Alcohol Related Brain Damage (ARBD)

A clinical management guide for the psycho-social rehabilitation of people presenting in secondary care with severe alcohol related brain damage

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Foreword

This guide was prepared in conjunction with Dr P Abbott, a Consultant Neuropsychiatrist specialising in acquired brain injury It has been informed by clinical experience in the rehabilitation of patients with frontal damage. The work was hosted by the Cheshire and Wirral NHS Foundation Community Trust and funded by a Development Grant.

We undertook a literature search relating to rehabilitation of both patients with ARBD and those suffering from traumatic or acquired damage. The guide draws on consensus opinion, in the absence of any randomised controlled trials examining the long-term outcomes of people with alcohol related brain damage.

Background

This document provides a description of a semi structured rehabilitation of patients presenting with severe degrees of alcohol related brain damage (ARBD). It is not supported by research trials but is developed from literature reviews and 15 years of clinical experience. It is important to note that:

- **It is not a 'treatment' manual (it is designed to provide ideas and guidance in the management of ARBD)**
- **There may be other guides that provide equally effective rehabilitation of people with ARBD.**
- **The guide does not need to be adopted in its entirety but should be adapted to cater for the needs of the individual patient, professionals and local health and social service demands.**
- **The guide is targeted towards people with experience of working in mental health (for example, qualified mental health workers) with view to facilitating and supervising less qualified and the inexperienced in working with patients suffering with ARBD.**

All 'clinical' examples are fictitious and based on experience with over 70 cases. No patient derived clinical information was used in this review.

Introduction

Context

Purpose: This document is designed to provide pragmatic clinical guidance to facilitate the purposeful, psychosocial management and rehabilitation of people under the age of 65 presenting with severe degrees of ARBD in secondary care. In this context 'ARBD' has been adopted as a generic term to include the wide diversity in presentation of people with chronic confusion caused by long term excessive alcohol consumption and varying degrees of vitamin deficiencies (in particular; thiamine deficiency).

The document will facilitate and provide guidance for the management of people with ARBD by non-specialist community mental health teams, working with untrained health professionals and carers in non-hospital settings.

The Original Patient group: Development of the guidance was conducted in the context of managing 41 patients with severe ARBD, under the age of 65, presenting through general hospital wards and secondary mental health services. All but two of the original patients presented with acute confusional states as a consequence of encephalopathy (inflammation of the brain), delirium tremens, or complicated alcohol withdrawal. The two patients presenting as non-acute were referred from secondary care mental health services, having been diagnosed as suffering from Korsakoff's syndrome and were resident in EMI nursing home settings. On referral to the service patients were incapacitated in terms of making decisions concerning care needed and choices concerning further alcohol ingestion.

All patients had a history of significant alcohol related liver damage. Most patients presented with significant nutritional deficiency. A significant proportion of patients had a history of pancreatic disease and/or portal varices (enlarged blood vessels around the liver). Cerebella (part of the brain associated with co-ordination) and peripheral neurological signs were evident in many patients. There was a high prevalence of cerebro-vascular disease (blocking of the small arteries of the brain) and brain trauma through head injury. Four patients presented through the intensive care unit of the general hospital. One patient had oral cancer. There was a high prevalence of hypertension and diabetes. The last few years have witnessed a 10% mortality rate in patients that had been referred to the team (these patients had been abstinent for some time before death). A full description of the patient population on which the guidance was developed has been published (Wilson et al 2012).

Guidance development

Forty-one patients were followed up for an average of 25 months. At the time of the review, 32 patients were either abstinent or in managed drinking and placed in appropriate community settings. Acute hospital admissions have been reduced by 85% whilst undergoing the rehabilitation programme. Honos-ABI (Health of the Nation Outcome Scale-Acquired Brain Injury) (Wing and Curtis et al 1996) domains have improved except for concomitant mental illness and self-directed harmful behaviour (which was negligible) (Wilson et al 2012). Further development of the manual was undertaken through increasing the patient population size and extending the follow-up period. This enabled some additional therapeutic modifications, increased experience of working with the English/Welsh Mental

Capacity Act (in this patient group) and development of a specific funding stream through working with the CCG and Local Authority.

Overview

The natural recovery of ARBD

This guidance describes the psycho-social rehabilitation and care of patients with ARBD. It is not a 'treatment manual'. This differentiation is important in that provided the psychosocial circumstances are optimised, there is evidence that most patients with ARBD will improve in terms of cognition, behaviour and socialisation through natural improvement of brain function and physical health in the context of abstinence. (Bates, Bowden and Barry 2002)

A patient presenting with, or at risk of developing Wernicke's encephalopathy should be physically stabilised and appropriate parenteral thiamine administered (Thomson et al 2013). In the context of on-going abstinence; significant cognitive improvement can be expected over the following three months (Oslin and Carey 2003). Further natural (but slower and more variable) improvement can be expected over the following year or two (Sullivan, Rosenbloom MJ, et al 2000). This is mirrored by brain recovery as demonstrated through scanning techniques (Alhassoon OM, Sorg SF, et al., 2012). Cognitive recovery may be compromised by concomitant physical illness, psychiatric disorders and further alcohol consumption. Rarely a patient presenting with entrenched Korsakoff's psychoses (patients with severe short term and long-term memory loss, often associated with false memories (confabulations and neurological damage) will show little improvement. In our experience, even these cases are likely to improve across many years in terms of socialisation and activities of daily living.

Terminology

This guideline is principally designed for mental health professionals. It includes several technical terms. Examples include: 'care planning'. This involves an allocated key worker from the mental health team, responsible for overview, co-ordinating and delivering the care programme. The term 'Best Interest meeting' is used in a formal sense as described under the English/Welsh Mental Capacity Act. An 'appointee' refers to someone appointed to look after the welfare benefits of an individual. The general term 'carer' is used to refer to Health Care Staff (usually in residential, nursing homes and domiciliary agents). 'Informal carers' refers to family or friends who have taken on responsibility for care and support of the patient.

Management Principles

Patients may have experienced years of progressive social isolation, chaotic domestic and social arrangements and financial distress. In our experience, a significant minority will have little understanding of managing anything other than limited self-care. Consequently, the rehabilitation may have to be conducted within a framework of financial and social supervision, appointeeship, and / or carer managing the funds. In cases in which capacity to make decisions is impaired then, Best Interest planning should be considered under the auspices of the Mental Capacity Act or equivalent.

The psycho-social rehabilitation of people with alcohol related brain damage is based on a few principles.

- To develop the individual's optimum level of autonomy (Ylvisaker and Feeney 1998). This is a holistic approach including the development of the emotional, intellectual, social, physical, financial and behavioural function of the individual in the context of natural recovery process (Prigatano, Glisky and Klonoff 1996).

- The programme should be facilitative; the individual should be given as much control of the management of their own rehabilitation as possible in the context of on-going risk management (Ylvisaker and Feeney 1998, Bates, Bowden and Barry 2002).

- The rehabilitation of the individual's life skills must be tailored to the individual's needs and priorities and is carried out in the context of the development of a therapeutic relationship (Ylvisaker and Feeney 1998).

- Rehabilitation is an active process, demanding therapeutic time, on-going re-assessment (with defined goals), care planning and long-term engagement (Wilson et al 2012).

- Rehabilitation should focus on life skill development and can take place in the home, institutions and other 'real world' settings (Ylvisaker and Feeney 1998, Wilson et al 2012).

- Non-experienced, care workers, family and community agents can be supervised in facilitating the rehabilitation process (Wilson et al 2012).

