

ESSS Outline

Palliative and end of life care for people with alcohol related brain damage

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Introduction

This evidence summary seeks to address the following question relating to palliative and end of life care for people with alcohol related brain damage (ARBD): *What is considered good practice in providing end of life and palliative care for people with ARBD?*

About the evidence presented below

We drew on a wide range of evidence, including academic research in relevant databases (e.g. ASSIA, ProQuest Public Health, SCIE Social Care Online and Social Services Abstracts) health and social care guidelines (e.g. NICE and NHS) and recommendations from specialist organisations (e.g. Alzheimer Scotland, Alzheimer's Society, Penumbra) to bring together suggestions for good practice for people with alcohol related brain damage, dementia, and general principles for palliative care.

We searched using relevant key terms and specific terminology, including alcohol related brain damage, alcohol related dementia, alcohol amnesic syndrome, Korsakoff's syndrome, Wernicke's encephalopathy, Wernicke-Korsakoff psychosis, alcoholic cerebellar degeneration, AODR (alcohol and other drug related) structural brain damage and palliative and end of life care.

Where specific guidelines were given relating to healthcare (e.g. nutrition) by non-health organisations, we critically evaluated the validity of the recommendations.

Overall there is a general lack of evidence in the literature and in current clinical practices relating to the care and treatment of people with ARBD ([Brighton et al. 2013](#)).

Accessing resources

We have provided links to the materials referenced in the summary. Some of these materials are published in academic journals and are only available with a subscription through the [The Knowledge Network](#) with an NHSScotland OpenAthens username. The Knowledge Network offers accounts to everyone who helps provide health and social care in Scotland in conjunction with the NHS and Scottish Local Authorities, including many in the third and independent sectors. [You can register here](#). Where resources are identified as ‘available through document delivery’, these have been provided to the original enquirer and may be requested through the [Iriss Evidence Search and Summary Service](#).

Background

Alcohol Related Brain damage (ARBD) is a term used to cover a spectrum of conditions and disorders: this includes alcohol related dementia, Korsakoff’s syndrome, Wernicke’s encephalopathy, alcohol related brain injury and alcohol amnesic syndrome ([MacRae and Cox 2003](#)). Research suggests that ARBD accounts for 10-24% of all cases of dementia (Alcohol Concern 2016). There is also evidence that excessive alcohol consumption is a factor in the development of vascular dementia and Alzheimer’s disease ([Brighton et al. 2013](#)).

Not all of the forms of ARBD are life-threatening or life-limiting. Unlike Alzheimer’s, ARBD is not progressive, in that it does not inevitably worsen over time, and [Alzheimer’s Society \(2015\)](#) explain for example that in the case of ‘alcohol-related dementia’ or ‘alcoholic dementia’ is a widely used but inaccurate term because although the symptoms are similar to dementia, with treatment the prognosis is not always terminal and that people stand a good chance of improvement over time.

Dementia is a progressive, incurable illness, which in its advanced stages results in eating problems (86%), pneumonia (41%), difficulty breathing (46%), pain (39%) and fever (53%) — caused by brain failure ([Mitchell 2015](#)). People with dementia experience complex needs, and high levels of dependency and morbidity at the end of their lives. This can be challenging for carers and services:

As the condition progresses, people with dementia can present carers and social care staff with complex problems including aggressive behaviour, restlessness and wandering, eating problems, incontinence, delusions and hallucinations, and mobility difficulties that can lead to falls and fractures ([NICE 2016](#)).

There is a lack of specific guidelines for end of life and palliative care for people with ARBD, and therefore general good practice and dementia-specific recommendations are provided, as well as general guidelines for care for people with ARBD.

