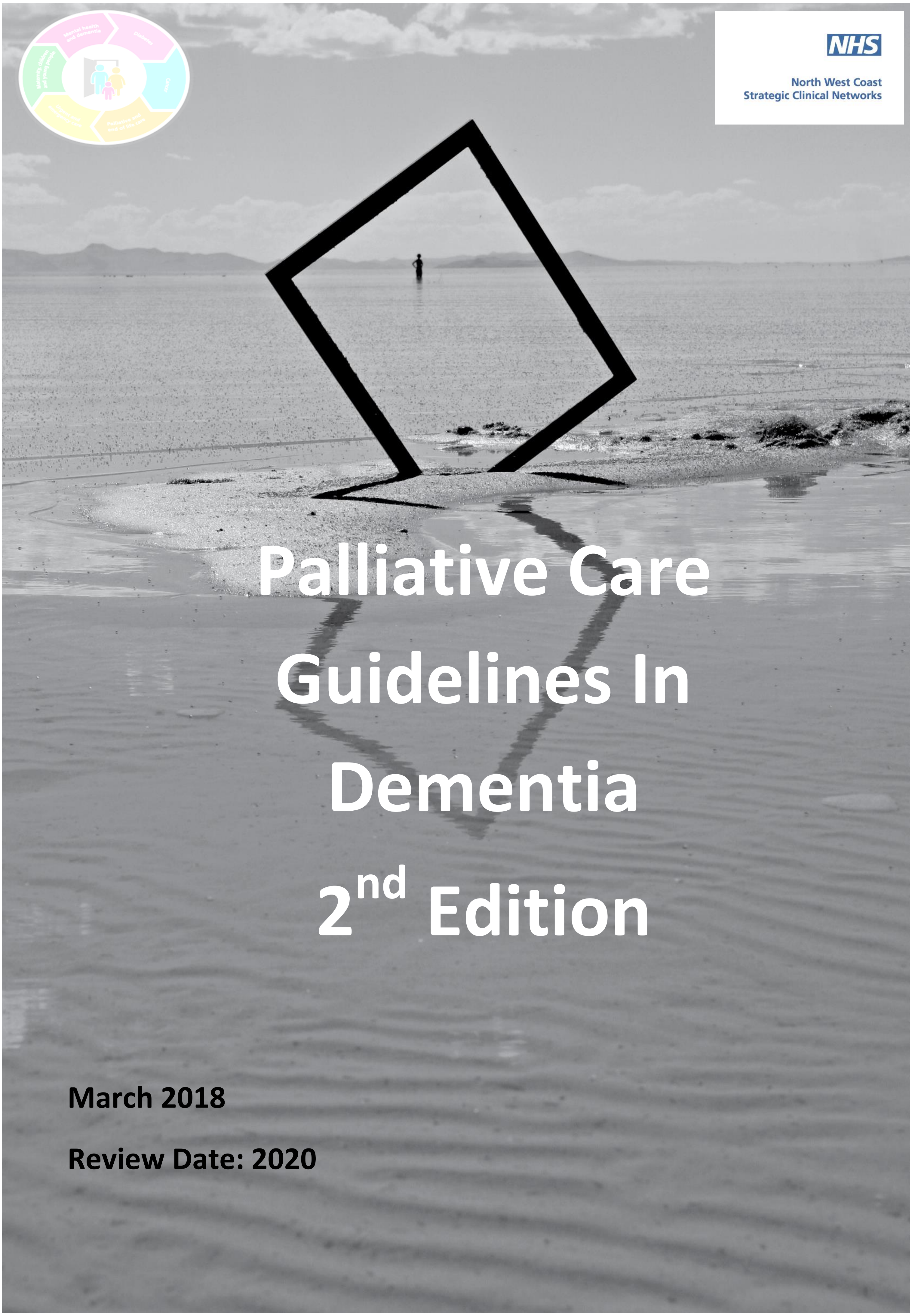

NHS
North West Coast
Strategic Clinical Networks

Palliative Care Guidelines In Dementia

2nd Edition

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Contents

Foreword

In 1995, I was working as a registrar in old age psychiatry in a large hospital which had long stay psychogeriatric beds. Having previously spent time working in a hospice and oncology, I was keen to make a difference to those patients with dementia who were coming to the end of their lives. The clinical staff were totally committed, and in a small way, I was allowed and encouraged to make a difference to how patients were being cared for, in terms of pain relief and what may be termed “comfort care”.

During that time, with the support of senior staff, I carried out a small audit of the palliative care for people dying with dementia on the long stay wards. This was published (Lloyd-Williams 1996) and was also presented at a national palliative care conference – at the end of my presentation there were no questions and the chair at the time, made the comment, that he was very surprised I had been selected to present such a topic in a palliative care meeting!

Twenty one years later, I am delighted that palliative care for dementia is now high on the palliative care agenda with hospices and palliative care teams working alongside nursing homes to facilitate care, initiatives such as the Dementia End of Life Programme within the End of Life Partnership, Hospices embracing dementia as part of their remit and families of people dying with dementia, being supported.

However there is still much to be done and it is easy for those of us working within the area where we strive for best practice, to sometimes forget, that we need to constantly share good practice, work alongside our acute, primary care and care home colleagues and as always learn so much from them as well as sharing what we have collectively learnt.