- The rehabilitative 'stages' and the institutional/domiciliary or clinical settings through which the individual will journey are likely to vary in nature and duration.

- Rehabilitation is carried out in the context of alcohol education and supervision (Wilson et al 2012).

- Use of the Mental Capacity Act or other appropriate legal framework should be considered when the capacity of the individual is compromised.

Developing Community Based Institutional care*:*

In the absence of local institutional facilities for community rehabilitation of people with acquired brain disease it is advised that the clinical team:

1. Utilises local community facilities: nursing homes, residential settings, supported living mental health institutions, domestic agencies.

2. Develop expertise with the organisations with which the team works.

Principles working with the private/third sector residential/nursing homes.

The following principles were adopted in collaboration with a local institution

1. That the home would accept working age adults with ARBD

2. ARBD patients would preferably be segregated from residents with dementia (where relevant)

3. The clinical team supports the institution through frequent reviews at the nursing/residential home

4. Arrangements need to be made with appropriate funding bodies to provide the costs required to rehabilitate the patient.

5. All cases should have a person-specific care plan of assessment and management which should be reflected in funding arrangements.

6. Process and outcome data should be maintained

7. Agreement should be made with the institution that the principle aim of the rehabilitation is to optimise the independence of the patient and potentially move the patient into a less dependent environment.

Training process

We adopted the principle of training nursing/care home staff through developing and supervising individual care plans with named key staff (of the institution) responsible for individual patients. The health team ARBD nurse was responsible for:

Initiating, overseeing the development and supervising care plans with key staff

Monitoring outcomes

Identifying problems and reporting to back to the team

Input was supported by occasional workshops conducted by the NHS team with the relevant staff/carers.

Working with people in domestic settings

In our practice, there are two principal groups of patients.

1. Patients discharged from acute medical care into their own home environment or supported living.

2. Patients rehabilitated through institutional care into a domestic or supported living environment.

In both situations, the rehabilitative process applies and should be adapted to the patient's needs. Specifically, in a domestic environment; the patient may be particularly vulnerable to:

a. Security risk/abuse (often patients with ARBD have been or are currently at risk of financial and other abuse)

b. Malnutrition

c. Difficulty in developing new routines

d. Maintenance of alcohol abstinence

e. Problems in accessing community facilities.

f. Problems in engagement of carers and families

g. Difficulties in the management of finances

h. Developing new social networks

i. Finding and maintaining employment.

The planned, supervised engagement of family/carers and domestic agencies, working within a structured rehabilitative program can go some way in mitigating these problems. The program should accommodate the physical, mental health and social needs of the patient and carers.

We found particular problems when:

1. The patient was co-habiting with a partner or friend that was using alcohol excessively.

2. The patient was settled back into accommodation near the heavy drinking social network from which he or she was originally admitted into the programme.

Rehabilitative interventions

The phases of management (reflecting the natural recovery process)

Each phase is characterised by objectives requiring clinicians/therapists to adopt different interventions (Wilson et al 2012, Royal College of Psychiatrists 2014).

Phase 1: Physical stabilisation and withdrawal. Objectives include assurance of the patient's safety, stabilising medical conditions, preventing further cognitive damage, reduction of risk and management of disturbed behaviour. In severe cases, this phase is usually undertaken in an acute hospital setting or a specialist alcohol treatment service. It includes alcohol withdrawal and the early initiation of parental thiamine therapy (if indicated) to reduce and prevent brain damage (Thomson, Marshall, and Bell 2013).

NB: Parental thiamine therapy should also be considered in patients identified as being 'at risk of developing thiamine deficiency (Thomson et al 2009):

A clinical history of the following:

Weight loss in past year, reduced body mass index (BMI)
General clinical impression of patient's nutritional status
Evidence of high dietary carbohydrate intake
Recurrent episodes of vomiting in past month
Co-occurrence of other nutritionally related conditions (numbness and weakness of limbs, visual problems, anaemia)

Early signs may include:

Loss of appetite
Nausea/vomiting
Fatigue, weakness, apathy
Giddiness, double vision
Insomnia, anxiety
Difficulty in concentration and memory loss

Later signs

Tremor of the eyes when following an object, unsteady, broad based and unsteady gait and confusion (Wernicke's encephalopathy)
Confabulations
Global confusion with disorientation in time/place

Phase 2: Psycho-social Assessment Phase: The primary objective is to establish the patient in an appropriate environment (Nursing/residential homes, supported living or at home) and undertake an on-going psycho-social assessment in a controlled, abstinent and safe environment. This phase usually lasts three to four months following withdrawal and physical stabilisation. During this phase the individual will improve as the acute effects of the alcohol insult on the brain wears off (Oslin and Carey 2003).

Phase 3: Therapeutic Rehabilitation Phase is usually characterised by a slow and gradual natural improvement. The main therapeutic objective is to facilitate this process through a

planned rehabilitation programme in the context of alcohol control (abstinence). During this phase the key worker works in partnership with the patient in developing life skills and improving independence. In uncomplicated cases, this can last up to three years. A minority of cases (often presenting with the classical signs of Korsakoff's psychoses or complicated by other psychiatric syndromes or physical illnesses) may take many years to show minor improvement.

Phase 4: The Adaptive Rehabilitation Phase: follows on, when it is deemed that the patient has achieved the optimum level of cognitive/social and behavioural improvement. The main objective of this phase is to enable the patient to live in an appropriate environment that optimises independence. During this phase, the individual is helped in finding the right environment and level of support that is needed to live as near normal life as possible.

Phase 5: Social integration and relapse prevention are the main priorities. In this phase, the individual is helped to develop social networks, build their life and manage any future risks related to alcohol misuse. This phase may last for many years.

- The duration of each phase will vary between individuals and will be informed by physical, psychiatric and social complications.
- The demarcation between phases may be blurred and phases may overlap a bit.
- In rapidly recovering individuals with little long-term alcohol related brain damage; the individual may skip phase three and four or move through these stages very quickly.

Guidance recommendations

Phase 1. Withdrawal regime and physical stabilisation

As the individual is usually suffering from acute confusion, the patient often presents through crisis in the community or through admission into acute hospital wards. The confusion may be a consequence of one or a combination of: delirium tremens associated with withdrawal from alcohol, Wernicke's encephalopathy, associated with thiamine deficiency, other encephalopathies or acute confusion associated with other or related physical conditions.

The main purpose of management is to establish a history of heavy, long standing alcohol misuse and exclude any acquired brain injury that is historically related to obvious deterioration of the cognition. The patient should be medically stabilised and emergency thiamine prescribed if indicated. Stabilisation of behavioural problems may well require the use of both major and minor tranquilisers and should adhere to NICE guidelines (England and Wales).

From a psycho-social perspective one of the main considerations is to assess the patient in the context of the Mental Capacity Act in terms of capacity relating to decisions concerning discharge, exposure to further alcohol ingestion and other issues relevant to the patient's safety, risk profile and management plan.

During this phase, the key worker should try and contact family members or people that have been trying to care for the individual. This enables an early understanding of the individual's

- Personal history (including alcohol consumption, drug misuse and problems prior to admission.
- Corroborative information recruited from people that have knowledge of the patient is helpful in assessing memory problems and confabulations: ARBD sufferers are particularly prone to have these false memories. These 'confabulations' are believed by the patient and may appear very convincing to someone who is unfamiliar with the patient's circumstances and past.
- Information that will contribute towards care planning and potential discharge from acute medical care.