Evidence for good practice

General recommendations for end of life care

Hayes, A et al. (2014) Pathways through care at the end of life : A guide to person-centred care. London: Jessica Kingsley (Available through [NHS Scotland Library Service](#))

A guide to providing excellent, person-centred end of life care. Following a pathway from initial conversations about end of life to care in the last days of life and after death, it covers assessing need and planning care, co-ordinating care between different agencies, and ensuring quality in different settings, such as at home, in a hospice, or in hospital. Good practice guidance on communication, ensuring the person's needs are met, support for their family and how to facilitate a good death is given. Case studies illustrate real life practice, and questions throughout each chapter encourage reflective

practice. This book is aimed at all those working with people at the end of life, such as nurses, social workers, GPs and home carers, as well as students in these fields. ([Abstract from SCIE](#))

NHS Scotland (2018) [Scottish Palliative Care Guidelines](#) (website)

The Scottish Palliative Care Guidelines reflect a consensus of opinion about good practice in the management of adult patients with life limiting illness. They are designed for healthcare professionals from any care setting who are involved in supporting people with a palliative life-limiting condition. The guidelines have been developed by a multidisciplinary group of professionals working in the community, hospital and specialist palliative care services throughout Scotland. It includes guidelines around pain, symptom control, palliative emergencies, end of life care and medicine information.

National Institute for Health and Care Excellence (2015) [Care of dying adults in the last days of life. NICE Guideline NG31](#) (website and pdf)

This guideline covers the clinical care of adults who are dying during the last 2 to 3 days of life. It aims to improve end of life care for people in their last days of life by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covers how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life.

Nosowska, G (2017) [Good practice at end of life for social care practitioners: practice tool](#). *Research in Practice for Adults* (downloadable file £7/10)

This resource explores how social practitioners can better support people who are dying and bereaved. It is aimed at frontline practitioners such as social workers and the managers and supervisors that support them. The resource covers: what people who are dying or bereaved want and need; the evidence around providing better support; the role of social care and social work; and how practitioners can increase their confidence and capabilities

around end of life care. It includes four practical tools to help with person-centred care, person-centred planning, coordinating care, and emotional support for practitioners. Quotations from people with lived experience are also included. ([Abstract from SCIE](#))

Skills for Care (2014) [Understanding roles: working together to improve end of life care](#) (pdf)

This resource describes a range of people and roles that may be involved in end of life care and how they work together, including information about what different professionals do, how they contribute and what they need from others. It provides links to support for health and social care professionals.

Skills for Care and Skills for Health (2014) [Common Core Principles and competences for social care and health workers working with adults at the end of life](#) (pdf)

This document is a framework for people engaged in managing, commissioning and delivering end of life care and support. Using it will help to equip workers, particularly those whose main role is not necessarily working with people at the end of life, to be competent and feel confident in working in this area. Competences include Communication Assessment and care planning, advance care planning, symptom management, and maintaining comfort and wellbeing.

Skills for Health et al. (no date) [Working together: Improving end of life care through better integration. What can I do? Practical messages for front line workers](#) (pdf)

This resource presents key messages for end of life care. The recommendations come from a series of discussions between carers and practitioners from different social care and health settings and relate to what people said about their own experiences, and what matters most to them. The recommendations may be incorporated into daily practice, for a positive impact on people using care and support services.

Dementia-specific recommendations for end of life care

Alzheimer's Society (2011) [Guidelines for care: person-centred care of people with dementia living in care homes: framework](#) (pdf)

These guidelines for care present a framework aimed at improving the quality of care of people with dementia in care homes through a person-centred philosophy. The framework is an evidence based foundation for the development of knowledge translation tools to enhance quality care. The guidelines consist of the following sections: what does a person-centred philosophy mean; what does person-centred care look like in a care home; ensuring family inclusiveness; extending a person-centred philosophy through end of life. ([Abstract edited from SCIE](#))

Kinnaid, L (2015) [Advanced dementia practice model: understanding and transforming advanced dementia and end of life care](#). Alzheimer Scotland (pdf)

This report sets out an integrated and comprehensive approach to supporting people with advanced dementia through to end of life, whether they are living in their own home, in a care home or spending time in a health care setting. The report looks at the experience of advanced dementia and outlines the issues that need to be addressed. Issues discussed include equality of access to services; advanced planning and decision making, nutrition and hydration, and psychological issues. It also looks at the support needs of carers providing day-to-day care for people with dementia. The report then outlines the Advanced Dementia Practice Model, which focuses the Advanced Dementia Specialist Team and the 8 Pillars that make up the model. These are: the Dementia Practice Coordinator; General health care and treatment; Mental Health care and treatment; personalised support; therapeutic approach; Support for carers; Environmental responses; and Community Connections. The report then makes recommendations and calls for the Scottish Government to test the Advanced Dementia Practice Model

as part of the objectives of the National Dementia Strategy 2016 in Scotland.
([Abstract from SCIE](#))

