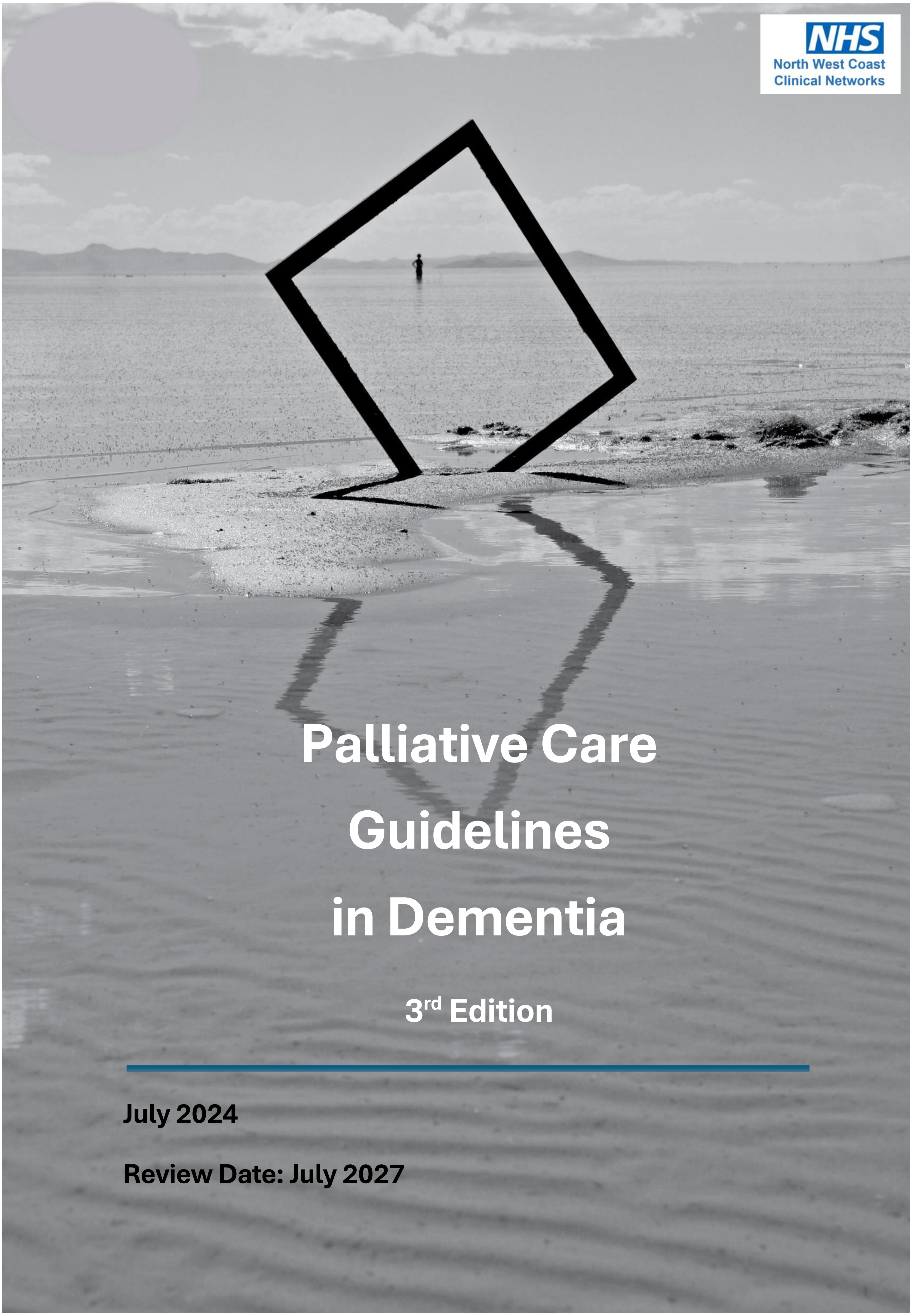

Palliative Care Guidelines in Dementia

3rd Edition

July 2024

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Contents

Cheshire and Merseyside Dementia Guidelines

Foreword

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One in two of us will be affected by dementia in our lifetime, either by caring for someone with the condition, developing it ourselves, or both.

In 2022, dementia was the leading cause of death across England and Wales, with the Office for National Statistics identifying dementia as accounting for 11.4% of all deaths. Despite this, accessibility and quality of end of life care for people with dementia remains variable. Too many people who are dying with or from dementia experience unnecessary emergency admissions or extended inpatient stays which can be distressing and can be detrimental to the person's overall wellbeing. Sadly, this can lead to the person dying in hospital which is not what they have chosen.

NHS England Transformation Framework (2022) describes a ***well*** pathway for dementia from prevention, diagnosis, supporting, living, and dying with dementia. A palliative and end of life care approach needs to be considered from the point of a dementia diagnosis. These guidelines are an easy to read and pragmatic guide to help health and social care professionals, working across the many organisations and services, to support those with a dementia diagnosis to live well with dementia whilst taking a holistic approach to personalised care planning towards achieving a good death. Working in this way will help to ensure that the Human Rights of people living with dementia are upheld during end of life care, including the provision of respectful and dignified care, reducing inequality due to the diagnosis of dementia and promoting autonomy in decision making about end of life care for both the person living with dementia and those who support for them.

The NHS Long Term Plan promotes a model of personalised care to improve the quality of end-of-life care, helping to reduce avoidable hospitalisations and enable people to die in their preferred place of death. The focus of personalised care is to see the person as an individual, who has their own rich and unique life's journey. They are so much more than a condition or a 'label' of dementia. Seeing the person and those important to them as individuals is the start to improving their lives by supporting them to feel important, valued and their beliefs and values respected. This is paramount to nurture their involvement in decisions being made about future care particularly in the last weeks/days/hours of their life.

Ensuring those dying with or from dementia die peacefully in the comfort of their own home, wherever that may be, surrounded by those who have loved and cherished them throughout their lives is what all health and social care staff desire to achieve. To be able to do this staff need to have access to high quality palliative and end of life care training, education and up to date resources which they can refer.

We endorse these palliative care guidelines as an invaluable resource to guide and support staff at a time when they may face a situation where guidance is needed to effectively manage a difficult or complex situation.

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Palliative Care Guidelines in Dementia

Quick Reference Guide

Advancing Dementia

Diagnosing dementia can be challenging, considering the different dementia syndromes (see page 8 of full guidelines)

Loss of capacity can occur early following diagnosis or prior to this so it is important to consider early assessment of capacity (p63) and advance care planning (p73)

Ongoing holistic assessment and a person-centred approach to care are essential (p16)

Management of cognitive and non-cognitive symptoms can be challenging (p36) and some medications should be avoided, if possible, in certain specific types of dementia (p41)

Assessment of social care needs and understanding of the individual's entitlement in light of the Care Act 2014 are very important (p46)

Carers need access to ongoing support (p48) and need to be given information about local services which they may find helpful to maintain their own health and wellbeing (p118)

Clinically assisted hydration/nutrition (p77), treatment of infection (p86) and goals of care can be particularly challenging issues in patients with dementia

As the patient deteriorates it is important to rationalise medication and discontinue non-essential drugs, reducing the number and frequency to the minimum needed for comfort (p94)

Identifying dying can be difficult in people with dementia (p88)

The 5 key priorities for care of the dying patient is a framework for holistic care of the patient in the final days and hours of life and those important to them (p102)

Carers should be able to access the appropriate level of bereavement support to meet their needs (p111)

Good communication is important throughout

Chapter 1- Introduction

These guidelines were first developed in 2011 in response to The Department of Health ‘End of Life Care Strategy’ (2008) and were designed to support professionals to provide the highest possible quality of end of life care to people with dementia. The guidelines were revised in 2018 to incorporate updated information to reflect the increasing numbers of people living with dementia. As knowledge and understanding about end of life care for people with dementia has continued to develop, we are pleased to welcome you to the third edition of the guidelines.

When the first edition was published, there were just under 700,000 people living in the UK with dementia. More recent figures published in 2021, estimated the number of people living with dementia being close to one million (Alzheimer’s Research UK, 2023). Dementia is described as a demographic time bomb with a dramatic projected increase in the number of people diagnosed with dementia. Each edition of these guidelines has seen the actual number of people with dementia increase when compared to the estimated figures from the previous edition. By 2040 the number is expected to rise to 1.6 million (Alzheimer’s Research UK, 2023).

One in two of us will be affected by dementia in our lifetime, either by caring for someone with the condition, developing it ourselves, or both. The leading cause of death in England and Wales in 2022 was dementia and Alzheimer's disease, with 65,967 deaths (11.4% of all deaths); this percentage was higher than in 2021 (61,250 deaths, 10.4% of all deaths) (ONS, 2022).

While rates of diagnosis vary significantly across the UK, there has been an increase in overall diagnosis rates. In England, the diagnosis rate was 63.1% (NHS Digital, Primary Care Dementia Data, May 2023), however this is often made:

Late in the illness

At a time of crisis

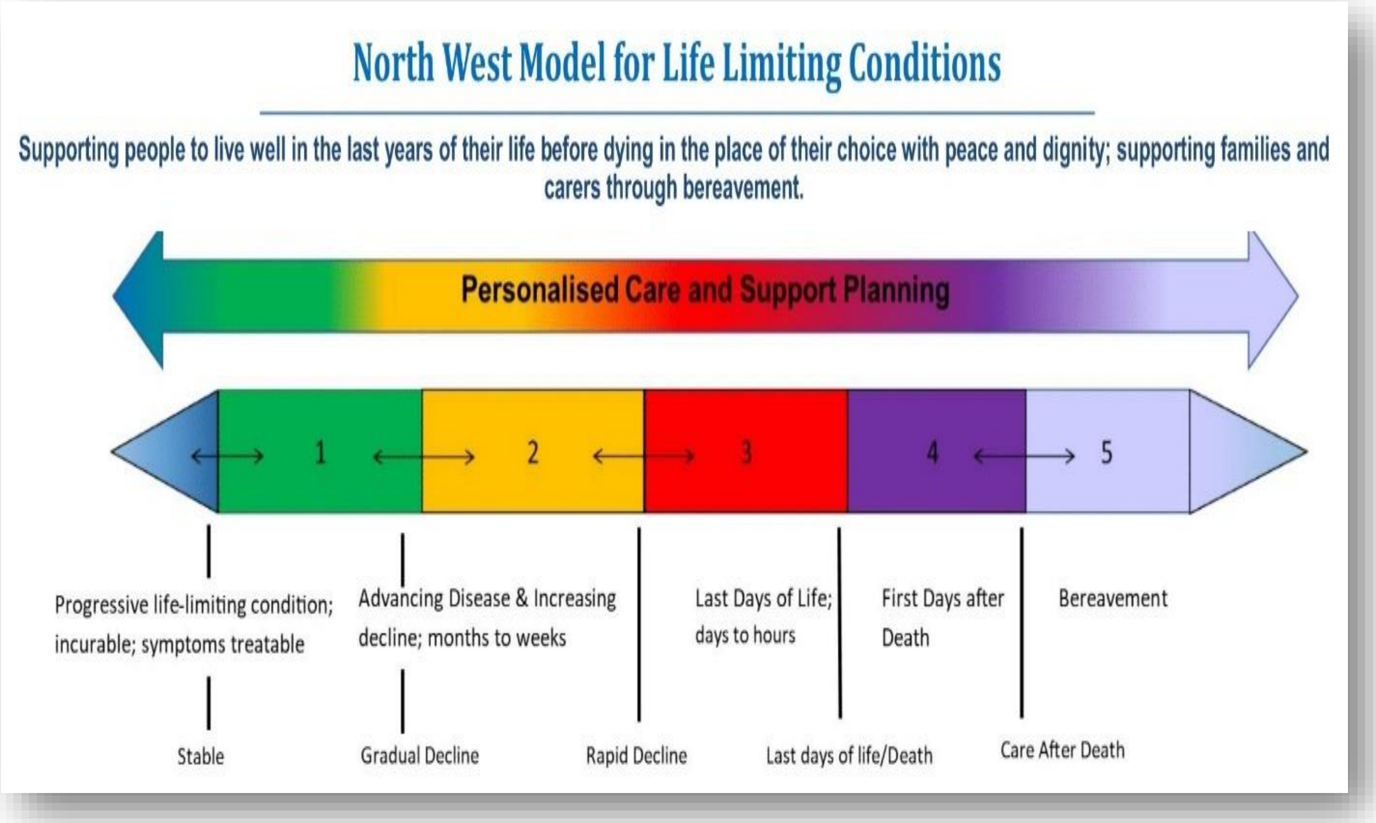
Too late for effective intervention

(Marie Curie, 2014)

Dementia as a cause of death is also increasing and the number of deaths with a mention of dementia recorded on the death certificate rose from 6.6% to 12.0% in England between 2001 and 2010 (Sleeman et al, 2014); although it is often not recognised as a life limiting condition. People with dementia may face additional complications at the end of their lives including diminishing mental capacity, difficulty communicating needs, such as pain and thirst and uncertainty in prognosis. There is widespread recognition that we need to improve care for people with dementia at the end of life (Sampson, 2020). Areas identified for change include engaging people with dementia in advance care planning and integrating palliative care earlier into the dementia care pathway (Wolverson, 2023). Professionals may also lack the skills and confidence to deal with these challenges (Smith et al, 2019).

These guidelines have been revised and updated to provide a practical resource for professionals who care for people with dementia at the end of life. They have been devised to allow the professional to access the sections relevant to them at any given time. They are intended to provide an overview of the subject and are not meant as an exhaustive guide. However, recognising that professionals will at times need more information, additional resources are cited throughout the guidelines and in a section at the very end.

In order to provide a structure to this guide, the sections have been organised in line with the North West Model for Life Limiting Conditions (The North West Coast Clinical Networks, revised 2021). The model comprises of 5 phases to support the assessment and planning process for people from the diagnosis of a life limiting illness, as seen below:



The guidelines begin with an overview of different dementia syndromes and considers a number of issues, such as assessment and communication, that have an impact on the person with dementia even before the person may be considered to be in the last year of life.

The guidelines move on to focus on some of the broader end of life issues such as clinically assisted nutrition & hydration and advance care planning before considering the last days of life issues such as prognostication and the terminal phase. The guide concludes with a section about bereavement.

As identified within the guidelines it is very difficult to prognosticate in dementia, but this document is designed as a resource to offer guidance in holistic care principally of those people with severe dementia with significant impairment of memory, functioning, speech and understanding for whom the palliative approach is especially relevant.

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Chapter 2- Descriptions of the Dementia Syndromes

What is Dementia?

Dementia is a syndrome that is caused by several diseases of the brain, the more common of which are considered below. Dementia is a progressive and irreversible syndrome that can cause:

Impairment of Cognition

Problems with memory, language, thinking clearly, orientation, calculation, problem solving

Problems With Psychaitric and Behavioural Disturbances

Personality changes, difficulties regulating emotional control, depression, agitation, delusional thoughts and hallucinations

Problems with Activities of Daily Living

Dressing, cooking and eating, shopping, etc

(American Psychiatric Association, 2013)

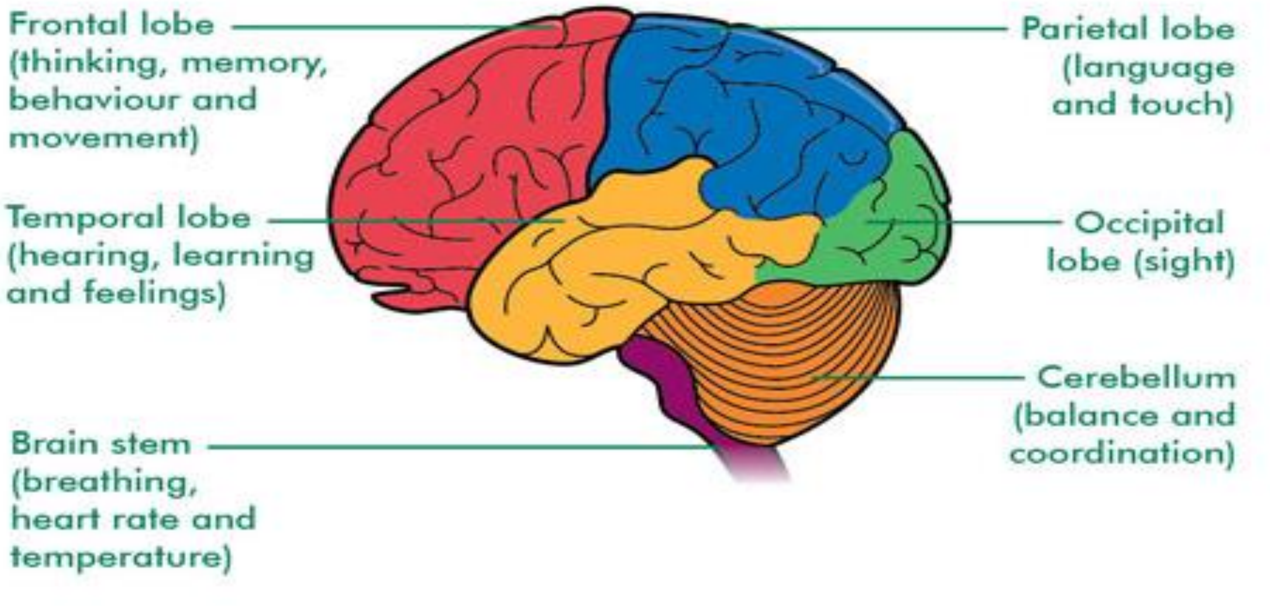
The most common subtypes of dementia are (Dementia; NICE CKS, 2021):

- Alzheimer's disease (50 – 75% of dementia cases)
- Vascular dementia (20-25%)
- Dementia with Lewy Bodies (10-15%)
- Frontotemporal dementia (less than 5%)

The prevalence of dementia amongst those aged over 65 in the UK is around 7% and the risk of developing dementia rises with age. For example, the prevalence of dementia in 65-69 year olds in the UK is around 1.7%, whereas the prevalence of dementia in those aged 90-94 is around 30%. (Wittenberg, 2019). Other risk factors for developing dementia include a positive family history of dementia, vascular risk factors (smoking, high blood pressure, diabetes, high cholesterol, obesity), head injury, social isolation, hearing loss and later life depression.

Details of Common Dementia Subtypes

There are usually subtle differences in the presentation of different types of dementia which provide important clues when it comes to diagnosing the illness (Rodakowski, 2014). For example, overall decline in all areas detailed above might point more towards Alzheimer's disease, whereas decline in one area may suggest a more localised area of damage that might be the result of a stroke or frontal dementia. This section looks in more detail at the more common types of dementias.



Age UK: Your brain, what is it and what it does (2023)

a) Alzheimer's Disease

In Alzheimer's disease there is a gradual deterioration of the outer most layer of the brain, the cerebral cortex. The brain shrinks (atrophies), the number of nerve fibres reduces over time, and the number of neurotransmitters also reduces (meaning brain cells cannot communicate with each other as well). This initially results in symptoms that are initially very subtle, hence the person or relatives might be unable to pin down when symptoms started with any degree of accuracy. Alzheimer's dementia tends to progress slowly over a period of years. By the time the person comes to the attention of mental health services, the degree of dementia can be quite apparent and more obvious cognitive deficits can be seen.

The person may initially forget appointments, names or recent events or they may have problems finding the correct words for things.

As the disease progresses, problems may arise with problems such as:

Aphasia

Difficulties with language or speech

Apraxia

Inability to carry out purposeful movements, such as dressing themselves or using cutlery correctly

Agnosia

Problems recognising people or objects. This can be particularly distressing if the person stops recognising family members

Problems With Planning or Making Decisions

In later stages the person may become increasingly confused and disorientated to time and place. This can result in wandering which can put the person at significant risk, especially in winter. Apathy can be seen, in which the person may show a lack of emotion, and eating habits often change. The ability of the person to provide their own care declines and incontinence may arise.

b) Vascular Dementia

In vascular dementia, the brain is damaged as a result of disease to the brain’s blood supply, and this is termed as cerebrovascular disease. Damage to the blood supply can lead to:

- a lack of delivery of blood to the brain as a result of a blockage (ischaemia)
- or the escape of blood from damaged blood vessels in the brain (haemorrhage)

Because this damage can occur in different parts of the brain, the presentation of vascular dementia is variable, and the clinical spectrum is wide. There can be significant overall variation in symptoms seen in Alzheimer’s dementia. People with vascular dementia may present with an insidious onset of cognitive problems or with a series of sudden and widespread physical abnormalities. As well as performing a neurological examination, it is important to record the blood pressure and look for evidence suggestive of vascular disease elsewhere in the body. For example, the presence of significant cardiac murmurs or atrial fibrillation should prompt further investigations as these conditions can trigger clots to form in the heart which may go on to block blood vessels supplying the brain. The presence of carotid bruits or absence of foot pulses also points to vascular disease.

Vascular dementia can be divided on clinical features into three major subtypes, although individuals may have features of more than one subtype:

Stroke related vascular dementia	• This could be dementia that results from one larger stroke resulting in a sudden and significant deterioration. • Or it may be a dementia that is the result of a series of smaller strokes, leading to multi-infarct dementia. An individual small stroke may not be recognised through physical symptoms, but these strokes can produce a step-like deterioration in cognition, with intervening periods when the person may remain stable (or may improve). • When there are cognitive problems following a stroke, the site of the lesion usually determines the clinical picture. For example, a dominant middle cerebral artery infarct can result in dysphasia, dyscalculia and dysgraphia. The dementia tends to be particularly severe in certain midbrain or thalamic strokes. Few people with dementia have formal neuropsychological assessment following a single stroke and it is likely that many mild cognitive deficits are not detected. As with physical disability, the cognitive problems may remain fixed or recover, partially or totally (Wardlaw, 2019).
Progressive small vessel disease (Binswanger's disease)	• This is also known as subcortical vascular dementia, and it is a rare cause of vascular dementia. • The course is of a slow intellectual decline, either gradual or step-like. The clinical picture may be dominated by the dementia, or there may be concomitant physical problems, such as gait disorders or dysarthria. Brain imaging reveals extensive white matter damage deeper in the brain. • The presentation in subcortical disease can mimic that of depression due to apathy and decreased motivation. Often this presentation can cause significant carer distress as the person's ability to initiate activities is impaired rather than their abilities per se. Often carers will suggest the person is being lazy or manipulative.
Mixed dementia	• In addition to those individuals with a pure vascular dementia, many individuals have clinical and pathological evidence of both Alzheimer's disease and vascular disease. This is termed as mixed dementia.

c) Dementia with Lewy Bodies

People who present with Parkinson's disease may develop a progressive dementia. Sometimes symptoms of dementia emerge prior to symptoms of Parkinson's disease, and this is called dementia with Lewy bodies. Lewy bodies are small abnormal protein deposits that form in brain cells and interfere with the normal function of the brain. When Lewy bodies develop in the brain stem, the person may develop symptoms similar to Parkinson's disease. Problems may emerge such as a shuffling gait, muscular rigidity and tremor. These are called extrapyramidal symptoms (McKeith 2017).

Features suggestive of dementia with Lewy bodies include rapid fluctuations in cognitive ability and visual hallucinations. Treatment with L-dopa and the standard anti-parkinsonian drugs often improves the motor symptoms but can lead to confusion and hallucinations. People with dementia with Lewy bodies are sensitive to neuroleptic medications, which can considerably worsen the extrapyramidal symptoms. Such people may respond well to the acetylcholinesterase inhibitor rivastigmine.

d) Frontotemporal Dementia

This dementia accounts for around 1 in 50 cases of dementia. The frontal and temporal lobes of the brain degenerate and shrink. Damage to these lobes results in personality changes and behavioural problems can emerge, as well as problems with communication. It is common to see problems with disinhibition with FTD. Memory is usually less severely impaired than when compared to Alzheimer's disease. Frontotemporal dementia usually affects younger people aged 45-65 and the symptoms progressively deteriorate. There are no specific treatment options available (Coyle-Gilchrist, 2016).

e) Mixed Dementia

Sometimes people present with two different dementing illnesses at the same time, such as Alzheimer's disease and vascular dementia, or vascular dementia and dementia with Lewy bodies. It can be difficult to determine to what extent each disease is causing what problems, and treatment is directed at what is thought to be the predominant cause where possible.

f) Other Diseases Which Are Associated with Dementia

There are over 200 subtypes of dementia (Dementia UK) some of which are extremely rare and can include infections, inflammatory diseases, tumours, toxic insults, metabolic disorders, or trauma. Many neurological diseases, including motor neurone disease, progressive supranuclear palsy and multiple sclerosis, are associated with dementia. Often the dementia occurs in people who have had these diseases for many years, but occasionally dementia can be an early or presenting feature. The cognitive assessment of these people is often complicated by their physical problems.