Phase 2: Psycho-social Assessment Phase:

During this phase, most individuals will make both cognitive and physical progress. Their intellect and ability to self-care usually improves over this 3–4-month period provided there is abstinence. The rate and level of improvement will depend on the degree of long-term damage that they have experienced and may be delayed by both psychiatric and physical ill health.

General Recommendations:

If the patient is in acute hospital care, then discharge to an appropriate environment should be arranged as quickly as possible. The nature of the environment will be informed by a comprehensive assessment of the individual. It may range from acute psychiatric care, through varying levels of institutional care, supported living and domestic care with (or without) support.

Alcohol abstinence should be prioritised and if the patient is unable to make informed decisions concerning exposure to alcohol because of cognitive damage, then appropriate protection should be put in place until capacity to make informed decisions is restored. Where necessary, the Mental Capacity Act or equivalent can be employed.

The environment should be safe, calm, stable ((Kopelman *et al*, 2009) and encourage daily routines and boundaries relating to behaviour. Appropriate nutrition should be prioritised (Malloy *et al*, 1990). In cases of significant cognitive damage, the patient may require specialist nursing care and employment of carers with experience of working with younger people with cognitive damage. Such staff will be familiar with the management of impulsive behaviour and de-escalation of aggression or agitated behaviour that may be encountered.

Phase 2 consists of five major therapeutic themes: **Normalisation, Therapeutic Relationship, Continual Assessment, Orientation and Memory Support** and introduction of **Alcohol Education.**

Normalisation

This principle assumes that most people presenting with ARBD are likely to have experienced a period of chaotic lifestyle, broken relationships, financial disruption, and physical ill health. Patients have often been pre-occupied by alcohol to the detriment of other activities and relationships. Consequently, it may have been some time since the patient has experienced routine aspects of daily living, including maintaining nutrition, understanding social boundaries and managing behaviour. An environment in which challenging behaviour can be managed may have to be found in the first instance in more disturbed cases. In these situations, institutions with access to mental health nursing may be needed. However, most cases will not require this and residential homes, supported living and the person's own domestic environment may be considered appropriate. Nutrition and medication compliance should be stabilised and monitored, daily routine is encouraged, and a personal safety should be facilitated.

Aspects of normalisation include:

Environmental;

- Familiarising the patient with routine and activities of daily living
- Understanding the immediate physical environment (including labelling, signs, colour coding, orientation cues)

Social:

- Identification of carers and key workers, knowing where to turn for advice and help, management of unacceptable and impulsive behaviour and social boundaries.
- Promotion of the optimal level of stimulation and reducing disruption (including noise management)

Financial management:

- Providing appropriate funding through health or social care for the rehabilitation programme.
- Assessing debt and liabilities and introduction of an advocate.
- Management of personal funds and budget in the context of capacity assessment.

Therapeutic relationship

In the first few months the patient often experiences fear, disorientation, disturbed behaviour and difficulty in understanding the circumstance. It is important for key workers to start to develop a therapeutic relationship and potential psycho-social support (MacRae & Cox, 2003; North *et al*, 2010; Wilson *et al*, 2012). As many institutions or domestic agencies work on shift or rotational basis it may be necessary to allocate more than one carer to enable the patient to have a named carer to whom they can turn. The role of the key worker is to build the trust of the patient. This is done through being familiar with the patient's background,

understanding the patient's view of the problems they face, being non-judgemental and truthful with the patient. It is important that key workers and carers are changed as infrequently as possible and that if change to a new key worker/carer is required then it should be discussed with the patient and undertaken in a planned fashion.
More specific issues include

- The enhancement of appropriate coping strategies
- Using distraction techniques to manage inappropriate or difficult behaviour
- Adopting an 'active' listening approach
  to engage and build a relationship with the patient.
- Building a personal history of the patient with the patient and family/carers (developing a personal passport)
- Introduction of personal journal

The introduction of a personal journal should be informed by the patients' presentation and condition. A premature introduction may cause cognitive problems for the individual. Principally, this is a diary. It may take several forms. The use of a white board in the patient's room or home is helpful to record what has happened in the day or week. This can be supplemented by the patient being encouraged to record in a notebook what they have done that day and their feelings about it. Eventually ARBD sufferers should feel a sense of 'ownership' and manage the book/journal themselves. They will require initial supervision and support.

The role of a journal

1. To facilitate recent memories (this may be helped by use of photographs of recent events)
2. To introduce the concept of routine and predictability through providing an aid-memoir or recent events.
3. To provide a medium through which the key worker /carer can build a relationship with the individual.
4. To introduce planning (see later).

- Involving family and other carers

This is an important aspect of early management. The aim are:

1. To work with people known to the individual with view to building an understanding of their personal journey and life before and during the patient's alcohol dependency.
2. To build and repair (where possible) relationships with family and carers so that they may be engaged in helping in in the rehabilitation programme.

3. To capture information regarding the individual's social circumstances to inform future care planning.

Orientation and memory support

Even in the early stages of this phase, appropriate signs, reminders and orientation cues will play an important part in helping to orientate the individual. Simple examples may include wall colour differentiation between rooms, signposts in the building, reminders of where the person is, clear signs stating the day and date, what and where the establishment is, and pictures of staff and key workers. More formal reality orientation and memory cueing may be introduced as the patient settles over the first few months. It is often useful to write out (with the patient) a summary of how the individual presented and specify the impact of alcohol on both their cognition and body. When agreed, this jointly developed brief document or 'letter' can be signed and dated by the individual and key worker, so providing an aid memoir for the individual throughout the day. Laminating this is useful as the patient may find the document useful over the next few weeks. This is then kept (by the patient and key worker/carer) and used to rehearse the journey of presentation and potential impact of alcohol on the individual.

Orientation and memory therapies also facilitate reduction in anxiety, redirection of negative behaviours, increase socialisation and provide a vehicle for constructive communication. Group work may prove useful (cognitive stimulation therapies have been employed successfully and shown to be beneficial in people suffering from dementia, (International Cognitive Stimulation Therapy (CST) Centre, 2019) however there has been no research conducted in people with ARBD). Note that some patients may find group involvement challenging, often a result cognitive damage.

Alcohol Education

It is important to remember that individuals with cognitive impairment may experience difficulties in engaging with treatment and educational regimes designed for people who do not have significant cognitive damage.

Most people with cognitive damage will experience some of the following problems:

- Memory impairment
    - Despite being able to have what appears to be a normal conversation with the patient in which the patient can recall information that has just been given to them, it is often the case that over the next hour or so, the individual has little or no memory of the conversation. (Alterman et al 1989, Schmidt et al 2005),
    - Suggestibility: ARBD related frontal lobe damage often makes the patient vulnerable to unconditionally agree with people without being aware of the implications. Hence they are quite likely to agree that they have a problem

one minute and deny a problem the next minute, depending on how the information is presented.