When we come across a difficult clinical situation in what is often a hugely busy clinical setting, we need to be able to access information quickly and easily. These Palliative Care Guidelines produced by the North West Coast Strategic Clinical Network will be invaluable to us all as we come across situations that we may be uncertain about and as we work alongside others

Professor Mari Lloyd-Williams, Professor and Director of Academic Palliative and Supportive Care Studies Group, University of Liverpool

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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 7 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 (p 48) and advance care planning (p 56)

Ongoing holistic assessment and a person-centred approach to care are essential (p 13)

Management of cognitive and non-cognitive symptoms can be challenging (p 24) and some medications should be avoided if possible in certain specific types of dementia (p 33)

Assessment of social care needs and understanding of the individual`s entitlement in light of the Care Act 2014 are very important (p 39)

Carers need access to ongoing support (p 40) and need to be given information about local services which they may find helpful to maintain their own health and wellbeing (p 84)

Clinically assisted hydration/ nutrition (p 59), treatment of infection (p 69) 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 (p 71)

Identifying dying can be difficult in people with dementia (p 67)

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 (p 75)

Carers should be able to access the appropriate level of bereavement support to meet their needs (p 82)

Good communication is important throughout

1. Introduction

These guidelines were first developed in 2011 in response to The Department of Health 'End of Life Care Strategy' (2008) to support professionals to provide the highest possible quality of end of life care to people with dementia. When the first edition was published, there were just under 700,000 people living in the UK with dementia. Today, that figure is now 850,000. This year, 225,000 people will develop dementia, that's one person every three minutes. Dementia is described as a demographic time bomb with a dramatic projected increase in the number of people diagnosed with dementia. By 2025, it is predicted to affect over 1 million people and this is due to soar to 2 million by 2051 (Alzheimer's Society, 2016).

Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease and stroke and 30% of people aged 65 or over will die with dementia (Dixon et al, 2015).

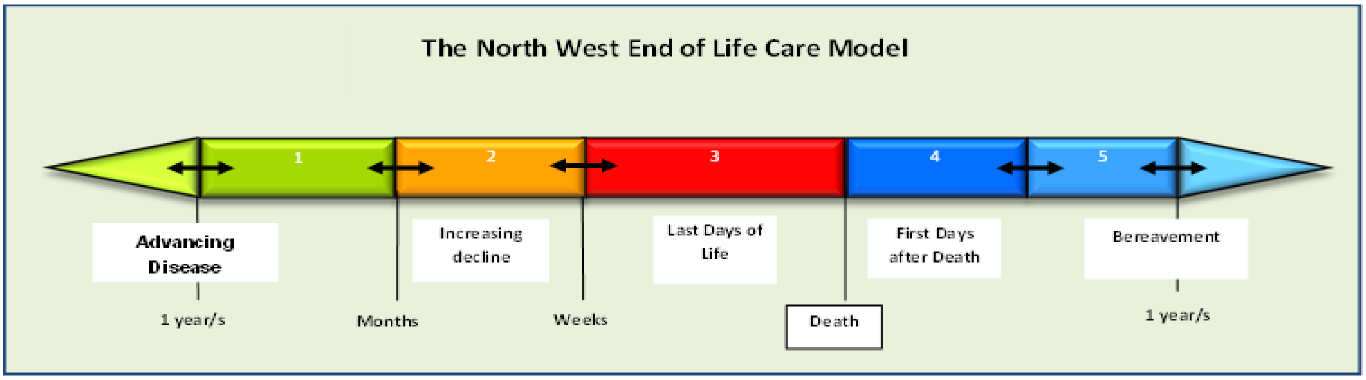
Rates of diagnosis vary significantly across the UK. In England it is estimated that the average rate of dementia diagnosis is 48% (Marie Curie, 2014). When made, diagnosis is most often:

- late in the illness
- at a time of crisis
- too late for effective intervention

Although dementia as a cause of death is increasing and the number of deaths with a mention of dementia recorded on the death certificate increased from 6.6% to 12.0% in England between 2001 and 2010 (Sleeman et al, 2014) 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 in communicating needs such as pain and thirst, uncertainty in prognosis. Professionals may also lack the skills and confidence to deal with these challenges and services may not be available or suitable for people with dementia (Alzheimer's Society, 2012).

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 End of Life Care Model (The North West Palliative and End of Life Care Operational Group, 2015). 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 North West End of Life Care Model, North West Palliative and End of Life Care Operational Group (2015)

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 and 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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2. Descriptions of the Dementia Syndromes

There are four clinical dementia syndromes accounting for 90% of all cases after excluding other common reversible causes of cognitive impairment. These four major diseases are Alzheimer's disease and vascular dementia, which together account for approximately 80% of dementias, dementia with Lewy bodies, and frontotemporal dementia (Muangpaisan, 2007). These and some of the less common forms are considered here.

Alzheimer’s dementia

Symptoms usually start insidiously and relatives are characteristically unable to pin down when they started with any accuracy. Often presentation is related to an identifiable life event (e.g. bereavement or retirement). The features may be observed by others. The person misses an appointment or forgets an arrangement had ever been made. Sometimes the first manifestation is a lack of self-care and the family notice the home becoming dirtier, personal care deteriorating and eating habits neglected. Wandering can be an early sign and is particularly dangerous if the person gets lost, especially during winter. By the time the person comes to the psychiatric services (with the exception of a select group of subjects who tend to refer themselves and make use of memory clinics) the degree of dementia is apparent and obvious cognitive deficits will be seen.

Amnesia

Forgetfulness (amnesia) is universal and characteristically said to be for recent memories. Not unusually, relatives say that the person is able to remember events happening many years ago but not earlier that day. Disorientation is the rule, with disorientation for time usually being more obvious than for place.

Aphasia

Disabilities in language, including understanding and expressing language and grammar (aphasia) usually occur later, and are often a mixture of receptive and expressive problems.

Apraxia

Disabilities in skills and actions (apraxia) are often tested for by asking the person to copy a design, or demonstrate a simple task. From the history there may be evidence of an inability to put on clothes in the correct sequence or there may be a suggestion of an inability to eat correctly with a knife and fork.

