoing alcohol detoxes in this context, too. This may be carried out by psychiatric liaison services or specialised alcohol liaison nurses.

The ongoing use of alcohol in patients with ARBD will lead to a deterioration, therefore supporting abstinence is key. There is no safe minimum consumption of alcohol in this group, and even minimal ongoing consumption can produce a disproportionate effect on thinking and memory.

Five stages of treatment have been proposed for ARBD[14]:

1. Firstly, **medical stabilisation** is often required and is likely to occur in a general hospital. The duration will vary depending upon an individual's physical condition and co-morbidities.
2. The next phase is **psycho-social assessment** which ideally should occur in a supported, safe environment such as a specialised ARBD unit or inpatient facility. The approach is holistic and will involve doctors, psychologists, social workers, and occupational therapists. With good community care this can take place at home. It typically requires approximately three months to complete and will emphasise abstinence, good nutrition, and establishing healthy routines. It is also important to begin to develop relationships with professionals, and to involve relatives and carers if possible[15].
3. The focus of the third phase is **therapeutic rehabilitation**. This may last up to three years. Patients are encouraged to begin gaining skills in independent living through behavioural programmes and cognitive rehabilitation. Ideally, this stage will happen in a domestic context.
4. The next stage is a period of **adaptive rehabilitation**, focusing on optimising the individual's environment in order to give them the best opportunity to gain any independence possible.
5. The final phase is **long-term maintenance and relapse prevention**. Building positive social relationships and developing structure and routine have been demonstrated to improve outcomes in this context.

This model requires specialist services which are not available in many areas of Scotland. We acknowledge that, in many instances, patients with ARBD will be managed by general adult psychiatry, alcohol services, on long-stay wards, or in care homes. In the absence of a specialised provision for ARBD, it has been found that an identified care co-ordinator can improve outcomes through regular reviews and a good therapeutic relationship[16].

Specialised and co-ordinated support has been shown to be effective, particularly at the second stage of treatment, but is not yet widely available across Scotland. We are aware of a number of 'step down' units across the central belt, where adults are able to move from the acute hospital setting when they no longer require ongoing medical intervention, but are unable to return home. These services are able to provide re-enablement support while reducing the number of days spent in hospital.

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[14] Wilson K, Halsey A, Macpherson H, Billington J, Hill S, Johnson G, Raju K, Abbott P "The psycho-social rehabilitation of patients with alcohol-related brain damage in the community," (2012): 304-311

[15] Ylvisaker M, Feeney TJ *Collaborative Brain Injury Intervention: Positive Everyday Routines* (San Diego: Singular Publishing Group, 1998)

[16] MacRae, R, Cox, S *Meeting the Needs of People with Alcohol Related Brain Damage: A Literature Review on the Existing and Recommended Service Provision and Models of Care* (University of Stirling Dementia Services Development Centre: Stirling 2003)

Support is provided by in-reach NHS staff, including psychiatry, psychology, social work, and occupational therapy.

In the later stages, the long-term placement of patients with ARBD can be challenging. Individuals with more severe ARBD may require significant levels of care and protection. A small cohort of individuals may be able to return home with a high number of hours to support them and close involvement with a specialist community ARBD team. However, there are nationally few facilities that cater specifically for younger, cognitively impaired people. We are aware of a small number of supported accommodation projects specifically for individuals with ARBD, but the numbers of this type of tenancy across Scotland is low. Most care homes are established to care for those over the age of 65 and are unsuitable for younger people with ARBD. Inappropriate nursing home placements can precipitate dependency in this patient group. We believe this is a deficit which should be addressed. Meantime, where specialist accommodation is not available, people with ARBD do better in smaller institutions and sheltered housing placements[17].

Stigma

Disorders relating to drugs and alcohol are often subject to stigma, in part due to the belief that these are self inflicted. This may also be a perception shared by the individual, who may be held back in their recovery by their own views that their condition is self inflicted. In the case of ARBD, this is compounded by the broader stigma that surrounds mental illness. Often patients with ARBD belong to wider groups that are marginalised in society. Individuals commonly become estranged from their families and are socially isolated[18]. In the case of those still drinking, anti-social behaviour may be a feature. As a result, those with ARBD are at risk of being excluded from services and society more broadly.

It is not uncommon for this group to relapse to alcohol use as they recover and this can result in pessimism among health professionals. This pessimism can add to the sense that helping people with ARBD and alcohol problems is difficult and unrewarding. It is important to recognise and challenge this combination of stigma and therapeutic nihilism, which can act as a barrier to the provision of appropriate services.

[17] Blansjaar BA, Takens H, Zwinderman AH ”The course of alcohol amnesic disorder: a three-year follow-up study of clinical signs and social disabilities,” *Acta Psychiatr Scand* 86 (1992):240–6

[18] Jacques A, Stevenson G *Korsakoff's Syndrome and Other Chronic Alcohol Related Brain Damage: A Review of the Literature*. (University of Stirling Dementia Services Development Centre: Stirling, 2000)

Part 2 – responding to ARBD

Consideration of legal interventions

People with ARBD can be exposed to significant risks to their health, safety and wellbeing. They are at risk of poor self-care and nutrition, poor mobility, exacerbation or neglect of medical co-morbidities, and falls and traumatic injuries. Furthermore, continued drinking is likely to result in a progression of the features of ARBD. They may also be subject to external risks such as assault from others, domestic fires, and road traffic accidents[19]. Finally, they can be vulnerable to both financial and physical exploitation.

Successfully preventing alcohol consumption may not only avoid harm, but also create potential for improvement of functioning, and the maximising of opportunities to gain social capital and develop new interests and relationships.

There is often a conflict between respecting the individual's apparent choices and protecting a potentially vulnerable person - and sometimes third parties.

In some situations interventions may be justified under legal frameworks which apply to everyone, for example environmental health. However, where mental health or incapacity law is relevant, the assessment of incapacity, or the closely related concept of significantly impaired decision making, is of crucial importance.

Decisions taken for people with ARBD have the potential to impact on their human rights. Most human rights can be limited in certain circumstances, providing that this is proportionate, justified, and necessary. Any intervention should be made with the aim of protecting the individual or protecting others. The underlying principles contained in Scots law reflect the European Convention on Human Rights and should be considered prior to any action taking place. We have published guidance for professionals in this area,[20] and a rights pathway advising staff of the rights of individuals in contact with mental health services[21].