- Understanding and reasoning (including social awareness)

Due to frontal lobe brain damage the patient may have significant problems in understanding. A variety of disturbances related to reasoning and understanding have been reported in the literature in patients presenting with ARBD:

- Difficulty in the ability to concentrate (DeFranco et al 1985)
- Difficulty in problem-solving (Beatty et al 1996) and explaining actions and reasons (Beatty et al 1996).
- The ability to understand complex information and concepts (such as alcohol dependency and with implications for behaviour) and difficulty in acquiring drink refusal strategies (Smith &McCrady1991).
- The ability to be able to change from one stream of thought to another with normal degrees of flexibility (difficulty in working in groups or following complex discussions) (Beatty et al 1996).
- Within the first few weeks of abstinence there is likely to be increased proneness to make impulsive decisions and there is less awareness of the longer term implications of decisions and actions (Weissenborn & Duka 2003, Davies et al 2005, Parks et al 2010).
- Understanding risk related to actions and decisions (Blume et al 2005)
- Reduced organisational skills (Parks et al 2010) and planning (Weissenborn & Duka 2003).
- Poor compliance to treatment programs (Copersino et al 2012).
- Reduced confidence (Bates & Pawlak 2006)
- Breakdown of interpersonal relationships (Patterson et al 1988).

The general approach and in particular, alcohol education must cater for these issues and reflect the needs of the patient. Adaptation of educational programmes may include:

- Patients with cognitive dysfunction are likely to find it ‘hard to engage’, a result of a wide variety of problems. Consequentially, an active policy of ‘engagement’ may have to be adopted, with more frequent contacts and more assertive attempts to make contact (Wilson et al 2011).
- Allowing for reduced levels of concentration (DeFranco et al 1985) and difficulties in swapping from topic to topic (Beatty et al 1996, et al 2000) may be helped through limiting subject discussions and the number of educational points within each contact with the patient.

- Providing 'rewards' relating to appropriate behaviour may be beneficial. These may be psychological or social but should be tailored to the individual and may help recall (Hochhalter et al., 2001)
- Providing increased time for individuals within contact sessions (VanDamme et al 2008)
- Sessions may have to be adapted to cater for problems in remembering new information. Getting the individual to frequently repeat information as soon as it is given may be of some help (Kessels et al 2007).
- Offering information in several ways, including verbal, written and diagrammatic methods may help. Memory cues (Morgan et al 1990) and reminders will play an important role.
- Planning and providing a timetable and structure may help (Arbias 2007).
- Working out simple rules to apply when dealing with problems may offer some help (Bardenhagen et al. 2007)
- Keeping drink management strategies very simple and easy to manage is likely to be important.
- In the first few weeks, particular emphasis should be placed on reducing exposure to risk because of increased likelihood of impulsive decision making (Parks et al 2010).

Continual assessment

As the patient is likely to improve over the first few months, on-going assessment is required. Assessment should be comprehensive and cater for all aspects of the patient's life, including a full social review so as to inform future care planning. Obvious areas of assessment include cognitive and functional performance. A standardised cognitive assessment instrument such as the Addenbrook's Cognitive Examination or equivalent should be used to capture change across time. Other standardised instruments can be used to identify functional areas of disability (e.g. activities of daily living) and the level of supervision required in caring for the patient. These will inform the care plan relating to the third phase of rehabilitation. It is recommended that formal assessments are carried out at about 3 months of post presentational abstinence.

Phase three: Therapeutic Rehabilitation

General points

Recovery in phase 2 may be substantial and in several cases, it may not be deemed necessary to undertake a further programme of active, therapeutic rehabilitation (phase 3). In such cases, there is usually little if any residual cognitive damage. However, in severe cases the majority will have some residual cognitive problems. These cases will be helped though targeted rehabilitation and management which may last up to three years.

Phase 3 is undertaken through care planning and a strong key worker relationship (MacRae & Cox, 2003). Throughout phase 3, the care plan should be regularly reviewed and adapted to the patient's needs and progress. There are several related issues which need to be considered:

1. **Developing autonomy**
2. **Promoting functional recovery**
3. **Orientation and memory support**

4. **Impulse and behaviour control**
5. **Managing apathy and motivation**
6. **Managing alcohol**
7. **Developing relationships**

1. Developing autonomy

This is usually a gradual process; however, it is probably the most important aim of the rehabilitative process. The aim is to optimise independence and capabilities to self-manage in the context of residual cognitive/functional deficits (Wilson et al 2012). Patient autonomy is facilitated through a trusting therapeutic relationship in which the patient is gradually empowered in the management of their program. This must be balanced with the management of risk. Obviously, this must be frequently evaluated in the context of the degree of cognitive disability, including level of insight.

In severely cognitively and functionally impaired patients, a strong supervisory role may initially be required. However, as the risk profile reduces, and the patient improves; the responsibility for care planning becomes progressively shared with the patient. Eventually, the patient should be empowered and have control of the care planning, with the key worker providing support, advice and on-going monitoring and assessment in collaboration with the patient. This provides the platform for the patient to develop optimal levels of functionality and autonomy as he/she develops into the later stages of the program. (Phases 4 and 5).

2. Promoting functional recovery

There are three principal components to this.

1. Maintaining a journal
2. Planning activities
3. Learning skills

1. Maintaining a journal

The maintenance of a journal (preferably commenced during phase 2 of rehabilitation) is to

- Provide the patient with memory cues relating recent events.
- Promote orientation.
- Provide a vehicle to develop a therapeutic relationship with the key worker.
- Enable the patient to record observations and thoughts relating to their experiences that can be discussed and reviewed with the key worker.

Journal keeping should be encouraged and the patient aided in remembering and recording events of the day (when necessary, by the key worker or carer). Most patients are keen to keep their own diary, and this is supported by recording events of the day on a white board or notice board in the patient's room. (The white board should be updated

at the end of each day by the key worker/carer, collaborating with the patient). The white board can also 'double' as an orientation cue in that it should have the day, date and other relevant information on it.

The sophistication of the journal can be developed as the patient improves. It may evolve to include photographs and other aid-memoires.

2. Planning

The white board provides the platform for the development of planning. The purpose of planning is to;

- Introduce planned structure and predictability for the near and more distant future
- Promote the patient's ability to plan
- Promote the patient's autonomy, self-determination and feelings of responsibility
- Provide a collaborative process by which the therapeutic relationship with the key worker/carer can be developed.

The planning process.

- Is often introduced slowly and informally, dependent on the patient's condition, motivation and other issues.
- Planning needs to be conducted as a collaborative process between the key worker /carer and the patient.
- Planned tasks, events or activities should be patient specific (but obviously do not exclude tasks or events that other people are doing, provided the patient wants to engage).
- The patient should be encouraged to have as much control over the process as possible.
- When establishing the planning of tasks, include tasks that the patient is already undertaking on a regular basis. This provides the patient with positive feedback and is tasks are readily achievable. Novel tasks can be slowly introduced against this background.
- It is best to identify one or two tasks for each week to start with; depending on the severity of problems experienced by the patient.
- Planned events, tasks or activities must be achievable, may vary in complexity and may be developed over time.

The white board can be used to plan events for the week and the patient should be encouraged to comment on the events/activities in his/her journal so that they can be reviewed and discussed at the end of each day.

Example:

The following patient was admitted to a nursing home. He suffered from severe cognitive damage as a consequence of multiple withdrawals, chronic alcohol ingestion and malnutrition. His presentation was complicated by severe depression associated with paranoid delusions which were medically treated. As his depression and paranoia resolved, he was slowly encouraged to come out of his bedroom and socialise in the nursing home environment. It was noted that he preferred to socialise at night-time, with the night staff and would join them for a meal in the middle of the night. It was also noted that he had very poor motivation and was reluctant to participate in activities when invited. The following activities were planned for him by his key worker, working closely with the patient over a few weeks.