Agnosia

Agnosia refers to problems in recognising people and objects. Failure to recognise faces (prosopagnosia) may lead to the belief that a relative is not real, and occasionally this misidentification is combined with a duplication or replacement phenomenon in which the person believes the loved one has been replaced or is a stranger dressed up to look like the loved one (Capgras syndrome). This can be very distressing for person and carer.

Psychiatric symptoms

Psychiatric symptoms are of three main types:

1) Disorders of thought content

These occur in about 15% of people with dementia and include delusions and paranoid ideation (persecutory beliefs not held with delusional intensity). Delusional ideas may take many forms. Simple uncomplicated beliefs may occur (e.g. that a handbag or other personal possession has been stolen, while in reality it has been misplaced). Generally, delusional ideas require relative preservation of cerebral structures.

2) Disorders of perception

These include visual and auditory hallucinations (affecting about 10–15% of people with dementia over the course of their disease). Various forms of misidentification have been described, including misidentification of mirror image, of other people, of events on the television and also the belief that another person is living in the house (the ‘phantom boarder’ syndrome, which may also be classified as a delusion). Hallucinations have been associated with a rapid cognitive decline. Misidentifications appear to be present in younger people.

3) Disorders of affect

These are relatively common, depression occurring in up to half of people with dementia but usually of a mild nature. Depressive symptoms requiring treatment can occur in up to 20% of people with dementia. By contrast, mania is rare.

Behavioural disturbances

Behavioural disturbances are particularly important as they can affect a person‘s ability to live in the community. Behavioural disturbances include: aggression, wandering, excessive eating, sexual disinhibition, explosive temper, incontinence and searching behaviour.

Personality changes

Personality changes are said to occur early in the course of dementia and changes often involve irritability, sometimes aggression and disinhibition, and lability of mood (easily weepy). They are often non-specific and so do not offer much in terms of diagnosis.

Subtypes

The early- and late- onset dichotomy has received widespread attention. It is said that cases with an early onset (defined as 65 years or less) have more aphasia and apraxia, a more rapid course, a poor survival rate and have a positive family history of dementia.

Vascular dementia

Vascular disease is the second most common cause of dementia after Alzheimer‘s disease. 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. The presentation of vascular dementia is variable and the clinical spectrum is wide. People with dementia may present with an insidious onset of cognitive problems, suggestive of a degenerative dementia, or with a series of strokes and widespread physical abnormalities.

Vascular dementia can be divided on clinical features into three major subtypes, although individuals may have features of more than one subtype: cognitive deficits following a single stroke, multi-infarct dementia and progressive small vessel disease (Binswanger‘s disease).

Cognitive deficits following a single stroke

The major causes of stroke (haemorrhage, infarct and embolism) can all produce dementia, although many single strokes leave little apparent cognitive deficit. 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 results 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.

Multi-infarct dementia

In a classic case of multi-infarct dementia, there is a history of successive strokes, each leading to greater cognitive deficits. These strokes produce a step-like deterioration, with intervening periods when the person may remain stable (or may improve). Multi-infarct dementia can be produced through similar mechanisms to a single stroke. The recurrent nature of multi-infarct dementia suggests that there is underlying disease predisposing to stroke, such as hypertension or valvular heart disease. Multi-infarct dementia can be produced by large vessel disease, small vessel disease or a combination of the two.

Progressive small vessel disease (Binswanger’s disease)

In Binswanger's disease the diagnosis may initially be less clear. 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 changes are often particularly marked on magnetic resonance imaging. There may be small distinct infarcts (lacunae), or more generalized white matter changes (leukoariosis). This subtype of vascular dementia has had a number of names, including Binswanger's disease and subcortical arteriosclerotic encephalopathy. The cognitive profile of progressive small vessel disease is suggestive of a subcortical dementia, with slowing of intellectual processes, rather than the specific deficits such as dysphasia and dyscalculia, produced by large cortical strokes. 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.

Clinical features

The variety of presentations of stroke are legion, and so are the features of vascular dementia. The differential diagnosis is usually between vascular dementia and a degenerative dementia, although treatable causes of dementia must not be forgotten. There are certain clinical features, such as the sudden onset of a deficit, which are highly suggestive of vascular dementia.

On examination there may be neurological damage such as a hemiparesis, hemianopia or pseudobulbar palsy. As well as performing a neurological examination, it is important to record the blood pressure and look for evidence suggestive of extracranial vascular disease. The presence of significant cardiac murmurs or atrial fibrillation should prompt further investigations. The presence of carotid bruits or absence of foot pulses signifies clinical vascular disease.

Other Dementia Syndromes

Dementia in Parkinson`s disease/ Dementia with Lewy bodies

People who present with Parkinson's disease may develop a progressive dementia, namely dementia in Parkinson's disease or dementia with Lewy bodies. There is a group of people with dementia who develop marked extrapyramidal problems such as a shuffling gait, muscular rigidity and tremor after developing cognitive problems. Such people are described as having dementia with Lewy bodies. Dementia with Lewy bodies can also develop after the onset of Parkinson's disease. However, there is clinical and pathological overlap in these patients with Alzheimer's disease and idiopathic Parkinson's disease. This is also the case in dementia in Parkinson's disease. Clinical features strongly 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 very sensitive to neuroleptics, which can considerably worsen the Parkinsonian symptoms. Such people often respond particularly well to the cholinesterase inhibitor rivastigmine.

Frontotemporal dementia

A significant minority of people with a degenerative dementia present with symptoms such as personality change and behavioural problems, suggestive of frontal lobe dysfunction. Such people often develop features suggestive of temporal lobe dysfunction as well such as word finding and object naming problems. In contrast to Alzheimer's disease, memory is affected later and less severely. Spatial orientation is well-preserved, even late in the illness. Insight is characteristically lost early. This syndrome has been described under many names. Usually people with this type of dementia present in middle life (50-60 years). There is a high proportion of familial cases, about 50% of pre-senile cases having a positive family history for dementia. The disease is steadily progressive and there is no specific treatment. People with clinical frontotemporal dementia may have a variety of other pathological features, including those of motor neurone disease in the absence of the typical clinical signs of these diseases.