The use of compulsory legal measures on behalf of a patient with ARBD will depend on the circumstances of each case. Often care plans may reflect a mix of formal and informal measures, depending on the intervention required and the overall ability to consent. Compulsory measures should be a component of a wider plan for care and treatment. In considering whether to pursue a legal intervention under the Adults with

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[19] Cox S, Anderson I, McCabe L (eds) *A Fuller Life: Report of the Expert Group on Alcohol Related Brain Damage* (University of Stirling Dementia Services Development Centre: Stirling, 2004)
[20] Mental Welfare Commission *Human Rights in Mental Health Services* (Mental Welfare Commission: Edinburgh, 2017) https://www.mwcscot.org.uk/media/369925/human_rights_in_mental_health_services.pdf
[21] Mental Welfare Commission *Rights in Mind* (Mental Welfare Commission: Edinburgh, 2017) https://www.mwcscot.org.uk/rights-in-mind/

Incapacity (Scotland) Act 2000 or Mental Health (Care and Treatment) (Scotland) Act 2003, the legal principles of the relevant legislation must be applied.

An overview of the legal options available

The following outlines the three main pieces of legislation of relevance when considering issues around the care, treatment, and welfare of patients with ARBD.

All three Acts contain broadly similar statements of principle, which anyone using the legislation should apply[22].

Mental Health (Care and Treatment) (Scotland) Act 2003

The 2003 Act authorises the compulsory treatment of people with mental impairment or disorder.

ARBD falls within the definition of mental disorder (the specific term used within the 2003 Act)[23].

Dependence on, or use of, alcohol is expressly excluded from the definition of mental disorder, however in the case of most patients with ARBD such dependence may exist *alongside* mental disorder. Where someone is misusing alcohol or has alcohol dependence but has normal cognitive functioning, they will not have a mental disorder for the purposes of the 2003 Act. An individual with cognitive impairment, acute confusion, or hallucinosis, secondary to alcohol misuse, would be considered as having a mental disorder.

Importantly the power to treat under the 2003 Act only extends to treatment for the mental disorder, not unrelated physical conditions. However, physical conditions which are a cause or consequence of the mental disorder may be treated under the 2003 Act. Furthermore, the range of treatment which may be authorised under the 2003 Act is very broad[24]. Treatment can mean nursing, care, psychological intervention, habilitation (including education, training in work, social, and independent living skills), and rehabilitation. The types of treatment within each of these categories is varied and it is important that practitioners are aware of the very flexible range of options for medical treatment for patients with ARBD.

The 2003 Act authorises three main types of detention in hospital: emergency detention (up to 72 hours), short-term detention (up to 28 days), and a compulsory treatment order (CTO) which can last initially for up to six months with further

[22] Adults with Incapacity (Scotland) Act 2000 s1; Mental Health (Care and Treatment) (Scotland) Act 2003 ss1-3; Adult Support and Protection (Scotland) Act 2007 ss1-2
[23] s328
[24] s329(1)(d)

extension available. A CTO can authorise hospital or community-based treatment, and can only be authorised by the Mental Health Tribunal for Scotland.

Adult Support and Protection (Scotland) Act 2007

The 2007 Act is designed to protect vulnerable adults from harm. The Act is broad enough to cover those with capacity but who are vulnerable, and may be useful when a patient with ARBD is deemed to be at risk.

The 'three-point test' often referred to when discussing the 2007 Act is as follows[25]: An adult is deemed to be 'at risk' if they are

a. Unable to safeguard their own well-being, property, rights or other interests,
b. Are at risk of harm and
c. Because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than adults who are not so affected.

The risk can be because another person's conduct is causing, or is likely to cause, harm to the adult or, importantly, if the adult "is engaging (or is likely to engage) in conduct which causes (or is likely to cause) self-harm."

The 2007 Act does not provide for compulsory care or treatment of an adult with ARBD. It
allows for a range of interventions on behalf of an adult at risk and broadly covers three main areas;

- Inquiries and investigations
- Protection orders
- Adult protection committees

Inquiries and Investigations

If a local authority becomes aware that an adult is at risk, there is a general duty under the 2007 Act to carry out inquiries and investigations. An inquiry is where the local authority needs to establish if an adult is at risk and requires any interventions. An investigation should be undertaken if the outcome of inquiries determines an adult is at risk and that the individual may need support and protection, with possible use of legislation.

Often people with ARBD will come to the attention of formal agencies as a result of an adult support and protection (ASP) referral, for example where there has been involvement with emergency services. The use of ASP multi-agency procedures offer opportunities to further investigate a person's circumstances and bring together a combined approach.

[25] Adult Support and Protection (Scotland) Act 2007, s3(1) (2)

These may not result in an application to court under the 2007 Act. Often the issues may resolve informally with appropriate informal supports, monitoring of the individual being put in place, or intervention under the 2000 or 2003 Acts.

Protection Orders

The Act provides for a range of protection orders to deal with situations when an adult is at risk from harm or abuse. These are short-term powers which may be used to temporarily remove a person from an unsafe situation. Generally speaking, the individual must consent to these orders, unless they are considered to be subject to undue pressure from another adult or adults. Where an individual is subject to coercion or abuse from another person, it is also possible to apply for a banning order preventing the third party from being in a specified place such as the adult's home.

Adult support and protection (ASP) committees

The Act places an obligation on all local authorities to establish multi-agency ASP committees. They are responsible for monitoring and advising on adult protection procedures and practice, ensuring co-operation between agencies, and improving the skills and knowledge of those with a responsibility for the protection of adults at risk. All of these issues become important when ensuring that the complex needs and risks of people with ARBD are highlighted and monitored.

Adults with Incapacity (Scotland) Act 2000

The 2000 Act provides the general legal framework with regards to decision making for adults who lack capacity in relation to their welfare, property, or finances. The Act is wide-ranging and provides for powers of attorney, guardianship and intervention orders for adults who lack capacity to make specific decisions about their welfare and/or finances[26]. It also contains provision regarding medical treatment for a person who is incapable of consenting[27]. We discuss the use of guardianship in detail later in this guidance.