	Monday *date*	*Tuesday* *date*	*Wednesday* *date*	*Thursday* *date*	*Friday* *date*	*Saturday* *date*	*Sunday* *date*
AM		*Go on mini bus trip with residents*					
PM	*Go to local shop with key worker*		*Go to local shop with key worker*		*Go to local shop with key worker*		
Evening/night	*Have meal with night staff*		*Have meal with night staff*		*Have meal with night staff*		*Have meal with night staff*

At times the patient refused to participate, but this was not presented as a failure, but as the patient wanting to have' time out' or a rest. As the patient had significant memory problems and was unable to keep a journal, considerable time was spent in reviewing the day's activities and where possible, re-enforcing the memories with digital photographs of the activities. In the early stages of his rehabilitation, most other aspects of activity of daily living were conducted or supervised by the staff of the nursing home.

With on-going encouragement, the patient engaged slowly, undertaking more activities over the following months as developed through planning. Eventually, the patient became more active in negotiating activities and as motivation improved, he took more responsibility for his own planning.

3. Learning Skills

The planning will increase in sophistication as the patient improves. Once the patient has become accustomed to the planning process, the opportunity should be taken to encourage further autonomy and responsibility through developing daily living skills. This should be carried out in the context of a functional assessment, preferably undertaken by an occupational therapist. However, in the absence of occupational therapy input, the patient's difficulties in carrying out a task should be observed, and the patient encouraged and supported and when necessary, directed through guidance. Repetition of the skill, building the activity into a routine behaviour and further development can be incorporated into the planner.

Identification, development and assessment of skill**s**

- Every attempt should be made by the key worker to make the patient feel that he or she is in as much control of this activity as possible.
- The targeted skill should be something that the patient wants to participate in (this may require persuasion and positive support).
- The skill should be relatively easy for the patient to achieve.
- Complex tasks (such as shopping for food) should be broken down into sub tasks, at first. Each sub task can then become a task in its own right. E.G.;

Shopping for food

  - Making a list
  - Getting to the shop
  - Selecting food
  - Using money

- Non completion of the task is seen as 'practice' and the patient should be congratulated on participation.
- Skill learning should be restricted to one or possibly two skills at any one time, dependent on the patient's condition and motivation.
- All skill learning will be associated with varying degrees of risk; preparation of food is an obvious example (e.g. not being able to utilise the cooker). Appropriate risk assessment and supervision should be provided.

Examples of daily living tasks include food preparation, laying the table, dressing and organising clothes, self washing, using a telephone, going on a bus or public transport, shopping, managing daily finances, and many more, depending on the ability and stage of recovery of the patient.

The assessment (and future assessments) of a patient's ability to undertake and improve in a specific task should be assessed by an Occupational Therapist or in the absence of an occupational therapist, through careful recording of the degree of supervision and help required.

In the absence of occupational therapy assessment, we have utilised a scale developed from the The UK Fim + Fam (Functional Assessment Measure) (Turner-Stokes 2010). The degree of supervision and help an individual needs in completing a particular task is graded by a carer. Seven grades range from: 'Having no problem and being able to manage all aspects of the task independently' through to 'Effectively unable or requiring constant supervision with intervention (several times a day)'.

This is a practical method of assessing the degree of dependency, carer support required, and monitoring functional change across time.

Once the task has been agreed with the patient, it can be incorporated into the weekly planner. The carer's role is to help the patient to do it themselves and only supervise, prompt or aid when necessary. It may take many rehearsals for the patient to achieve an optimum level of independence in any one skill. Improvement may be seen across months or even years of repetition. Once the patient has developed a satisfactory or optimal level of independence, the task can be made more complex or training in other skills can be introduced.

Example 1:

A 45-year-old woman presented with a long history of recurrent alcohol withdrawals, varying levels of anxiety, and a confusional state. She was admitted from the acute medical ward into a nursing home in which arrangements had been made for a carer to be assigned and supervision was provided by one of the community specialist team. During phase 2, the patient made significant improvement, but progress was limited because of varying and severe anxiety. This responded to appropriate medication. She eventually engaged in keeping a journal and progressively participated in activities run through the nursing home. Planning was introduced, which included visiting her daughter (under supervision). After about 6 months of nursing home care, it was evident that she had an interest in cooking. She was assessed by the carer and supervising key worker in terms of her ability to prepare a simple fried meal. She was categorised as having a degree of independence but requiring supervision. In agreement with the patient, cooking was scheduled into her planner.

At first, she required 'hands on' help, but was encouraged to participate more and more, becoming progressively independent. Her daughter was introduced in helping in the rehabilitation. The patient was subsequently supervised in undertaking preparation of the same meal on supervised visits to her daughter's home. This was a planned activity and represented in the planning process through discussion with both daughter and patient. Over the following months the patient became fully independent in the preparation of this meal and increasingly (under supervision) began to prepare more complex meals which included planning a shopping list and going to the shops to buy the food.

At each stage, the particular skill was monitored, and the level of independence was recorded with the patient and included within the journal and records. This had the added

advantages of providing evidence for the patient of self improvement and making a case to the funding authorities for continuation of funding as part of a rehabilitation process.

Example 2

The patient is a married female, living in her family home, with a daughter. She has many years of alcohol misuse and has progressively become dependent on her daughter and husband, to the extent that all house-hold tasks are done by her family, and she carries little, if any responsibility. This has been the situation for some years. As a consequence of her alcohol problems, her relationship with her daughter was strained. She was admitted into hospital with an encephalopathy. During Phase 1 of management, she was commenced on intravenous thiamine and underwent controlled withdrawal from alcohol. On post withdrawal assessment she had significant cognitive impairment, with pronounced difficulty in short term memory, problems in reasoning and little insight. She was placed in a nursing home that catered for younger people with dementia. During phase 2 of rehabilitation, she made some improvement. The following year witnessed increased responsibility for maintaining her journal and planning her activities. Within the nursing home environment, she regained skills which she had not utilised for many years and established a routine of regular food intake, self-hygiene, simple financial planning and shopping skills.

As her confidence, autonomy and skills increased she began re-building relationships with her husband and daughter. At first this presented some difficulties as there had been a long history of damage to these relationships, associated with her drinking habits. The husband and daughter were counselled by the team, concentrating on a psycho-educational approach relating to alcohol and its effect on cognition. Through planned visits home (at first accompanied by nursing home staff as part of the commissioned care package) her relationships developed and both family members were engaged as 'co-therapists'. This required several supervised visits to the individual's home by an experienced team member. On each occasion, the patient was given home based, achievable tasks that could be supervised by the daughter. A graded discharge from the nursing home was planned, introducing more direct supervision by the community team, enhanced by domestic agencies working under the direction of the team nurse and working with the family. Her planner started off as quite simple; with one or two tasks but became more sophisticated as she improved:

An example of one of the week's planned activities: Each of these activities was monitored and the level of supervision required recorded.

	Monday	*Tuesday*	*Wednesday*	*Thursday*	*Friday*	*Saturday*	*Sunday*
AM	*Laying the breakfast table in nursing home*	*Cleaning room in nursing home*	*Going home with supervision* *Laying table for lunch with husband and daughter*	*Going to local shops with supervision from key worker and buying personal items.*		*Going home with key worker and learning how to use washing machine*	*Journal keeping* *Planning next week*
PM		*Planning budget for the week*	*Cleaning sitting room at home*			*Laying table at home and having lunch with family*	
Evening			*Return to nursing home*			*Return to nursing home*	

In this case, each day was discussed with the patient and levels of supervision monitored with the patient's daughter and husband. As her confidence grew; routines developed, the planner became less relevant but was maintained as a diary and list of things that had to be done.