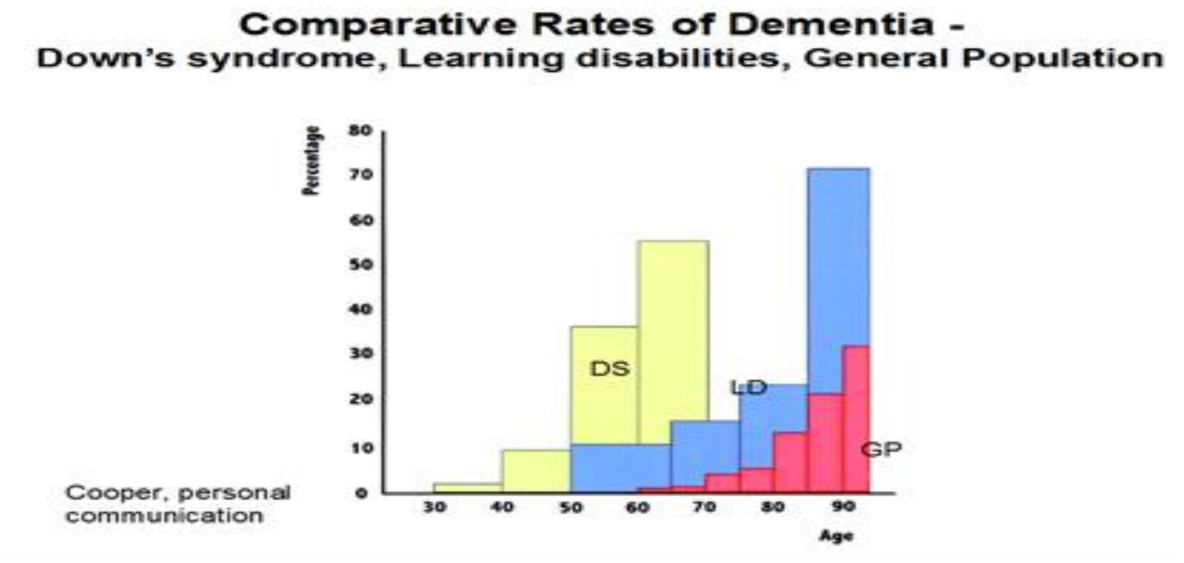
Below is a very brief summary of some other diseases associated with dementia:

- **Huntington's Disease**: This is a genetic condition that may present with cognitive problems and movement disorders. It is inherited as an autosomal dominant pattern and can be diagnosed using genetic techniques. Progression is slow leading to death in 10-15 years. There is a particularly high risk of suicide in this illness.

- **Prion Dementia**: A group of disorders characterised by an accumulation of an abnormal form of a normal human protein, prion protein. Creutzfeldt-Jakob disease (CJD) affects about one person per million per year. Affected individuals develop a rapidly progressive dementia with ataxia and muscular jerks (myoclonus). People suffering with this die within a few months of onset of the disease.

- **HIV Dementia:** This diagnosis is reserved for those with a diagnosis of HIV and concurrent progressive cognitive deficits. Such people complain of forgetfulness, slowness, poor concentration, and apathy. This presentation can be confused with depression. Physical examination reveals tremor, imbalance, ataxia, exaggerated reflexes, and impaired eye movements. This syndrome is likely to become more common as survival rates improve and prevalence rates increase.

- **Dementia in People with Down's syndrome:** There are certain groups who may have a higher prevalence of developing what is referred to as "early onset dementia", where dementia is diagnosed in individuals under the age of 65. One of these groups is people with Down's syndrome who have a higher incidence of early onset dementia. Initial symptoms may be seen as changes in behaviour which may be misinterpreted or misdiagnosed. Estimates suggest that 75% of people with Down's syndrome will develop Alzheimer's disease when they move into their 60's (Kerr, 2007). Assessment tools for dementia in the general population are not appropriate for people with Learning Disabilities. For example, widely used tools such as the Mini-Mental State Examination (MMSE) (Folstein & Folstein, 2001) assume the pre-morbid level of functioning to have been within the average range. It may be necessary to access a specialist assessment and specialist practitioners to ensure an accurate assessment is completed by a member of a Community Learning Disability Team (CLDT).



Cooper et al (1997)

Behavioural and Psychological Symptoms in Dementia (BPSD)

BPSD are common in dementia. Behavioural symptoms are particularly important as they can affect a person's ability to live in the community and include problems such as aggression, disinhibition and agitation. How these can be managed is considered in Chapter 5.

Psychological symptoms can result in problems with:

Affect	Depression occurs in up to half of people with dementia but is usually of a mild nature. Depressive symptoms requiring treatment can occur in up to 20% of people with dementia. By contrast, mania is rare. Lability may be seen in which the person is easily tearful.
Thoughts	Problems with the content of thoughts occur in about 15% of people with dementia and include delusions and paranoid ideation. Delusional ideas may take many forms. Simple uncomplicated beliefs may occur, for example, believing that a handbag or other personal possession has been stolen, while it has simply been misplaced. Generally, cerebral structures need to be relatively intact in order for delusional ideas to develop.
Perceptions	Problems with abnormal perceptions include visual and auditory hallucinations and affect about 10–15% of people with dementia over the course of their disease. Various forms of misidentification can be seen, including misidentification of mirror image or of other people, or of events on the television. It is quite common to find that the people with dementia believe that another person is living in their house (the 'phantom boarder' syndrome, and this may also be classified as a delusion).

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Chapter 3- Assessment in Dementia at End of Life

People with dementia have unique life histories, which, when combined with issues of co-morbidity and frailty can make the process of assessment at end of life seem complex. NICE (2018) states that *'from diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be.'* (p.45). It emphasises that the needs of the person with dementia should be considered to maximise their quality of life.

A truly person-centred and holistic approach to care needs to be taken throughout the disease trajectory and care giving process focussing on the goals of care (see Fig 1). Assessment is only the first part of an ongoing, cyclical process, where information is gathered, care is planned, implemented, and evaluated with the person with dementia and those important to them.

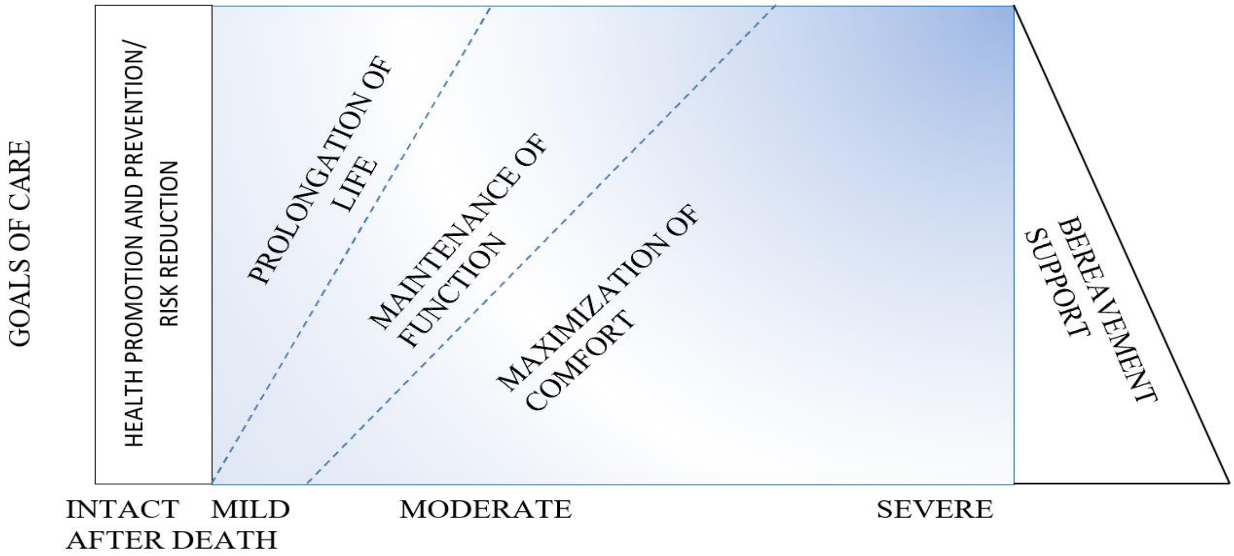


Fig 1: Model of changing care goals and priorities throughout the course of dementia (European Association of Palliative Care, 2015)

Traditionally health professionals have approached the assessment of people with dementia using the medical model, focussing on brain function. However, to be truly person centred and holistic a bio-psycho-social-physical-spiritual model is needed as indicated by Kitwood (1997) in his pioneering work. Good communication and observation skills are required in order to carry out person-centred assessments, and to build a good therapeutic relationship between professionals, the person with dementia, their carers, and family. Information gathered needs to be well documented and shared with the wider multi-disciplinary team, with consent and confidentiality maintained, to ensure continuity and good quality person-centred care. It is equally important to assess and support the family and carers' understanding of dementia and how this is affecting the person with dementia, and care interventions planned.

Defining End of Life Care and End of Life Care Planning

End of life care, according to the End of Life Care Strategy (Department of Health, 2008), *'helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.'*

In order to maximise the benefits of assessment and care planning to support people to live as well as possible with dementia until they die, end of life care planning should take place within the last months or years of life. The use of a prognostic indicator tool may help to identify when a person with dementia may be approaching the later stages of their life. Further discussions on prognostication can be found in Chapter 13 - Identifying dying in advanced dementia.

The mental capacity of the person with dementia should be regularly assessed and considered when care planning (see Chapter 9 - Mental Capacity Act 2005 and Chapter 10 - Advance Care Planning).

Models such as the North West Model for Life Limiting Conditions (2021) is advocated by the North West End of Life Care Operational Group as a whole systems approach to adults with life limiting diseases.

Person Centred Dementia Care

Tom Kitwood first introduced the paradigm of person-centred care in the 1990's which has influenced the culture of care and the developments in dementia care over the past few decades and continues to do so. The focus of person-centred care is to see the person rather than the condition or 'label' of dementia. Like palliative care, person-centred care can be viewed as both a philosophy and an approach to care, with the emphasis on the person still being seen as an individual, with their own beliefs and values right until the end of their life (Dame Cecily Saunders, 1969).

Kitwood (1997) identified five core psychological needs of people with dementia (see Fig 2) that need to be met within the care giving process. As dementia advances, these needs become increasingly important, emphasising the importance of people with dementia feeling valued, having their individual needs met, their perspective understood, and actively encouraged to take part in their social environment (Brooker, 2007).

1. **Attachment-** the need to feel connected to someone and safe
2. **Comfort-** to feel warmth, pain free, closeness and tenderness
3. **Identity-** individuality and preferences to be recognised by others
4. **Occupation-** to be involved, meaningful activity and purpose
5. **Inclusion-** to feel part of something, included, and not left out

(Fig 2: Kitwood, 1997)

The core elements of person-centred care-based assessment, according to NICE (2019) include:

Diversity, including gender, ethnicity, age (younger or older), religion and personal care

Ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities

The life story and preferences of people with dementia and their carer/s (where possible) including diet, sexuality and religion

Maintaining independence

Information needs

Along with:

- Assessing what is important to the person in a collaborative relationship.
- Assessing mental capacity for any decision or intervention, ensuring that this is clearly documented.
- Obtaining informed consent wherever appropriate and ensuring that this is clearly documented.
- Focussing on life history, quality of life, best interest, goals, future planning and preferred place of care.
- Agreeing an individual plan of care that meets the person’s needs and wishes in collaboration.
- Regular monitoring, reviewing and recognising changes.
- Reflecting the individual’s emotions, values and beliefs.

Holistic Assessment

Effective holistic assessment provides an understanding of individuals’ needs, preferences, and priorities, and what actions should be taken to meet these. The document ‘Holistic common assessment of supportive and palliative care needs for adults requiring end of life care’ is an excellent resource and can be found at:

https://webarchive.nationalarchives.gov.uk/ukgwa/20130718122250/http://www.endoflifecare.nhs.uk/search-resources/resources-search/publications/imported-publications/holistic-common-assessment.aspx [Last accessed 21/12/2023]

People nearing the end of their lives with dementia need to have their needs assessed and their wishes taken into account in order to make them feel comfortable but also to enable them to die with dignity in a place of their choosing (NICE, 2018)

Assessment forms a key part of providing person-centered care. Ideally, structured holistic assessments will be undertaken throughout the care giving process, and at each of the following **key points** in the individual's end of life care pathway:

- identification of the end of life phase
- the point at which dying is diagnosed
- at any other time that the individual, or their carers, may request
- at any other time that a professional carer may judge necessary

The holistic common assessment is divided into five domains:

- Background information and assessment preferences
- Physical needs
- Social and occupational needs
- Psychological well-being
- Spiritual well-being and life goals

The assessment at each key point should cover all of these domains. However, as the person moves along the end of life care trajectory, the depth to which each of the domains are covered may change depending on individual circumstance. Assessment within each domain should be 'concerns–led', focusing upon items of particular concern to the individual, or their carer. For the person with dementia, while it may be possible to gain information from the person (and this should happen whenever possible), assessment may also be based on previous expressions of their wishes (see Chapter 10 - Advance care planning) and from others such as families, friends, and formal caregivers.

Another useful tool to promote holistic assessment is the 'PEPSICOLA' which has been developed as an aide memoir by the Gold Standards Framework (2009). The 'PEPSICOLA' provides a guide to and means of documenting holistic needs. The tool can be found at the end of this section.

Life Story Work

Life story work involves developing a biography of a person through talking to the individual and important people who know them well and can recount important elements and past experiences of someone's life, for example: work history, family members, places, life events, likes and dislikes. This can form an enjoyable activity for the person with dementia and for family or carers. This information can be very useful in different care settings to provide an understanding of a person, important information to support person-centred care planning, and also as a tool to distract or minimise distress if needed. The potential benefits of this type of intervention have been well documented for some time in improving assessment and promoting person-centred care as well as in building relationships and promoting communication. Dementia UK, Creating a life story for a person with dementia (2023) offers guidance on how to carry out life story work and a life story template that can be adapted as required.

The Alzheimer's Society 'This is Me' (2023) is a useful document which also asks for key information about the person with dementia. It is a useful tool when transferring between care settings to share some valuable information about the person with dementia. This can be downloaded directly from their website.

Assessment in the Last Days of Life

The five priorities of care (Leadership Alliance, 2014) have been identified as good basic care principles to be followed when undertaking assessment and care planning in the last days of life (Fig 3). Arguably, many of these principles are relevant and should be followed throughout the care giving process.

1. **The possibility that the person is dying is recognised, communicated clearly, decisions and actions are taken in accordance with the person's wishes, and regularly reviewed and revised accordingly**.
2. **Sensitive communication takes place between the person, staff and those identified as important to the person.**
3. **The person, and those identified as important to them, are involved in decisions, to the extent that the person wants**.
4. **The needs of the family and those important to them are identified, explored and met wherever possible**.
5. **An individual plan of care, which includes diet, fluid, symptom control, psychological, social and spiritual support is agreed, co-ordinated and delivered with compassion.**

(Fig 3: Leadership Alliance (2014) Five Priorities for the Care of Dying People)

Also see Chapter 15 Caring for a person with dementia in the final days of life.

Assessment of Symptoms such as Pain and Distress

Research still shows that pain recognition, assessment and treatment remain inadequate for people with dementia resulting in pain still being undetected and untreated (McGuire et al, 2010). A Marie Curie study (2015) demonstrated that 50% of people with dementia were still experiencing pain in the last 48 hours of life.

The cognitive impairment of dementia can affect people's ability to verbally express if pain is being experienced and a barrier to assessing if pain medication given has provided appropriate relief. Often, it is believed that pain in people with dementia is expressed through 'challenging behaviour', 'aggression', or 'agitation'.

Pain is a subjective experience that varies from individual to individual. If left unrecognised or untreated pain can cause an exacerbation of the behavioural and psychological symptoms of dementia (Alzheimer's Society, 2009), and therefore should be assessed and documented routinely using a validated assessment tool. NICE (2015) 'Care of dying adults in the last days of life' states that *'for a person who is unable to effectively explain pain, for example, someone with dementia or learning disabilities, use a validated behavioural pain assessment to inform their pain management'*.

There are numerous pain assessment tools suggested for use with people with dementia, for example:

- PAINAD;
- DOLOPUS 2;
- ABBEY;
- PACSLAC;
- NOPPAIN;
- CNPI.

However, the Assessment of Pain in Older People: UK National Guidelines (Schofield, 2018) recommends NRS or verbal descriptors in mild to moderate cognitive impairment and use of PAINAD and/or DOLOPUS-2 for people with severe cognitive impairment, although the Abbey pain scale is still widely used.

Indicators of pain in people with dementia are often non-specific, reflected in changes of sleep, mood, eating, mobility, behaviour, and vocalisation, and these need to be considered when assessing for the presence of pain along with the observational changes associated with pain (*see Table 1*). *Table 2* (Collett et al, 2007) lists a number of practical suggestions for scale selection. At the end of this section, a number of pain specific assessment tools such as the Doloplus-2, Abbey Pain Scale and PEPSICOLA are located. These are valuable observation tools to assist in the assessment of pain for people who are unable to clearly articulate their needs.

Table 1. Observational Changes Associated with Pain	
Type	**Description**
Autonomic changes	Pallor, sweating, tachypnoea, altered breathing patterns, tachycardia, hypertension.
Facial expressions	Grimacing, wincing, frowning, rapid blinking, brow raising, brow lowering, cheek raising, eyelid tightening, nose wrinkling, lip corner pulling, chin raising, lip puckering.
Body movements	Altered gait, pacing, rocking, hand wringing, repetitive movements, increased one, guarding*, bracing**.
Verbalisations/vocalisations	Sighing, grunting, groaning, moaning, screaming, calling out, aggressive/offensive speech.
Interpersonal interactions	Aggression, withdrawal, resisting.
Changes in activity patterns	Wandering, altered sleep, altered rest patterns.
Mental status changes	Confusion, crying, distress, irritability.
***Guarding** – ‘abnormal stiff, rigid or interrupted movement while changing position. ****Bracing** – a stationary position in which a full extended limb maintains and supports an abnormal weight distribution for at least three seconds.	

Table 1: Observational Changes Associated with Pain. (British Pain Society, 2007)

Type of Pain Assessment	Practical Suggestions for Scale Selection	Comments and References
Self report **Mild to moderate dementia**	Numeric graphic rating scale Verbal rating scale or numeric rating scale (0 – 10)	High validity & reliability in older people Can be used in mild/moderate cognitive impairment
Moderate to severe dementia	Pain thermometer Coloured visual analogue scale	Easy to use Validity not fully evaluated Well understood in early and mid-stage AD
Observational pain assessment **Severe dementia**	Abbey pain scale	Short, easy to apply Needs more detailed evaluation
Multidimensional assessment **Minimal dementia**	**Brief pain inventory**	15 item scale – severity, impact on daily living, impact on mood & enjoyment of life

Table 2: A summary of the types of scale for assessing pain in older people by level of cognitive/ communication impairment (Collett et al, 2007)

Other tools for the assessment of distress (where distress may be a manifestation of pain) such as the ‘DisDAT’ (Disability Distress Assessment Tool) should also be considered for use.

Distress is a symptom within its own right, often labelled as anxiety or agitation in people with dementia and may not always be due to pain. People with dementia may become agitated for other reasons including a response to a distressing situation. Superimposed delirium may also exacerbate distress and should always be suspected with any change in behaviour, cognition, or level of distress. Consider and assess for potential reversible causes, such as infection, constipation, urinary retention, dehydration, nausea, or a combination of causes. A validated tool, such as 4AT (4AT - Rapid Clinical Test for Delirium Detection (n.d.) can help to support the detection of delirium.

The use of a tool such as the 'DisDAT' (Disability Distress Assessment Tool, 2006) may help professionals to explore the meaning of distress for the person with dementia, as its intended use is for people with cognitive impairment or physical illness and severely limited communication.

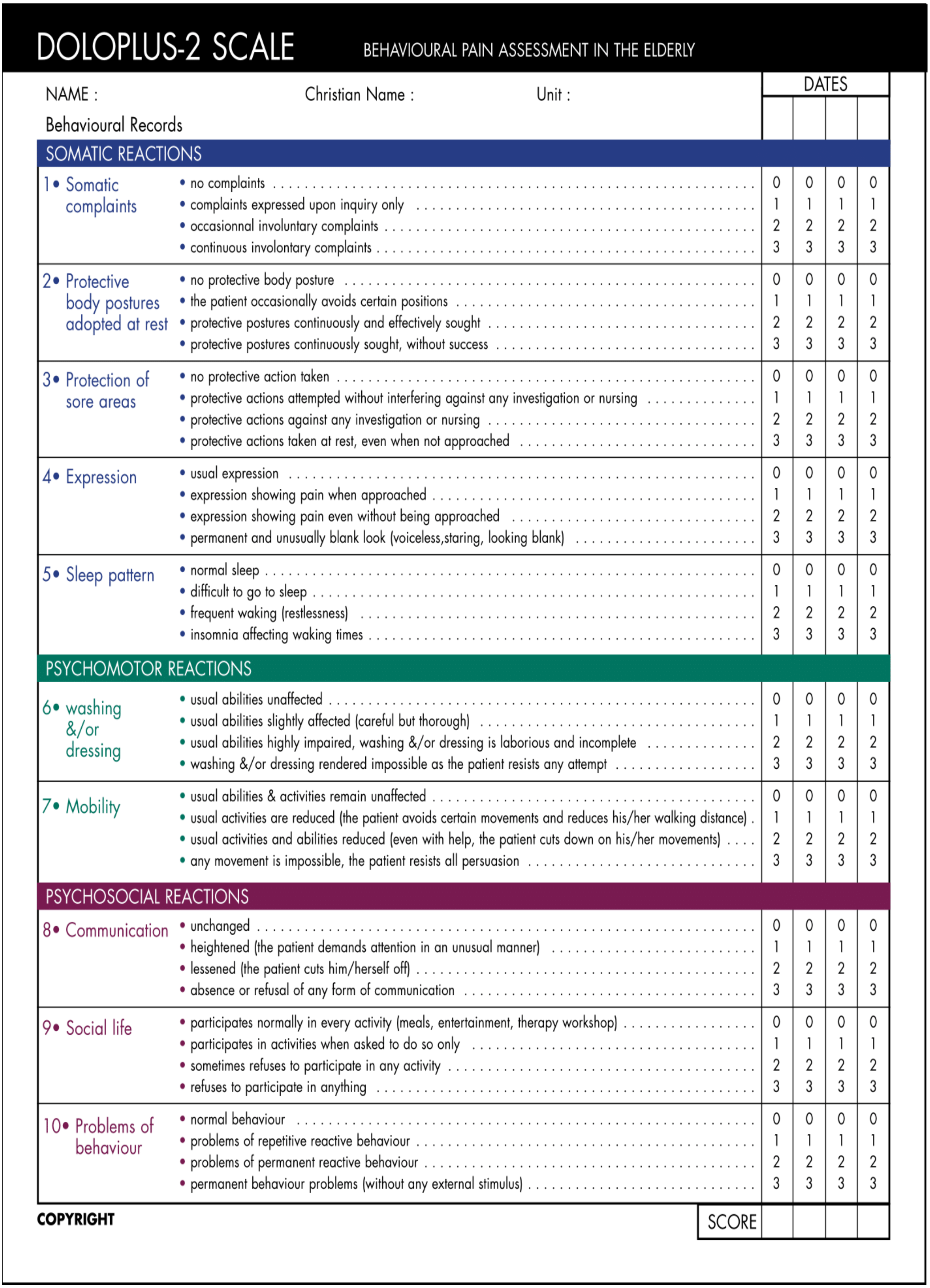
The National Council of Palliative Care have produced a booklet 'How would I know? What would I do?' (2012) which is a useful resource and guidance for both professionals, carers and family members in recognising pain and distress in people with dementia.

Supporting Carers

Chapter 17 is entitled Carer's Health and Wellbeing, and it is important to read this to remember the importance of supporting carers at all stages of care. Under The Care Act (2014) the local Authority have a legal duty to assess the person with dementia and also their carers' needs and likely future needs (you can find further information about this in Chapter 7 - 'Living with Dementia'*)*. However, carers report feeling isolated and lacking in support when caring for someone with dementia and should be signposted to organisations such as Dementia UK who offer the Admiral Nursing service, or the Alzheimer's Society and Age UK who offer a Dementia Advisor service. Carers and professionals can refer into their local branches through contacting the national helplines:

Dementia UK – Admiral Nursing Dementia Helpline	0800 888 6678
Alzheimer's Society Dementia Support Line	0333 150 3456
Age UK Advice Line	0800 678 1602

Carers often report that they had not understood how dementia could affect a person physically as well as cognitively, therefore it is important for all care professionals to understand dementia and be able to provide appropriate and timely information and support to carers and family members.