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[26] Mental Welfare Commission *Working with the Adults with Incapacity (Scotland) Act* (Mental Welfare Commission: Edinburgh, 2007) https://www.mwcscot.org.uk/media/51918/working_with_the_awi_act.pdf; Mental Welfare Commission *The Adults with Incapacity Act in general hospitals and care homes* (Mental Welfare Commission: Edinburgh, 2017) https://www.mwcscot.org.uk/media/339351/awi_in_general_hospitals_and_care_homes.pdf

[27] Mental Welfare Commission *Consent to Treatment* (Mental Welfare Commission: Edinburgh, 2018) https://www.mwcscot.org.uk/media/392186/consent_to_treatment_2018.pdf; Scottish Government *Adults with Incapacity (Scotland) Act 2000: Code of Practice (Third Edition): For Practitioners Authorised to Carry Out Medical Treatment or Research Under Part 5 of the Act* (Scottish Government: Edinburgh, 2010) https://www2.gov.scot/Publications/2010/10/20153801/0

Advocacy

The Mental Health Act affords everyone with a mental disorder a right of access to independent advocacy. This right is not restricted to those subject to compulsory measures under the Mental Health Act. Problems with short-term memory and recall are a key feature of ARBD, and patients may benefit from the introduction of an advocacy worker to support their engagement and decision making throughout the care and treatment process.

The 2000 Act does not provide an express right to advocacy, but encourages its use. The role of advocacy is key when consideration is being given to applications for welfare guardianship or intervention orders. An advocate can help the individual with case conference attendance, discussions on care planning, and court proceedings. Likewise there is an ongoing role in terms of long-term support, care plan review, and any legal review in terms of claiming rights.

Section 6 of the Adult Support and Protection Act places a duty on a local authority to have regard to "the importance of the provision of appropriate services including independent advocacy." The participation of the adult, and their views and wishes, are also central to adult support and protection.

Assessment of capacity and decision-making ability in ARBD

An assessment of an individual's capacity may be required for a variety of reasons and take a number of forms: an initial assessment to determine whether statutory intervention is required, an assessment for the purposes of confirming incapacity to trigger the use of welfare powers under a power of attorney, or a statutory medical report to accompany a guardianship application[28].

Best practice in undertaking a capacity assessment[29]

An important consideration is the timing of the capacity assessment. ARBD produces significant deficits in memory and thinking which may impair capacity. In a patient who continues to drink, these deficits will worsen, while with abstinence there may be improvement[30]. This improvement can lead to better functioning and regaining capacity. For this reason, in those who achieve abstinence, any definitive capacity assessment should be deferred to allow for this. The clinical course of ARBD would suggest that while improvements may continue for many months of abstinence, the greatest changes will take place within the first 12 weeks. We suggest that a formal

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[28] Adults with Incapacity (Scotland) Act 2000 s57(3)(a)

[29] NICE *NG108: Decision Making and Mental Capacity* (2018) https://www.nice.org.uk/guidance/NG108. This relates to English law and is not specific to ARBD, but is useful for general advice on capacity assessments.

[30] Cox S, Anderson I, McCabe L (eds) *A Fuller Life: Report of the Expert Group on Alcohol Related Brain Damage* (2004) For more general guidance on capacity, albeit in an English context, see NICE Guideline NG108 on Decision Making and Mental Capacity: https://www.nice.org.uk/guidance/ng108

capacity assessment should ideally take place at between six and 12 weeks' abstinence.

The following describes our view of an optimal three-stage assessment process, but we recognise that many assessments will take place in far from optimal settings or situations. This may relate to ongoing alcohol use, non-optimal distance from alcohol use, incomplete information, and poor setting. If patients continue to drink alcohol, acute intoxication will hinder their thinking, judgements, and any attempts to assess their capacity to make decisions. Health professionals may find it difficult to meet with patients when they are not under the influence of alcohol.

The first step is detailed information gathering. This will include personal, family, and social history. A focus should be on relationships or community links which have been retained. It may be hampered by the lack of family or a wider social network to provide collateral information. There should then be the consideration of recent risks. This information may come from GP, medical records, social work accounts, and family reports. A detailed account of the current social circumstances, finances, and supports from a social worker or carer will also be essential. This should be followed by an up-to-date functional assessment from occupational therapists, nursing staff, and support staff. This can often reveal a surprising degree of impairment. Information about functional ability may be at odds with the individual's own view, and will also be crucial evidence in the event of court presentation. A multidisciplinary team (MDT) meeting will be a useful forum for information gathering and sharing, and to come to a consensus about issues affecting capacity and risk to the individual.

The second stage is the patient assessment. This may have to take place in the patient's home or their current hospital placement. Ideally, however, the assessor should seek a neutral setting, free from distractions, and allow plenty of time. In taking the history it is useful to break up large volumes of information. This will maximise any residual capacity an individual may have. Providing written or pictorial information might be helpful.

A key focus of assessment of capacity is definitively establishing the diagnosis, including obtaining up-to-date cognitive testing. Incapacity cannot be inferred from any particular objective score, but it will give some measure of severity. The process of obtaining cognitive testing can also give useful information as to the individual's information processing and decision making, and demonstrate evidence of cognitive rigidity, perseveration (for example repetition of a particular response). The adult's attitude to alcohol, including whether they are prepared to consider abstinence, will be important. While a refusal to stop drinking is not in itself proof of incapacity, it is common for patients with ARBD to lack insight into their problems and the associated risks. This often means that they are not co-operative with attempts to assess their capacity.

Applying the legal criteria to people with ARBD

Assessment of capacity for an intervention under the 2000 Act must be in line with the test in statute[31]. Practitioners making an assessment of capacity for an ARBD patient should consider whether the individual:

1) Has a general understanding of the decision required, the information relevant to the decision, and an understanding and belief that the decision and information are relevant to them at the current time,
2) has an adequate knowledge of the risks and benefits associated with the decision, is able to retain this knowledge, and use and weigh it in coming to a decision,
3) is aware of alternatives and the consequences of acting, and not acting,
4) is not under undue external influence, and is aware of their right to refuse any choice or intervention, and
5) how their current choices and actions align with their previously expressed views and their family, social, and cultural background.

Capacity should be assessed in the context of *the particular decisions that require to be made*. It is contrary to the principles of the 2000 Act to assess capacity in a general sense.