It is important to note that over time, as most patients continue to recover; skill complexity (and patient autonomy) should also develop. Failure to cater for cognitive improvement in this way can lead to increasing frustration, breakdown in therapeutic relationships and rejection of the programme.

3. Memory support

Journal keeping

The journal provides an opportunity for regular review (with the key worker or carer) and facilitates memory of recent and past events and the individual's experiences. Likewise, provided the journal is appropriately dated, it will provide a framework to enable the patient to orientate in time (and place). Reviews of journals should take place at least weekly, and the patient should be facilitated in recalling additional information relating to each event. Photographs may play a useful part, using a digital camera or equivalent. Visual cues may enhance recall of events and provides the patient with evidence that they have participated in the event.

Journals should preferably be kept by the patient on them (in a pocket for example) as one of the main problems faced by an ARBD sufferer is that they forget to refer to or complete their journal and may need frequent reminding.

The White Board.

In this context the white board offers an opportunity to provide a continuous and easily observable reminder of recent events and orientation in terms of providing the date, day and location. It should be in a prominent position (in an institutional environment it is often kept in the patient's bedroom), easily accessible for both patient and key worker (and co-therapist/carer). It is very important for it to be updated daily. Any changes to the white board should be done in collaboration with the patient (where possible). It can be very useful in a domestic environment and may play an important role in reminding the individual about visiting carers.

Keeping lists of things to do and remember

Lists provide a simple extension of the planning process as described above. It is important that the patient is encouraged to take as much responsibility for the list development as possible, in negotiation with the key worker or carer. Lists also provide an aid memoir in that the patient can prepare a task or activity and use a list as a reminder of things to do. An obvious example of this is a shopping list.

Signposts and aid memoirs

Both orientation and memory prompts can be provided through signposts and other aid memoirs around the house/institution. These should be kept up to date by the key worker/carer (preferably working with the patient). They should include orientation and prompts about recent events etc.

Formal orientation and memory therapies

A range of approaches have been used in the context of dementia care and may be applicable to people with ARBD. Group work may be tried. As already mentioned, Cognitive Stimulation Therapy (International cognitive stimulation therapy 2019) is such an example and may well prove to be adaptable to this patient group: This technique has not formally been tested in the context of ARBD but has been researched in the context of improving

cognitive function in patients with dementia. It is usually carried out in group settings and potentially relevant components include reminiscence, identifying groceries, current affairs discussions, photograph recognition of public figures, word association games, discussions of previous places in which people have lived (using maps of the local areas), games (dominos, cards etc), categorising pictures of objects (e.g. table ware, clothing, people, animals), word identification games (scrabble, hang man etc).

4. Impulse and Behaviour control

People with ARBD have cognitive difficulties due to damage to the frontal areas of the brain. These areas are important in helping people control their emotions and behaviour and damage can give rise to a range of difficulties including controlling impulsive behaviour of which the individual is unaware of associated risk. This may result in disinhibited social behaviours. Examples include invading other people's personal space; inappropriate touching; 'speaking without thinking' (for example, insulting people, making jokes at inappropriate times or disclosing personal information) as well as more challenging behaviours such as verbal abuse or physical assaults. People with ARBD may have difficulty coping with stressful situations, with relatively minor stresses (such as being given a task to do which is too difficult or having an unexpected visitor) being potential triggers for challenging behaviour (this may include relapsing into heavy alcohol drinking). Sometimes these reactions may seem disproportionate ('catastrophic') in relation to the trigger event. Patients are also prone to tiredness, which may increase the risk of such reactions occurring. They may be sensitive to overstimulation and may be more likely to become stressed in noisy and distracting situations or if confronted with more information than they are able to comfortably understand and take on board.

ARBD sufferers may be able to identify for themselves potential triggers such as tiredness or being placed in situations which make them feel stressed. However, it is more likely that key workers, family members or other carers may observe trigger situations for the individual. It is very important to obtain the best information possible as to which situations may trigger impulsive behaviour by asking the person themselves and the carers, as well as observing the person's behaviour whenever possible.

General aspects of a rehabilitation programme will help to reduce the risk of impulsive and disturbed behaviours.

General features of a rehabilitation programme:

- Making the surroundings as calm and relaxing as possible to avoid 'over-stimulation', particularly when engaging the person in a conversation or activity (avoiding distractions where possible);

- Structuring the person's day to make it as predictable as possible, using aids such as planners, diaries and checklists as reminders. These maintain the person's orientation, provide reassurance and increase the person's self efficacy.

- Making sure that the person has enough rest breaks scheduled into their planned programme, as well as ensuring that any activity does not exceed their abilities in

terms of both degree of difficulty and duration of attention and concentration. Some activities may need to be broken down into separate stages.

- Giving information in small amounts, using short and simple sentences to avoid 'information overload'.

More specific interventions which may be needed to reduce impulsive challenging behaviour:

- Avoiding known trigger situations as far as possible.
- If a potentially stressful situation is unavoidable, prepare the person in advance as far as possible (for example, by talking the situation through with them) and providing additional support if they are unlikely to be able to cope on their own (for example, by arranging for someone else to be with them if they need to fill in a form, negotiate with an agency, etc);
- Try to avoid direct confrontation and use distraction if the patient is becoming aroused and angry (for example, if the person is becoming angry because they have been told that a request they have made cannot be met, distract their attention onto another topic of interest to the patient).

5. Apathy and motivational difficulties

Apathy and motivational difficulties are commonly experienced by people with ARBD. These problems may not be highlighted by the person themselves but reported by family members or other carers. Patients may be viewed as lazy or 'just being awkward' by others not aware that these problems are a consequence of damage to the brain and a core feature of ARBD. It is important to exclude a depressive illness (which is a treatable condition). The psychological symptoms (such as hopelessness, lack of enjoyment in life and feelings of worthlessness) are important symptoms in terms of making the diagnosis of depressive illness in this population. It is also important to distinguish apathy from fatigue, frequently experienced by recovering patients.

As in the management of impulsive behaviour, general features of rehabilitation programme help to reduce apathy and low motivation. More specific interventions for apathy and reduced motivation include:

When an apathetic, poorly motivated patient is confronted with a choice to engage in an activity or not, then it is likely that the offer will be refused. Preparation is essential. When asking the patient to participate in an activity it is important to promote an 'expectation' of engagement. This includes repeated discussion, using the planner, and showing a clear expectation (demonstrable expectation) that the patient will participate, well before the expected participation.

A patient with poor motivation will most likely partake in activities in which little effort is required. For example, watching television is easier than going on an outing. However, in the context of preparation (recurrent reminding that an outing is planned) and clear expectation that the television is switched off, the patient may find it psychologically easier to participate in the outing or planned activity. It is important however to always allow the patient to have the final say and not to fall into a

deteriorating relationship through adopting a dictatorial attitude or creating a hostile environment. Building a milieu of expectant engagement in the agreed programme is a critical component of the rehabilitative programme. It is essential to develop this in the context of a therapeutic, collaborative relationship with the patient.

The avoidance of under-stimulation is just as important as preventing overstimulation for patients showing evident of apathy and reduced motivation. The provision of a structured day with prompts such as daily timetables, planners and diaries is very important. Continuing support of the programme may be necessary until it is well established after which time the additional support and prompting may be gradually withdrawn. It is important to check that the patient has been able to maintain the routine and has not reverted to the previous level of inactivity. For some patients, additional external prompts such as alarm clocks or bleeps may be helpful in initiating an activity and maintaining the structured day.