DOLOPLUS-2 SCALE

BEHAVIOURAL PAIN ASSESSMENT IN THE ELDERLY

NAME : Christian Name : Unit :

Behavioural Records		DATES			
SOMATIC REACTIONS					
1• Somatic complaints	• no complaints	0	0	0	0
	• complaints expressed upon inquiry only	1	1	1	1
	• occasionnal involuntary complaints	2	2	2	2
	• continuous involontary complaints	3	3	3	3
2• Protective body postures adopted at rest	• no protective body posture	0	0	0	0
	• the patient occasionally avoids certain positions	1	1	1	1
	• protective postures continuously and effectively sought	2	2	2	2
	• protective postures continuously sought, without success	3	3	3	3
3• Protection of sore areas	• no protective action taken	0	0	0	0
	• protective actions attempted without interfering against any investigation or nursing	1	1	1	1
	• protective actions against any investigation or nursing	2	2	2	2
	• protective actions taken at rest, even when not approached	3	3	3	3
4• Expression	• usual expression	0	0	0	0
	• expression showing pain when approached	1	1	1	1
	• expression showing pain even without being approached	2	2	2	2
	• permanent and unusually blank look (voiceless,staring, looking blank)	3	3	3	3
5• Sleep pattern	• normal sleep	0	0	0	0
	• difficult to go to sleep	1	1	1	1
	• frequent waking (restlessness)	2	2	2	2
	• insomnia affecting waking times	3	3	3	3
PSYCHOMOTOR REACTIONS					
6• washing &/or dressing	• usual abilities unaffected	0	0	0	0
	• usual abilities slightly affected (careful but thorough)	1	1	1	1
	• usual abilities highly impaired, washing &/or dressing is laborious and incomplete	2	2	2	2
	• washing &/or dressing rendered impossible as the patient resists any attempt	3	3	3	3
7• Mobility	• usual abilities & activities remain unaffected	0	0	0	0
	• usual activities are reduced (the patient avoids certain movements and reduces his/her walking distance)	1	1	1	1
	• usual activities and abilities reduced (even with help, the patient cuts down on his/her movements)	2	2	2	2
	• any movement is impossible, the patient resists all persuasion	3	3	3	3
PSYCHOSOCIAL REACTIONS					
8• Communication	• unchanged	0	0	0	0
	• heightened (the patient demands attention in an unusual manner)	1	1	1	1
	• lessened (the patient cuts him/herself off)	2	2	2	2
	• absence or refusal of any form of communication	3	3	3	3
9• Social life	• participates normally in every activity (meals, entertainment, therapy workshop)	0	0	0	0
	• participates in activities when asked to do so only	1	1	1	1
	• sometimes refuses to participate in any activity	2	2	2	2
	• refuses to participate in anything	3	3	3	3
10• Problems of behaviour	• normal behaviour	0	0	0	0
	• problems of repetitive reactive behaviour	1	1	1	1
	• problems of permanent reactive behaviour	2	2	2	2
	• permanent behaviour problems (without any external stimulus)	3	3	3	3
COPYRIGHT	SCORE				

Visit here to download the full Doloplus-2 Scale [Doloplus 2_Tool.pdf (coh.org)]

Abbey Pain Scale

For measurement of pain in people with dementia who cannot verbalise.

How to use scale: While observing the resident, score questions 1 to 6

Name of resident: ………………………………………………………………………..

Name and designation of person completing the scale: ………………………….

Date: ……………………………………….Time: …………………………………….

Latest pain relief given was………………………..………….…….at ………..hrs.

Q1. Vocalisation
eg. whimpering, groaning, crying — Q1 ☐
Absent 0   Mild 1   Moderate 2   Severe 3

Q2. Facial expression
eg: looking tense, frowning grimacing, looking frightened — Q2 ☐
Absent 0   Mild 1   Moderate 2   Severe 3

Q3. Change in body language
eg: fidgeting, rocking, guarding part of body, withdrawn — Q3 ☐
Absent 0   Mild 1   Moderate 2   Severe 3

Q4. Behavioural Change
eg: increased confusion, refusing to eat, alteration in usual patterns — Q4 ☐
Absent 0   Mild 1   Moderate 2   Severe 3

Q5. Physiological change
eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor — Q5 ☐
Absent 0   Mild 1   Moderate 2   Severe 3

Q6. Physical changes
eg: skin tears, pressure areas, arthritis, contractures, previous injuries. — Q6 ☐
Absent 0   Mild 1   Moderate 2   Severe 3

Add scores for 1 – 6 and record here → Total Pain Score ☐

Now tick the box that matches the Total Pain Score →

0 – 2 No pain	3 – 7 Mild	8 – 13 Moderate	14+ Severe
☐	☐	☐	☐

Finally, tick the box which matches the type of pain →

Chronic	Acute	Acute on Chronic
☐	☐	☐

Abbey, J; De Bellis, A; Piller, N; Esterman, A; Giles, L; Parker, D and Lowcay, B.
Funded by the JH & JD Gunn Medical Research Foundation 1998 – 2002
(This document may be reproduced with this acknowledgment retained)

https://www.apsoc.org.au/PDF/Publications/APS_Pain-in-RACF-2_Abbey_Pain_Scale.pdf

PEPSI COLA Aide Memoir – Palliative Care monthly checklist SCR4

Patient`s Name _ ____

	Date	Date	Date	Date
P -Physical Symptom control Medication - regular & PRN Compliance / stopping non-essentials Complementary therapies				
E -Emotional Understanding expectations Depression and adjustment Fears /Security Relationships				
P -Personal Spiritual / religious needs Inner journey Quality of life Pt/carer's agenda				
S -Social Support Benefits/Financial Care for carers Practical support				
I –Information/ Communication Within PHCT Between professionals To and from patient To and from carers				
C -Control Choice, dignity Treatment options/ Management Plan Advance directive Place of death				
O -Out of Hours/ Emergency Continuity Communication to out of hours/pts/carers Carer support Medical support Drugs and equipment				
L -Late End of life/Terminal care Stopped non-urgent Rx Patient and family aware Comfort measure Spiritual care Rattle, agitation				
A -Afterwards Bereavement Follow-up/others informed Family support Assessment/Audit Support team				

Holistic checklist- PEPSI COLA aide memoire copyright © National Gold Standards Framework Centre Thomas K (2009)

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Chapter 4- Communication

Being able to communicate is something we all take for granted and is an essential part of life. We need to be able to communicate to share with others our thoughts, wants and desires. We also need to understand others; communication is integral to interpersonal relationships. Communicating with others helps us to establish who we are and gives us a sense of identity, building our feelings of self-worth, making communication an important part of personhood in dementia care.

Living with dementia means that our ability to communicate is likely to get worse over time. The person will begin to have word-finding difficulties, memory loss and confusion, all which impact on their ability to communicate effectively and have their thoughts, wishes, desires and needs heard and met. There are however several things we can do differently to help the person with dementia both in terms of understanding and aiding communicating with others. It is important to adopt a person-centred approach and culture when working with people. Aim to match the communication skill you utilize to the cognitive capacity of the person with dementia.

Supporting Receptive and Expressive Communication

Your Approach

Always approach the person from the front to take account of a loss of peripheral vision, and so as not to startle them.
Make sure you identify yourself when speaking to the person with a warm introduction, and a clear smiling face.
Always address the person by using their preferred name first, followed by what you want to say to gain their attention.

Communicating With a Person with Dementia, Verbal and Non-Verbal Communication

- Speak slowly and clearly in short simple sentences; people with dementia will process information more slowly than someone with a normal functioning brain.
- Stick to one topic at a time, not jumping from one thing to another.
- Don`t give more than one instruction at a time.

- Non-verbal aspects of communication including tone of voice, facial expression, eye contact and a relaxed posture are important to help a person with dementia to feel safe and listened to.
- Keep your body language and posture relaxed and open. If you appear tense or agitated, it will get in the way of being able to communicate effectively and can also cause distress in the person you are trying to engage with.
- Standing over a person can feel intimidating to anyone. Cognitive impairment can make it difficult to interpret this positively. Get on the person`s eye level, smile and be calm and friendly. Touching them on the shoulder or shaking their hand may help to put them at their ease.
- Pictures, gestures and writing appropriate to the person`s level of understanding can be helpful.
- Don‘t press the person for an answer as this may distress them.
- If the person is struggling with making choices or giving you information, try to simplify your questions to more closed ones which can be answered with a ‘yes’ or a ‘no’.
- Try to avoid the temptation to constantly correct the person‘s statements if they include the wrong information (e.g. when the person is getting past and present mixed up). Reassure and acknowledge what they are expressing even if it is about their past.
- If you cannot understand what the person is saying to you, apologise to them and ask them to repeat what they said.
- Over time the person will become less able to initiate conversation, so you will have to take a lead on initiating interaction.
- When the person is at a stage where they are no longer able to communicate verbally with you, it is important to keep talking to them. Talk to them about familiar things you know were important to them in their lives like loved ones, yourself, family, and friends.
- The person may be able to tell you how they feel now even if not able to say how they felt yesterday or how symptoms have changed.
- Consider hearing loss as a factor impacting on communication. The Royal National Institute for Deaf People (RNID, 2023) has resources to support and Communication tips for people with hearing loss are also available from Action on Hearing loss, (n.d.)

Tools That Support Communication

- Patient passport tools are useful for providing prompts & cues to support conversation with someone with dementia. This is a short document, so health and social care professionals know things about the identity of the person with dementia plus their likes, dislikes and preferences. A good patient passport can help fill the gaps you need to enable a positive relational interaction. They provide evidence for making reasonable adjustments to support care needs. For example: Alzheimer‘s Society `This is Me` document, Dementia UK, 2023 Creating a ‘Life Story’ leaflet, or the organisation’s own passport.
- Use diaries, signage, and memory joggers, especially in the early stages of dementia when the person is getting a little forgetful. Consider whether pictures or words are preferred.

- Reading and following instructions can be challenging in early to moderate stage dementia when we want to encourage occupation and engagement in activity. The use of picture schedules can be helpful if the person is struggling with words or reading instructions. Images of single steps in a sequence help the person know what's coming next to carry out and achieve a task with multiple steps.
- Try objects of reference when clear speech is no longer possible, or the person is unable to recognise objects in pictures. This involves linking concrete objects to the topic of conversation/choice for the person to make, for example, if you want the person to indicate whether they want tea or water, reinforce your words by offering them a mug, cup, and a glass. Have the appropriate drink in each so the person associates the taste with the object they have chosen. Similarly, when it is time for the person to brush their hair, give them the hairbrush as you speak. Linking in concrete actual objects can help reinforce what you are saying and give the person a clear prompt.
- Easy read resources and information leaflets can help conversation when reasonable adjustment is needed. MacIntyre have a wide range of resources developed for people with learning disabilities and dementia: MacIntyre, Resources. (n.d.). Available at: https://www.macintyrecharity.org/our-approach/resources/ [Last accessed 10/11/2023]

Communication Approaches in Dementia Care

Reality Orientation

Reality orientation approach to care would be more effective to an individual in the early stages of dementia. This was developed by Folsom and Taulbee in 1958 and was common practice in hospitals for veterans. As the name suggests, orientation to reality involves reinforcing information regarding the current time, place, and people in the present moment. The overarching aim is to reduce the feelings associated with disorientation, confusion, and memory loss, as well as improving self-esteem.

Techniques that promote the reality orientation approach could be having large clocks with the time and date, clear signage including labels on doors and drawers. Directing conversation to mention specific events that are occurring in the present helps to orientate an individual with dementia. Reality orientation can help an individual with dementia when they are agitated, through gentle reorientation in time and place. It can offer the person reassurance and keep them grounded.

Cognitive Stimulation Therapy programmes offer activities to stimulate general cognition and have largely superseded reality orientation as a therapeutic intervention with people with dementia. The 'Cochrane Review Cognitive stimulation to improve cognitive functioning in people with dementia' (2012) concludes:

"There was consistent evidence from multiple trials that cognitive stimulation programmes benefit cognition in people with mild to moderate dementia over and above any medication effects. However, the trials were of variable quality with small sample sizes and only limited details of the randomisation method were apparent in several trials. Other outcomes need more exploration but improvements in self-reported quality of life and well-being were promising" (Woods et al 2012).

Validation Approach

Validation is more appropriate for supporting people with mid to late stages of dementia, where feelings are more significant and important than being orientated to the present. Naomi Feil introduced the approach in the 1960s, and developments were ongoing into the 1980s. Accepting the person with dementia's own reality underpins the approach. The professional or caregiver must consider the person with dementia's perspective and use empathy in their communication and interaction.

We know that for a person with moderate to late dementia, reality may be based in the past and they may be reliving past experiences with people who are no longer living in their life. The validation approach involves techniques such as mirroring the person, using eye contact, and listening for the meaning behind words, linking to psychological unmet needs. Memory boxes or reminiscence items are validation tools that promote personhood, and support communication.

"What is Truth? An Inquiry About Truth and Lying in Dementia Care" (Mental Health Foundation, 2016)

The Joseph Rowntree Foundation commissioned and funded this work, led by a panel of experts. It is enlightening, and progressive in its appraisal of interpersonal care of people with advanced dementia. The original aim of the inquiry panel was defined as *"investigating ways of reframing our understanding of some of the most challenging and distressing symptoms of dementia – confusion, disorientation, and 'delusions' usually experienced by people with more advanced dementia".* The report uncovers language used to describe people with dementia and explores helpful and unhelpful narratives. It addresses difficult conversations including diagnosis. Furthermore, the report explores the impact of psychosis on dementia, and the scope of truth telling and engaging in 'lies' when we are communicating with people with dementia. It describes truth telling and telling lies as on a continuum and clarifies 'therapeutic lying' as a concept in dementia care. You can find the report here: https://www.mentalhealth.org.uk/explore-mental-health/publications/what-truth-inquiry-about-truth-and-lying-dementia-care

Palliative Care and End of Life Communication

- It is better to start conversations about forward planning as early in the disease process as possible when the person may be more able to voice their hopes, wishes and what is important to them.
- Discussions about end of life are very individual and need to be tailored to the person. There is no right time to begin having discussions with people about how they want to be supported towards the end of their life and what their hopes and wishes are in relation to this. Look for cues the person may be giving that they want to talk about their death and always keep avenues of communication open to make it as easy as possible for the person to begin to think about how they would like their final journey to be.

- Tools are available to support advance care planning; Preferred Place of Care (PPC) document, Advance Decisions to Refuse Treatment (ADRT) and advance statements help with this process (see Section 9 Mental Capacity Act 2005 and Section 10 Advance Care Planning). It is a very difficult conversation for people and their families to have but can be liberating for the person, given the right support.

Links to useful sites and advice leaflets

Action on hearing loss, Communication tips for people with hearing loss (n.d.).	Available at: Communication-Tips-Card.pdf (rnid.org.uk) [Last accessed 12/11/2023]
Alzheimer's Society (n.d.)	Available at: http://alzheimers.org.uk/factsheets/ [Last accessed 13/11/2023]
Dementia UK (n.d.)	Available at: https://www.dementiauk.org/get-support/legal-and-financial-information/advance-care-planning/ [Last accessed 13/11/2023]
Dementia UK (n.d.)	Available at: https://www.dementiauk.org/get-support/our-leaflets/ [Last accessed 13/11/2023]
Dementia UK (n.d.)	Available at: https://www.dementiauk.org/get-support/advice-videos/ [Last accessed 13/11/2023]
Dementia UK. (2023)	Available at: Creating a life story for a person with dementia - Dementia UK [Last accessed 14/11/2023]
RNID (2023) Communication for health and social care professionals	Available at: Communication tips for health and social care professionals - RNID [Last accessed 12/11/2023]
MacIntyre Resources (n.d.).	Available at: https://www.macintyrecharity.org/our-approach/resources/ [Last accessed 10/11/2023]

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Chapter 5- Therapeutic Interventions in Dementia

The National Institute for Clinical Excellence (NICE, 2018) has produced guidelines for managing and supporting people living with dementia and for their carers.

The aims of treatment are to reduce symptoms of dementia and maintain function, with a view to promoting independence. Due to differences in types of dementia, severity of the dementia, and responses between individuals, people with dementia will respond differently to the variety of management options available.

Non-Medication Treatment Options:

Support and Care – the principal focus of care should be on maximising independence as much as possible and for as long as possible. This starts with involving services early in the disease process and formulating an individual care plan detailing the person's specific needs. It is also important to involve carers and provide them with locally available support and advice.

Support from the following professionals should be considered:

- **District Nurses**
- **Occupational Therapists**
- **Social Services**
- **Local Voluntary Organisations**
- **Community Psychiatric Nurses/ Psychiatrists**
- **Physiotherapists**
- **Specialist Advice on Legal and Financial Matters**

Monitoring how the patient's needs change as the illness progresses is required.

Simplify Routines, Provide Memory Aids and Orientation Assistance– some relatively simple measures can help maintain function:

- Written notes/reminders for day to day tasks such as taking medications, locking the door and how to use the television can help maintain independence and function.
- Putting frequently used items like medications and keys in more prominent places can help.
- Ensuring information is readily available to assist with communication and orientation can also help e.g. large clear clocks/calendars, use of written words or pictures if verbal communication is becoming more of a problem.

Cognitive Stimulation – it is important to maintain cognitive function as much as possible through activities tailored to the person's preferences to encourage use of memory and problem solving. Activities such as multisensory stimulation, music therapy, art therapy, animal-assisted therapy, massage and aromatherapy should be considered. People with mild to moderate dementia often have persevered long-term memory, hence reminiscence therapy through discussing past experiences can help in providing cognitive stimulation (WHO, 2018 & van der Steen, 2018).

Physical Activity – reviews suggest that exercise may improve cognition or offer scope for improving activities of daily living (Liang, 2018).

Pharmacological Interventions for Dementia

Medications for Alzheimer's Dementia:

Recommendations from NICE technology appraisal guidance on acetylcholinesterase (AChE) inhibitors (2018) advise that the medications donepezil, galantamine and rivastigmine can be initiated by a specialist in dementia care in order to treat Alzheimer's dementia. Alzheimer's disease is linked to low levels of acetylcholine, a neurotransmitter utilised by neurones to communicate with each other. AChE inhibitors prevent an enzyme from breaking down the neurotransmitter, thus the medications help to maintain levels of acetylcholine (Birks, 2006).

AChE inhibitors should only be used to manage mild to moderate Alzheimer's disease.

If a person with Alzheimer's disease struggles to tolerate AChE inhibitors or should the disease progress to a moderate or severe severity, a different type of medication called memantine is recommended.

It is now also recommended that if a person is already taking an AChE inhibitor, we can consider memantine in addition to the AChE inhibitor if moderate or severe disease develops.

These medications may delay progression by around 6 months, but they do not reverse or prevent long term progression of the disease. They tend to have a modest beneficial effect on memory, ADLs and behaviour.

Both AChE inhibitors and memantine are not recommended in the treatment of mild cognitive impairment, vascular dementia or frontotemporal dementia. AChE inhibitors and memantine should be considered in the management of dementia with Lewy bodies.

Be aware of other medications that may cause cognitive impairment.

Some commonly prescribed medicines can increase the anticholinergic burden which block the action of acetylcholine. This can worsen cognitive impairment. Minimising their use, or considering alternatives, should be considered. Various tools which may assist with this are available through searching for terms such as ‘Anticholinergic Cognitive Burden Scale’.

Managing Non-Cognitive Symptoms

People living with dementia may develop non-cognitive symptoms that can cause significant distress and also become problematic for the carer(s). For example, the person may become agitated or aggressive. They may become sexually disinhibited, wander or repetitively shout. Such behaviours may put themselves and others at risk of harm. NICE emphasise the importance of not seeing such behaviours purely as a symptom of dementia, but as resulting from psychological and/or biological factors.

Non-Pharmacological Management of Behaviour That Challenges

It is important to carry out an early structured assessment to determine what factors might trigger such challenging behaviours. Factors to consider include things such as over or under stimulation, overcrowding, poor communication, conflicts and lack of privacy. Sometimes other people’s reactions to such behaviours can unintentionally worsen the behaviours.

It is also important to address clinical and environmental causes such as infection (which can result in delirium), pain and inappropriate care. Use of antibiotics, laxatives, analgesia and hydration can successfully alleviate the problems.

Pharmacological Management of Behaviour That Challenges

Medication to manage non-cognitive symptoms for people with dementia should only be offered if the person is at risk of harming themselves or others, or if they are displaying signs of severe distress through experiencing agitation or seeing or hearing things that are not really happening (hallucinations). The person may also be experiencing delusional thoughts, in which they believe something is happening even though it is not. These beliefs might be upsetting and cause distress and changes in behaviour. For example, the person may start to believe that their money is being stolen or an intruder is getting into their residence, or that their partner is being unfaithful.

Antipsychotic Medications can be considered to help manage such problems. It is important to attempt to discuss the benefits and risks of the medications with the person and their family or carers if appropriate. Some studies suggest there is an increased risk of mortality, especially in vascular dementia, when people with dementia take antipsychotics medications. These medications also cause sedation and can increase risk of falls. They can also increase risk of pulmonary embolism or deep vein thrombosis.

NICE (2018) offer a decision aid on use of antipsychotics for the management of behavioural and psychiatric symptoms of dementia (BPSD).

If it is agreed that antipsychotic medication is required, it should be started at the lowest possible dose and used for the shortest time possible. Dose increases should occur slowly. The ongoing use of antipsychotic medication should be reassessed at least every 6 weeks. If there is no clear benefit, the medication should be stopped, following discussion with the person and family where possible.

Risperidone is the first line choice and is licenced for use in 'short term treatment of persistent aggression in patients with moderate to severe Alzheimer's dementia unresponsive to non-pharmacological interventions when there is a risk of harm to self or others' (Maher, 2011). Other antipsychotic options that might be used off-licence include olanzapine, quetiapine, aripiprazole and amisulpride. The choice can be determined on an individual basis when side effect profiles and risks are considered.

If the person has dementia with Lewy bodies or Parkinson's disease dementia, it is important to note that antipsychotics can worsen the motor features and trigger significant sensitivity reactions. Quetiapine has the most favourable side effect profile in such circumstances; hence it is the antipsychotic that should be considered first. It is also possible to consider the use of clozapine but this is quite rarely used.

Other Medication Options to Consider

Antidepressants such as sertraline or trazadone can be helpful in the management of BPSD. (Seitz, 2011 and Watt, 2018). NICE recommends that they should not be used routinely in the management of mild to moderate depression in people living with mild to moderate dementia unless they are indicated for a pre-existing severe mental health problem. Tricyclic antidepressants should be avoided as they carry a high anticholinergic burden and may worsen cognitive symptoms (Dudas 2018).

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Chapter 6- General Considerations for Medicines Management in People with Dementia in Need of Palliative Care

For people living with dementia who are approaching the end of life it is important to involve the person and their family or carers as much as possible. Progression of dementia is often difficult to predict, and an anticipatory healthcare plan should be formulated where possible (Alzheimer's Association, n.d.).

Advance care planning whilst a person is living well with dementia can help with deciding:

Support with advance statements or an advance decision to refuse treatment (ADRT) is important.

Covert Administration of Medications

Covert medications are administered in a disguised format, perhaps in food or drink or through a feeding tube. This is done without the person knowing they are taking a medication.

It may be appropriate to consider the use of covert administration of medication in a person with dementia who refuses their medication and lacks capacity to understand the consequences of their refusal. The capacity is determined by the Mental Capacity Act 2005.

The decision to prescribe covertly needs to be taken in the person's best interests and may be taken whether or not the person is at the end of life. It is usually the case that the medication is essential for the health and wellbeing of the person. Decisions need to be taken as part of a multi-disciplinary team process and recorded in a management plan. It is helpful to involve relatives, carers, or advocates.

Local trusts will usually have their own policy regarding covert medication use and it is important to follow this guidance. Regular reviews should take place and if a person's capacity fluctuates then the covert administration plan should only go ahead when the person lacks capacity.

Guidance from the Care Quality Commission (CQC, 2022) states that the following information should be recorded in a covert medicine care plan:

- **actions taken to give medicines in the normal manner**
- **how medicines will be administered covertly**
- **specialist input to show suitability of the method chosen, for example crushed or mixed with certain food or drinks**
- **whether the medicine is unpalatable**
- **adverse effects (actual or perceived)**
- **swallowing difficulties**
- **lack of understanding about what the medicine is for**
- **lack of understanding of the consequences of refusing to take a medicine**
- **ethical, religious, or personal beliefs about treatment**
- **what to do if the person refuses food or drinks**

Where the covert medication is considered to be restrictive and administered within a hospital or care home, consideration around the remit of DOLS, and if extension of criteria is required, would be advised.