ARBD patients can often initially present as having a greater degree of capacity than they actually have, due to preserved verbal skills and a good social façade. Particular consideration should be given to factors seen in ARBD patients:

Acting and making decisions

In some patients the impairment may be so severe that they do not even realise there is a decision to be made. Many potential decisions relate to addressing risk. The patient may have no insight as to their deficits, or fail to appreciate or remember information they have been told about risk.

Frontal lobe damage can mean that the person being assessed may be unable to act to safeguard their own interests e.g. gatekeeping their own tenancy, buying and eating nutritious food, looking after their own personal care, keeping away from others whose intention is to exploit them.

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[31] Section 1(6) Adults with Incapacity (Scotland) Act 2000. An adult has incapacity in relation to a decision if they are incapable of:

- Acting; or
- Making decisions; or
- Communicating decisions; or
- Understanding decisions; or
- Retaining the memory of decisions

by reason of mental disorder or inability to communicate that can't be rectified.

Communication
This is often apparently unimpaired. Compared to other dementing conditions, patients with ARBD often have preserved verbal abilities[32] and may exhibit confabulation. This can result in an ability to give plausible, but false, explanations and answers to questions.

Retain memory of decisions
Poor memory, particularly working memory, is a feature of most ARBD cases. In relation to capacity decisions, the issue to be decided is whether they can they retain information pertinent to the decision long enough to use it. Poor memory can also lead to an underestimation of risk, due to the inability to retain information about those risks or appreciate recent deterioration in function.

Understanding
The issue of whether the patient is able to understand the information sufficiently to make a decision can be the most difficult of all. It is possible for different practitioners, making the same observations and using the same information, to come to a different view. The issues for consideration are whether the person is able to believe the information about their deficits, appreciate its personal relevance to them, and use and weigh the information, particularly as the situation changes or deteriorates due to a cognitive rigidity. The interviewer should explore the contrast between the patient's understanding of their situation and the risks, and the objective account gathered above.

Assessments of capacity in ARBD should not be made on one occasion only. Given the possibility of fluctuating cognition and capacity, regularly reviewing this decision at roughly six-monthly intervals is recommended.

Completing court papers in guardianship applications

In the completion of a statutory medical report to accompany a guardianship application the doctor must specify the mental disorder in terms of the meaning specified in s328 of the 2003 Act. This will generally state 'alcohol-related brain damage', with or without additional diagnoses. In the medical opinion, the practitioner should set out:

- The results of their assessment, and in particular how the identified medical condition affects the individual's capacity,
- the likely duration of the incapacity, the extent to which they have been able to communicate with the individual, and
- the extent of consultations with other people with knowledge of the individual.

[32] Bates ME, Barry D, Bowden SC "Neurocognitive impairment associated with alcohol use disorders: implications for treatment," *Exp Clin Psychopharmacology* 10 (2002):193-212.

Where the doctor is asked to indicate the likely duration of the incapacity, this can be difficult, as dramatic improvements are possible in the early stages of abstinence. It may be appropriate to bear in mind that, with appropriate care, there is the potential for gradual improvement, with the extent and timescales of possible improvement in line with the timescales suggested above.

Significantly impaired decision making (SIDMA)

In order to detain or compulsorily treat an adult under the civil provisions of the 2003 Act, it is necessary that the adult has, or is likely to have SIDMA[33]. The code of practice for the Act explains[34] that the factors which may establish that a person has SIDMA are similar to those which are relevant to incapacity. However, the intention is that the test is less binary in nature, and can be applied more flexibly[35].

The time available for an assessment of SIDMA is likely to be short, so not all of the features of best practice described in relation to a capacity assessment may be practicable, but they are still relevant so far as they can be achieved.

Interventions while capacity is maintained

Case study 1 – John

John is 66. He is a retired professional who lives alone with no family contact. The Scottish Fire and Rescue Service have made several ASP referrals following small accidental fires in his house. The conditions in his house are described as squalid. John was intoxicated and unsteady on his feet each time the fire service have responded. Social work has visited, but John refuses all offers of intervention. Neighbours and a local councillor have complained that something should be done.

Two ASP case conferences are convened within a brief period. Initially John is judged not to meet the three-point test for an adult at risk of harm, because there is not strong enough evidence of his being "affected by disability, mental disorder, illness or physical or mental infirmity", which has led to his being particularly vulnerable. At the second conference a removal order is considered, to get access to the house to clean it. John has refused access saying he had valuable items all over his house. John puts his views forward clearly at the conference and is thought to have capacity. He does not consent to the removal order.

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[33] For Compulsory Treatment Orders see Mental Health (Care and Treatment) (Scotland) Act 2003 s64(5) (d)

[34] Scottish Government, *Mental Health (Care and Treatment) (Scotland) Act 2003 Code of Practice Vol 2* (Scottish Government: Edinburgh, 2005): 22-27

[35] For a discussion of the nature of SIDMA, albeit with a different patient group, see Mental Welfare Commission *'Significantly impaired decision-making ability' in individuals with eating disorders* (2017) https://www.mwcscot.org.uk/media/190042/sidma.pdf

Both addiction services and the community mental health team feel they cannot work with John, as he is continuing to drink. After another incident in his home, and an additional referral from the GP to the addiction team, a worker is allocated who works jointly with social work services. The support worker visits John at home to talk to him and persuade him to agree to minimal support. The purpose of this is to see John regularly, build a relationship with him, and ensure his home is maintained to an acceptable level.

In addition, staff can ensure that John is taking nutrition and build up a clearer picture of his overall needs. On the days John can't eat, he will agree to a cup of hot Bovril which provides him with nutrients he needs. Support staff are also keen to ensure that John's environment is safe and that the fire risks are diminished.
It is agreed to keep capacity and the three-point test under regular review, and to monitor how well he tolerates the planned interventions.

Learning points and best practice

- Building a fuller assessment – many individuals such as John will strongly oppose intervention from services, insist on drinking, and have no support. In instances such as this, minimal contact, which is primarily performing a basic welfare check, can also add to a fuller assessment over time. With regular brief contact, support staff may be able to determine small changes and deterioration in both physical and mental health. This can be key to assisting professionals in knowing when to intervene.