Manthorpe (2016) [Serious case reviews into dementia care: an analysis of context and content](#). *The British Journal of Social Work*, 46(2), pp. 514–531 (Open Access)

This paper presents the results of a study undertaken in 2013 analysing Adult SCRs where the person who was at risk of harm, or had been harmed or died, had a dementia. Some of the SCRs included in the analysis report harms to and unnatural deaths of a people with dementia or where dementia was possible, in care homes. It may provide an insight into the problems to avoid, including:

- Physical attack by other residents
- Sexual assault by other residents
- Pneumonia
- Hypothermia
- Falls
- Pressure sores

National Institute for Health and Care Excellence (2016) [Dementia: supporting people with dementia and their carers in health and social care](#). Clinical Guideline CG42 (website and pdf)

Practice guideline to improve care for people with dementia by promoting accurate diagnosis and the most effective interventions, and improving the organisation of services. Based on the best available evidence the guideline provides recommendations on: integrating health and social care; prevention and early identification; diagnosis and assessment; interventions for cognitive and non-cognitive symptom; interventions for comorbid emotional disorders in people with dementia; palliative care; and support for carers. The guide is for health and social care staff who work with people with dementia and their carers, and those who work with older people and people

with learning disabilities. Originally published in 2006 and last updated in 2016. ([Abstract from SCIE](#))

National Health Service (2011) [Routes to success in end of life care: achieving quality environments for care at end of life](#) (pdf)

This guide identifies a number of key environmental principles to help improve privacy and dignity for patients and relatives. These principles can help to support the bereaved whose memories live on once their loved one has died. It is designed to be of use at each stage of the end-of-life care pathway and across all care environments, including hospitals, hospices and care homes. The aim of the guide is to provide practical support to those charged with delivering end-of-life care services, showing how patients' and relatives' experience can be improved through relatively small scale environmental changes. These can be as simple as de-cluttering corridors and notice boards or as far-reaching as establishing a hospital bereavement centre. The guide also considers the end-of-life pathway from an environmental perspective, separating it into 4 overlapping sections. These are: how environments can be created for relatives, for those receiving palliative care, bereavement centres, and mortuary viewing facilities. Each section outlines the relevant step or steps of the pathway as well as listing questions to ask and tips on how to get started. Case studies highlighting best practice are also included. ([Abstract from SCIE](#))

Sachs, G et al. (2004) [Barriers to excellent end-of-life care for patients with dementia](#) (Open Access)

This paper suggests approaches for overcoming barriers to excellent end of life care in the domains of education, clinical practice, and public policy. It highlights some of the key shortcomings of end of life care for people with dementia, including that dementia increases the risk of inadequate pain treatment. It conceptualises dementia as a terminal illness and argues that it should be viewed as a terminal condition in order to more readily allows clinicians, patients, and families to consider hospice and other palliative measures and improve end of life care.

Social Care Institute for Excellence (2014) [End of life care: achieving dignity for those with dementia](#) (video with transcript)

This film illustrates the steps involved in supporting a person with dementia to die well, through the experience of Mairead Smart and her family. It is crucial to recognise when a person with dementia enters the final weeks and days of their life and to respond with support that avoids unnecessary interventions and reflects the wishes of the individual and their family. Person centred care, advance care planning, the Gold Standards Framework and the Liverpool Care Pathway can all help care staff to deliver good dementia care and good end of life care. ([Abstract from SCIE](#))

Recommendations for general, palliative and end of life care for people with ARBD

[Alzheimer's Society](#) provides some general guidance for treating and supporting people with ARBD:

Unlike Alzheimer's disease or vascular dementia, ARBD is not certain to worsen over time. There is a good chance of stabilisation or improvement if the person is given high doses of thiamine, remains free from alcohol and adopts a healthy diet with vitamin supplements. Brain scans show that, with abstinence, some of the damage caused by excessive drinking can be reversed. However, if the person continues to drink and eats poorly, ARBD is likely to continue to progress.