Dementia associated with other neurological diseases

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. Often there are features of Parkinson's disease in addition to the dementia syndrome such as in Lewy body dementia, dementia in Parkinson's disease, multi-system atrophy and progressive supranuclear palsy. The term 'Parkinson's plus syndromes' has been developed to address such situations.

Huntington's disease

There are many genetic causes of dementia, the best known of which is probably Huntington's disease. This condition may present with cognitive problems, or a movement disorder. It is inherited as an autosomal dominant trait in that it transmits through each generation without missing generations. The gene responsible has been named as Huntington. The disease can now be diagnosed using molecular genetic techniques. Progression is slow leading to death in 10-15 years. There is a particularly high risk of suicide in this syndrome. Rarely, it can occur spontaneously without a positive family history. Often people present first with treatment resistant depression prior to the development of motor symptoms.

Prion dementia

These are a clearly defined group of disorders characterised by an accumulation of an abnormal form of a normal human protein, prion protein. Creutzfeldt-Jakob disease (CJD) is a rare disease, affecting about one person per million per year. Affected individuals develop a rapidly progressive dementia with ataxia and muscular jerks (myoclonus). Typically people die within a few months of onset of the disease. Neuropathological examination reveals spongiform degeneration in the brain.

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

Down's syndrome is a well-recognised genetic condition defined by individual differences in cognitive and functional ability. Dementia is a disorder of later life which manifests itself in those areas of function that may already be impaired in people with learning disability. The detection and diagnosis of this condition are particularly important, given its effect on cognitive and functional abilities.

Prevalence

Many studies have now confirmed that age-related cognitive decline and dementia affecting people with Down's syndrome occur 30 – 40 years earlier in life than in the general population in fact 50% of people aged 50-59 will develop Alzheimer's disease. The pattern of cognitive change observed in people with Down's syndrome is similar to the ones associated with Alzheimer's disease in the general population.

It is perhaps generally less well known that people with a learning disability not due to Down's syndrome also suffer from dementia at higher rates and at an earlier age than the general population. Statistics show that 21% of people with a learning disability over the age of 65 will develop dementia compared to 5.7% of the general population.

Obviously clinical presentation of dementia in individuals will be influenced by the severity of their learning disability. The milder the learning disability is, the closer the symptoms will resemble those seen in the general population with dementia.

The National Dementia Strategy states that people with dementia should not be excluded from any services because of their diagnosis, age or co-existing learning disabilities.

Assessment and intervention

Appropriate diagnostic, assessment and intervention services as well as a variety of resources should be available to meet individual needs and support the healthy ageing of people with Down's syndrome and dementia.

Flexible and individual packages of care should be considered within an environment that minimises disruption and disorientation throughout all stages of their illness with interventions being planned to maximise the abilities of people with dementia to enable them to live their lives to their full potential as part of their local community.

There can be problems of 'diagnostic overshadowing', and of dismissing changes in behaviour, personality or abilities that in the general population would be taken very seriously. However, for people with Down's syndrome these changes can be missed although particularly relevant and this can lead to late diagnosis and lack of appropriate interventions. Cognitive assessment should ideally be undertaken directly with the person with Down's syndrome and not inferred from information given by carers or family. There is no single cognitive test for the diagnosis of dementia in people with Down's syndrome / learning disabilities and no agreed cognitive battery for the assessment of cognitive abilities used for this group within the UK (RCS, BPS 2009).

The individual, their family carers and / or other people who support them should be kept informed and where appropriate involved at every stage of the process of assessment, planning and provision of services.

A person-centred approach is important remembering that it is essential that all information, including diagnosis, is provided in a respectful way, as well as being in a format that is meaningful to the individual and their family / carers.

As with the general population when planning and providing support for people with Down's syndrome affected by dementia all services should be committed to exploring and considering all options to ensure that the individual whenever possible can live in their preferred place of care to the end of their life.

Summary

The delivery of best quality services that respond to the needs of people with Down's syndrome and dementia can only be achieved by ongoing collaboration and continued joint planning, developing and implementation of appropriate pathways of care. Promoting a better understanding of the needs of people with Down's syndrome and dementia within the wider workforce will also help to ensure high quality, evidence based services are provided.

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[Last accessed 14/08/17]

3. Assessment in Dementia and 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 (2016) states that ‘the care team should make sure that palliative care is available to people with dementia from the time that they are diagnosed until the end of their life’ (p13). It explains palliative care is simply ‘care that helps to relieve symptoms, such as pain and anxiety, of an illness that cannot be cured.’ (p17). It emphasises that the needs of the person with dementia should be considered in order 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 focusing on the goals of care (see Fig1). 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.