Medication Review

As a person with dementia approaches the end of their life it is important to consider the use of the minimum number of medicines possible. This helps reduce problems related to side effects, as well as distress that can result from administering medications. For example, medications such as vitamins or supplements may no longer be essential at the end of life. Some medications used in palliative care can cause increased confusion, particularly in people with dementia, who are often more susceptible to side effects. Doses should be increased cautiously and if possible, only make changes to one medication at a time.

Problems With Swallowing and Medications

Support with eating and drinking should be offered to aid nutritional needs. Consider involving a speech and language specialist if there are concerns over the person’s ability to swallow medication or their safety when eating and drinking.

It is advisable to contact the pharmacy team for advice regarding alternative medication formulations or to determine if capsules can be emptied or tablets crushed to aid swallowing. Medications are not licensed to be crushed as it can impact on the way the drug works, hence it is important to seek advice from the pharmacy team and the prescriber. For example, a tablet designed to be slowly released through a protective coating may be absorbed very quickly once it is crushed, and this could result in overdose.

If the person with dementia is living at home or in a care home, the local community pharmacist should be able to advise. If the person in an inpatient, the medicines information service or hospital pharmacy team will be able to assist.

NICE (n.d.) has produced a decision aid on tube feeding for people with severe dementia. Overall, the view is to not routinely use enteral feeding in people with severe dementia unless it may resolve a reversible health condition. This is because tube feeding does not help to make the person more comfortable or give them a better quality of life or longer life. Tube feeding may be distressing, uncomfortable and brings with it its own risks such as infection (Sampson, 2009).

Specific Recommendations About Medications Used Commonly in Palliative Care

Some medications used in palliative care should be used with caution or sometimes avoided in people with dementia:

Anticholinergic Medications	Medications that can cross the blood brain barrier with anticholinergic side effects such as hyoscine hydrobromide, cyclizine, levomepromazine and amitriptyline can lead to increased confusion so should be used with caution. Other medications used in palliative care such as glycopyrronium and hyoscine butylbromide do not cross the blood brain barrier but still pose an anticholinergic burden which can result in the discomfort of a dry mouth.
Antiemetics	Medications such as haloperidol, levomepromazine and metoclopramide can cause extrapyramidal side effects and should be avoided in people with dementia with Lewy bodies or Parkinson's disease dementia. Adverse effects in such patients may trigger a rapid deterioration from which the person may not recover even on cessation of the drug. As mentioned above, cyclizine should also be used with caution in people with dementia due to its' anticholinergic burden.
Analgesia	It is estimated that over 60% of people with dementia suffer with pain (Moens, 2014). As dementia progresses, the ability of the person to report pain can diminish hence it is important to be mindful that pain may be present. Opioid analgesics offer significant benefits but can increase confusion and if they are used they should be started at low doses and titrated up slowly. Morphine can be considered as first line. Other opioids such as buprenoprhine and fentanyl are available in patch form and may result in less sedation, delirium and hallucinations. This may be more convenient if there are swallowing difficulties or if the severity of the dementia results in difficulties ensuring adherence.
Benzodiazepines	Midazolam and other benzodiazepine medications should be used with caution as they can also increase risk of confusion or agitation.

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Chapter 7- Living With Dementia: A Guide to The Care Act 2022 and Their Impact on Local Authority Provision, Continuing Health Care and Finances

The Care Act 2014 replaced nearly all the old legislation and supporting guidance covering the care needs and rights to support both adults with social care needs and their carers. Most of it came into force in England from April 2015 and is now supported by the Health and Care Act which came into force on 1st July 2022. The 2023 amendments to the Care Act 2014 in this new Act contain key provisions and rights for carers including recognition in legislation of carers as a distinct and clear group. The statutory guidance is available from health-and-care-act-2022-summary-and-additional-measures-impact-assessment.pdf (publishing.service.gov.uk)

Wellbeing

The duty placed on local authorities to carry out their work in a way that promotes "wellbeing" remains central and applies whether the person is someone with dementia or a carer looking after another adult.

Wellbeing, as defined by the Act, includes:

- **Personal dignity (including treating you with respect)**
- **Physical and mental health and emotional wellbeing**
- **Protection from abuse and neglect**
- **Control by you over day-to-day life (including your care and support arrangements)**
- **Participation in work, education, training or recreation**
- **Social and economic wellbeing**
- **Domestic, family and personal relationships**
- **Suitability of your living accommodation**
- **Your contribution to society**

This applies to all stages of adult social care involvement and is set out at the beginning of the Care Act because it is an important principle that adult social care did not have to consider under the previous law. At the heart of this reformed system is an assessment and planning process that is a genuine conversation about people's needs for care and support and how meeting these can help them achieve the outcomes most important to them. Promoting wellbeing therefore does not mean simply looking at a need that corresponds to a particular service.

Assessment

If the person or carer needs care or support, the Local Authority has a legal duty to assess needs and the assessor must consider the person's likely future needs, not just the situation today. The duty to carry out an assessment applies regardless of the person's financial situation at this stage, must be proportionate and appropriate and should be a critical intervention in its own right.

The assessment will identify if the person meets the eligibility threshold, which is different for people with care needs and for carers. The Local Authority then has a clear duty to ensure that the person's eligible needs are met.

If the dementia/or illness prevents the person achieving two or more outcomes listed below and that results in a significant impact on wellbeing, the threshold is met.

Listed outcomes in the regulations are:

- **Managing and maintaining nutrition**
- **Maintaining personal hygiene**
- **Managing toilet needs**
- **Being appropriately clothed (includes being able to get dressed)**
- **Being able to make use of the adult's home safely**
- **Maintaining a habitable home environment**
- **Developing and maintaining family or other personal relationships**
- **Accessing and engaging in work, training, education, or volunteering**
- **Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services**
- **Carrying out any caring responsibilities the adult has for a child**

The regulations go on to say that the person will be treated as unable to achieve an outcome if he/she is:

- Unable to achieve it without assistance
- Able to achieve it without assistance but doing so causes significant pain, distress or anxiety
- Able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the person or of others
- Able to achieve it without assistance but takes significantly longer than would normally be expected.

FOR CARERS you will meet the eligibility threshold if:

- The carer has needs connected with providing necessary care; and
- those needs mean that the carer's physical or mental health is deteriorating or is at risk of deteriorating, or the carer is unable to achieve any of the outcomes set out below; and that results in a significant impact on the carer's wellbeing.

Listed outcomes in the regulations are:

Carrying out any caring responsibilities the carer has for a child

Providing care to other persons for whom the carer provides care

Maintaining a habitable home environment in the carer's home (whether or not this is also the home of the adult needing care)

Managing and maintaining nutrition

Developing and maintaining family or other personal relationships

Engaging in work, training, education, or volunteering

Making use of necessary facilities or services in the local community, including recreational facilities or services

Engaging in recreational activities

A carer will be treated as unable to achieve an outcome if he/she is:

- unable to achieve it without assistance
- able to achieve it without assistance but doing so causes the carer significant pain, distress or anxiety or
- able to achieve it without assistance but doing so endangers or is likely to endanger the health or safety of the carer or others.

It is worth noting at this point that The Care Act 2014 guidance makes it clear that when the local authority/adult social care is deciding whether the person cared for meets the eligibility criteria, they cannot, at this stage, take into account, the care that the carer provides.

Care and Support Planning

If eligibility criteria is met, the next stage is for adult social care to work closely with the person and/or carer to plan how to support the person to meet eligible needs. If the person is receiving health services, the new Act sets out 4 key provisions in relation to carers which places a duty on Integrated Care Boards to promote the involvement of each carer where appropriate, in relation to decisions about prevention, diagnosis, treatment and care. What this means practically is that there should be more engagement and involvement for carers on a strategic level but also on an individual level about things that will affect them because they are caring for a patient receiving health services.

The Act also places a duty on NHS Trusts and Foundation Trusts to involve carers, where appropriate, in planning for hospital discharge as soon as is feasible. As the local authorities already have strong responsibilities towards carers any decisions affecting commissioning arrangements would apply in an Integrated Care Partnership.

Carers UK are in the process of providing detailed briefings on each of the new provisions in relation to carers.

Advice and information must be given to prevent or delay needs developing or increasing and could include reablement at home or intermediate care as respite for the carers for which the first 3 to 6 weeks could be free of charge.

It could be decided that needs can be met without the support of the LA by other provision in the local area by, for example, joining luncheon clubs or societies. If after that, there are still unmet eligible needs the LA has a duty to support the person to meet those needs.

A "personal budget" figure is then worked out on the basis of how much it will cost to meet eligible needs, net of any charge made to the person. (See charging policy later). In planning on how to meet needs or support needs of the carer, the list of services available under the old community care laws has been replaced by "personalisation" to enable the person or carer to focus on what they are looking to achieve through the care plan and to find creative ways that mean the person has as much choice and control as possible. The person must be involved in the preparation of care and support plans, however if the person would have substantial difficulty in being involved in these processes and there is no appropriate individual available, then the local authority must arrange an independent advocate to facilitate involvement. (Sections 67 and 68 of the

Care Act 2014). To ensure seamless advocacy, the same advocate can provide support as an advocate under The Care Act and under The Mental Capacity Act, ensuring the recognition of the right to make unwise decisions and if capacity is lacking, that the best interest procedure is followed.

There are 3 main ways of arranging a personal budget:

As a managed account held by the LA with care support purchased and provided in line with the persons wishes.
As a manages account held by a third party with care and support purchased and provided in line with the persons wishes
As a direct payment

Further advice can be found in Factsheet 24, (2022) a free information sheet published by Age UK along with recent developments in a local authority circular LAC (DHSC, 2022).

Access to day care and or respite services can be arranged via the assessment and social worker. For those people who are able to function quite well, ordinary day care could meet their needs, however where non-concordance is a major problem specific day services can be arranged as part of the care and support planning. Where the care and support planning process has determined that a person needs to live in a specific type of accommodation to meet their needs, the person will have the right to choose the particular provider or location, subject to certain conditions. Where the person lacks the capacity to express a choice for themselves, LAs should act on the choices expressed by the person's advocate or carer in the same way they would on the person's own wishes and is emphasised in the new Health and Care Act (2022).

Nursing homes offering permanent residential care can be found on the internet from the Care Quality Commission (n.d.) via Care Quality Commission (cqc.org.uk)

Charging

Unlike health care, for which the NHS is responsible, social care is not generally free at the point of delivery. It is a means tested system and LAs can charge anything up to the full cost to them of meeting the care and support needs. An important development will be the introduction of daily living costs for residential care, referred to as "hotel costs". It will cover accommodation and ordinary living costs such as food, rent and energy bills, but not personal care costs for help such as dressing, bathing, going to the toilet and is set at £200 per week. If you ask the local authority to commission your care, they will need to provide you with options where daily living costs are no more than £200 per week. You can choose to pay more than this, if, for example you would like a nicer room.

Once adult social care has decided that eligibility criteria has been met, there will be a detailed financial assessment looking at both capital and income to decide a person's contribution. This may not include the value of your home if you or your partner still live in it. Upper and lower capital limits at present are set at £23,250 and £14, 250 although these are likely to change in the future. Those with assets over the upper limit are deemed to be able to afford the full cost of their care, those with assets between the lower and upper limits deemed as able to make a contribution and if this cannot be met from income, a tariff of £1 for every £250 from chargeable assets will be expected and any capital below the lower limit disregarded. There are differences in how income is treated in a care home and all other settings, but only the income of the cared-for person can be taken into account and the LA should also consider the implications for the cared for person's partner. A list of disregarded income is set out in Annex C of the Care Act statutory guidance.

Self – Funders

This term generally refers to people assessed as having sufficient financial assets to pay the full costs of care, either domiciliary care at home, or residential care in a care home. Prior to the Care Act, if a person moved into a care home, the LA could take into account the capital value of their home (depending on who was still living in that home e.g. spouse/partner) and this has led to people having to sell their home when they would prefer not to. There is now a legal duty on the LA to consider entering into a deferred payment agreement, which operates like a mortgage and will have to be repaid once the house is sold and is referenced in chapter 9 of the Health and Care Act 2022. If a care home is necessary for a self-funder, the LA can give advice and information, but will generally leave it to the person and family to arrange it but should assist if it cannot be managed. If continuing to live at home, the LA must provide information about how home care works, and they cannot charge for this. However, if the LA makes the arrangements of finding the right care staff and setting up contracts, the LA can charge an arranging fee, but must be free of charge if someone lacks the mental capacity and has no-one to assist them.

Discharge from Hospital

The Health and Care Act 2022 stipulates that where a relevant trust is responsible for an adult hospital patient and considers that the patient is likely to require care and support following discharge from hospital, the relevant trust must take steps to involve the patient and any carer, including young carers who might be caring for an adult.

Current guidance can be found here:
Hospital discharge and community support guidance - GOV.UK (www.gov.uk)

Red Cross operates a home from hospital service in most areas, for help with practical tasks and monitoring for up to 6 weeks with no cost to the person. Details can be found on www.redcross.org.uk, Head office 0344 8711111

NHS Continuing Healthcare

Eligibility for this fully funded care is based on an individual's assessed needs and not a diagnosis. The assessments, a checklist, and a decision support tool, consist of 11 domains and each domain describes a hierarchy of need. Completion is by the relevant professional i.e. the discharge liaison nurse in a hospital, a social worker or district nurse in the community. The views of the patient, where possible, and the carer are central to the documentation.

NHS Funded Nursing Care

Introduced in 2001, refers to assessment and funding provided to nursing homes by the NHS to support the provision of nursing care by a registered nurse for those assessed as eligible and is paid direct to the care home.

Lasting Powers of Attorney

It is advisable that from early diagnosis, consideration should be given to appointing a welfare and health attorney and/or a property and financial affairs attorney (see section 9 Mental Capacity Act).

Both cost £82 each to register, a procedure which normally takes 8 to 10 weeks. However, if in receipt of certain benefits, it is possible that a fee exemption might apply. If the donor's gross annual income is less than £12,000, there may be eligibility for a 50% fee remission.

Forms can either be completed online or downloaded from the Office of Public Guardian Office of the Public Guardian - GOV.UK (www.gov.uk) as can further information regarding payment. Comprehensive guidance on completion is also available on the same website. If it is felt necessary to engage the help of a solicitor, costs are likely to increase considerably.

For some people, it might be necessary for adult social care to engage a Court-Appointed Deputy from the Court of Protection (MCA, 2005) to deal with ongoing financial affairs and welfare decisions.

Safeguarding

Safeguarding procedures are designed to protect adults who may be vulnerable to abuse or neglect. Until the Care Act 2014, adult safeguarding was only dealt with in guidance, but now has statutory underpinning similar to child protection.

This means that adult social care must carry out an investigation if they have reasonable cause to suspect that an adult in their area:

Has needs for care and support applicable for many people with dementia (whether or not the local authority is meeting any of those needs) is experiencing, or at risk of, abuse or neglect; and

as a result of those needs is unable to protect her/himself against the abuse or neglect or the risk of it

An investigation may lead to extra care support or a change in the way services are provided.

Benefits

Section 4 of the Care Act makes it a duty of the local authority to give people access to independent financial advice regarding their care and support and will also ensure that all state benefits are being claimed. Help can also be obtained from;

- Citizens Advice Bureau
- Carers UK via advice@carersuk.org
- Department for Work and Pensions Benefits
- Department for Work and Pensions: State Pension

A number of benefits are available for which people with dementia and their carers could be eligible.

Disability Benefits

Disability Living Allowance This benefit is now replaced by PIP for people over 16 (see 'Personal independence payment'). If you were born after 8 April 1948 and already receive DLA, you will be reassessed for PIP at some point. The DWP will contact you if you need to change to PIP. However, if you were born on or before 8 April 1948 and claimed DLA before you were 65, you will not need to change to PIP. You will remain on DLA as long as you continue to meet the eligibility criteria.

Personal Independence Payment (PIP) As above, this replaces Disability Living Allowance and similarly is a tax-free benefit paid out regardless of income for people under 65 who have an illness or disability and need help carrying out daily living activities, and/or problems with mobility. If a person qualifies, it can be paid at either a standard or enhanced rate depending on how much help is needed.

Attendance Allowance (AA) As with PIP, this is a non-means tested benefit for those people who have reached pensionable age, who require help with activities of daily living because of physical or mental disablement. It is paid at two rates depending on the amount of care needed.

Earnings Replacement Benefits

Carer's Allowance- If you are providing at least 35 hours of care to someone who claims or is going to claim the Daily Living component of PIP or AA, then you may be able to claim Carer's Allowance subject to meeting the other qualifying conditions. However, if you do not qualify, you might still qualify for Carer's credit or a Carer's premium. Refer to your local Jobcentre Plus for advice or the website.

Statutory Sick Pay or Contributory Employment Support Allowance ESA Employment and support allowance (ESA) ESA may be claimed by anyone under the State pension age who has limited ability to work because of an illness or a disability. ESA has two forms:

- Contributory ESA – this replaced Incapacity benefit and the DWP now refers to it as new-style ESA
- Income-related ESA – this is means-tested and is being gradually replaced by Universal Credit

Bereavement Support Payment- Payable on the death of your partner if married or in a civil partnership, depending on the deceased's NI record and you are under pension age. It consists of a one-off payment and a monthly payment for 18 months. It is tax-free and paid on top of all other benefits.

Universal Credit

Universal Credit is a payment to help with your living costs. It’s paid monthly - or twice a month for some people in Scotland.

You may be able to get it if you’re on a low income, out of work or you cannot work.

Universal credit is now available in all areas. It has replaced many older benefits (known as ‘legacy benefits’), including:

- Income-based Jobseeker’s allowance income-related Employment and support allowance
- Housing benefit
- Income support
- Working tax credit
- Child tax credit

Other Essentials Paid on Low Income Whether Working or Not:

- Council tax support
- Free school meals
- Health benefits

Statutory sick pay is paid by employers to employees below pension age. It is paid for up to 28 weeks in any one period of sickness that lasts for four days or more. In most cases, you won’t get Statutory sick pay for the first three days that you aren’t able to work. To qualify, you must be employed and earn a set amount or more each week before tax (for the current amount go to alzheimers.org.uk/benefitrates). Statutory sick pay is paid at a flat rate and is taxable. If you know you will continue to be unable to work, you can start a claim for contributory ESA up to three months before the end of your statutory sick pay. Your employer will need to complete the SSP1 form.

Eligibility for top-up benefits can be complicated to work out, it might be easier to call the Universal Credit Helpline on: 0800 328 9344 or contact the local Citizens Advice Team.

Another useful guide is the Turn2Us benefits checker to see what you are able to apply for.

Special Rules

Special rules can apply if there is a probability that the claimant has a terminal illness, the definition of which changed from April 2022 to "a progressive disease where death as a consequence of that disease can reasonably be expected within 12 months".

The intent of this change from 6 months to 12 is to align with the current NHS/GMC definition of "end of life" which states that a person is likely to die within the next 12 months.

The Special Rules allow people nearing the end of life to:

Get faster, easier access to certain benefits

Get higher payments for certain benefits

Avoid a medical assessment

This change affects five benefits, Universal Credit (UC), Employment and Support Allowance (SA), Personal Independence Payment (PIP), Disability Living Allowance (DLA), and Attendance Allowance (AA).

A new medical evidence form, the SR1 (form.e-SR1@dwp.gov.uk) has replaced the DS1500. The form can be completed by a GP, hospital consultant, hospice doctor or registered nurse who has acquired the clinical competencies. The completed SR1 form can be returned through the person who completed it or given to the person to return via post to Personal Independence Payment. Further information can be found at The ‘Special Rules’: how the benefit system supports people nearing the end of life - GOV.UK (www.gov.uk)

Local Advice and Support Includes:

- Alzheimer’s Society Our dementia support services | Alzheimer's Society (alzheimers.org.uk)
- Dementia Services Alzheimer's Society | Live Well Cheshire West (cheshirewestandchester.gov.uk)

- Memory Café Home | Live Well Cheshire West (cheshirewestandchester.gov.uk)

- New Admiral Nurse Service Specialist dementia support service launched in Chester | Wirral Globe

- Age UK also have an advice line (0800 678 1602) and Carers Trust can offer a sitting service which is free for the first 3 months. https://cheshireandwarringtoncarers.org

Similar services are offered across different areas.

A personal budget must also reflect local market conditions and a person must not be asked to "top-up" because of market inadequacies or commissioning failures and must ensure there is a genuine choice. However, should the person or carer themselves choose a more expensive accommodation, a "top-up" arrangement will be sought. Further details can be found in the DOH Care and Support statutory guidance Annex A.

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Chapter 8- Spirituality and People with Advanced Dementia

There have been many difficulties in defining spirituality due to its complexity and subjective nature. The terms spirituality and religion are often used interchangeably yet have different meanings for the individual. Religion can be associated with a personal or institutional system of beliefs, practices and attitudes related to god or a higher power. Spirituality, however, encompasses a person‘s broader beliefs and values. A religious person is a person with a spirit, yet not every spiritual person will embrace a formal religious faith, nor may a religious person’s total needs be met by religion alone.

When it comes to relating spirituality to people with dementia, there is increasing attention within the literature (Trusswell and Tobert, 2019). However, this is often restricted to people with early stage dementia who have relatively intact cognitive skills. Unsurprisingly, this cohort were found to have similar beliefs and needs to those of any other older group of people. As dementia progresses, it bears its hallmark in the loss of a person‘s connection (i.e. from time and place, family and friends, and religious and work communities). Spiritual care is recognised as being as important as the physical and psychological care for a person with dementia. Despite this, within dementia care, spiritual needs are often unmet due to a person‘s inability to communicate, and the professional’s lack of confidence and experience to provide a supportive spiritual environment.

Bell and Troxell (2001) identified the following as dimensions of an individual‘s spiritual need:

To connect or have connections with others
To be respected as a valuable person
The need to love and be loved
To feel recognised, known and understood
The need to be compassionate, caring and helpful
To be productive and successful
The need to become, and still be in the flow of life
To have hope

Good spiritual care for people with dementia requires an impeccable holistic assessment. An assessment needs to be individualised and sensitive in order to identify aspects of the individual‘s spiritual being and/or religious beliefs. Spiritual history taking involves asking about the importance of values, beliefs, and faith. It may not always be easy to assess this in the latter stages of the illness; therefore, these discussions should take place as soon after diagnosis as possible. If this is difficult due to the progression of the disease, the person should still be involved in such discussions, but can include a detailed biography from family members and friends. This also enables family carers to value the person with dementia and to continue to share life with them.

Familiarity with a person`s past helps staff to honour and respect cultural traditions and spiritual beliefs. Broad discussions at this time also facilitate better discussion of Advance Care Planning for the future and discussion of a person's preferred place of care.

Communication with a person with dementia is an essential component of maintaining their spiritual self, even in the absence of any response. It is important to use the person`s preferred name as this is shown to anchor the individual and reassure them that they are known. It shows the individual they are valued. Good communication can improve the quality of a person`s care. Sensitive communication reinforces respect for the individual. It is important to simplify words and instructions, and structure small sentences to limit confusion.

The practice of spiritual care is often less contentious than the definitions of spirituality. The Institute for Research and Innovation in Social Services (Iriss, 2013) identified a number of activities that can support spiritual care for older people, but their impact on the person with dementia needs to be carefully gauged as they may unknowingly provoke emotions or memories that are not positive ones.

1. Life Review / Life History / Life Story Work

Birren and Schroots (2006) researched the value of life review and found that it provided an increased sense of personal power and importance and enhanced adaptive capacities, drawing on forgotten or dormant skills. This allowed people to face end of life matters with confidence. A life history or storybook, which can include photos and pictures, can be an enjoyable and empowering activity for a person with dementia. Dementia UK, (2023) produces a very useful resource that includes a template and guidance for putting together life storybooks.

2. Reminiscence

Remembering previous spiritual events or occasions (i.e., those that are meaningful to the person) gives both professionals and people with dementia a chance to recall spiritual needs and develop new friendships with each other. Reminiscence may be completed with an individual or within group or family sessions. For those who have difficulty communicating, finding other ways to stimulate memories, such as visual (photographs, paintings, pictures or objects), using smell or taste, or touching items and different textures may be more appropriate.

3. Music / Song

The positive effects of music and singing on wellbeing have become widely acknowledged and the power of music, especially singing, to unlock memories and kick-start the grey matter is a developing feature of dementia care. Music can draw upon melodies, tunes and songs that are known to be significant to the person with dementia. Organisations like 'Singing for the Brain', 'Music for Life', 'Lost Chord', 'Golden Oldies' and 'Live Music Now' have made it possible for care homes to access live musicians, both professional and amateur, with many trained to deal with the special needs of an elderly, memory-impaired audience.