It is very important to try to tap into the person's previous interests (that they can recall) and incorporate these activities into the structured day. This makes the programme more patient-specific and will increase the chances of success for the whole programme. Positive feedback about completing activities is also very helpful, building the patient's sense of independence and self-efficacy. It is important to be aware that if a patient has participated and enjoyed a recent activity, he or she may not remember having experienced it so will not be motivated to participate again by drawing on that particular memory. Frequent reminding and the use of a journal may be of considerable use in these situations

6. Managing alcohol

Alcohol craving is not usually predominant during phase 1 of management (acute physical stabilisation and withdrawal). During the first 3-6 months of abstinence (phase 2 and early phase 3) several patients will crave alcohol and may demonstrate behaviours designed to access alcohol. However, in severe cases, this does not usually present as an over-riding problem. Obviously, it is important to continue to re-iterate the link between alcohol ingestion and physical conditions that the individual has recently or is currently experiencing. This should include difficult-to- talk-about issues such as vomiting blood, ascites, cancers, malabsorption, blood related problems etc. It is also important to illustrate the degree and nature of cognitive impairments so that the patient does have access to all the relevant facts and dangers associate with further drinking.

<u>Counselling and education</u>

Any counselling must be adapted to the individual and cater for the intellectual problems with which the patient presents. Counselling should be on-going throughout the rehabilitation programme. Where appropriate alcohol treatment services should be engaged.

When working with people with cognitive damage, it is important to remember that the patient may be suffering from brain damage related apathy and poor motivation. In addition to these problems the patient may be suffering from memory problems and lack of insight and understanding because of the brain damage. Therefore, engagement may have to be more 'active, with more frequent attempts to engage. It may be unreasonable to expect a

new patient with ARBD to attend a clinic or educational workshop without additional support. Specific modifications have been reported:

- Note pads and encouragement to write down thoughts
- Educational components should be confined to essentials
- Lectures, films and other didactic presentations should be kept brief
- Specific strategies should be practiced repeatedly
- Written materials, descriptions of homework including detailed instructions
- Use of repetition in skills training and education
- Gradual introduction of new information
- Breakdown long term goals and complex treatment goals into smaller sub-goals
- Provide a structure for moving from one more easily managed task to the next
- Use of easy language in written material
- Frequent and brief meetings/supervision, coaching and prompting to keep patient on task
- Problem solving specific, concrete examples of strategy

7. Developing relationships

The main objectives concern:

1. Building a therapeutic relationship
2. Building relationships with other concerned people
3. Setting the background against which further integration into society can take place.

1. Building a therapeutic relationship.

A therapeutic relationship will take some time to develop. The number of key workers should be limited, so that familiarity can be developed, with as little disruption as possible. Key features of the therapeutic relationship should be non judgemental, acceptance, truthfulness, consistency, collaborative and empathic. The most important purpose of a therapeutic relationship is to provide the context in which a patient may develop autonomy and self reliance.

The key worker(s) should:

- Have regular and fairly frequent contact with the patient.
- Become familiar with the individual's background and life story.
- Work closely with the individual in journal keeping, planning and skill learning.
- Facilitate memory and orientation cueing
- Facilitate alcohol education
- Help keep records of progress.
- Get to know other carers, relatives and friends of the patient.

- Be aware of the patient's concerns and worries
- Work with and be supervised by more expert staff where appropriate.

2. Building relationships with other concerned people

As the patient improves, during phases 2 and 3, it is important to assess and potentially develop relationships with people that are still in contact with the patient. At first, it is important to explain the process of rehabilitation to these individuals and begin to educate them with regard to the rehabilitative programme. The purpose of this exercise is to

- To facilitate social support for the patient
- To explore the possibilities of engaging potential carers in the rehabilitation programme
- To obtain background information regarding the patient
- To educate people close to or friendly with the patient about the effects of alcohol on the patient.

3. Setting the background against which further integration into society can take place.

Whether the patient is rehabilitated through institutional care or supported in a community setting, it is important to facilitate the building of new relationships and the development of relationships (where possible) that might have been damaged through many years of alcohol misuse. In community settings, phase 3 can be used to develop social activities and potentially build new social relationships which will play an important role in later stages of rehabilitation and provide a 'buffer' against isolation and relapse.

Phase 4 Adaptive rehabilitation

During phase 3 the patient's autonomy will slowly improve as cognition and related behaviour responds to the therapeutic environment. Eventually, the patient will reach an optimum level of recovery. The duration of phase 3 will vary between patients and will slowly merge into phase 4, as the patient's improvements slow down and they settle into a routine life. During the transition phase it is important to re-assess the patient's functional ability and the amount of support required to sustain them in an optimum environment. Long term excessive care will promote over reliance on help, de-motivation and institutionalisation.

A full assessment of activities of daily living is recommended regarding needs assessment. It should include a review of any adaptations made to the environment and care package that the patient requires.

Often Phase 4 will involve the transfer of care from an institutionalised setting to a less dependent environment or reduction of carer support so that optimum levels of autonomy are achieved. Such transfers should be considered as a high-risk process. There is an increased likelihood of relapse into alcohol dependency and re-adoption of old, long-standing mal-adaptive coping skills. This is of particular risk if the individual is returning to their old drinking environment and social acquaintances. Transfers of this nature should be undertaken in a planned manner, working with the individual patient and key workers and

other carers and family members. It is important to facilitate the transfer of the patient's newly acquired skills to the new environment and to educate and supervise new carers and key workers. The following example illustrates a 'graded discharge' from a nursing home to a domestic environment.

Example

Ms X was a 50-year-old woman who presented with a Wernicke's encephalopathy after several years of heavy drinking and several unplanned acute withdrawals. She lived at home with her son and husband. The pre referral five years had witnessed increased alcohol misuse, progressive breakdown in the family relationships and related hostility towards her. During this time, she had become profoundly dependent; unable to undertake any household tasks and had abdicated responsibility for running the home to her husband (who was a taxi driver) and her son who was still in school.

She was admitted from hospital, early in phase 2 of her rehabilitation, into a local nursing home specialising in younger people with cognitive damage. She was under the supervision of the clinical team working with the named carers within the nursing home in developing the programme. When admitted to the nursing home, she was disorientated, had problems in most areas of activity of daily living and had significant memory problems. Over the next three to four months, she began to settle and was encouraged to commence a journal. She slowly developed planning skills and we introduced skill learning, adapting her journal into a planner as well as a record of activities. Towards the end of 18 months of rehabilitation she was significantly improved in all aspects of her functioning but still required prompting in areas of function and still had some memory difficulties. In the early stages of phase three we started to introduce her family (through encouraging visits to the nursing home as part of the planning process) and educating them about the effects of alcohol and how it changes cognition and behaviour. It was evident that there had been significant damage done to the patient's relationships with both her husband and son. It took many visits and considerable engagement of the key workers in trying to engage the family but as the patient improved, the relationships slowly improve. This happened to the extent that we were able to undertake supervised visits to the patient's home. These visits included working with the husband and son (when possible) in helping the patient to resume some of the daily household tasks. Again, this process was subjected to supervised monitoring and planning with the husband. Currently, the patient is now visiting home most days and we are in the process of attempting a night 'stay-over' at home, without tam supervision.

The main problems that we have run into are:

- *The hostility of the family to the patient relating to previous behaviour and the difficulty in forging new relationships.*
- *We have run into funding problems in that the commissioning agency now determine the help as social care and are charging the family.*

There are a number of skills required by the patient that need focused attention as a consequence of the patient never having had to undertake these tasks in the past. An example of this is the new washing machine that was purchased when the patient was

incapacitated during the year prior to admission; consequently, she had never learned to use it.