- Individuals with an alcohol problem can sometimes present well, and articulate their needs clearly even when still drinking. This can be superficial. Assessment in these situations should take place over a period of time and involve a holistic approach, with consultation taking place with as many different professionals as possible.

- Consideration should be given to noting how many ASP referrals are being made in relation to an individual with ARBD. Even if a person is deemed not to meet the three-point test, a series of referrals within a short space of time should trigger consideration of a case conference.

- Regular nutrition plays a vital role. Deficiencies can occur with thiamine, a type of vitamin B, when an individual is only consuming alcohol. Provision of nutrition high in vitamin B can help John in the long term. Identifying who has responsibility to take on this role is important at a case conference stage.

- Many addiction services will adopt a policy of individual responsibility in relation to individuals being referred. That is, the will and motivation to stop drinking has to be evident so that work can progress. Many people with ARBD are past the point of wanting to stop drinking, or not able to recognise that they have an issue. They will state clearly that they do not wish to engage with

services and want to continue to drink. This can lead to services not taking on referrals, or removing individuals from waiting lists. While we recognise why some services operate with this ethos, ultimately local authorities and the NHS have a responsibility to ensure support is available for people who are incapacitated by ARBD to an extent which prevents them from engaging on a voluntary basis.

- Even where an individual meets the three-point test under the 2007 Act, formal intervention may not be indicated. In this case the removal order cannot proceed, because John does not consent and there is no evidence of undue pressure. But the duty to investigate under the Act, and to bring together agencies, can lead to a more co-ordinated plan which may keep John safe or help establish the basis for a later intervention.

- Some people will have very little contact with health and social care services and, if owner occupiers, with housing agencies. Organisations such as the Fire and Rescue Service can play an important role in identifying people at risk[36].

Interventions where capacity is more uncertain

Case study 2 - Lisa

Lisa is 40 years old and lives in a flat rented from the local authority. She has been drinking on a regular basis for the last five years but is still in employment. She has two children of primary school age. Lisa has an adult social worker who has been trying to get her engaged with addiction services. Lisa is often under the influence of alcohol when the social worker visits, but has refused all offers of support. The situation deteriorates over time and the children are placed with foster carers. Lisa also loses her job. Her mood is low and the house is becoming more and more unkempt.

Environmental health and housing become involved due to the poor condition of the flat, and are considering taking action to evict her from the tenancy. The social worker feels that Lisa's cognitive abilities are impaired.

A multi-disciplinary case conference is called by social work under the 2007 Act. Given her diagnosis of depression, coupled with her alcohol dependence, the local authority feel that Lisa meets the three-point test and is at risk of emotional and financial harm. An ASP protection plan is drawn up.
The plan includes the following:

[36] Discussed further in Care Inspectorate and HMICS *Joint Inspection of Adult Support and Protection* (2018) http://www.careinspectorate.com/images/documents/4453/Review%20of%20adult%20support%20and%20protection%20report%20(April%202018).pdf

- Social work services arrange for the flat to be cleared of debris and cleaned. The cost of this is met by social work, as Lisa is in debt and has limited funds.

- A specialist mental health homecare team is allocated to support Lisa, by visiting on a regular basis and building up a relationship with her. At the same time staff are monitoring her well-being and her safety at home.

- The GP is identified to assess her capacity in relation to welfare decision making with the aim of this being kept under review by the same GP and consideration given to reassessment by specialist services. At this point, the GP concludes that Lisa retains capacity.

Lisa continues to drink to excess and is often found on the floor when home care workers go in. Lisa agrees to a key safe, as long as workers from the mental health team knock and wait to be asked to come in. They agree with Lisa that they will only use the key safe if they are unable to gain entry. Over time, Lisa gets to know the team members and does not object when they clean up around her. She remains passive most of the time but is also very angry and upset at times that her children were removed. However, she does not keep to contact arrangements, despite support from social work to help her to do this. Her alcohol intake does not reduce.

Learning points and best practice

- This case study highlights the dilemmas around intervening with individuals who are drinking heavily, but have yet to be diagnosed with ARBD. Often there will be poor engagement with services and all offers of support are refused. Common issues identified by social work staff at this point will be a deterioration in physical health, and a steady decline in household maintenance. The former can lead to brief hospital admissions, involving GPs and hospitals, while the latter can result in numerous house cleans and attract the attention of housing services. Both health and housing authorities can struggle to make inroads into these situations, and it is social work services that require to co-ordinate the multi-agency response.

- Assessment of capacity – in this instance this is undertaken by GP, but not all practitioners are confident in this area and it may be worth being clear with the local GP about what level of assessment is required. There can be a reluctance for community mental health teams to take on a role if an individual is not known to their service. It is our opinion that capacity assessments are within the responsibilities of the GP or an approved medical practitioner (AMP) based in the community mental health team (CMHT), although they should consider when a more specialist assessment should be initiated. This can be frustrating for staff concerned particularly if capacity is viewed to be fluctuating. It is important to keep this under review.

- The use of the 2003 Act or the 2000 Act in a case such as this may be appropriate and professionals should understand and reflect collectively on the legislative options, although, as here, it may often be concluded either that the statutory tests are not met or the use of compulsory interventions is not justified. At times, a limited and consistent care plan may be the best that can be achieved.

Using the Mental Health Act in urgent situations

Case study 3– Tadeusz

Tadeusz is a 55-year-old man with a long history of alcohol dependence. He has previously worked with alcohol services, but is not currently in follow-up and is drinking six litres of strong cider a day. He lives in a homeless hostel and has little contact with his family. He regularly has admissions to hospital in relation to falls and liver disease.

There has been concern from staff that Tadeusz's memory is worse and that he is not functioning as well as he did. However, until now it has been felt that he has the capacity to make his own welfare decisions and has not been suffering from a mental impairment, other than alcohol dependence.

Tadeusz has another fall and his GP visits him at home. He is prescribed opiate painkillers for his injuries. Tadeusz is not able to get out for a few days, and the hostel staff refuse to buy him cider. Two days later, they contact the GP again with concerns that Tadeusz seems agitated, more confused, and is uncharacteristically aggressive. His GP visits and finds him disorientated, unsteady on his feet, and with a cut to his forehead.