4. Worship / Prayer / Ritual

Providing continuity for older people in terms of their familiar rituals and routines sustains memory and wellbeing and should be celebrated. Maintaining contact with a religious organisation, or reconnecting where this has been lost is important, even if that person has not actively been involved in organised religion for a long period of time. Formal religious care should be provided based on what the person needs rather than the predilections of those giving the care. For many people with dementia, the presence of familiar religious symbols such as a cross, rosary beads or yarmulke, maintain their significance, however information is needed to ensure that the symbol is appropriate. For example, some Christians would react very badly to a crucifix but might cling to a very plain cross, and Jewish artefacts can have differences depending on which strand of Judaism the person comes from. For the person with dementia, understanding what their familiar practice involves is important; extempore prayers, modern language and cadences often lead to complete mystification and sometimes an aggressive or frustrated response. We must remember that even where individuals share a religious faith, their interpretation of beliefs can be quite different.

5. Active Listening

Careful listening is a spiritual practice. Active listening, picking up on clues in what may seem to be a muddled conversation, is important, as is the use of positive body language, and hand gestures to convey meaning. The use of touch, as appropriate, is important in terms of connection with an individual and conveys care, concern and involvement.

6. Namaste Care Programme

The Namaste Care Programme was developed in 2003 in the USA by Professor Joyce Simard and means ‘to honour the spirit within’. The programme was established to meet the needs of people with advanced dementia and offer human contact, sensory stimulation, meaningful activity, comfort and pleasure. Namaste combines compassionate nursing care with music, therapeutic touch, colour, food treats and scents. Families can be involved with Namaste, providing meaning and emotional connection to the family member as well. See www.namastecare.com for further information.

7. Caring for Carers

Finally, as a (formal or informal) carer for a person with dementia, it is important to consider and enrich our own spiritual life. This not only helps in terms of coping with the challenges of caring, but also in communicating and conversing with those affected to involve them in a life outside of dementia. Approaches such as mindfulness training can help to improve the outlook on life for those caring for a person with dementia and may have advantages to those with earlier stage dementia. Find further information at: The Mindfulness Initiative

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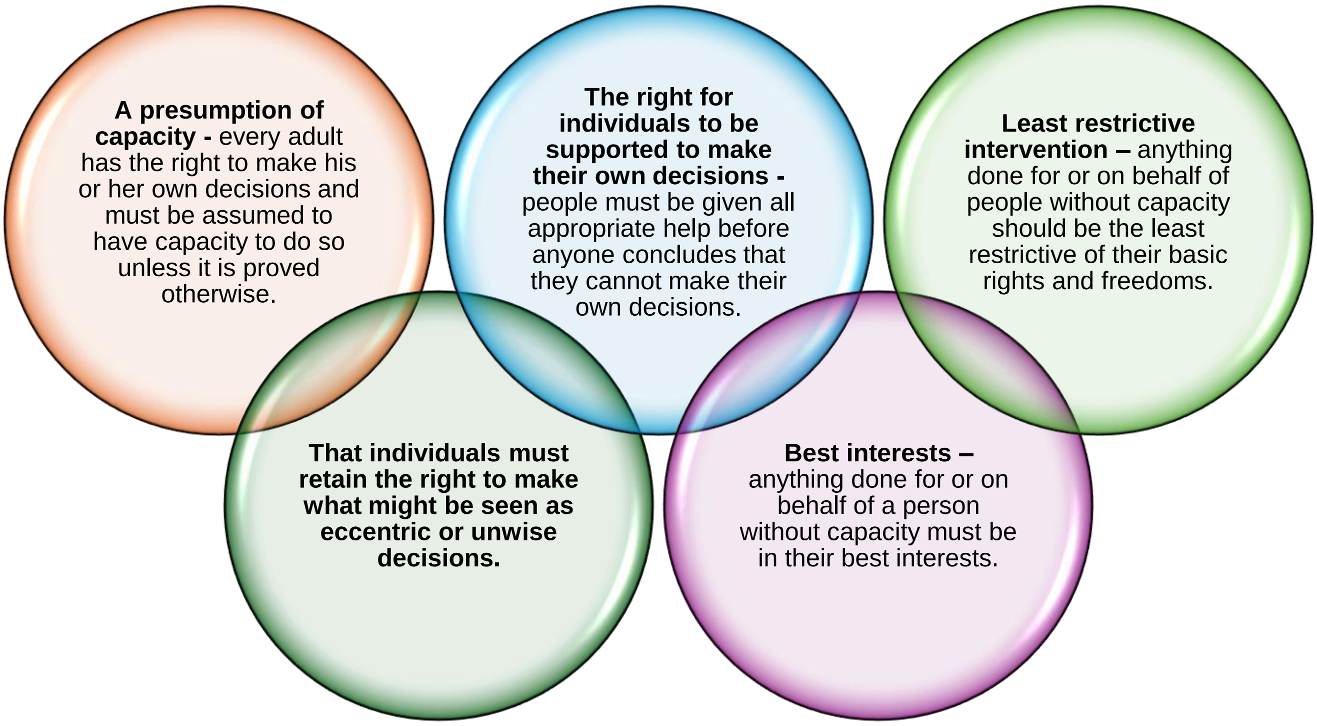
Chapter 9- The Mental Capacity Act 2005

The Mental Capacity Act 2005 (Updated May 2016) for England and Wales provides a framework to empower and protect people who may lack capacity to make some decisions for themselves. It makes it clear who can take decisions in which situations, and how they should go about this. It also allows people to plan ahead for a time when they may lack capacity.

It will cover major decisions about someone's property and affairs, healthcare treatment and where the person lives, as well as everyday decisions about personal care (such as what the person eats), when the person lacks capacity to make those decisions themselves.

This guidance does not apply to patients who are detained under the Mental Health Act 2007

The Mental Capacity Act is underpinned by a set of five key principles:



A presumption of capacity - every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.

The right for individuals to be supported to make their own decisions - people must be given all appropriate help before anyone concludes that they cannot make their own decisions.

Least restrictive intervention – anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

That individuals must retain the right to make what might be seen as eccentric or unwise decisions.

Best interests – anything done for or on behalf of a person without capacity must be in their best interests.

Capacity

The Act sets out a clear test for assessing whether a person lacks capacity to take a particular decision at a particular time:

- Diagnostic criteria - an impairment or disturbance of mind or brain.
- Functional criteria - inability to understand, retain, use or weigh information or to communicate a decision.

Capacity may fluctuate and it is important to reassess regularly and to provide support to enhance capacity.

See Assessment of Capacity Flow Chart – Appendix 1

Advance Decisions to Refuse Treatment (ADRT)

People may make a decision in advance to refuse treatment if they should lose capacity in the future. An advance decision which is valid, applicable and specific is legally binding. If the decision is to refuse life-sustaining treatment there must be an express statement that the decision stands, even if life is at risk.

Advance Statement

An advance statement may be made by the person requesting treatment or giving details of the person's wishes and preferences regarding care. This may be in the form of a Preferred Priorities for Care Document and may include details of the patient's preferred place of care and/or death. Advance statements are not legally binding but must be taken into account when making care decisions.

Lasting Power of Attorney (LPA)

The Act allows a person to appoint an attorney to act on their behalf if they should lose capacity in the future. A donee of Lasting Power of Attorney for Health and Welfare is enabled to give or refuse consent for medical treatment and must be consulted when treatment decisions are to be considered. Treatment refusals are legally binding; requests for treatment are not legally binding but must be taken into account. Proxies under an LPA can only make decisions about life-sustaining treatment if the person gives them express power to do so. An LPA is only valid if in a prescribed form and registered with the Public Guardian.

Independent Mental Capacity Advocate (IMCA)

An IMCA is someone appointed to support a person who lacks capacity but has no one to speak for them. The IMCA makes representations about the person's wishes, feelings, beliefs and values, at the same time as bringing to the attention of the decision-maker all factors that are relevant to the decision. The IMCA can challenge the decision-maker on behalf of the person lacking capacity if necessary.

An IMCA must be appointed to represent and support a patient who lacks capacity in relation to provision of serious medical treatment or accommodation by an NHS body or local authority if there is no other person whom it would be appropriate to consult.

The exceptions to this are if there is someone nominated by the person to be consulted, a donee of Lasting Power of Attorney or Enduring Power of Attorney, a Court Appointed Deputy, an obligation under the Mental Health Act or a need to provide treatment urgently.

Court Appointed Deputy (CAD)

The Act provides for a system of court appointed deputies to replace the current system of receivership in the Court of Protection. Deputies will be able to take decisions on welfare, healthcare and financial matters as authorised by the Court but will not be able to refuse consent to life-sustaining treatment. They will only be appointed if the Court cannot make a one-off decision to resolve the issues.

Family and Carer Discussions

If the person lacks capacity, specific treatment decisions must be discussed with close family members and informal carers. The views of family and carers are not legally binding but must be taken into account and must be in the person's best interests.

Deprivation of Liberty Safeguards (DOLS)

See DOLS Flow Chart – Appendix 2

People who lack mental capacity to consent to the care or treatment they need, should be cared for in a way that does not limit their rights or freedom of action.

In some cases, they may need to be deprived of their liberty for treatment or care because this is necessary in their best interests to protect them from harm. Less restrictive ways of providing care should be considered first. If this is not possible the hospital or care home should apply to the supervisory body (ICB or Local Authority) for authorisation. Six assessments are undertaken by a Best Interest Assessor to assess Age, No Refusals (eg by ADRT, LPA etc), Mental Capacity, Mental Health, Eligibility and Best Interests. In an emergency, the hospital or care home may issue an urgent authorisation which is valid for 7 days until a standard authorisation is obtained.

Following a Supreme Court ruling in March 2014 the following criteria apply to patients being cared for in hospitals, hospices and care homes.

The test to determine whether a person is under a deprivation of liberty is now:

- **Patient or resident lacks the capacity to consent to make a decision to be accommodated in the care setting**
- **They are not free to leave**
- **Staff have complete and effective control over the person**

Complete and effective control means that the person is not able to leave the place where they are now living and would be supervised when out in the public square.

If a person meets the above test and is likely to be in the place of care for more than 72 hours a DOLS should be applied for:

- If the patient meets the criteria laid out in the test AND is non-compliant with placement, or there is a lack of consensus about the placement with family/carers, then complete a DOLS application indicating an Urgent and a Standard Authorisation is needed.
- If they simply meet the criteria of the test and are compliant, then complete a DOLS application indicating a Standard Authorisation is required.

Forms should be sent to the appropriate local authority for DOLS assessment.

The following factors are no longer relevant to deprivation of liberty decisions. To clarify further, the following are not relevant and have no bearing on whether a person is under a deprivation of liberty:

Whether or not they are complying with the requirement to live in their place of care and/or treatment and/or support

Whether or not they are able physically and/or cognitively able to undertake the actions necessary to leave their place of care and/or treatment and/or support

Whether or not there is consensus on the person's place of care or treatment and/or support.

Whether or not they have supported access to universal services and other services such as day services

Whether or not that support, to access universal services, is required for their own safety

whether or not they have unrestricted access to family and other significant others

The Coroner's office has advised that all patients who die when under a Deprivation of Liberties Safeguard must be referred to the Coroner for advice and it is likely that an inquest will follow.

The Deprivation of Liberty Safeguards (3rd April 2017 onwards) have been reviewed by the Law Commission and in March 2017 it was recommended that they be replaced with a new system to be called 'Liberty Protection Safeguards'.

Best Interests

Once it has been established that the person lacks capacity to make a particular decision someone else must make that decision on their behalf and must make the decision in the person's best interests.

According to the Mental Capacity Act when assessing the person's best interests, the person making the decision must apply a specific process:

- They must not determine the person's best interests merely by reference to the person's age, appearance or to any condition or aspect of his behaviour which might lead others to make unjustified assumptions about their capacity.
- They must consider all relevant circumstances.
- They must take the following steps:
    - Consider whether, and if so when, the person might have capacity to make the particular decision for themselves at some time in the future.
    - So far as is reasonably practicable, allow and encourage the person to take part or improve their ability to participate in the decision or action.
    - Where the decision relates to life-sustaining treatment the person making the decision must not, when considering what is in the person's best interests, be motivated by a desire to bring about the person's death.
    - Consider, so far as is ascertainable:
        - The person's past and present wishes and feelings, and in particular any relevant written statement the person made when they had capacity.
        - The beliefs and values likely to influence the person's decision if they had capacity.
        - Any other factors the person would consider if they were able to do so.
    - Consider, if practicable, the views as to what would be in the person's best interests of anyone the person has named to be consulted, anyone involved in caring for the person or interested in their welfare, any advocate with Lasting Power of Attorney and any Court-appointed Deputy.

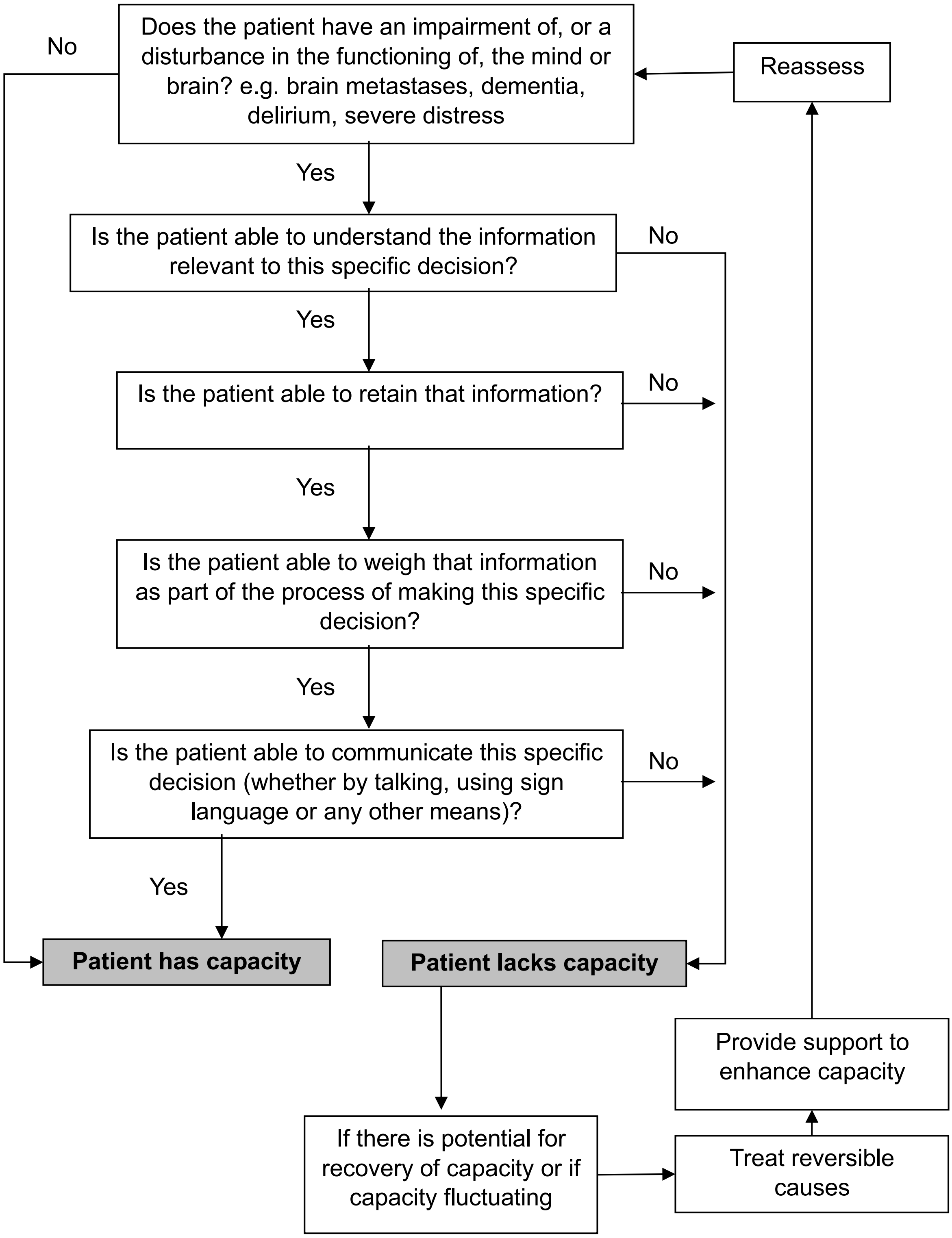
Good Practice in Decision-Making

The General Medical Council (2010) has published guidelines which set out the principles on which good clinical decisions should be based, and which provide a framework for good practice when providing treatment and care for patients who are reaching the end of their lives. Other guidance is available for best interest's decision-making and care planning at the end of life with practical examples and case studies.

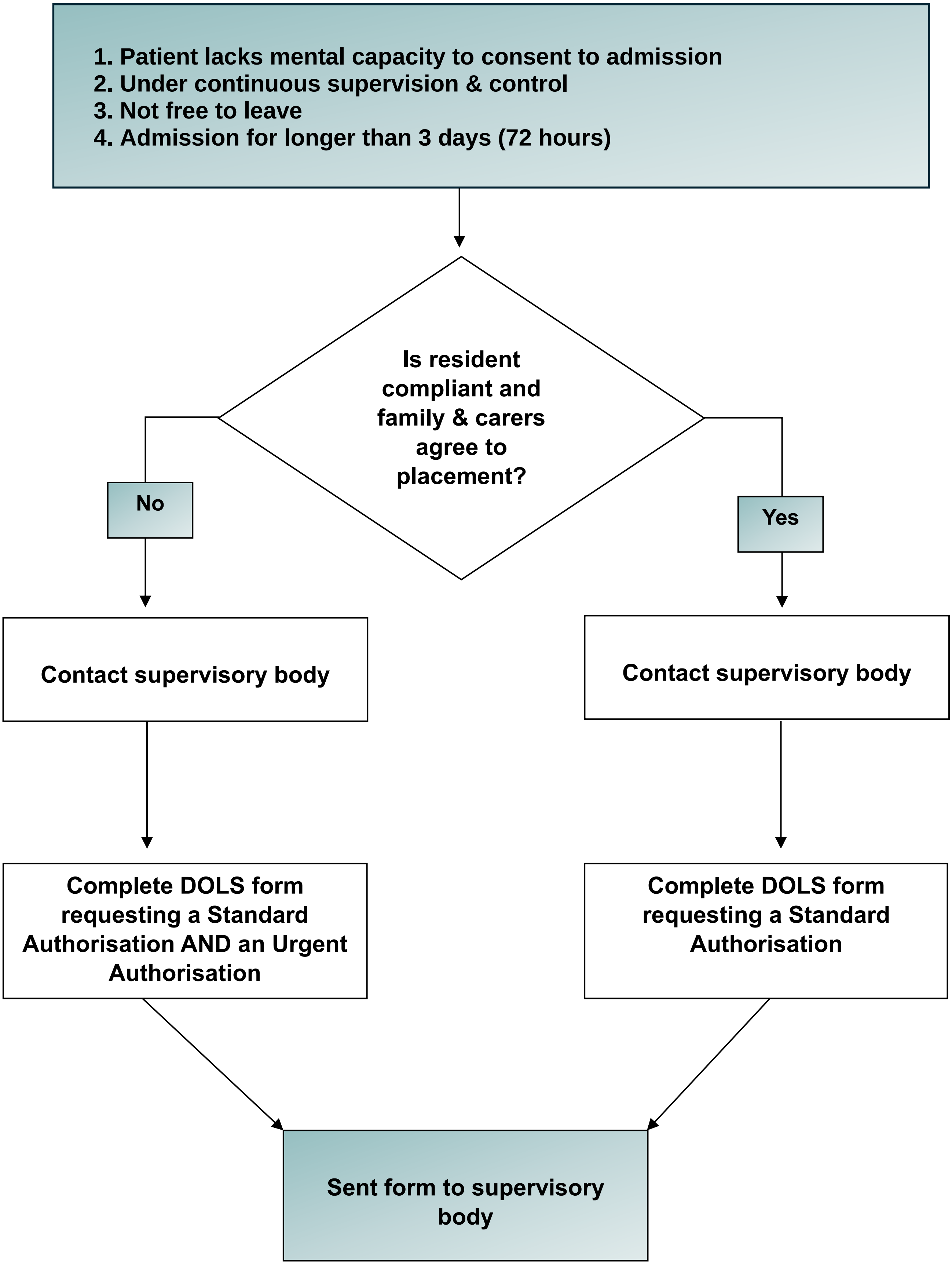
Mental Health Act 1983

Amendments to the Mental Health Act were enacted on 3 November 2008. If a person is thought to be a risk to themselves or to others, or if it is felt that their health is at risk, they can be detained in hospital under the Act. Individuals called guardians can also be appointed under the Act to make decisions on behalf of people who do not have mental capacity.

APPENDIX 1 - Assessment of Capacity Flow Chart



APPENDIX 2 – DOLS Flow Chart



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Chapter 10- Advance Care Planning

The process of Advance Care Planning in dementia is far from straightforward; as dementia progresses, the ability to consider future thoughts and actions becomes compromised, thus affecting decision-making abilities (Harrison Dening et al, 2019). Advance Care Planning is crucial in the care of patients with advanced dementia, and it is the strongest and most consistent modifiable factor associated with avoiding unwanted or unnecessary treatments (Mitchell, 2021). This chapter first addresses the key principles of ACP and then moves on to consider some of the specifics for those with a diagnosis of dementia.

Advance Care Planning (ACP) is a voluntary and personalised process of discussion between an individual person and their care providers irrespective of discipline. Their family and friends may be included in the discussions if the person wishes. With their agreement, this discussion should be recorded, regularly reviewed, and communicated to key persons involved in their care. The basic premise of ACP is that the person has the mental capacity to engage in the discussion at the time and fully understands any decision they choose to make about their future care.

An ACP discussion might include:

The person's concerns

Their important values or personal goals for care

Their understanding about their illness and prognosis

Preferences for types of care or treatment that may be beneficial in the future and the availability of these

The process of ACP aims to identify a person`s wishes at a time when they are able to make and communicate decisions about these. It usually takes place in the context of an anticipated deterioration in a person`s condition and associated loss of capacity to make decisions and/or lack of ability to communicate their wishes to others.

Advance Care Planning is an umbrella term covering personal, legal, clinical, and financial planning and can include:

- A statement of preferences and wishes, such as the Preferred Priorities for Care (PPC) document, which is not legally binding, but should be considered when decisions are being made in the best interests of a person who lacks capacity.
- An Advance Decision to Refuse Treatment (ADRT) related to a specific medical treatment which the person wishes to refuse, under specific circumstances if they indicate this within the document. The ADRT would come into effect if the person were to lose capacity to make a decision about the treatment at some point in the future. A valid and applicable ADRT is legally binding (see Chapter 9 ‘Mental Capacity Act 2005’).
- A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision is made by the person and/or their doctor or healthcare team. A DNACPR decision is usually recorded on a special form. Different doctors or hospitals might use different forms, but they all serve the same purpose. Some examples are a DNACPR form, a treatment escalation plan, or a recommended summary plan for emergency care and treatment (ReSPECT) process.
- A legally appointed advocate with Lasting Power of Attorney (LPA) is a statutory form of power of attorney created by the Mental Capacity Act (2005). An LPA in relation to decisions about personal welfare only applies if the person lacks capacity to make a particular decision for themselves, can extend to giving or refusing consent to a particular treatment but only applies to life-sustaining treatment if specified within the LPA. An LPA must be in a prescribed form and must be registered at the Office of the Public Guardian before it can be activated (see Chapter 9 ‘Mental Capacity Act 2005’).

Decision Making and Capacity for people with Dementia

Dementia can affect a person's ability to make decisions because it can affect the parts of the brain involved in remembering, understanding, and processing information. This does not necessarily mean that a person with a diagnosis of dementia lacks capacity to make future decisions – capacity is time and decision specific. Even a person with moderate or severe dementia, with obviously impaired capacity may still be able to indicate a choice and show some understanding. However, as dementia progresses, the person may become less able to make decisions for themselves and are said to lack the ‘mental capacity’ to make a specific decision at that time, thus highlighting the importance of timely and proactive advance care planning.

When to Initiate ACP with people with Dementia?

Although it has been found that ACP discussions with people with dementia are often not carried out early enough (Azizi et al, 2022) it is advised to start as early as possible and integrate ACP into the daily care of people with dementia, ideally before the health of the person with dementia deteriorates. This needs to very carefully take into account the person’s and their family’s receptiveness or reluctance.