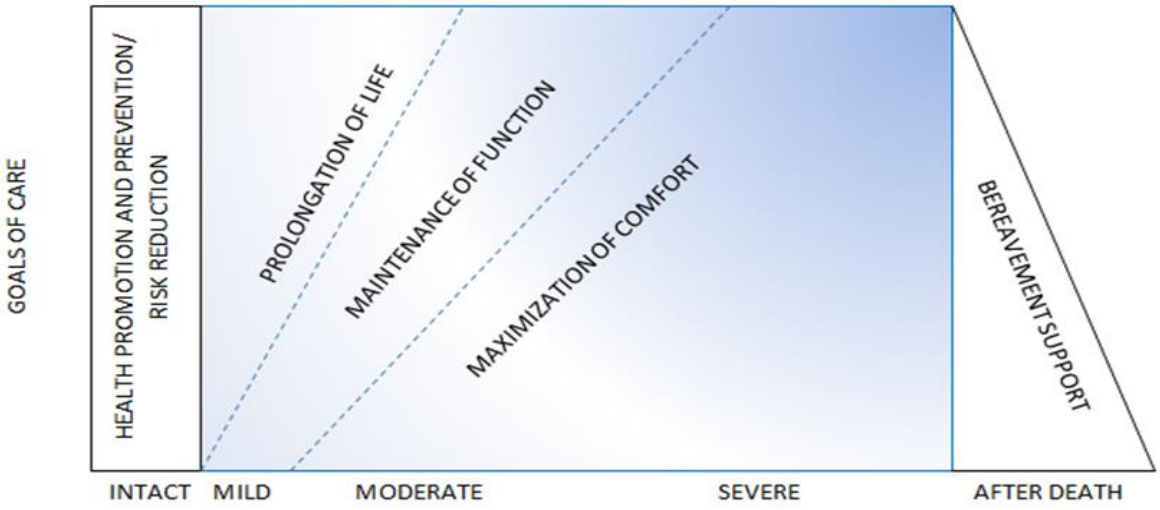

Fig 1: Model of changing care goals and priorities throughout the course of dementia (European Association of Palliative Care, 2015)

Traditionally, health professionals have approached the assessment of people with dementia using the medical model, focusing on brain function. However, to be truly person-centred and holistic, a bio-psycho-social-physical-spiritual model is needed (Haworth and Dluhy, 2001; Kitwood, 1997). 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

There appear to be differing views and definitions of what end of life care is or when it should take place, therefore this paragraph aims to give some clarification of the terminology used.

End of life care, according to One Chance To Get It Right (Leadership Alliance, 2014) should ‘Improve people’s experience of care in the last few days and hours of life’. 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 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 End of Life Care is advocated by the North West End of Life Care Operational Group as a whole systems approach to adults with life-limiting diseases, and can be found at:

http://www.nwcscnsenate.nhs.uk/strategic-clinical-network/our-networks/palliative-and-end-life-care/education-reso/north-west-end-life-care-model/ [Last accessed 27/07/76]

Person-Centred Dementia Care

Tom Kitwood first introduced the paradigm of person-centred care in the 1990s which has influenced the culture of care and the development 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 (Saunders, 1969).

Kitwood (1997) identified 5 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).

These needs are:

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 (2010) 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

- Focusing on life history, quality of life, best interests, goals, future planning and preferred place of care
- Agreeing an individual plan of care that meets the persons' 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:

http://webarchive.nationalarchives.gov.uk/20160805140434/http://www.nhsiq.nhs.uk/resource-search/publications/eolc-hca-guide.aspx [accessed 17/07/17].

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, 2016).

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 memoire by the Gold Standards Framework (2009). The 'PEPSICOLA' provides a guide to and means of documenting holistic needs. The tool can be found on page 18 of this chapter.

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). Guidance on how to carry out life story work and a life story template that can be adapted for use is available from the Dementia UK website at:

https://www.dementiauk.org/for-healthcare-professionals/free-resources/life-story-work/ [Last accessed 17/05/17].

The Alzheimer's Society 'This is Me' 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 from their website:

https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=399 [Last accessed 27/07/17].

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, 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 to 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, coordinated and delivered with compassion.

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

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 remains inadequate for people with dementia resulting in pain still being undetected and untreated (Zwakhalen et al 2006, Closs et al, 2004, McGuire et al, 2010). A recent Marie Curie (2015) study 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' (Section 1.5.14).

There are numerous pain assessment tools suggested for use with people with dementia, for example: PAINAD; DOLOPUS 2; ABBEY; PACSLAC; NOPPAIN; CNPI. However, the Royal College of Physicians National Guidelines for Pain in Older People (2007) does not specifically recommend any one particular assessment tool for the use of assessing pain for people with cognitive impairment, therefore, this is down to personal or organisational preference. However, the use of a pain assessment tool in routine care for people with dementia is highly recommended (see Table 1).

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 2). Pain specific assessment tools such as the Abbey Pain Scale (see page 17) and Dolopus 2 are valuable observation tools to assist in the assessment of pain for people who are unable to clearly articulate their needs. 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. The use of a tool such as the 'DisDAT' (Disability Distress Assessment Tool) 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. This can be found at:

http://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf [Accessed 27/07/17]

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	East 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 1: A summary of the types of scale for assessing pain in older people by level of cognitive/communication impairment (Royal College of Physicians, 2007)

Table 2. 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 2: Observational Changes Associated with Pain. (British Pain Society, 2007)

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

http://www.ncpc.org.uk/sites/default/files/How_Would_I_know.pdf [accessed 27/07/17].

Not forgetting Carers

Under The Care Act (2014) the Local Authority have a legal duty to assess the person with dementia and their carers' needs and likely future needs (for further information see 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. Carers and professionals can refer into their local branches through contacting the national helplines:

- Dementia UK – Admiral Nursing Direct - 0800 888 6678
- Alzheimer's Society National Helpline - 0300 222 1122
- Age UK Advice Line - 0800 169 2081

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.