They provide easy to understand descriptions of Initial stabilisation, alcohol treatment services and rehabilitation as well as a set of tips for supporting a person with ARBD (these are not specific to people needing end of life care):

- Ask professionals involved in the person's care how you can best help them. Professionals should see you as a key partner in their recovery. The person needs to be supported to remain completely alcohol-free. By doing so they give themselves the best chance to recover

- Be positive and help the person to do things to retain and improve their skills. Do things with them, not for them
- Encourage the person to keep a diary. They will benefit from structure and a daily routine
- Break down complex tasks (eg cooking a meal) into smaller steps to make them easier to follow.
- When talking to the person, remember that they may not keep information for very long afterwards. Give the person more time and encouragement when they are speaking. Be patient, use short phrases and recap at the end
- Place clues (eg pictures or labels) around the person's environment to help support them
- Help the person to look after themselves generally, such as getting enough sleep
- Support the person to attend a self-help group. If you are a family member, consider joining one too

Symptoms of ARBD

Symptoms of ARBD are shared with other forms of dementia and some may be condition-specific to Wernicke's encephalopathy, Korsakoff's syndrome and alcoholic dementia. Symptoms include:

Cognitive problems

- Disorientation, confusion or mild memory loss
- Problems with language – there may be difficulties in remembering words or the names of friends and family, or problems like forgetting the end of a sentence halfway through
- Difficulty in acquiring new information or learning new skills
- Changes in personality – at one extreme the person may show apathy (unconcern, lack of emotional reaction), or at the other, talkative and repetitive behaviour
- Depression and irritability – this can also include apathy, a lack of interest in people or events and a lack of spontaneity or motivation

- Difficulty concentrating – it can be hard for people with ARBD to focus on one thing for more than a few minutes
- Lack of insight into the condition – even a person with large gaps in their memory may believe that their memory is functioning normally
- Confabulation – where a person creates events to fill the gaps in day-today memory
- Poor planning and organisational skills, and problems with decision-making, judgement and risk assessment
- Problems with impulsivity (for example, rash financial decisions) and difficulty controlling emotions (for example, irritability or outbursts)
- Problems with attention and slower reasoning
- Lack of sensitivity to the feelings of other people
- Behaviour which is socially inappropriate ([Alcohol Concern 2016](#); [Alzheimer's Society 2016](#))

Physical problems

- Undernutrition
- Involuntary, jerky eye movements or paralysis of the muscles that move the eyes
- Damage to the liver, stomach and pancreas – all of which can affect brain function
- Pins and needles and numbness or burning sensation in arms and legs – this can increase the risk of falls and accidents
- Slow, wide, stumbling gait (ataxia) – this can make it difficult for someone to walk, and they may find balancing difficult
- Poor temperature control, muscle weakness and disturbed sleep patterns – these are all caused by shrinkage of the brain and by tissue damage ([Alcohol Concern 2016](#); [Alzheimer's Society 2016](#))

In addition to symptoms caused by their condition, people with ARBD needing palliative or end of life care may also experience symptoms as a result of their treatment. For example, withdrawal of alcohol can cause the

person to have delirium, intense sweating, and behavioural problems such as agitation and hallucinations.

Gridley, K et al. (2013) [Good practice in social care for disabled adults and older people with severe and complex needs: evidence from a scoping review](#) (Open Access)

This article reports findings from a scoping review of the literature on good practice in social care for disabled adults and older people with severe and complex needs, including adults who had suffered a brain injury, people with substance misuse problems and people with dementia. The authors found that there is a general lack of well-supported evaluation evidence for approaches, but the strongest evaluation evidence relevant to this summary indicated the effectiveness of intensive case management for older people with advanced dementia, a specialist social worker with a budget for domiciliary care working with psycho-geriatric inpatients, and interprofessional training for community mental health professionals.

Recommendations for delirium, anxiety and terminal agitation

It can be difficult to distinguish between delirium and dementia because symptoms overlap, and some people may have both conditions ([NICE 2014](#)). This includes people with ARBD who may experience delirium as a result of alcohol withdrawal.