How to Have an ACP Conversation with a Person with Dementia

- Start ACP as early as possible and integrate ACP into the daily care of people living with dementia
- Always assume mental capacity; consider capacity as a fluctuating rather than static condition; stay alert for signs of loss of capacity; judge mental capacity task-specifically, that is, for a certain decision at a particular moment in time
- Adjust conversation style and content to the person's level and rhythm
- Lead the conversation but do not force it to become too formulaic or phased
- Try to understand the whole person living with dementia; explore their life story, important values, norms, beliefs, and preferences
- ACP conversations are not one-off occurrences and are best held on several occasions and over a longer period of time
- Explore the person's current experiences, their fears and concerns for the future and for the end of life
- Evaluate their disease awareness and inform them about the expected disease trajectory and possible end-of-life decisions
- Keep connected with the person with dementia to ensure their maximum participation; respond to their emotions; attend to nonverbal communication; observe their behaviour

Piers et al, (2018) Advance care planning in dementia

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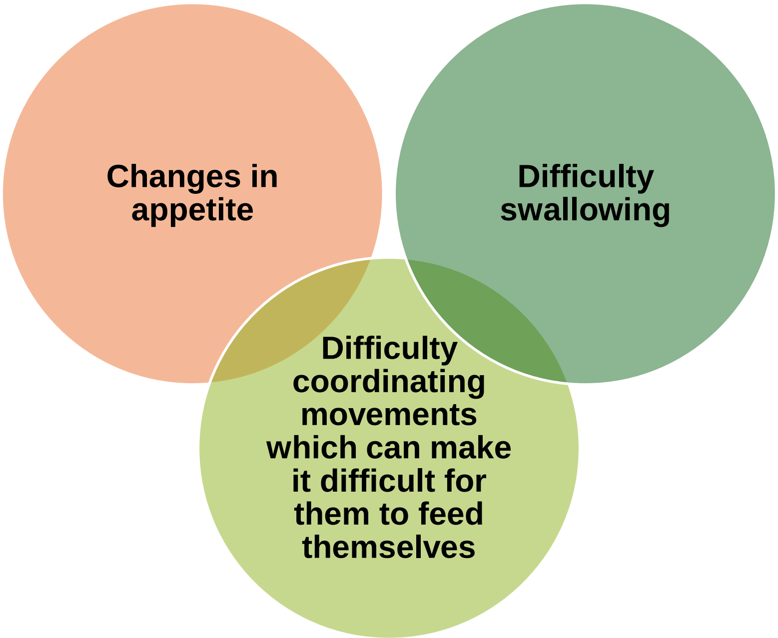
Chapter 11- Clinically Assisted Nutrition and Hydration in People with Dementia

Clinically assisted nutrition and hydration refer to methods used to provide nutrition or hydration to people unable to take them by mouth. These include administration of nutrition or hydration via Percutaneous Endoscopic Gastrostomy (PEG) tube, Radiologically Inserted Gastrostomy (RIG) tube, naso-enteric tube or intravenously, or, for fluids only, subcutaneously. Clinically assisted nutrition and hydration are classified as medical treatment unlike oral nutrition and hydration which are basic care and should always be offered. The decision of whether or not to use clinically assisted nutrition or hydration is often emotive and complex and may include consideration of social, ethical, cultural and emotional as well as clinical factors. Clinically assisted nutrition and hydration can be withheld or withdrawn if not believed to be in the person`s best interests and the decision to initiate these treatments should be based on an objective assessment of the balance of benefits, harms and risks involved.

The benefits and harms of clinically assisted nutrition and hydration and their role in people with advanced dementia, especially in the terminal phase, are uncertain and controversial as there is limited scientific evidence. There are no randomised controlled studies comparing use of clinical nutrition to hand feeding or other methods of nutritional support in these people and only retrospective observational studies have been performed which may be limited by selection bias.

People with dementia may experience:



Some people with dementia, typically those with vascular dementia and Alzheimer`s disease, develop dysphagia relatively early on in their illness, whilst they still have much awareness. In the larger group of people with dementia difficulty in feeding is due to dyspraxia and a loss of interest in food tending to occur together. This is more typical in advanced Alzheimer‘s disease.

The role of clinically assisted hydration and nutrition would differ in a person with dementia who developed difficulty swallowing early in their illness than in a person entering the terminal phase and a decision regarding whether clinically assisted hydration and nutrition are likely to be of benefit should be made for an individual based on a holistic assessment of their needs. The decision should include consideration of such aspects as:

The speed of deterioration in the person‘s condition

The person‘s current or previously expressed views

The view of carers and family

The potential benefits and side-effects of nutrition and/or hydration

The potential routes available

Difficulty eating and swallowing is often an indication that a person with dementia is approaching the terminal phase of their illness. Reasons given for insertion of a feeding tube in such people include improvement of nutritional status, skin integrity and functional status, prevention of aspiration pneumonia, comfort, improvement of quality of life and prolongation of life, but there is no evidence that tube feeding can achieve any of these outcomes. PEG and NG tubes do not prevent aspiration. There is evidence that the incidence of aspiration may be increased, and that PEG and naso-enteric tubes may be associated with significant morbidity. The risk of aspiration may be less with jejunostomy. The prognosis of people with dementia who stop eating is very poor even in those who have a PEG tube, and poor oral intake may be a marker of a pre-terminal stage not remediable with clinically assisted nutrition or hydration. People with PEG tubes or intravenous fluids may require restriction or sedative medication to prevent them from pulling out the PEG tube or intravenous cannula and restraints may increase agitation, pressure sores and risk of aspiration.

Gastrostomies can enable patients to continue some medications such as anticonvulsants independent of their ability to swallow and can offer an alternative to the oral route for administration of antibiotics, enabling infection to be treated in the patient`s usual care setting. They can facilitate a patient being able to eat for pleasure rather than struggling to eat for survival, avoiding exhaustion and stress associated with prolonged mealtimes in some situations. There is a lack of data and understanding about symptoms and effects of malnutrition such as taste changes, anorexia, fatigue, delayed wound healing, susceptibility to infections, gastric stasis and risk of refeeding syndrome resulting in severe electrolyte deficiencies.

In some people with dementia who are acutely unwell due to a reversible condition such as infection short-term feeding may be considered but this decision should be made on an individual basis and will depend on such factors as where the person is in their overall disease. It will rarely be of benefit in such circumstances to people with advanced dementia. However, there are a few cases where without a PEG tube or naso-enteric feeding the patient will be poorly nourished but with such treatment may live well. A lack of good evidence to support clinically assisted hydration and nutrition in patients with advanced dementia does not prove that they are never indicated and reluctance to start such interventions should not be translated into a blanket policy.

Side-effects of clinically assisted nutrition and hydration include:

- **Risk of infection**
- **Fluid retention**
- **Oedema**

Fluid balance, renal function and electrolytes should be monitored. Complications of PEG tube placement includes gut perforation and peritonitis, site complications such as infection, leakage or bleeding, tube dislodgement or blockage and such gastrointestinal complications as diarrhoea, regurgitation, nausea and vomiting. In a study by Givens et al (2012) feeding tube-related complications were a significant cause of hospital admissions/attendances accounting for 47% of attendances at the Emergency Department. Insertion of a feeding tube carries risks in patients with advanced dementia who have a higher mortality following the procedure than those without dementia. PEG tube insertion is associated with greater mortality in acutely ill patients with dementia and it may be appropriate in some situations to defer placement for 30 to 60 days, using a naso-enteric tube in the interim with a nasal retention device to minimise displacement. Patients with advanced dementia have a higher rate of mortality at 1 month and 1 year than those without dementia following PEG insertion.

If it is considered appropriate to offer the person clinically assisted nutrition and hydration, a person with capacity should be fully informed about the likely benefits and risks and may decide to accept or decline the treatment. They have the right to refuse clinically assisted nutrition and hydration even if the health care team believes that it may be of benefit to them.

If the person does not have capacity to make a decision about clinically assisted nutrition and hydration the decision is governed by the Mental Capacity Act (see Section 9 Mental Capacity Act, 2005). If the person has made an Advance Decision to Refuse Treatment (ADRT) specifically refusing clinically assisted nutrition and hydration or has appointed a legal advocate with Lasting Power of Attorney (LPA) to make welfare decisions about clinically assisted nutrition and hydration these should be consulted. In the absence of these a decision must be made in the person`s best interests and the family should be consulted within this assessment.

There is no legal or ethical distinction between withholding a treatment not thought to be in a person`s best interests and withdrawing it should it fail to have an effect or no longer be judged to be in the person`s best interests. Thus there is no distinction between a decision not to initiate clinically assisted nutrition and hydration and discontinuing administration of fluids or nutrition via a PEG, RIG, naso-enteric tube or cannula.

In people with advanced dementia conservative alternatives to clinically assisted nutrition and hydration should be considered. Eating difficulties may be reduced by discontinuing nonessential medications which may aggravate swallowing difficulties such as anticholinergics, sedatives and antipsychotics. It is important to exclude and treat such conditions as depression, which may manifest as disinterest in food or refusal to eat, constipation, oral thrush, poor dentition, dental infection, xerostomia and sore mouth which may contribute to anorexia or difficulty eating. Body position during eating may be important and other potentially helpful techniques include offering of finger foods and preferred foods, strong flavours, liquid supplements, food thickeners, increased personal assistance with meals and alteration of frequency and size of meals. Hand feeding may help to provide and maintain some quality of life for a person with advanced dementia as it ensures continuity of human contact and social interaction and can provide stimulation and comfort. The main goal of oral feeding is to provide food and drink to the extent that it is enjoyable for the patient with the focus on comfort and palliation rather than on a prescribed daily caloric intake. This is the approach recommended by the American Geriatrics Society (2013) as well as the American Board of Internal Medicine`s Choosing Wisely Campaign (2013) as the best evidence fails to demonstrate any health benefits of tube feeding in advanced dementia and as discussed there are risks with the intervention. Conscientious hand feeding is labour intensive, but its success can be improved by minimising distractions, emphasizing sensory clues, providing assistive feeding utensils, optimizing patient positioning and scheduling meals at times of greatest alertness and function. There is evidence that high-calorie supplements promote weight gain but are unlikely to improve other outcomes. There is only low-quality evidence that appetite stimulants, assisted feeding and modified foods result in weight gain. Oral feeding options have not been shown to improve function, cognition or mortality for people with moderate to severe dementia (Hanson et al, 2011).

Referral for a swallowing assessment, advice from the local speech and language therapist and referral to a dietician for dietary advice and support may be appropriate.

On the basis of available data, evidence does not support the use of tube feeding in dementia and feeding tubes are seldom warranted in patients in the final stages of dementia when the balance of risks and benefits is considered. However, a decision about the appropriateness should be made on an individual basis following a full holistic assessment of the person with dementia by a multidisciplinary team including discussion with their carers. If clinically assisted nutrition or hydration is initiated there should be clear goals of what this treatment is aiming to achieve, regular reviews of whether or not these aims are being achieved and a clear plan regarding those circumstances in which such treatment should be discontinued. Adequate information should be shared with relatives and carers to ensure their expectations of what tube feeding can achieve are not unrealistic.

People with advanced dementia often experience problems with swallowing. Swallowing problems can be well managed. Towards the end of life, a person with dementia may take in very little food and fluids, which may make family carers worry that the person is starving to death, when in fact they are not.

Most health professionals now believe that tube feeding at the end of life is not good practice and prefer food and fluids to be given by mouth.

Conclusions

The role of clinically assisted nutrition and hydration in people with advanced dementia is controversial

The benefits and harms of clinically assisted nutrition and hydration in the palliative care setting, especially in the terminal phase, are uncertain

There is no evidence that tube feeding can improve nutritional status, skin integrity and functional status, prevent aspiration pneumonia, improve comfort or prolong life

Side-effects of clinically assisted nutrition and hydration include risk of infection, fluid retention and oedema, and fluid balance, renal function and electrolytes should be monitored. Complications of PEG tube placement include gut perforation and peritonitis, site complications such as infection, leakage or bleeding and such gastrointestinal complications as diarrhea, regurgitation, nausea and vomiting

On the basis of available data evidence does not support the use of tube feeding in dementia and feeding tubes are seldom warranted in people in the final stages of dementia when the balance of risks and benefits is considered

However, the lack of good evidence to support the use of clinically assisted hydration and nutrition in people with advanced dementia does not prove it is never indicated and reluctance to initiate these treatments should not be translated into a blanket ban

Decisions about clinically assisted nutrition and hydration should be made on an individual basis including consideration of such factors as how quickly the patient has deteriorated, the patient`s current or any previously expressed views, the views of carers, the potential advantages and side-effects of nutrition and/or hydration, the potential routes available and potential disadvantages of these

Decisions about clinically assisted nutrition and hydration should be made on an individual basis with clear identification of the goals of treatment, regular review of whether or not these are being achieved and a plan regarding when treatment should be discontinued

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Chapter 12- Treating Infection in End Stage Dementia

Longitudinal studies have found that hospitalisation for infections, such as pneumonia and urinary tract infections, is associated with at least 1.4 x higher risk in people with dementia compared to those without (Mills, 2020). Patients with advanced dementia are usually bedbound, immobile, and often have difficulties with swallowing which makes them vulnerable to pneumonia. Urinary tract infections (UTIs) are the most common infection among nursing home residents with dementia (Mitchell et al, 2014).

It can prove difficult to diagnose infection in its earlier stages in people with communication difficulties (McDanel & Carnahan, 2016). Often infections only become apparent when signs of increasing confusion or behavioural changes occur (Pace et al, 2011). This may present as aggression, withdrawal, or resistance to care/interventions. Patients may also exhibit signs of delirium as infection is one of the most important risk factors for delirium (Kuswardhani, 2017).

The use of antibiotics can be controversial as it may provide comfort measures and symptomatic relief (Morrison & Sui, 2000). On the other hand, others debate that it is reasonable to treat infections such as UTIs, but that treating pneumonia is often ineffective (Parsons & van der Steen et al, 2017). It is also argued that not treating pneumonia would almost certainly lead to a less protracted dying phase (Heerema, 2022). Often the decision to treat can be clouded by the lack of recognition that dementia is a terminal disease (Arcand, 2015: van der Steen et al, 2009).

However, the effectiveness of repeated antibiotic treatment for pneumonia may be limited and as such decisions to treat should therefore be made on an individual basis, weighing up all the pros and cons of each situation. Consideration should be based primarily on goals of care, taking into account the burden of treatment and the patient’s wishes or best interests according to family and professional caregivers (Arcand, 2015).

Antibiotics may be considered if a person with dementia is acutely unwell with an infection, but this decision should be made in the light of where the person is in their disease journey and should be reviewed on each episode of infection. This is often more straightforward if the patient is able to take oral medication and is able to remain in their place of care. The intravenous therapy required to administer the strongest antibiotics frequently needed by people with dementia can often cause them distress, discomfort, or pain, and much of the time confusion and fear. (van der Steen, 2018).

Should a decision be made not to treat an infection then care should be focussed on controlling symptoms and supporting patient and relatives during the dying phase.

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Chapter 13- Identifying Dying in Advanced Dementia

Introduction

Advanced dementia is an incurable, progressive condition. With time, managing symptoms, maximising quality of life and supporting personalised and individualised care become the primary goals of care.

However, recognising this phase is often very complex as survival rates vary greatly for people with advanced dementia, and is hard to predict. There is a considerable variation in the time from presentation to death — people diagnosed in their late 60s to early 70s have a median lifespan of 7–10 years, but this is reduced to 3 years for people diagnosed in their 90s (Schott, 2020).

In relation to impending end of life, there are two principal stages of advancing dementia that it is beneficial to try to identify. The first stage involves the period when the person is entering the last months or years of life; the other is that shorter time scale when the person is approaching the active dying stage - the last few days or weeks of life.

These two stages may be distinguished as, for the longer term, **'the palliative phase'** and, for the later shorter term, **'the active dying phase'**.

The benefits to a timely recognition of dying include:

- enabling better advance care planning for patients, families and professionals. If done early enough, the person may have capacity in certain aspects to make decisions for themselves.
- supporting the most appropriate management of people with dementia, which may include giving necessary treatments and avoiding inappropriate interventions or hospital admissions. It helps to prevent last minute, unplanned decisions.
- promoting good end of life care and good symptom management. The provision of appropriate end of life care is recognised to make the process of dying more comfortable and meaningful for a person and their family (Bamford et al, 2018).
- encouraging honest, realistic conversations, enabling families and significant others to become aware of the situation. It may help to prepare for the situation when the person does enter the final dying phase. It may also help in supporting families and significant others to develop realistic expectations and coping mechanisms.

Identifying the Palliative Phase

Prognostication is complex and often intuitive, and does not follow a linear criteria, especially in conditions other than terminal cancer (Johnson et al, 2013). Dementia is characterised by an overall prolonged and progressive decline but is complicated by a high rate of co-morbidity and age-related care needs.

Several variables may affect the trajectory and duration of dementia. Brodaty et al (2012) found that amongst different dementia types Alzheimer’s disease had the maximum reported survival times, exceeding those of other dementia types by more than 1 year. Studies have shown survival in men is, on average, no different or less than for women. While age at diagnosis is a factor, this may be confounded by the fact that the older you are, the shorter you have to live anyway and with greater age comes the greater risk of comorbidity. The more severe the illness, including the level of mobility, at the time of diagnosis, is associated with a shorter prognosis.

Attempts have been made to develop and validate models to predict survival in advanced dementia. Although some may have limited function, generally these lack accuracy, reliability and consistency (Brown et al, 2013). Furthermore, a systematic review (Browne et al, 2021) evidenced that a definition for end of life in dementia remains poorly defined, and unrepresentative of the general population with dementia. They found that research studies investigating palliative care primarily focused on cognitive or functional decline, leading to a failure to recognise other significant signs and unmet needs relevant to dementia and end of life.

While there has to be the recognition of the complex nature of end of life within and between individuals, some general guidance and indicators have been developed to support the assessment of a person’s need for palliative/supportive care. Although only a very approximate guide to prognosis, they can act as a guide to indicate to those in primary care and in secondary services that a person may be in need of palliative/supportive care. Two examples are:

The Gold Standards Framework (2016)

Supportive & Palliative Care Indicators Tool SPICT™ (2019)

Both have indicators specifically relating to dementia.

Gold Standards Framework (GSF) - Proactive Identification Guidance

These clinical prognostic indicators are a guide in estimating when people have advanced disease and are in the last year or so of life. These are only indicators and must be interpreted with clinical judgement for each individual. They are drawn from expert sources from the UK and abroad and updated regularly.

Primary care teams may include these people on their supportive/palliative care registers and hospital staff may suggest to GPs in discharge letters that such people are included on the registers.

The GSF Proactive Identification Guidance advocates the use of 3 steps: the "Surprise Question"; general indicators of decline; and specific clinical indicators.

The Surprise Question

The question, ***"Would I be surprised if this patient died in the next few months, weeks or days?"***, if answered "No", is an intuitive way of identifying people at the end of life. However, as the progress of dementia is often slow and subtle, clinicians may find it difficult to spot the likelihood of death within a year (Pace et al, 2011).

Specific Clinical Indicators

A person with dementia is likely to have other underlying conditions in addition to dementia. These can influence the presentation of any clinical indicators and should be taken into account when prognosticating. The triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk without assistance and
- Urinary and faecal incontinence, and
- No consistently meaningful conversation and
- Unable to do Activities of Daily Living (ADL)
- Barthel score <3 (online at: https://www.sralab.org/sites/default/files/2017-07/barthel.pdf [Last accessed 10/10/2021]

Plus, any of the following:

- Weight loss
- Urinary tract Infection
- Severe pressures sores – stage three or four
- Recurrent fever
- Reduced oral intake
- Aspiration pneumonia

SPICT™ (Supportive & Palliative Care Indicators Tool)

The SPICT™ is used to identifying people at risk of deteriorating and dying with one or more advanced conditions for palliative care needs assessment and care planning.

The assessment includes an observation of six general indicators of poor or deteriorating health, plus a further six clinical indicators from a list related to dementia/frailty. (Note that people often have other life-limiting conditions as well as dementia that further increase the risk of deterioration).

(See http://www.spict.org.uk/the-spict/ to view or download) [Last accessed 10/10/2021]

However, when considering the discussion by Browne et al (2021), they propose that there is a need to refocus discussions from defining end of life based on stage of disease and consider end of life beyond prognostication. This in turn leads to responding to individual needs to improve end of life care in dementia. Furthermore, they say that refocusing this attention clinically would encourage clinicians to manage and work with uncertainty and consider a needs-based approach for their patients. This closely aligns with the outcome from the work of Goodman et al (2015) who identified that end of life interventions need to provide strategies that can accommodate or "hold" the inevitable and often unresolvable uncertainties of providing and receiving care.

Recognising Dying

In the final few days when death is imminent, the changes that occur can be very similar to other conditions or illnesses and may include:

- **Increased drowsiness**
- **Not wanting to eat or drink**
- **Changes in breathing**
- **Cold skin, hands, feet and extremities (the skin may become mottled or blue or patchy and uneven in colour)**
- **Restlessness and agitation with possible confusion and/or hallucinations**
- **Loss of control of bladder or bowels**
- **Closed eyes**

Communicating

Recognising that a person is in the final phase of life is only part of the challenge, as discussing these issues is often a very difficult situation. Even when professionals are able to identify the stage the person is at, there is often a reluctance to discuss prognosis for a number of reasons. These may include worrying about the emotional impact on the patient and family, a perceived lack of training on the part of the professional to have these conversations, or a feeling of hopelessness regarding the availability of further curative treatment. Not providing the information reduces the positive consequences (as identified above) that timely recognition can facilitate. Giving the information in an abrupt or inappropriate way can make the situation more distressing than necessary for patients and families.

To provide this information requires confidence and insight by professionals. It also requires a relatively high level of knowledge and communication skills and judgement. Giving information about prognosis and end of life issues should be an on-going process over time. Patients and families need the opportunity to have their personal information needs met, without being overwhelmed by too much information. Communication needs to be based on an empathic, person centred style, using appropriate verbal and body language at a pace suited to them. The person’s understanding needs to be clarified to be able to determine the level of information provided. When working with a person with dementia, it is likely that their need for information diminishes over time, while the needs of the family or significant others’ increases.

Conclusion

Although it is very difficult to accurately predict prognosis in advanced dementia, there are adverse consequences of failing to recognise impending death. Models to identify risk are not currently accurate, but a combination of the knowledge of the types of events that could indicate a shorter prognosis, coupled with a knowledge of the patient, means that future events may be anticipated and planned for. Leading on from this, discussions with the patient and/or their family and significant others can identify and prepare for how they would wish to be cared for in the future.

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Chapter 14- Rationalisation of Medication in Advanced Dementia

Most patients with dementia are elderly and have several comorbidities, meaning that an individual may be taking many different medications for various ailments. Drugs are taken either to treat a particular condition, or to reduce the likelihood of disease in the future (e.g. statins, osteoporosis prophylaxis).

The burden of taking drugs increases with frailty. In addition, as comprehension diminishes, it may be harder for an individual to understand the need for medication, or to cooperate with its administration. Ironically, increased focus on palliation care and relief of symptoms may increase the number of medications an individual takes.

As dementia advances, mobility diminishes; incontinence often develops; loss of appetite, weight loss and swallowing difficulties then typically develop, which may have a direct effect on medical conditions, or the medication given. As life expectancy diminishes, the benefits of risk reducing drugs lessen, and the increasing priority becomes that of maximizing comfort for the individual.

In addition, diminished renal function may affect the metabolism and clearance of medications, with a risk of accumulation and toxicity.

Thus, it is important to review medication regularly, reducing the number and frequency of drugs to the minimum needed for comfort. Alongside this is a reduction in the frequency of monitoring conditions routinely – e.g. capillary blood glucose testing, blood pressure checks.

When referring to “advanced dementia” below, this means that the condition has reached a level at which the individual has severe difficulties with everyday living, needing assistance with dressing, bathing, and incontinence, developing diminished vocabulary, losing ambulatory ability and beyond. Individuals differ in their disease progression and needs, and all decisions must be individualised.

Acetylcholinesterase (AChE) Inhibitors and Memantine

- These treatments are not licensed in severe dementia. However, there is evidence for continuing use in this patient group. For example, a large multicentre study demonstrated that patients with an MMSE score as low as 3 benefitted from continued donepezil treatment.
- The effect of memantine on functional impairment may actually be better in severe disease.
- NICE guidance states that AChE inhibitors should not be stopped because of disease severity alone.
- The decision to withdraw medication must be made in the patient’s best interests, incorporating the view of the family, carers and professionals involved.

- Suggested reasons for stopping treatment include:

When the patient/caregiver decides to stop (after being advised of the risks and benefits of stopping treatment).

When the patient refuses to take the medication.

When there are problems with patient compliance which cannot be reasonably resolved.

When the patient's cognitive, functional, or behavioural decline is worsened by treatment.

When there are intolerable adverse effects.

When co-morbidities make treatment risky or futile (e.g. terminal illness).

Where there is no clinically meaningful benefit to continuing therapy.

When dementia has progressed to a severely impaired stage (Global Deterioration Scale stage 7: development of swallowing difficulties).

- When the medication is withdrawn, it should preferably be tapered off to reduce the risk of a withdrawal reaction.