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 *Absent 0 Mild 1 Moderate 2 Severe 3*	Q1	☐
Q2.	Facial expression eg: looking tense, frowning grimacing, looking frightened *Absent 0 Mild 1 Moderate 2 Severe 3*	Q2	☐
Q3.	Change in body language eg: fidgeting, rocking, guarding part of body, withdrawn *Absent 0 Mild 1 Moderate 2 Severe 3*	Q3	☐
Q4.	Behavioural Change eg: increased confusion, refusing to eat, alteration in usual patterns *Absent 0 Mild 1 Moderate 2 Severe 3*	Q4	☐
Q5.	Physiological change eg: temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor *Absent 0 Mild 1 Moderate 2 Severe 3*	Q5	☐
Q6.	Physical changes eg: skin tears, pressure areas, arthritis, contractures, previous injuries. *Absent 0 Mild 1 Moderate 2 Severe 3*	Q6	☐

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.
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www.wales.nhs.uk/sitesplus/documents/862/FOI-286f-13.pdf [Last accessed 27/07/17]

PEPSI COLA Aide Memoir – Palliative Care monthly checklist

Person`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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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 in order to share with others our thoughts, wants and desires. Communicating with others helps us to establish who we are and gives us a sense of identity, building our feelings of self-worth.

Living with dementia means that one's ability to communicate is gradually eroded over time. The person will begin to have word-finding difficulties, memory loss and confusion, all of which impacts on their ability to communicate effectively and to have their thoughts, wishes, desires and needs heard and met. There are, however, a number of things we can do differently to help the person with dementia, both in terms of understanding and communicating with others. It is important to adopt person-centred thinking and culture when working with people to help open up channels of communication that would otherwise be closed off by a more professional or formal stance.

What follows is a series of 'top tips' that family members and carers can try to help aid communication between them, to prolong the person's ability to stay grounded in terms of time/space and to help to promote a sense of value and self-worth.

Top tips for aiding communication

Speech & body language

- Always approach the person from the front so as not to startle them.
- Make sure you identify yourself when speaking to the person.
- Always address the person by using their preferred name first, followed by what you want to say in order to gain their attention.
- Speak slowly and clearly in short, simple sentences. Stick to one topic at a time, not jumping from one thing to another. Pictures, gestures and writing appropriate to the person's level of understanding can be helpful.
- Non-verbal aspects of communication including tone of voice, facial expression, eye contact and relaxed posture are important to help a person with dementia 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.
- Don't give more than one instruction at a time.
- 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 that can be answered with a 'yes' or '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 the 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 still 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.
- Never stand over the person you are talking to; this will intimidate them. Get on the person's eye level, smile and be calm and friendly. Touching them on the shoulder or shaking their hand my help to put them at their ease.
- 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.

- Help them to name what they are feeling and validate their feelings.

The environment

- Some people with dementia are more responsive at particular times of day. Quite often people‘s ability to concentrate, understand what you are saying and communicate fluctuates across the day. Choose the right time to engage with the person, especially if you want the person to be as fully involved in the decision-making process as possible.
- Make sure you let other people in the person‘s life know what times of day are better than others for communicating with the person.
- Communication is easier if there are no distractions. Turn off things like radios, TVs and other background noise. Think about where you are when communicating, if you are in a busy area move to somewhere quieter with fewer distractions.
- Ensure that lighting is good to give the person more chance of being able to see your face, clearly/watch your body language and see any visual aids/prompts you might want to use.

Show respect

- Do not speak down to the person or let others speak down to the person.
- Try and include the person in any conversation you are having whether that is in a social setting or in a consultation type setting with doctors/nurses/social workers etc. By including the person as much as you can in the conversation it helps the person feel valued and promotes a sense of identity.
- Do not speak about the person as if they are not in the room. Just because someone is struggling to communicate doesn‘t mean they are not able to hear and understand. Always include them in the conversation and try and check out what you are saying about them with them, even if you do not get a response. This also helps to demonstrate you still value the person and helps to ensure others treat the person with dignity and respect.

Aids & adaptations that help improve communication

- Processing information may take the person longer than normal and the silence may feel uncomfortable or unnatural. Resist the urge to fill the silence with more words. Give the person the time to see if they are able to articulate what they want to say or give you a response.
- During the early stages of dementia you may want to help the person put together a Preferred Priorities for Care (PPC) document available in a more accessible format which includes picture prompts and can be more suitable for a person with dementia. This document shows what the person‘s choices are for care decisions at times when making choices might become more difficult and for making end of life care decisions. By doing it in a more accessible format it will also help as a memory jogger for the individual when reading becomes problematic.
- Think about using things like the Alzheimer‘s society leaflet `This is Me` or the hospital passports that exist for other client groups when going into hospital or accessing primary care services. `This is Me` is a short document that helps hospital staff know what the most important things are for the person when they come into hospital. It contains useful information such as people to contact, how the person communicates, their likes and dislikes and helps you think about what reasonable adjustments may be required.
- Remember when people are accessing hospital or primary care services clinicians need to find out whether they have any additional needs they should take into account and make reasonable adjustments in order to ensure the person can access the service. Such adjustments could include things like first appointments so the person doesn‘t have to wait; appointment times which coincide with the time of day where the person is at their best to allow them to be as involved as possible in their own care; using pictures or objects to get your message across; setting up the room in a specific way and so on. The important thing here is that the reasonable adjustments you agree with the person and/or their family are ones that are individualised and useful to that person.