The GP recommends admission for Tadeusz to investigate his confusion and head injury, but he refuses to accept this voluntarily. Given the suspicion of a mental disorder in addition to dependence, Tadeusz's impaired decision making, and the significant risks to his health and well-being the GP detains him under an emergency detention certificate (EDC).

Tadeusz is brought to the emergency department and has a brain scan, which does not reveal any significant abnormalities. It is thought he may be suffering from delirium tremens, WKS, or hepatic encephalopathy precipitated by the opiates. He requires treatment for his alcohol withdrawals, and thiamine. The EDC authorises his detention in hospital, and an approved medical practitioner (AMP) and mental health officer (MHO) review is arranged for the following morning.

Overnight, Tadeusz becomes very behaviourally disturbed, and ultimately breaks a sink and assaults a nurse. He appears very frightened and is "seeing things". A senior doctor decides that urgent treatment is required and that this can be

authorised by s243 of the 2003 Act. Tadeusz receives diazepam, and quickly becomes much more settled.

The following morning, the AMP and MHO agree to convert the EDC to a short-term detention certificate (STDC) and, after a further three days in hospital, Tadeusz appears more settled. An Addenbrooke's Cognitive Examination ACE-III is performed and he scores 84 out of 100, suggesting mild cognitive impairment. On further discussion, Tadeusz's decision making is improved, he is felt to have regained decision making ability, and the STDC is revoked. He is discharged with reiterated advice about support from alcohol services.

Learning points and best practice

- An EDC authorises a person to be held in hospital for up to 72 hours while their condition is being assessed, provided the conditions of the 2003 Act are met. There must be a reasonable suspicion of a mental disorder. New or additional mental health conditions, such as delirium or ARBD, can authorise detention in individuals who are alcohol dependent.
- Even in cases where an individual has been deemed to have capacity, the situation can change rapidly, especially if there are concurrent physical ill-health or withdrawal symptoms.
- Crisis admissions should primarily be for the safe management of the emergency situation. However, they can allow for short periods of assessment of cognition and functioning without the influence of alcohol.
- An EDC does not authorise the giving of medical treatment without consent. Urgent general medical treatment may be administered to a patient subject to an EDC under s243 of the 2003 Act[37].
- Provided the conditions are met in terms of the Act, a STDC can be used as authority to remove a patient with ARBD to hospital, transfer the patient from a general hospital to a psychiatric hospital, detain the patient for up to 28 days, and give the patient medical treatment in terms of part 16 of the Act. A STDC may be appropriate in the case of acute withdrawal and allow further assessment.
- Ideally, people might leave from a short period of detention with a more comprehensive discharge plan. We recognise this is often not the case.

[37] Where it is necessary as a matter of urgency, treatment can be given for the purposes of saving the patient's life, preventing serious deterioration in the patient's condition, alleviating serious suffering on the part of the patient and preventing the patient from behaving violently or being a danger to self or others. See Scottish Government, *Mental Health (Care and Treatment) (Scotland) Act 2003 Code of Practice Vol 1* (Scottish Government: Edinburgh, 2005): Ch 10 paras 81-87

Longer-term interventions

Using the Adults with Incapacity (Scotland) Act 2000

A welfare guardianship order may be sought when a person is deemed incapable of making decisions about their welfare and finances. It is an important piece of legislation in planning and managing the future needs of individuals with ARBD, and can confer a range of powers on an appointed welfare guardian.

A guardianship order should be part of a wider plan for the care and treatment of the patient, and will in many cases be a tool to underpin the care plan.

What powers should be sought?

With the exception of a few limited prohibitions[38] the Adults with Incapacity Act has a wide scope, conferring powers to deal with matters in relation to the adult's property, financial affairs, and/or personal welfare. The powers sought should be based on the needs and strengths of the individual, and should be personalised. They should not necessarily be limited to those that might be immediately required. Any powers that might be deemed necessary for the duration of the guardianship order should be included, provided this can be evidenced and supported by the principles of the Act.

Some general powers, for example to determine where the individual should live, are commonly sought. Where ongoing alcohol misuse is an issue, it is often appropriate to seek some specifically tailored powers. We believe this needs to be better understood. We looked at powers relating to welfare guardianship orders relating to ARBD for a six-month period, and found that less than half featured targeted powers that aimed to address drinking or problem behaviours associated with this.

The following specific powers might be useful:

- To consent, or withhold consent, to the consumption of alcohol on behalf of the adult;
- to restrict the adult's access and consumption of alcohol, and to take any necessary steps to prevent the adult consuming alcohol;
- to make decisions about, or to consent or withhold consent on, the adult's participation in cultural, social, or recreational activities;
- to decide who shall accompany the adult on cultural, social, or recreational activities;
- to decide with whom the adult can consort;
- to search the adult's accommodation for the purposes of finding and confiscating alcohol; or
- to consent, withhold consent, or make decisions about any person having access to or contact with the adult.

[38] Adults with Incapacity (Scotland) Act 2000 s64(2)

It is important when considering powers that the necessary care and support to implement the powers are available. Authority can be delegated, for example to care staff, and it is important that the care providers are aware of these powers, their legal authority, and how they can implement these powers.

We do not cover financial guardianship in this guidance. Where the individual's only resources are social security benefits, these may be appropriately managed under Department of Work and Pensions (DWP) appointeeship. If the individual has other funds, financial guardianship, a financial power of attorney, or management of the funds under part 3 or 4 of the 2000 Act may be appropriate. For further guidance, see the Commission's publication *Money Matters*[39], and the website of the Office of the Public Guardian (Scotland)[40].

Who should act as welfare guardian?

If it has been determined that a guardianship order is appropriate, the question of who should be appointed requires careful and early consideration. The 2000 Act allows *any* person claiming an interest in the property, financial affairs, or welfare of an incapable adult to seek appointment as guardian, either on their own or jointly.

The local authority is under a duty to apply where no application has been made, or is likely to be made, where an individual is incapable and there is no other appropriate way to safeguard or promote the individual's property, financial affairs, or personal welfare[41].

It is important to ascertain quickly if there is someone both suitable and willing to seek appointment as guardian, failing which the local authority should take steps to promptly progress an application[42].