Antipsychotic Drugs

- Antipsychotics should not be used routinely to treat agitation and aggression in people with dementia.
- These may be appropriate for short-term management of behavioural and psychiatric symptoms of dementia (BPSD); occasionally if psychosis develops, or was already present, they may need to continue for longer periods on an individual basis.
- BPSD may be due to uncontrolled pain or other symptoms – the use of antipsychotics is inappropriate here (except in the very short term to reduce the risk of harm).
- There is an increase in mortality in people taking any antipsychotic drugs, particularly in the first weeks of treatment, so the benefit of treatment must be balanced with this, taking into particular account the patient’s cerebrovascular risk factors.
- Consider non-pharmacological methods of managing specific BPSD symptoms first.
- Use antipsychotic drugs at the lowest effective dose and consider tapering off antipsychotic medication once the condition has been stabilised.
- Consider reduction or cessation in the late stages of dementia.
- If the antipsychotic medication is being used for a non-psychiatric problem (e.g. haloperidol for nausea due to cancer) then consider this on its own merits.

Statins

- The benefits of lowering lipids diminish with reduced life expectancy. It is not known whether the benefits of statins outweigh the risks in persons with advanced dementia.
- There is no evidence that statins help in the treatment of cognitive decline in dementia.
- In addition, if there is diminished food intake and/or cachexia, the level of lipids will tend to reduce.
- Therefore, statins should be stopped in advanced dementia.

Antibacterial Medication (see also Chapter 13 'Treating Infection in End Stage Dementia')

- Towards the end of life, patients can be more susceptible to infection and more likely to develop symptoms which may be mistaken for infection.
- Although giving an antibiotic may extend life in certain circumstances, it may not necessarily improve quality of life and may prolong the dying phase. There is also the potential for harm, through side-effects or complications (e.g. *Clostridioides difficile*) and through promotion of antimicrobial resistance in the wider community.
- It may be useful to give antibacterials to reduce specific symptoms e.g. dysuria with a urinary tract infection; production of mucopurulent sputum in a chest infection. They are generally not indicated just for treatment of fevers or the presence of pathogenic bacteria in culture. If there is doubt, then discuss with a Microbiologist.
- Other medicines including mucolytics, muscle relaxants, analgesics, antipyretics, and antitussives should be considered as alternatives for relief of infection-related symptoms.
- If an intravenous route is considered, this should be balanced against the deleterious effects of transferring a person with dementia to a hospital or other site if this would be required for such treatment.
- Decisions about the patient's priorities of care should be taken jointly between the clinician and the family/carers. However, there may be pressure from family to prescribe antibacterials. Agree clear treatment goals, as well as limits of therapy.

Diabetes Mellitus Medications

The goal is to keep the person asymptomatic. Tight blood glucose control, mainly needed to reduce the risk of long-term effects of diabetes, is no longer relevant, and runs an increasing risk of hypoglycaemia. Assessment of frailty (e.g. using the Rockwood Clinical Frailty Scale) is one aspect that may identify when the emphasis of care switches from strict control of glucose and monitoring of HbA1C to control of symptoms and avoidance of complications including hypo- and hyperglycaemia.

In severe dementia, there may well be a change in preferred tastes, e.g. for sweeter foods. It is preferable to accommodate this, as limiting this may affect food intake overall, and may diminish pleasure in eating.

The family/carers of a person with diabetes may view the continuation of treatment as very important. Involve those people in discussions about ongoing monitoring and treatment.

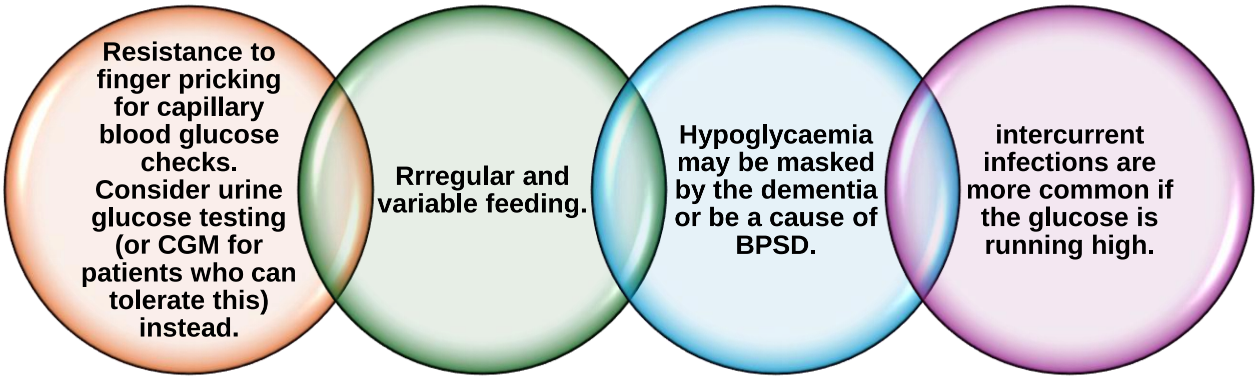
Be aware that some end-of-life medications may precipitate hyperglycaemia, including corticosteroids, octreotide, and risperidone.

Type 2 Diabetes

- Drug therapy here is generally not life-sustaining. The risk of ketoacidosis is low.
- Irregular feeding in a person on sulphonylureas (e.g. gliclazide) has a risk of hypoglycaemia.
- Metformin can diminish the appetite and should be stopped if the person has anorexia and/or significant weight loss. It should not be used if eGFR is < 30ml/min/1.73m^2 (and needs review if it is < 45ml/min/1.73m^2).
- Sulphonylureas should also be used in caution in moderate to severe renal impairment.
- GLP-1 receptor agonists also diminish the appetite.
- SGLT2s also have a diuretic effect. SGLT2s are reliant on kidney filtration and are therefore not appropriate for patients having trouble maintaining hydration.
- People with type 2 diabetes managed on insulin often need this less or not at all in the later stages of dementia.
- If the person has lost weight, the need for antidiabetic medication diminishes or ceases. This should be reviewed. A capillary blood glucose level mainly below 15 mmol/l, with no hypoglycaemia is acceptable. Regular monitoring is not required but checks may be indicated on clinical grounds.
- When food intake diminishes or ceases, then oral hypoglycaemic treatment may be stopped. Blood glucose monitoring is not required unless the person has signs or symptoms suggesting significant hyper- or hypoglycaemia.
- For patients at risk of hypoglycaemia, consider a continuous glucose monitoring (CGM) device, if tolerated.

Type 1 Diabetes

- There is less consensus here. More careful individual assessment is needed. Advice from a Diabetes Specialist may be helpful.
- Problems include:



- In cases of irregular feeding, it may be preferable to focus on short-acting insulin tailored to the food intake rather than long-acting insulin regimens.
- In advanced dementia if there is little or no oral intake of food, insulin requirements generally diminish. In some cases, it may be appropriate to consider stopping insulin. If capillary blood glucose is consistently above 15 mmol/L then a simplified insulin regimen may be considered – e.g. a long-acting insulin once daily.

- If blood glucose levels consistently rise above 20 mmol/l, check urine for ketones. If the person has diabetic ketoacidosis, then treatment may require hospital admission. However, if the person is in the last days or weeks of life, it may be more appropriate to accept this is part of the dying process for this person. This decision should be a joint one between the responsible doctor, senior nurse and health proxy/relatives or partners/family or others close to the person.

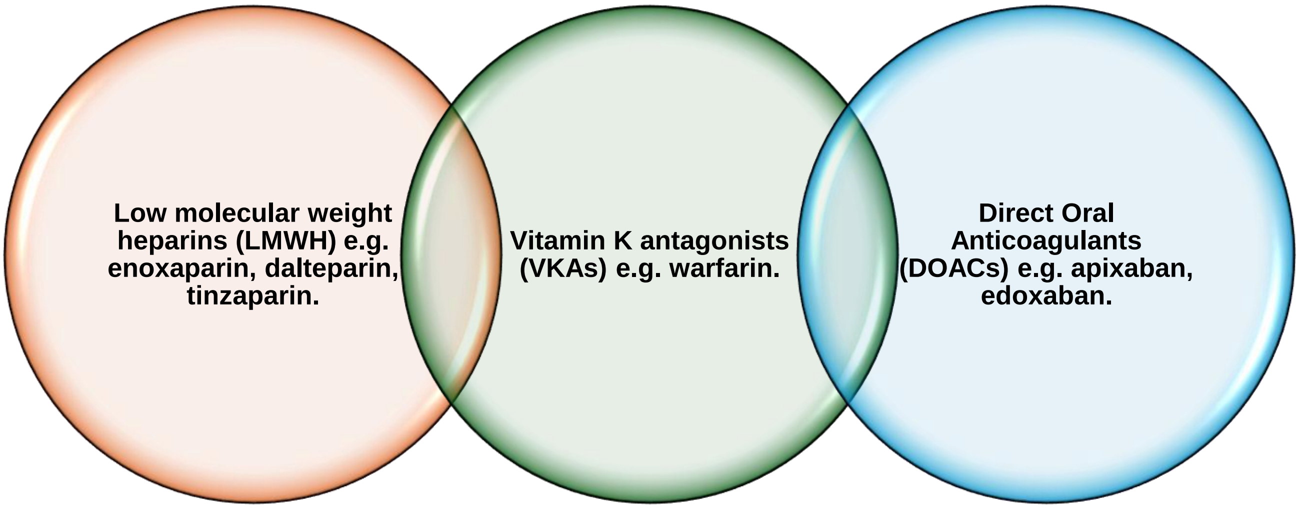
Further information on the management of diabetes at the end of life can be found at https://www.diabetes.org.uk/professionals/position-statements-reports/diagnosis-ongoing-management-monitoring/end-of-life-care [Last accessed 02/02/2024]

Antihypertensive Drugs

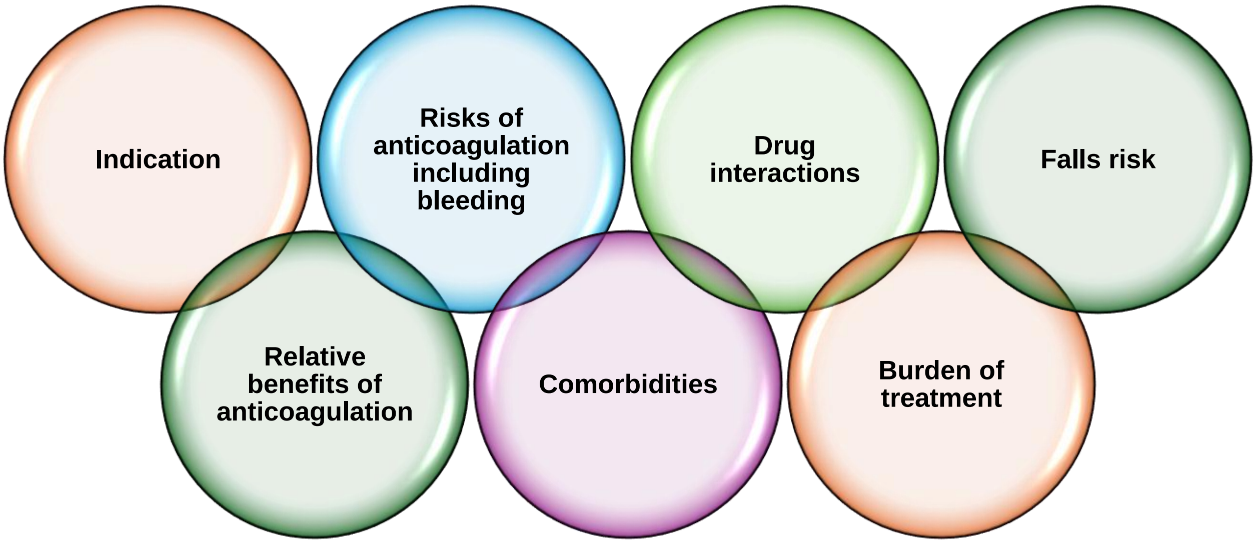
- Strict blood pressure control reduces the risk of stroke and heart disease over a period, depending on the severity of the hypertension.
- However, it also carries the risk of falls and trauma due to postural hypotension.
- Blood pressure itself may fall due to weight loss, dehydration or other medication used (e.g. opioid analgesia, antipsychotics, antimuscarinic drugs and some antidepressants). It often reduces in the latter stages of dementia.
- Consider reducing and withdrawing hypotensive medication as dementia progresses. If it is continued, the blood pressure should be monitored and checked for a postural drop.

Anticoagulants

- The use of anticoagulation is potentially more hazardous as dementia develops. Factors including impaired nutrition, weight loss, hypoalbuminaemia, compliance and polypharmacy increase the risk of under or over coagulation.
- The main anticoagulant medications used are:



- Anticoagulation should generally be continued. However the appropriateness of continuing anticoagulation should be considered. Treatment regimens should be individualised and based on shared decision making with the patient and those important to them.
  When having such conversations the following should be considered:



- It should be appreciated that therapeutic anticoagulation can result in severe and life-threatening bleeding.

Osteoporosis Prophylaxis

- Alendronate is contra-indicated if the patient is unable to sit upright to take it, and for 30 minutes afterwards.
- The use of calcium and vitamin-D supplements has not been researched in advanced dementia, and it becomes questionable once the person is bed-bound.
- Unless there is a pressing clinical need (e.g. high falls risk), this treatment should be stopped in advanced dementia.

Effect of Renal Failure

- In the presence of impaired renal function, there is a risk of accumulation of some drugs or their active metabolites e.g. NSAIDs, morphine and codeine, metformin, benzodiazepines. This may cause prolonged effects or toxicity. Review the need for continued therapy. If essential, consider alternatives which are more suitable in renal impairment.
- In addition, some medications can affect renal function e.g. diuretics, NSAIDs.
- If drugs are used that may reduce or be affected by a reduced renal function then this should be monitored regularly every 2-3 months at least, more so if clinically indicated. In cases of acute renal failure, it may be necessary to withhold or reduce the dose of certain medications. Ensure that these are reviewed if the acute failure is resolved.
- Refer to the BNF for individual entries for the relevant drugs.
- In people towards the end of life, the need for renal function testing becomes less or nil. It should be restricted to tests that would direct a clinical course of action that affects the person's comfort.

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Chapter 15- Caring For a Person with Dementia in the Final Days of Life

This chapter refers specifically to care for a person with dementia who is in the final days of their life. A person with later stage dementia often deteriorates slowly over many months which makes it challenging often to specially identify when a person with dementia is close to death and there is inherent uncertainty which needs to be considered when planning their care (Goodman, 2015).

National guidance from the Leadership Alliance for Care of Dying People (LACDP) advocates an approach focused on achieving the five key priorities for care, which make the dying person the focus of care in the final days of life.

Priorities for Care of the Dying Person

The Priorities for Care are to be considered when it is thought that a person may die within the next few days or hours.

1. Recognise	The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person`s needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Communicate	Sensitive communication takes place between staff and the dying person, and with those identified as important to them.
3. Involve	The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wishes.
4. Support	The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. Plan and do	An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

LACDP `One Chance to Get it Right` (2014)

Recognise

Knowing when a person is in the last days of life can be difficult in a slowly progressive illness. This is particularly true for a person with advanced dementia especially where there are comorbidities, as is often the case in an older patient. The person may be dying specifically from their dementia or from another cause, such as cancer or heart failure.

For some people with dementia, death can be sudden and unexpected but for the majority there are signs that a person is dying. Often a multidisciplinary approach to care is the most helpful. If a person has deteriorated suddenly, it is important to consider whether this is due to reversible causes, such as infection, and whether treatment of these would be appropriate. This will often be done in collaboration with doctors, nurses, the individual if possible, and those important to them. Where treatment may be an option but would be burdensome (e.g. admission to hospital for intravenous antibiotics) this should be balanced against the potential benefit to comfort and best interests, and is a decision best tailored to the individual. Treatment of infection becomes less successful with repeated episodes (see Chapter 13 'Treating Infection in End Stage Dementia'). Discussion with family members and carers can help to determine the best interests of the individual, as well as keeping them informed. The progression towards death will often be that symptoms will have been more prevalent and worsened over a two-to-three-week period.

There are often signs that somebody is approaching the terminal phase of their illness.
These may include:

- Profound weakness
- Reduced mobility, often being totally bedbound
- Inability or difficulty in taking oral medication
- Inability or difficulty in taking diet and fluids
- Sleeping for increasingly long periods and difficulty rousing
- Needing total assistance with all activities of daily living
- Gaunt appearance
- Disorientation to time or place
- Difficulty concentrating
- Agitation or restlessness

It is quite possible that some people living with advanced dementia will have already experienced these symptoms for some time, making death difficult to recognise. It is important to highlight that in preparing for a potentially imminent death we are not doing anything to hasten it happening. If the person's condition stabilises, there is no reason for care not to continue as previously.

The focus of care in the final days and hours of life should be the person who is dying and their needs and wishes. Some people approaching the last days of life, particularly those with dementia, may lack the mental capacity to understand and engage in shared decision-making, and the principles of the Mental Capacity Act (2005) should be followed (see Chapter 9).

Uncertainty is common and needs to be allowed for. The person’s condition may vary from day to day. The full realisation and diagnosis that an individual may be dying may take several days. At times, the condition may improve, sometimes following a reduction in the burden of medication, sometimes with relief of a source of discomfort or distress. On other occasions the cause of the improvement is not apparent. Where there is uncertainty, this should be recognised, acknowledged, and shared. Regular reassessments over time can help reduce this.

Communicate

Hopefully at an earlier stage of the illness advance care planning will have ascertained what the person`s wishes would be regarding their terminal care. It is important to revisit this and ensure that the person`s wishes with regard to place of care are met as far as is possible.

If the person has chosen to complete documents such as an Advance Decision to Refuse Treatment (ADRT) or a Preferred Priorities for Care (PPC) document these should be consulted (see Chapter 10: Advance Care Planning). A “Do Not Attempt Cardiopulmonary Resuscitation” (DNACPR) order should be considered if not already in place. The chance of successful restoration of heart and respiratory function at all is very low, and the risk of further brain and other physical damage to the few that do survive is significant. Outside of hospital, initiating CPR and calling a “999” ambulance will require the person being transported to the local hospital. If the wish not to be resuscitated is part of an established ADRT then it should be in place. If not already done, this decision should be discussed sensitively with the appropriate members of the family and close others. Local policy should be followed.

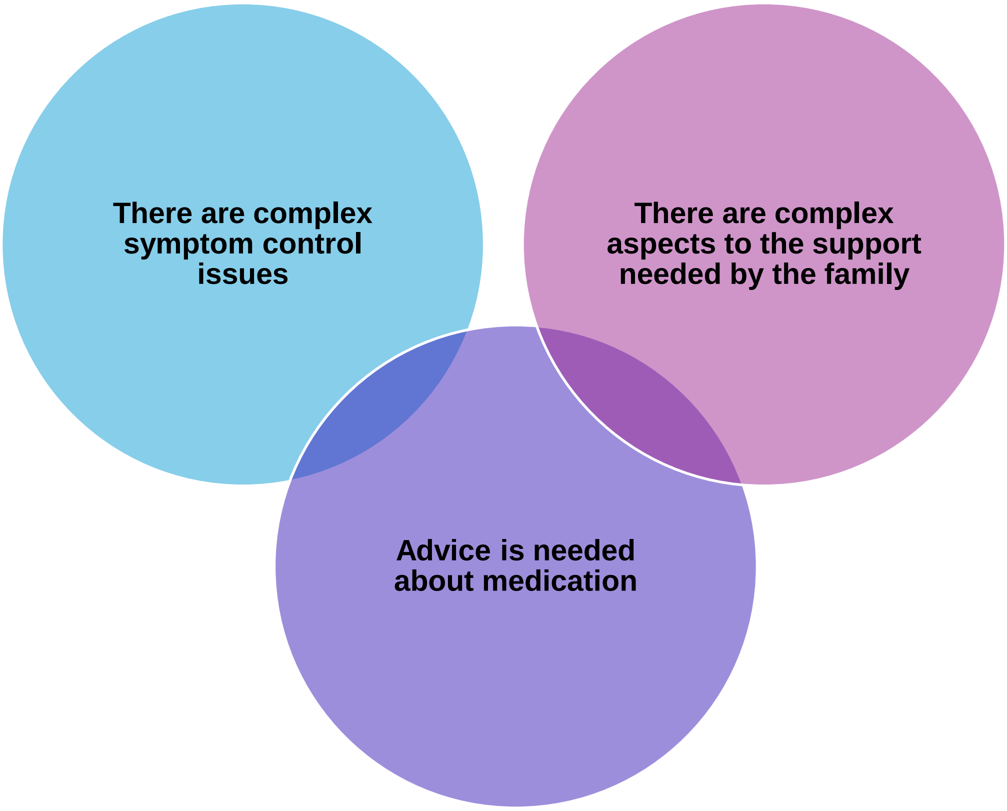
Communication with the dying person where appropriate and those important to them about the situation and recognition that they are thought to be in the final hours and days of life should include the uncertainty around this.

Involve

It is of course crucial to involve the person`s family and those close to them. Their support is paramount and a clear explanation as to what is happening and what may happen should be a priority. Healthcare professionals should establish the family`s wishes at this time. Do they wish to stay with the person? Would they hope to be present when the person dies? Do they know what to do afterwards? It is important that family is informed that the health care team feels that the person may die in the forthcoming days. When someone has lived with advanced dementia for some time it can often be a shock for those close to them to recognise that death is imminent, and this conversation needs to be handled sensitively.

Family may wish to be involved in the care at this phase of their loved one`s illness, although it is important they feel no pressure to support care if they do not wish to. Family members may wish to support personal care and be shown how to perform mouth and lip care if they choose. It is important to explain why the person does not require diet and fluids at this point, and that by applying Vaseline to the lips and moistening the mouth the family are maintaining their loved one`s comfort and symptom control. Ideally personal care should be maintained by those that have supported the person for some time and those they are familiar with.

It is normally preferable to support the person in their familiar place of care, where carers and staff are accustomed to and know them, but there may be a need for increased nursing support, equipment, provision of night sits or assessment for continuing health care funding. For some this might mean a change of care environment e.g. to a private room or maybe to a local hospice if complex symptomatic care is needed due to intercurrent illnesses, or there is difficulty managing care at home in the last days of life, according to local providers' policies and resource availability. This should be discussed on an individual basis. Advice from the local specialist palliative care team may be helpful if:



The team may be able to advise directly or indicate suitable local sources of help.

Support

The needs of families and others identified as important to the dying person should be explored, respected and met as far as possible. It can be particularly difficult for those close to a person with a prolonged illness, such as dementia, which affects an individual`s cognition or psychology as they may experience feelings of loss and grief and the associated emotions throughout the different stages of the illness, including when it is recognised that they are in the final hours and days of life.

See also Chapter 18 'Carers Health and Wellbeing' and Chapter 16 on 'Bereavement'

Plan and Do

Once the health care team has ascertained that the person is likely to be in the last days of life because reversible causes of their condition have been excluded the plan of care should focus on the most important and achievable aspects of care at this stage:

- **Comfort - by identifying and alleviating symptoms and causes of discomfort and anxiety**
- **Reduction of burdens of medications that are no longer essential**
- **Avoidance of unwanted transfers or hospital admissions**
- **Avoidance of interventions and investigations that will not help the person’s current or future condition**
- **Help to support relatives and others close to the person, including informing them of what is happening and what to expect**
- **Ensuring that appropriate religious and other desired individual spiritual support is enabled**

There should be a medical review by the general practitioner or appropriate doctor in a residential or in-patient care setting. The doctor should ensure that anticipatory drugs are prescribed and available for the potential symptoms that might be anticipated at the end of life, in particular:

- agitation, restlessness - these may be due to discomfort, anxiety or fear, and causes for these should be sought and dealt with as far as possible. However, they can also be features of dying, termed “terminal restlessness”
- respiratory tract secretions
- pain
- vomiting
- dyspnoea

Most people with dementia are elderly, and older people are often taking many different medications. The individual’s treatment regimen should be regularly assessed and rationalised as time goes on, taking into account the person’s needs (see chapter 14 - Withdrawal of Medication in Advanced Dementia). Reduced oral intake typically also means that the person has difficulty or an inability to take oral medication. Ongoing medication for comfort should be maintained. A syringe pump may be needed for continuous subcutaneous medication, and knowledge of how to obtain one should be sought in anticipation. Nonessential medications and procedures (i.e. doing observations, taking blood) should be discontinued, unless they will help direct further care.

An individualised plan of care should be developed for the person, involving them and those important to them as much as they wish. Some localities have developed documentation to support care of the dying person and those important to them, such as the 'Care and Communication Record' in use in West Cheshire or the Symptom Control Prescription Drugs and Administration Record ("Blue Booklet") in Mid and East Cheshire.

Health care professionals should also discuss spiritual and religious support that the individual and those important to them may wish for at this point. If a person has particular religious or spiritual wishes, whether individual or a part of a religious or cultural community, these must be communicated within and between teams and care settings. Familiar religious observations and practices can remain a practical and psychological comfort and will also have meaning to those close to the person. If in doubt, ask the family for specific wishes, and ensure contact with appropriate religious representatives is enabled, if desired.