Let's Respect (2011) [Do you see me?: recognising, understanding and caring for people with dementia, depression and delirium. Toolkit for care homes](#) (pdf)

Aimed primarily at staff working in care homes who want to know about the mental health needs of older people in order to improve practice and standards of care, this guide is based on the journey of any person entering the care home world. It is designed to be used as a resource in induction of new staff, in staff supervision sessions, in group discussions and in training. The approach emphasises the importance of knowing the service user, their story and who they are. The guide covers the welcoming environment and

aspects of design and layout, life story work and the benefits of life story for carers, health and wellbeing in later life including delirium, dementia and depression, everyday living and quality of life, rights, capacity and decision-making, death, dying and end of life care, and staff health and wellbeing at work. A list of useful resources is included. ([Abstract from SCIE](#))

NICE (2014) [Quality standard: delirium in adults](#) (pdf)

This quality standard covers the prevention, diagnosis and management of delirium in adults (18 years and over) in hospital or long-term care settings. It includes a set of quality statements with recommendations for practice around:

1. Assessing recent changes in behaviour
2. Interventions to prevent delirium
3. Use of antipsychotic medication for people who are distressed
4. Information and support
5. Communication of diagnosis

NICE (2010) [Clinical guidance CG103: Delirium: prevention, diagnosis and management](#) (website and pdf)

This guideline covers diagnosing and treating delirium in people aged 18 and over in hospital and in long-term residential care or a nursing home. It also covers identifying people at risk of developing delirium in these settings and preventing onset.

Whyte, G (2016) [Delirium, anxiety and terminal agitation](#) (pdf)

This is a presentation from a Consultant in Palliative Medicine at the Marie Curie Hospice Glasgow. It gives an overview of the symptoms of delirium, anxiety and terminal agitation including in people with experiences of alcohol excess and polysubstance misuse/dependence. It provides examples of assessment, treatment and management and emphasises the importance of early recognition of symptoms.

Recommendations for nutrition and supplements

Acreman (2009) states that nutrition in palliative care is important for “the management of troublesome symptoms as well as to enhance the remaining life”.

Alzheimer’s Society recommend ensuring people with ARBD have a high uptake of thiamine. This is because of the role of thiamine deficiency in alcohol-linked neurological disorders:

Up to 80% of people with chronic alcoholism develop thiamin deficiency because ethanol reduces gastrointestinal absorption of thiamin, thiamin stores in the liver, and thiamin phosphorylation. Also, people with alcoholism tend to have inadequate intakes of essential nutrients, including thiamin. ([National Institutes of Health](#))

Thiamine deficiency is the established cause of an alcohol-linked neurological disorder known as Wernicke–Korsakoff syndrome (WKS) and contributes significantly to other forms of alcohol-induced brain injury including the most severe, alcohol-induced persisting dementia ([Martin et al. 2004](#)).

Alzheimer’s Society recommend the encouragement of a balanced diet with foods containing thiamine, including avocados, baked potatoes (skin on), leafy green vegetables, fish (eg mackerel and sardines) and wholegrains. However, the evidence of the efficacy of the bioavailability (the proportion of the substance that enters the circulation when introduced into the body and so is able to have an active effect) of thiamine from food is limited ([National Institutes of Health 2016](#)). A Cochrane review (2013) concluded that the evidence from randomized clinical trials is insufficient to guide healthcare providers in selecting the appropriate dose, frequency, duration, or route of thiamine supplementation to treat Wernicke-Korsakoff syndrome in patients with alcohol abuse.

The World Health Organization (1999) recommends daily oral doses of 10 mg thiamin for a week, followed by 3–5 mg/daily for at least 6 weeks, to treat mild thiamin deficiency. There is limited evidence of the efficacy of high doses of oral thiamine supplements, which may not be effective in raising blood thiamine ([National Institutes of Health 2016](#)).

The recommended treatment for severe deficiency consists of 25–30 mg intravenously in infants and 50–100 mg in adults, then 10 mg daily administered intramuscularly for approximately one week, followed by 3–5 mg/day oral thiamin for at least 6 weeks ([World Health Organisation 1999](#)). However, evidence suggests there is a lack of sufficient knowledge from randomised controlled clinical trials to “guide clinicians in determining the dose, frequency, route or duration of thiamine treatment for prophylaxis against or treatment of WKS due to alcohol abuse” ([Day et al. 2013](#)).

References

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Clinical Guideline CG42 (website and pdf)

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