Where a suitable private individual is willing to apply to be welfare guardian, they need to be aware that, even with legal aid, there may be residual costs at the outset. They also need to be aware that if they were to be appointed, this may bring them into conflict with the individual. Will they be in a position to exercise and, where necessary, enforce the powers that they have been given? Is the prospective guardian in a position to instruct a solicitor, and engage with the legal process without delay?

[39] https://www.mwcscot.org.uk/media/216003/money_matters.pdf
[40] http://www.publicguardian-scotland.gov.uk/
[41] Adults with Incapacity (Scotland) Act 2000 Section 57(2)(b)
[42] Section 57(1)

While the 2000 Act prohibits a local authority from seeking appointment as financial guardian, the authority may submit the application and propose an independent financial guardian be appointed, for example a local solicitor.

The Court process

The Sheriff Court deals with all guardianship applications under the 2000 Act. Following the necessary statutory reports, the application may be subject to further delays due to notification periods, court time, or the appointment of a safeguarder[43].

Interim orders for guardianship can be sought in cases where powers are needed urgently[44]. However, a full summary application with the accompanying statutory reports will still be required. Therefore where urgent intervention is required, consideration of the Mental Health Act and ASP Act may be necessary.

Non-compliance with a guardianship order

Welfare guardians are entitled to apply to the sheriff for an order ordaining the individual to comply with the decision that they have made on the adult's behalf, in terms of the powers that have been granted to them. A warrant can also be sought to order a third party, such as a relative or carer, to implement a guardian's decision, in the event that they are not complying with a decision of a guardian in terms of the powers.[45]

If an adult fails to comply with a decision as to their place of residence, the sheriff can grant a warrant authorising a police officer to enter premises where the adult is and remove them to such a place as the guardian directs. The 2000 Act only makes specific provision for a warrant authorising a police intervention when the failure to comply relates to the individual's place of residence.[46]

In the case of a patient with ARBD, if all other options are exhausted, a warrant may be useful as a last resort when conveying them to new place of residence in the event of refusal to go, with all other options being exhausted, or returning them to that place in the event that the adult absconds.

Any application to the sheriff seeking such a warrant would be a last resort and would require to demonstrate that it complies with the general principles of the Act. It would be for the guardian to demonstrate that the granting of the warrant would be

[43] Section 3(4)
[44] Section57(5)
[45] Section 70
[46] Section 70(1)(b)

the only means of achieving the proposed benefit to the adult, and that other means have been exhausted.

The sheriff has the power to dispense with the requirement for notice to the adult of such proceedings in cases of extreme urgency and high risk.[47]

Case study 4a - Iain

Iain is a 58-year-old man, with a long history of alcohol dependence which began after he left the army. He separated from his wife some years ago as a result of his drinking. He lives alone in a housing association tenancy, and has had very little contact with social or health services.

Iain is admitted to hospital following a serious physical assault, during which he sustained a head injury and a fractured arm. He requires treatment for alcohol withdrawal and is given i/v thiamine. Unfortunately he remains very confused, is determined to self-discharge, and is unaware of the risks he would pose to himself if he left the hospital. He is placed on an STDC under the 2003 Act. Psychiatry are able to conduct a thorough assessment of his cognition and it is confirmed Iain has ARBD and ultimately meets the criteria for further detention under a CTO.

It is clear that his decision-making ability is severely impaired. Iain's mental health officer (MHO) completes a social circumstances report. They discover that Iain has been allowing acquaintances to use his flat as a place to drink, and it is likely they have also been financially exploiting him. The ward physiotherapist and OT assess Iain, and report significant concerns about his risk of falls and his functioning. Care in his own home is no longer an option.

Iain remains in hospital, but the orthopaedic team feel he is "medically fit" for discharge and there is some pressure to find a placement for Iain. Staff on the ward feel frustrated with his inappropriate placement, and Iain is very restricted in terms of his activities. He is now homeless and will require a great deal of support due to his ongoing cognitive impairment. Iain is more settled in terms of his behaviour as he has become accustomed to the environment and his responsible medical officer (RMO) is able to revoke the CTO as it is no longer necessary.

Fortunately, a local ARBD unit has recently been set up, where patients with ARBD can be transferred for treatment and rehabilitation. Iain is assessed by this service and accepted. Following transfer there, Iain settles in well. He engages in the group activities and enjoys the company of the other residents. He is gradually encouraged and supported to do more for himself, including washing and shopping. He is assessed by the specialist OT and psychologist.

[47] Section 70(4A)

Iain's cognition is slow to improve, particularly his short-term memory. Despite stating he would like to remain abstinent, this is variable, and support staff have observed him in the alcohol aisle at the supermarket when on supervised passes. He does not fully understand and believe the role of alcohol in ARBD. The decision to proceed to welfare guardianship for Iain is discussed at an AWI case conference, attended by psychiatry, the unit nurse manager, the OT, physiotherapy, and the MHO. Those who attend comment on Iain's capacity, and discuss his current support needs. Iain and an advocacy worker also attend and Iain's wishes to be discharged are recorded.

At the case conference there is a discussion of the powers, how they are to be used, and how they would be linked into a care plan. The powers under consideration relate to the areas where Iain lacks capacity, but also promote the use and development of his residual skills. Iain is opposed to the welfare guardianship order, and does not recognise that he has an issue with alcohol. He feels that he can safeguard his own welfare, and that he should be allowed to return home. He does not agree with plans for him to move to a supported residential setting.

Learning points and best practice

- It is important that key staff who are able to contribute specific information in relation to capacity, behaviours, and future care planning attend the case conference. If attendance is difficult, then written statements or reports should be provided in advance.
- The presence of an individual with ARBD on a general hospital ward can be challenging, and there is often pressure on social work staff to relieve bed space. This is understandable, but it is important for ward staff to understand the condition and the process required to authorise a safe and legal discharge. A person with ARBD and complex care needs should receive a full assessment and care plan which provides for those needs to be met in the community, upon discharge.
- There are very few specialised ARBD units available. However, where present, such units are able to provide specialised rehabilitation for patients with ARBD, as well as expertise in terms of the assessment of capacity in this cohort.
- Some powers may be delegated to residential care staff. These may be difficult to implement. Staff must feel confident that they have the legal authority to act. This is often not conveyed, and at times knowledge of powers is limited. These discussions and decisions should be recorded. We recommend a copy of the order and the delegation of powers is kept with an individual's care plan in a care setting.