People should be supported to eat and drink if they wish and are able to but should be monitored for signs of aspiration/ choking or distress. A diminishing appetite and desire for fluids is a natural part of the dying process and explaining this to relatives can be helpful. Frequent care of the mouth and lips is important to minimise the sensation of thirst. When considering whether a dying person should be given clinically assisted hydration, an individualised approach should be used, considering any preferences they may have expressed previously, their level of consciousness, their oral intake and level of thirst, any swallowing difficulties, the risk of pulmonary oedema and whether they are experiencing symptoms of dehydration. There is no evidence that giving clinically assisted hydration will prolong the dying phase or that not giving fluids will hasten death. Clinically assisted hydration may relieve distressing symptoms of dehydration and may reduce myoclonus and sedation at the end of life but may cause other symptoms including pain, discomfort or swelling at the infusion site and may aggravate oedema, ascites and pleural effusions. In addition, tubes and drips may be pulled out by the person particularly if they are distressed. Although robust evidence regarding the benefits, burdens and risks of clinically assisted hydration in the dying phase is lacking, potential risks and benefits should be discussed with patients and families (see also Chapter 11 'Clinically Assisted Hydration and Nutrition'.)

Episodes of aspiration are common and become more frequent in the later stages of dementia. Aspiration is a poor prognostic feature. It is more common in people who have tube feeding (naso-gastric or by gastrostomy), require suction for secretions, have pre-existing chronic respiratory disease, contractions, malnutrition or treatment with strong sedative medication (Pick, 1996; Langmore, 2002).

When the person is in the final days or hours of life, they may lose consciousness and may be unable to swallow. Their breathing pattern may change and they may have periods where they breath regularly then stop breathing for a few seconds. The breathing may be intermittently moist due to breathing through saliva or respiratory secretions in the pharynx. These patterns occur when the person is deeply unconscious, and it is appropriate to reassure those at the bedside that, although they may be disconcerting to witness, the person themselves would not be aware, nor suffering due to them. The person`s skin may become pale and clammy and their fingers and feet may become cold and blue in colour as the circulation around the body slows. The person themselves is generally unaware of this. It is helpful to inform and prepare the family for changes that may be expected in the last hours of life.

The focus is on the patient's comfort, and things that may help this change with time. For example:

- **Is a different mattress needed?**
- **Is a hospital style bed required?**
- **Does lighting need to be altered – raised or lowered?**
- **Is the ambient noise level best for that person? Is it the right sort?**

Consistency is important for the dying individual. Touch, conversation and familiar wanted sounds (television, radio, and music) should be continued. Dignity in care should always remain a priority.

After death, or when death is anticipated, the health care team should consider if there is specific need to support the family in bereavement, offering support according to local services available.

Caring for the person dying with dementia can be challenging. By maintaining the best symptom control and support for that person, the health care team can feel rewarded at having made a difficult time as comfortable as possible for all those involved.

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Chapter 16- Bereavement

When a person dies following a prolonged illness which changes cognition or psychology, the family and friends have often already experienced many losses. This is especially true with a death due to dementia (Alzheimer's Society, 2021). As dementia progresses, the person may lose skills and abilities. Relationships change as well: family and friends who are facing the eventual death of a loved one can grieve this loss before it happens, which can further affect the relationship with the person who is living with dementia. Family and friends may feel all the emotions you would expect to feel after the person has died such as anger, shock, sadness, denial and fear. This is known as anticipatory grief. As the illness progresses, they may find that they come to terms with a specific loss only to find the person has deteriorated further and the process of grieving starts over again resulting in a feeling of losing the person twice (Grief Chat, 2020).

Anticipatory grief is normal and can be a helpful adaptive state, enabling some carers to cope better with the grief they experience after bereavement. However, some carers may become depressed and when anticipatory grief becomes prolonged, as with dementia, it can become problematic and detrimental. In these circumstances existing support systems may not be adequate and additional help may be required.

An acceptance of death can vary dependent upon individual coping styles, relationship with the person, a family's perception that a person is actively dying and the quality of care that they receive. Unfortunately for people living with dementia, prognostication can be difficult and there is an increased likelihood of hospital admissions and burdensome treatments at end of life. Andrews et al (2017) identified that the majority of family members could not recognise the terminal nature of dementia nor understand what to expect at the end of life. This can leave families practically and emotionally unprepared for the death of their loved one, even when they may have been highly dependent and deteriorating for some time.

While bereavement following a period of being a carer is similar in many ways to any other type of bereavement, some traits may be magnified. For example, when the person living with dementia has died, the former carer may feel enhanced guilt they did not 'do more' for their loved one or feel remorse for any time they lost their temper or felt frustration. A prolonged period of caring may have left the individual exhausted even before they try to deal with their loss. If life has revolved around appointments, medication, routine and safeguarding, the individual might feel their life has a lack of meaning or focus now, and they may feel more isolated. Encouraging the individual to look back in a balanced way at their time as a carer may be helpful, as well as encouraging them to explore any hobbies, clubs, or social connections they may wish to pursue, while still giving themselves time and space to adjust. Professional assistance such as counselling or support groups may be useful in helping the individual work through their feelings and new situation.

Feelings of loss and grief are normal during the bereavement process and will be experienced by everyone at some time in their lives. Normalising the process for the person and encouraging them to use existing support systems can help them to make sense of what is happening to them and increase their coping mechanisms. While most people will have an unproblematic bereavement, complicated grief due to bereavement is a recently recognised condition that occurs in about 7% of bereaved people (Shear, 2012). It is estimated that additional psychosocial support other than information will be required and of those 2-4% will require specific psychiatric/psychological therapy treatments to cope with a serious mental health problem related to loss by death.

Guidance from the Irish Hospice Foundation (2020) regarding bereavement care recommends a four-tiered framework of bereavement support and recognises that professionals have a duty to ensure that carers' bereavement risks are assessed and that they are sign posted or referred to the appropriate service(s). The guidance also highlights that bereavement can cause a wide range of needs, including practical, social, emotional, spiritual and loss of income and loss of role. The assessment of a carer's bereavement risks should enable an appropriate plan to be put in place to meet their identified needs. A report for Sue Ryder (2019) recommended that specific approaches to bereavement support should be considered to meet the varied needs of people dependent on their experience or situation. Access to additional support should be offered to those for whom this is insufficient or in whom it is anticipated that difficult grief reactions may be experienced.

Bereaved people should be offered support to facilitate grieving to prevent the detrimental effects of bereavement, often referred to as complex grief (Thompson, 2019), and in some cases there may be specific needs for a mental health service intervention to cope with a complex bereavement reaction. The forms of support that should be provided for those experiencing bereavement include information, befriending and self-help groups. These may include formal and organised service provision (includes signposting/referral services, appropriate counselling/psychotherapy, clear referral pathways and accessible services aiming to meet the needs of those with complicated grief reactions and those needing low-intensity support (Irish Hospice Foundation, 2020).

Dooley and Stewart (2015) highlight the impact of impairments of memory and personality on the grieving process when a person living with dementia experiences bereavement and the subsequent diagnostic, management, and ethical challenges this presents. Bereavement services vary from locality to locality and are provided by both statutory and voluntary sectors. It is important to ensure that carers are given information about the experience of bereavement support services available within their locality and how to access these. Bereavement support may be required on a longer term basis, and for some before death.

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Useful Websites

- Alzheimer`s Society: https://www.alzheimers.org.uk/

- West Cheshire Bereavement Service: Family Support & Bereavement Services - Hospice of the Good Shepherd

- Bereavement Advice Centre: Bereavement Advice Centre | What to Do When Someone Dies

- Cruse Bereavement Support: https://www.cruse.org.uk/

- Survivors of Bereavement by Suicide: https://uksobs.org/?doing_wp_cron=1667736297.5987339019775390625000

Useful Contact Telephone Numbers

- Age UK (National contacts): https://www.ageuk.org.uk/services/ or in booklet form: ageukig10_useful_contacts_inf.pdf

- Cruse Bereavement Support helpline: 0808 808 1677

- West Cheshire Bereavement Service: 01244 853193

Chapter 17- Carers Health and Wellbeing

Palliative Care

Palliative care supports people to live well when that person has been diagnosed with a life-limiting condition, including dementia. It focuses on making a person’s quality of life as good as possible by relieving discomfort or distress. Palliative care may continue for any length of time, up to several years. Palliative care may be offered alongside other medical care, especially in the earlier stages of dementia. Palliative care will continue **alongside** end-of-life care. www.nhs.uk/conditions/dementia/palliative-care/

End of Life Care

End of life care provides care in the last 12 months of a life-limiting condition, supporting a person to live as well as possible until they die. It also supports family and carers during the final stages, as well as after the person has died.

End of life care aims to enable the person to die in the way that they would have wanted, giving priority to the things that matter most to them. This can be helped by having conversations with the person you care for; this is known as Advance Care Planning. There will be important decisions to make as the person nears the end of life, including what they may wish for their funeral, whether they should be resuscitated if they have a heart attack, and any religious practices they want observed. Advance care planning can help to ensure that a person's wishes are known and respected.
www.alzheimers.org.uk/get-support/help-dementia-care/end-life-care-making-decisions#content-start

Spirituality

Spirituality means different things to different people. Religion and faith might be part of it, but spirituality isn’t always religious. Everyone has spiritual needs throughout their lives, which can include the need to connect or be connected to others, the need for meaning in life, to love and feel loved, to feel a sense of belonging, to be able to express gratitude, to have hope, to feel recognised and understood. Depending on what’s important to them, people do different things to meet those needs. Some people do things within their religion such as prayer or attending a faith group. For others, it might include being with friends and family, doing hobbies or spending time in nature.

Health and Wellbeing

Although caring for a person with dementia can be a rewarding experience and help bring you closer together, it can also be exhausting, frustrating and lonely. Over time this can have a negative impact on you and your relationships. A carer's own health and wellbeing is just as important as that of the person they care for. So, it's important to keep an eye on how you're coping and try and get help and support when you need it.

It is important to try and stay well so that you can keep going, keep caring and keep doing things that make you feel yourself. Different people need different types of help and support to stay well, depending on their individual situations and needs. So, it can be useful to talk to someone who understands you to work out the best ways of looking after yourself.

This could mean getting some time off with respite care, getting outside and being physically active more, or making changes to what you eat to feel healthier. Talking to others can also be a good way to spot coping methods that aren't so healthy, and which may end up making things harder for you, such as drinking more alcohol or becoming more socially isolated.

Below are some issues that many carers find important for staying well. Some may apply to your situation more than others. If you see some that look relevant to you, make a note to talk to someone about how you might be able to fit them into your daily life better. This could be a friend or family member who knows you well, or it could be a health or social care professional. The NHS Live Well website has some excellent information on how to take care of yourself. However, any solutions need to be able to work for you and your individual situation. www.nhs.uk/every-mind-matters/

- Try to find the time to eat well – ideally eat a balanced range of different types of foods and at regular times through the day. As a carer, it can be easy to fall into the habit of 'grabbing' food when you can but over time this isn't good for you – either physically or mentally. The NHS Eatwell guide has some useful information on how to stay healthy by eating well. www.nhs.uk/live-well/eat-well

- Being a carer may mean that you don't get much time sitting, but it can be hard to find the time to do more vigorous types of physical activity. This can keep you feeling well, both physically and mentally. You don't need to join a gym (unless you want to). Walking, gardening, dancing, swimming or riding a bike are all good forms of exercise, as are more structured activities such as Yoga or Pilates. Whatever you choose it should be something you enjoy as this will make it much easier to keep it going over time. www.nhs.uk/live-well/exercise/

- Having hobbies and interests is also good for your mental and physical health. Group activities can also help to reduce feelings of loneliness or isolation.
- Research local carers groups that you, or both of you, could join. Information on local groups may be found through your health care professional or GP surgery www.alzheimers.org.uk/find-support-near-you

- Try to get enough sleep. Sleep is very important as it helps the brain and body recover from fatigue. It can be very difficult though if the person you care for has disturbed nights. A good way to get more sleep is to try to encourage a better sleep routine for the person you care for. You may find it easier to sleep when the person you care for is sleeping, and you may be able to take advantage of short daytime naps. If you are unable to get enough sleep due to the needs of the person you care for, talk to your GP. They may be able to suggest services or techniques, such as mindfulness or meditation, that may help.
  - Simple Tips for Better Sleep from Every Mind Matters - https://www.youtube.com/watch?v=OvQTjAIlvI8
  - Alzheimer's Society booklet – Understanding Sleep Problems

- Recognise your status as a carer; register your carer status with your GP and with the GP of the person you care for. If you are invited for any regular screening or check-ups take the opportunity to attend.

- Check whether you will be eligible for a carers review with your local Council Social Services.www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-assessments/

- Inform your employer of your carer's status; they may have procedures in place to support you.

- If you have a Lasting Power of Attorney (LPA) set up register this with relevant agencies. LPA can be for Health and Wellbeing (register with the GP) and Finance (register with the bank and other appropriate organisations) www.gov.uk/power-of-attorney

- If you have a physical disability or a sensory problem, such as being partially sighted or hard of hearing, then these are likely to make it harder to cope with a caring role. It is important to make sure you are receiving all the support you are entitled to. Speak to your GP or local social services department.

- If you have to help the person move around, be careful to avoid injuring yourself. The NHS website at https://www.nhs.uk/conditions/social-care-and-support-guide/practical-tips-if-you-care-for-someone/how-to-move-lift-and-handle-someone-else/#:~:text=Your%20local%20council%20has%20an,for%20an%20occupational%20therapy%20assessment. has some excellent tips on moving and lifting safely. Speak to Social Services for advice; they may be able to provide further support or advice on any specialist equipment that may be available to help you in your tasks. Speak to your GP who may be able to refer you to a Physiotherapist or Occupational Therapist. Some local carers' organisations also provide training sessions on safe lifting and moving.

- If you are struggling to cope or feel depressed, anxious, or stressed, talk to your GP. You can also call dementia or mental health support lines run by charities, such as Alzheimer’s Society, Dementia UK, and MIND. There are options available such as counselling and extra support services, and these problems are easier to manage at an early stage. Self-support techniques can be helpful in the first instance. There is a simple quiz that can help you with practical hints and tips to help you when you feel you need extra support www.nhs.uk/every-mind-matters/mental-wellbeing-tips/your-mind-plan-quiz/

A comprehensive list of organisations is included below where you will be able to access advice, support and further information.

Organisation	Website	Telephone / Email	Area
Age UK	www.ageuk.org.uk	0800 678 1602	Helpline
	www.ageuk.org.uk/cheshire	01606 881 660	Chester, West Cheshire, Northwich and Vale Royal
	www.ageuk.org.uk/cheshireeast	01625 612 958	Macclesfield, Wilmslow, Knutsford, Poynton, Handford & Congleton
	www.ageukwirral.org.uk	0151 482 3456	Wirral
	www.ageconcernliverpoolandsefton.org.uk	0151 330 5678	Liverpool
		01704 542 993	Sefton
	www.ageuk.org.uk/midmersey	0300 003 1992 enquiries@aukmm.org.uk	Central number for all areas
Alzheimer's Society	www.alzheimers.org.uk/	0333 150 3456 03300 947400	National Dementia Support Line Welsh speaking support line
		0151 426 4433 knowsley@alzheimers.org.uk	Knowsley
		07972 572054 enquiries@alwaysactive.org.uk	Macclesfield, Knutsford, Handforth, Poynton, Bramhall (Cheshire East)
		0300 3690570 cheshire@alzheimers.org.uk	Northwich (Vale Royal and Cheshire West)
		0151 420 8010 halton@alzheimers.org.uk	Halton / St Helens / Widnes
		0151 670 0777 cws@wired.me.uk	Wirral

Alzheimer's Research UK	www.alzheimersresearchuk.org	0300 111 5 111 infoline@alzheimersresearchuk.org	Dementia Research Infoline
British Association of Counselling & Psychotherapy	www.bacp.co.uk	01455 883 300 bacp@bacp.co.uk	Enquiry Line
Care Choices	www.carechoices.co.uk	Search engine	Search engine for care and support available in your area
Carers Trust	www.carers.org	0300 772 9600 info@carers.org	Head office
		01928 580 182	Halton Carers Centre
		0151 549 1412	Knowsley Carers Centre
		0151 709 0990	Liverpool Carers Centre
		01744 675 615	St Helens Carers Centre
	www.crossroadscarenw.org.uk	01744 612 499	Main number
	www.knowsleycarers.co.uk	0151 549 1412 enquiries@knowsleycarers.co.uk	Kirby Office
		0151 448 9771	Halewood Office
		0151 482 6279	Huyton Office
	www.sefton-carers.org.uk	0151 288 6060 help@carers.sefton.gov.uk	Main number
	www.sthelenscarers.info	01744 675 615 info@sthelenscarers.org.uk	St Helens Office
Cruse Bereavement Care	www.cruse.org.uk	0808 808 1677	Helpline
	www.citizensadvice.org.uk	0800 144 8848	

Citizens Advice Bureau			Advice Line (England)
Dementia UK	www.dementiauk.org	0800 888 6678	Dementia Helpline and Admiral Nurses
Department of Work and Pensions	Attendance allowance	**Attendance Allowance helpline** Telephone: 0800 731 0122 Textphone: 0800 731 0317 Relay UK (if you cannot hear or speak on the phone): 18001 then 0800 731 0122 Video relay service for British Sign Language (BSL) users	
	Carer's allowance	Carers Allowance unit Telephone: 0800 731 0297 Textphone: 0800 731 0317 Relay UK (if you cannot hear or speak on the phone): 18001 then 0800 731 0297 Video relay service for British Sign Language (BSL) users - check you can use this service	
	Carer's Allowance Unit Carer's Credit	Telephone: 0800 731 0297 Textphone: 0800 731 0317 Relay UK (if you cannot hear or speak on the phone): 18001 then 0800 731 0297 for British	

	DWP - PIP Claims Personal Independence Payment	Telephone: 0800 917 2222	
		Textphone: 0800 917 7777	
		Relay UK (if you cannot hear or speak on the phone): 18001 then 0800 917 2222	
		Video relay service for British Sign Language (BSL) users - check you can use the service	
Healthwatch	www.healthwatch.co.uk	0300 3230 006 info@healthwatchcheshire.org.uk	Cheshire East and Cheshire West
		0300 777 6543 enquiries@healthwatchhalton.co.uk	Halton
		0151 449 3954 enquiries@healthwatchknowsley.co.uk	Knowsley
		0300 777 7007 enquiries@healthwatchliverpool.co.uk	Liverpool
		0800 206 1304 info@healthwatchsefton.co.uk	Sefton
		0300 111 0007 info@healthwatchsthelens.co.uk	St Helens
		01925 246 893 contact@healthwatchwarrington.co.uk	Warrington
		0151 230 8957 info@healthwatchwirral.co.uk	Wirral
	www.housingcare.org	0800 377 7070 (Advice line suspended as of	First step Care Advice Line

Housing Care (EAC First Stop)		October 2023. Please refer to website)	
Local Authority	www.warrington.gov.uk	01925 443 322	Warrington Borough Council
	www3.halton.gov.uk	0303 333 4300	Halton Borough Council
	www.cheshirewestandchester.gov.uk Dementia | Cheshire West and Chester Council	0300 123 8123	Cheshire West and Chester
	www.cheshireeast.gov.uk	0300 123 5500	Cheshire East
	www.wirral.gov.uk/	0151 606 2000 (switchboard)	Wirral
	www.sthelens.gov.uk	01744 676789	St Helens
	www.knowsley.gov.uk	0151 489 6000	Knowsley
	www.sefton.gov.uk	0345 140 0845	Sefton Council
	www.liverpool.gov.uk	0151 233 3800	Careline for adults
Live Well Liverpool	www.thelivewelldirectory.com	0300 777 7007 thelivewellteam@healthwatchliverpool.co.uk	Live Well is a directory of care and support services, activities and information covering Knowsley and Liverpool
Macmillan	www.macmillan.org.uk	0808 808 0000	Helpline
Making Space	www.makingspace.co.uk	01925 571 680	Cheshire and Merseyside
Marie Curie	www.mariecurie.org.uk	0800 090 2309	Support Lines
MIND	www.mind.org.uk	0300 123 3393	Information
	www.mindhalton.org.uk	01928 563 612	Halton
	https://www.youinmind.org/	01625 500 644 hello@youinmind.org	Cheshire’s Mental Health Hub
	https://www.midcheshiremind.org.uk/	01606 863 305	Mid Cheshire

	www.sthelensmind.org.uk	01744 385 137	St Helens
	www.wirralmind.org.uk	0151 512 2200	Wirral
NHS Business Services Authority	www.nhsbsa.nhs.uk	0300 330 1343	Low income scheme
		0300 330 1341	Prescription pre-payment certificate
NHS	www.cwp.nhs.uk	0800 195 4462 Advised to ring 111 for out of hours	Patient Advice and Liaison
		0800 145 6485	Central number
		01244 397 300	Bowmere Hospital, Chester
		0151 343 5500	Springview, Clatterbridge Hospital
	www.merseycare.nhs.uk	0800 328 2941	Patient Advice and Liaison
		0800 145 6570	Liverpool and Sefton
		0800 051 1508	Halton, Knowsley, St Helens, Warrington
NHS Online Help	Talking Therapies Service (IAPT) - NHS	Online service	NHS - Self-referral for psychological therapies - online service
NHS Trusts	www.wuth.nhs.uk	0151 678 5111 (0800 432 0251)	Arrowe Park Hospital (patient experience team)
		0151 334 4000	Clatterbridge Cancer Centre
	www.liverpoolft.nhs.uk	0151 706 4903 - patient advice line 0151 706 2000	The Royal Liverpool University Hospital
		0151 706 2000	Broadgreen Hospital

NHS Trusts	www.lhch.nhs.uk	0151 600 1616	Liverpool Heart and Chest Hospital
	www.thewaltoncentre.nhs.uk	0151 525 3611	The Walton Centre
	www.aintreehospitals.nhs.uk	0151 525 5980	Aintree University Hospital
	www.merseywestlancs.nhs.uk	Whiston and St Helens 0151 426 1600 Newton Community Hospital 0151 290 4835 Southport and Formby Hospital 01704 547 471 Ormskirk Hospital 01695 577 111	Mersey and West Lancs Teaching Hospital* *Formerly St Helens and Knowsley Teaching Hospitals NHS Trust and Southport and Ormskirk Hospital NHS Trust
	Home: Warrington and Halton Hospitals NHS Trust (whh.nhs.uk)	Warrington Hospital 01925 635 911 Nightingale Building 01928 714 567	Warrington and Halton Teaching Hospitals NHS Foundation Trust
	www.coch.nhs.uk	01244 365 000	Countess of Chester
	www.mcht.nhs.uk	01270 255 141	Mid Cheshire Hospitals NHS Foundation Trust
	www.eastcheshire.nhs.uk	01625 421 000	East Cheshire NHS Trust Macclesfield District General Hospital / Congleton War Memorial Hospital / Knutsford & District Community Hospital
NHS Choices	www.nhs.uk	111	Non-emergency
		0300 123 1053	Carers Direct

Samaritans	www.samaritans.org	116 123	Free 24 hour phone line
SURF (Service Users Reference Forum)	www.surfdementia.org	n/a	Part of Liverpool Dementia Action Alliance
Office of the Public Guardian	www.gov.uk/power-of-attorney	Telephone: 0300 456 0300 Textphone: 0115 934 2778	Make, register or end a lasting power of attorney
TIDE Together in Dementia	www.tide.uk.net	0151 237 2669	Carers network
British Deaf Association	bda.org.uk/dementia		Information on Dementia in British Sign Language
	Dementia-Toolkit-A4.pdf (bda.org.uk)		
Local Solutions - Carers Centre	Local Solutions - Carers Centre The Live Well Directory for Liverpool City Region	0151 705 2307	Information and advice
		carerscentre@localsolutions.org.uk	
The Herbert Protocol	Dementia -The Herbert Protocol - Safeguarding Hub	Dementia -The Herbert Protocol - Safeguarding Hub	A scheme offering help if a person living with dementia goes missing
	People with dementia at risk of going missing (Herbert Protocol) | Merseyside Police	Vulnerable people at risk of going missing | Merseyside Police	
	People with dementia at risk of going missing (Herbert Protocol) | Cheshire Constabulary	Vulnerable people at risk of going missing | Cheshire Constabulary	
The Sunflower Scheme	The Hidden Disabilities Sunflower (hiddendisabilitiesstore.com)		The Disabilities Sunflower lanyard or pin indicates to people including staff, colleagues, and health professionals that you may need additional support, help or a little more time.

Chapter 18- Useful Resources

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