- Most hospitals have dignity/dementia teams that can be contacted in advance to either arrange orientation visits or additional support while at appointments or prior to elective admission.
- If the person is struggling to make choices, keep choices to a minimum, maybe one or two at a time.
- Remember to break things down into steps for the person and talk them through every step before you either expect them to do it, or you do it for/to the person.
- Use of diaries and memory joggers are useful, especially in the early stages of dementia when the person is getting a little forgetful.
- Stick to set rituals/routines throughout the day and when doing specific care tasks. It is important that **everyone** around the person does things in the same way as this helps the person to remember sequences and makes making choices easier.
- In order to keep the person as independent as possible they may need help with sequencing tasks and so will need you to look at building in good communication cues so that they know when the task has started and when it‘s finished. For example, in order to vacuum the floor try sprinkling 'shake & vac' on the area as this gives the person a clear visual sign about when the task starts and when it is completed. Try and communicate clearly beginnings, middle and endings to tasks. Think about using visual cues like coloured dots on the microwave dial and corresponding coloured dots on food packaging so the person knows where to turn the dial to in order to cook something fully and so on.
- Use of picture schedules can be helpful if the person is struggling with words/ reading. Simply use photographs of people, places, tasks and so on in the diary to help the person know what‘s coming next, where they will be going and who will be doing the task with them in order to promote communication.
- Use of pictures for making choices is also helpful if the person is struggling with either the written word or has word-finding difficulties. Showing people pictures of the things that are on offer and them being able to point or pick up the one they want can be quite liberating for the person.
- Use of talking diaries & books can be helpful. There are a number of communication aides that can be programmed to give answers on the person‘s behalf that can be very useful and are based on picture symbols where the person presses the relevant picture and it says the word or a series of words for them.
- Memory books with people‘s names, places and so on written underneath can aid communication and help keep the person orientated. They also are very useful in helping others initiate conversation with the person at times when the person is not able to initiate conversation independently. Memory videos can be used in the same way.
- If the person is at a point where they are really struggling with speech or unable to recognise objects in pictures you may want to try objects of reference. Start to link concrete objects to set things you are wanting the person to make choices around and for things you want to tell the person, for example if you want the person to indicate whether they want tea or water you can say this and reinforce it with offering them a brown cup and a glass. Initially you will have to have the appropriate drink in each so the person associates the taste with the object they have chosen. When you want to let the person know it is time to brush their hair give them a hairbrush etc. Linking in actual objects can help reinforce what you are saying and give the person a clear prompt. It‘s essential if you start to use objects of reference that you make a list of what objects you are using to represent what so that other people in the individual‘s life can make sure they use the same ones, so as not to confuse the person.

End of life discussions and planning

- There is no right time to begin having discussions with people about how they would want to be supported towards the end of their life and what their hopes and wishes are in relation to this. Discussions about end of life are very individual and need to be tailored to the person. Ensure you are tuned in to cues the person may be giving that they want to talk about their death and keep avenues of communication open at all times to make it as easy as possible for the person to begin to think about how they would like their final journey to be.

- It is better to start conversations about forward planning as early on in the disease process as possible when the person may be more able to voice their hopes, wishes and what is important to them. Advance care planning tools like the Preferred Priorities for care (PPC) document, Advance Decisions to Refuse Treatment (ADRT) and other advance statements should be used to help with this process (see Section 9 *Mental Capacity Act 2005* and Section 10 *Advance care planning).* Many people will not know such tools even exist so awareness-raising as part of the overall consultation conversation may be beneficial to the patient and their families/carers. The adapted version of the PPC is presented in an accessible format that can be used for people who are struggling to remember things as it holds a number of picture prompts. It is a very difficult conversation for people and their families to have but can be liberating for the person, given the right support.

Acute Health Care Trusts now have dementia teams who are able to assess patients with memory problems and are able to link in with appropriate services.

Useful web links

http://alzheimers.org.uk/factsheets/

http://alzheimers.about.com/

http://www.nhs.uk/Planners/end-of-life-care/Documents/Preferred_Priorities_for_Care.pdf

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5. Therapeutic Interventions in Dementia

Part 1: Cognitive symptoms and function

The National Institute for Clinical Excellence (NICE) and the Social Care Institute for Excellence (SCIE) developed a national guideline on supporting people with dementia and their carers (NICE and SCIE, 2006). It identifies the main therapeutic interventions and when they should be used.

People with dementia are likely to respond differently to the variety of psychological strategies and medications, due to the variety of responses between individuals, different types and different stages of dementia. Professionals need to be aware of the full range of interventions, know which ones may be most appropriate for an individual, and understand how to recognise whether an intervention is helping. The guidance identifies the main principles for promoting independence and maintaining function, which are vital aspects of treatment and care.

This guidance categorised interventions in dementia care by therapeutic goal and in relation to the following three major areas:

- maintaining function (including cognitive function)
- managing behaviour that challenges
- managing psychosis
- reducing co-morbid emotional disorders

Promoting independence and maintaining function

Care

The principal focus of care should be on maximising independent activity and enhancing function. Often this will involve helping people with dementia to adapt and develop the skills to minimise their need for support.

This should start in the early stages of the condition and may involve many services and the person‘s carers and wider social network.

Providing care in a manner that promotes independence is likely to take more time but it is the core therapeutic intervention for people with dementia.

The NICE and SCIE (2006) guideline identifies key interventions that should be used to maximise functioning.

Care plans are vital and should include activities that are important for independence. They should take account of the individual‘s needs, type of dementia, preferences, interests and life histories.

Good communication is at the heart of all effective psychological interventions. This entails being aware of non-verbal cues and speaking appropriately for the person‘s level of comprehension, sensory abilities and culture. The written word or pictures may also be helpful. It is important to appreciate that some people with dementia may need vision and hearing tests. Working with people with dementia requires flexibility because their abilities may fluctuate and this needs to be accommodated. Advice and skill training on activities of daily living should be given by occupational therapists (see Box 1).

Box 1. Activities of daily living skill training

This involves assessing a person‘s abilities, impairments and their capacity to perform everyday tasks (such as dressing, feeding and washing) and to understand the underlying physical, psychosocial and neurological factors involved.

Individual programmes may be developed to enable people to perform as many everyday tasks as possible by themselves. The programmes include graded assistance, whereby carers give the least amount of assistance needed at each step to help a person to complete the task.

Strategies may include verbal or visual cues demonstrating how to perform the task, physical guidance, partial physical assistance and problem-solving.