- Powers under guardianship may be used to prevent the individual from consorting with people who may exploit or abuse them. An alternative approach is to consider a banning order under the 2007 Act.[48]
- Although welfare guardianship is normally the preferred option for long-term management of someone who lacks capacity, a community-based compulsory treatment order (CCTO) under the 2003 Act may also be considered, as a way to ensure structure and support continues to be provided. Under a CCTO, the individual can be required to reside at a specified place, attend specified places to receive treatment or services, and to allow professionals or care providers to visit the individual.

Maintaining support during recovery

Case study 4b – Iain

Iain is now in a residential setting, and has been abstinent from alcohol, is eating well, and taking part in some activities. This is assisted by the powers contained in the welfare guardianship order, and the provision of good care and support. After eight months he appears to have regained some elements of capacity. Iain complains of being bored in his current setting and frequently talks about his past home. The social worker is aware that Iain may no longer meet the grounds for all of the powers contained within the current welfare guardianship order, and that his capacity should be reassessed. The MHO/social worker is required to advise Iain of his rights, which includes the right to challenge the guardianship on the basis that he may no longer be incapable of making some welfare decisions.

Iain, although well looked after, is miserable, and has begun to refuse to engage with activities at the care home. He is frustrated at not being able to resume his past social life, but has no insight that this led to his diagnosis of ARBD. His social worker organises a review of his capacity by his local mental health team.

Learning points and best practice

- It is important that a thorough reassessment of care needs, care deficits, and capacity takes place, which takes into consideration supporting information from care staff. For example, are they able to evidence from Iain's behaviours that he is actively seeking alcohol? What are his current views on alcohol, and his understanding of its likely effects on him? If an individual does not have the capacity to understand the consequences of drinking again, this aspect of decision making may need to be tested before revoking the powers completely.

[48] Adult Support and Protection (Scotland) Act 2007, sections 19-34. This can bar someone from being in a specified place, such as the home of an adult at risk. Further information is in *Adult Support and Protection (Scotland) Act 2007 Code of Practice* (Scottish Government: Edinburgh 2008) Ch 11 https://www2.gov.scot/Publications/2009/01/30112831/13

- The medical assessment needs to clearly address the legal criteria of incapacity, but should also be set in context of Iain's history of misuse of alcohol and what has brought him to his current position. Some individuals can present as articulate, well presented, and can superficially present with capacity at the point of assessment. It is important that the assessment is undertaken by an AMP and preferably someone with experience in this area.
- Even if professionals are confident that an individual would continue to benefit from structured care and abstinence, a guardianship order can only be maintained in the long term if the conditions continue to be met, including that the individual lacks capacity in relation to some decisions. Unlike the Mental Health Act, the AWI Act does not specifically provide that there is a responsibility to revoke the order immediately if someone regains capacity. It is reasonable to consider if this could be a transient and short-lived recovery. The powers could continue to be used for a period, pending a fuller assessment and consideration of available options.
- Ultimately, if there is evidence of a sustained regaining of capacity, the local authority should consider revoking the order[49]. Iain should also be advised of his ability to seek a recall of the order[50]. He should be assisted by legal support and advocacy.
- A decision by the local authority to revoke a welfare guardianship order should, if possible, be made following a multi-agency case conference where a consensus agreement is reached. Likewise, if after a period in the community Iain's care plan is not effective, then a discussion about the future use of guardianship should be held within this forum. Best practice would suggest that Iain's return to the community could be tested from the security of the care placement. It is essential for the MDT to recognise aftercare planning as their continued responsibility.
- If an individual dislikes the constraints of a care setting this needs to be taken seriously, even if there is good reason to believe it is keeping them safe. This reflects the principles of the AWI Act, and the requirement under the United Nations Convention of the Rights of People with Disabilities to respect the "rights, will and preference" of disabled persons. Adults with ARBD might reasonably be miserable in some of the care settings in which they are placed. They should be entitled to a care setting which reflects their age and interests, just like anyone else. In considering ongoing compulsion, it is important to consider if this will be breaching someone's human rights by imposing a way of life which may be intolerable to them. The answer should

[49] Under s73 of the 2000 Act, the local authority may recall guardianship if the grounds are no longer met. Under s73A, if the guardian is the Chief Social Work Officer, other interested parties may object and the matter would then be referred to the sheriff.

[50] The adult can ask the local authority to recall the order under s73, or apply to the sheriff under s71. A form to apply to the local authority can be downloaded at https://www2.gov.scot/Topics/Justice/law/awi/forms/Local-Authorities/newformawi12word

not be to abandon this group to their fate, but to develop more appropriate services.

- If it is established that capacity is recovered, professionals may ultimately have to accept that people with capacity are entitled to resume a self-destructive lifestyle. But services should do all they can to plan appropriately before ending an order, put in supports, and consider ongoing ASP issues. As discussed in part 9, vulnerability may be a component of incapacity if it can be established that a person is at severe risk of exploitation by others, and lacks the executive function to protect themselves.

Summary – key learning points

1. ARBD is a mental impairment, with a significant disease burden, and NHS boards and local authorities have a responsibility to provide appropriate supports, including measures directed at prevention and early intervention.
2. There are examples of excellent practice which should be used as a basis for the development of ARBD services nationally.
3. Many people with ARBD will initially present to generic services (A&E, police, housing, GPs), and there should be clear pathways to access appropriate assessment and care planning. This will potentially save money and reduce demands on frontline services.
4. Building trust and a therapeutic relationship, and long-term multi-disciplinary interventions, are crucial.
5. There are effective treatments for ARBD, and legal interventions can often help to ensure these treatments can be delivered, and the chances of long-term recovery maximised—whether short term interventions in a crisis using the ASP Act or the Mental Health Act, or longer term measures under the AWI Act.
6. For interventions under incapacity and mental health law capacity, incapacity, and SIDMA, are fundamental. There are particular challenges in carrying out capacity assessments with ARBD, so assessments should be carefully planned and carried out by specialists wherever possible.
7. The powers needed to support someone with ARBD may not be the same as for other individuals, and services should make creative and individualised use of the range of powers available under welfare guardianship.
8. ARBD presents complex ethical issues around human rights and respecting autonomy while keeping people safe, and careful multi-disciplinary planning is extremely important.

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