Phase 5 Social integration and relapse prevention

There are three major therapeutic principles that need to be addressed in this phase:

1. To prevent relapse into alcohol misuse

2. To maintain an optimum level of independence and quality of life over the long term.

3. To develop a social network and social esteem

This phase is principally informed by the Department of Health Document (Models of Care for Alcohol Misusers (MoCAM) which provides recommendations for the long-term management of alcohol misusers.

The main goals of phase 5 are to:

- maintain personal commitment to their drinking goals
- avoid the company of heavy drinkers
- find housing (or appropriate accommodation)
- find employment (or structured engagement, e.g. voluntary engagement)
- access training and education to develop employment and life skills
- manage personal finances (or arrange supervision and help in financial management when the patient is unable)
- achieve lasting changes in their lifestyle.

These priorities should be informed by the patient's level of function and cognitive abilities and should be appropriately adapted in the context of continuing care. Hopefully by phase 5 the patient has been encouraged to be as independent as possible and has developed regularity and routine in terms of activities of daily living. It is important to support a planned and structured program of social integration in the context of on-going emotional and practical support.

We have found that patients may benefit from voluntary work as an aid to enhance self-esteem, social networking and routine. In the first instance, the key worker attended the voluntary work with the patient so as to build confidence and familiarity. Over a month or so, this support was slowly withdrawn.

Example

Mr X is a 55 year old man who was referred to acute hospital care, having accidently set fire to his house. He presented with an acute encephalopathy in the context of many years of heavy alcohol misuse, deterioration of marital and family relationships and alienation from his children. He was admitted into an 'out of area' nursing home with experience in managing people with traumatic head injuries with a specialised commissioned care package. The community team provided supervision regarding development and delivery of the rehabilitation programme. Phase 3 recovery was relatively uncomplicated, utilising journal keeping, planning and skill learning in the context of orientation, memory training and alcohol education. He was monitored, using HoNos (Health of the Nation Outcome Scale) and, the Addenbrooke's Cognitive Examination. His HoNos scores showed considerable improvement over the first two years of rehabilitation, but he remains quite impaired from a

cognitive perspective, with a score of 75 out of 100 on the ACE-R. In particular, he has significant problems with planning and working through problems.

During the late stages of the second year of phase 3, the patient was leaving the nursing home and making his way to a local warehouse and storage company where he was able to undertake supervised voluntary work three days a week. However, his brother lived some distance away, coming from the same area from which the patient was originally referred. As the patient's wife had separated from the patient and he had an irreparable relationship with his children, his brother remained his only close living relative. It soon became evident that the patient wanted to move back to the neighbourhood of his brother's family. This entailed considerable risk as it required:

- *Moving out of an institutional setting associated with close support and structure*
- *Losing confidant relationships with local nursing home key workers and friendships with other nursing home residents*
- *Giving up the local voluntary job*
- *Going back to the same district from which he was originally referred and the possibility of meeting with old drinking partners*
- *The need to find a new voluntary job/employment*
- *The need to find more independent living accommodation and putting in a commissioned support package.*

We carried this out with close collaboration of the brother and his family through a stepped transition to new accommodation with a support package, based on regular needs assessment. Our team key worker, worked with a domestic agency in providing appropriate input, and supervising activity planning. During the early stages of transfer, we explored those local charitable organisations that provide voluntary and paid job opportunities for people with mental health problems. The patient's finances are still managed through the Court of Protection.

Long term follow-up

We have found that the duration of follow-up, after the patient has been settled in an optimum environment with appropriate social support varies. Length of time is dependent on the individual circumstances. A significant number of patients will have presented with concomitant mental health issues, e.g. serious degrees of depression and paranoid psychoses. In these cases, the patient is followed up through the normal psychiatric service provision (integrated into the ARBD team). Obviously, a significant minority of patients will relapse into alcohol misuse (approximately 20%). If these patients are deemed to have made capacitated decisions concerning their drinking, they are encouraged to limit or cease drinking and are frequently referred to the alcohol treatment services. This can cause some difficulties in that the local ARBD service and alcohol treatment services are not integrated and run by differing organisations.

Incapacitated alcohol misusers usually end up being referred back into the ARBD team. If cognitive damage is permanent and does not respond to appropriate nutrition and abstinence (phases 2 & 3) then the patient may well be maintained in an appropriate environment for many years. Even in these cases there frequently appears to be improvement in social intelligence and the patient may develop a reasonable quality of life

over time. We have had cases in which seven to ten years post presentation we have been able to place the patient in less restrictive environments.

Capacity assessments.

Our Team works within the legal context of the English/Welsh Mental Capacity Act. It is not the intention of this document to present a 'how-to do-it' instruction but to merely highlight some of the issues that we have come across in the local context.

In summary, The Mental Capacity Act demands that the clinician examines the ability of the patient

- To remember information so that they can make a decision.
- To understand the information that is provided
- To weigh up the issues required in making a decision
- To communicate the decision that has been made.

The clinician is expected to support the person in terms of undertaking these processes.

Main questions to be addressed in the assessment of patients with ARBD

Obviously every patient will differ in the precise decisions that need to be considered. We have found that two issues are certainly common:

1. Does the patient have the capacity to make decisions concerning the care that they need?
2. Does the patient have the capacity to make decisions concerning further alcohol drinking?

In order for the patient to be able to understand and weigh up the relevant issues relating to these decisions, it is self-evident that the individual should be aware of the degree and nature of cognitive damage that alcohol has caused and understand the limitations imposed through these problems in terms of being able to look after themselves.

Common cognitive deficits likely to affect decision making.

We make no attempt to provide an exhaustive list but draw on our experience relating to some of the more common problems encountered in our practice when considering the patient's capacity to make decisions.

Memory problems:

In a normal conversational interview, a patient with ARBD may well appear to have an intact memory. However there are a number of issues that become apparent on more exacting examination.

The important thing is to test the patient's ability to retain information over a significant period of time. We have found that the best way to 'test' this is to check the person can remember the issues (and decisions) discussed in the interview in a second interview, an hour or two later (or the next day). Visual memory is often preserved so the patient may recognise the interviewer but may not have any recall of the conversation (hence the potential importance of written summaries).

Secondly, many patients presenting with ARBD will experience loss of long-term memory. They may present with only vague and inconsistent memories relating to more recent years. There may often little or no memory of previous hospital admissions, periods of alcohol related illness, related domestic and financial problems etc. Hence it is unsafe to assume that decisions the patient makes are informed by personal, previous experiences. We have found it useful to re-iterate the number of hospital admissions and go over relevant biographical history in some detail including physical health issues, forensic issues and any other material that we can get from relatives or case notes.

In the presence of memory difficulties, patients may generate false memories (confabulations) to try and make sense of life experiences. Despite being false, these 'confabulations' are considered as being 'true' by the patient. Consequently, they are very plausible and without corroborative histories are sometimes difficult to identify.

Reasoning difficulties

A wide range of reasoning problems have been found in patients with varying degrees of ARBD as already indicated. These issues can only really be examined in the context of the person's 'real life experience'. Consequently, when considering the capacity of a person with ARBD in terms of decision making, behaviour and associated risk taking, it is important to be aware of the individual's biographical and social history. Previous experiences should play an important part in informing the overall assessment of the individual and are likely to have implications for future behaviour in less structured settings.

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