Any environmental modifications that might aid independence, including assistive technology, should be considered. This might require advice from an occupational therapist and/or clinical psychologist.

Obtaining advice on independent toilet skills is important – if incontinence occurs, all causes should be assessed and treatment options tried before concluding that incontinence is permanent.

Physical exercise should be facilitated and encouraged where possible, with assessment and advice from a physiotherapist when needed. Exercise is thought to help improve continence, slow loss of mobility and improve strength, balance and endurance. It is also used in falls prevention (NICE, 2004).

It is vital to provide support to enable people to do things in their own time and to continue to take part in activities they enjoy. Consistent and stable staffing and familiar environments are important and relocations should be avoided.

Specific interventions for cognitive symptoms

Cognitive symptoms, that is, those affecting thought processes and memory, are integral to any definition of dementia. The NICE and SCIE guidance (2006) aimed to forge the link between improving cognitive symptoms and maintaining day-to-day functioning. The guideline development group considered this when assessing the effectiveness of interventions for cognitive symptoms.

Psychological interventions

Often in milder stages of dementia people can work well with a technique known as cognitive stimulation.

This entails exposure to and engagement with activities and materials involving some degree of thinking, challenge and stimulation. These should be appropriate to the group and person-centred. The emphasis should be on social activities that participants enjoy. Sometimes these activities might focus on problem-solving, education, practical management of forgetfulness or reminiscence.

Medication strategies

Alzheimer's disease: the NICE and SCIE (2006) guideline incorporated recommendations from the NICE (2006 amended 2007, 2009, 2011) technology appraisal on acetylcholinesterase inhibitors. Treatment should be initiated only by a specialist in dementia care – in most cases this would be a psychiatrist or GP with a special interest in dementia care, although some nurse prescribers can undertake the secondary prescribing of these drugs.

Acetylcholinesterase inhibitors and memantine should not be used to treat cognitive decline in vascular dementia (NICE, 2006). Acetylcholinesterase inhibitors should not be used to treat mild cognitive impairment. Acetylcholinesterase inhibitors may be used in Lewy Body Dementia.

Part 2: non-cognitive symptoms (behavioural and psychological symptoms of dementia)

Non-cognitive symptoms of dementia include delusions, hallucinations, depression, anxiety, agitation and associated behaviours. They often take the form of a co-morbid emotional disorder and can encompass 'behaviour that challenges'. This includes aggression, marked agitation, wandering, hoarding, sexual disinhibition and disruptive vocal activity such as shouting.

It is thought that up to 90% of people with Alzheimer's disease have such symptoms (Robert et al, 2005). Although the difficulties reflect distress patients may be experiencing, other people's reactions to such behaviour may also add to patient's discomfort.

It is important that the context and reason for the non-cognitive symptoms, especially challenging behaviour, are understood. For instance, wandering may be due to a wish to escape from the immediate environment, or the person may be looking for someone or something, or experiencing restless agitation, boredom or a need for exercise.

When these sorts of behaviours occur it is important to consider the influence physical disorder can have on the mental health of such people. Many problems can be successfully managed through good use of antibiotics, laxatives, analgesia, hydration and good nutrition.

Treatment should reflect possible causes of non-cognitive symptoms and assess whether the behaviour is a serious problem for the person, carers or professionals. NICE and SCIE (2006) emphasise the importance of not seeing such behaviour solely as a symptom of dementia but as resulting from psychosocial and/or biological factors. It is therefore crucial for professionals to be able to differentiate and distinguish the factors or difficulties leading to a particular behaviour so that tailored treatment can be offered. Anticipating and addressing the causes of challenging behaviour can obviate the need to use potentially harmful drug treatments.

Psychological interventions

Typically the first-line treatment for non-cognitive symptoms and challenging behaviour is a non-pharmacological intervention. People should be offered an assessment as soon as possible to identify possible factors influencing their behaviour (see Box 2).

For people who are very agitated the following interventions may be considered:

- aromatherapy
- multisensory stimulation (also known as Snoezelen therapy, this involves active stimulation of the senses using a room with appropriate lighting, sound and equipment)
- therapeutic use of music and/or dancing
- animal-assisted therapy (which involves using companion animals to improve mood)

- massage

Box 2. Assessment and care-planning approach

The following should be assessed:

- physical health
- mood
- depression
- possible undetected pain or discomfort
- side-effects of medication
- individual biography
- psychosocial factors
- physical environmental factors
- spiritual/religious

Behavioural and functional analysis should be undertaken in conjunction with carers and care workers using an ABC approach. This would examine a specific behaviour in relation to antecedent events (A), the actual subsequent behaviour (B) and the consequences of that behaviour for the person and carers (C).

Individual care plans should be developed and recorded in notes of the person with dementia. These should be reviewed regularly with carers and other staff.

When deciding which therapy to offer, the person‘s abilities, skills and preferences should be considered. Once therapy has started, their response should be monitored and the care plan adjusted accordingly.

Pharmacological interventions

Pharmacological interventions should only be considered as first-line treatment for non-cognitive symptoms or challenging behaviour if the individual is severely distressed or if there is an immediate risk of harm to themselves or others. The person with dementia should be assessed and the care-planning approach used (see Box 2).

In some diseases antipsychotic medications have greater relative risks, and should only be used if the benefits of their use outweigh these risks. In Lewy Body dementia they can have a marked adverse effect and may cause a dramatic decline due to extra-pyramidal effects, which may not recover with cessation of the drug. In vascular and mixed vascular-Alzheimer’s dementia, there is an increased risk (3-fold) of cerebrovascular morbidity and mortality (MHRA, 2009; Banerjee, 2009)

Although this has been noted with the more recently introduced atypical antipsychotic drugs, there is evidence that conventional antipsychotics are no safer (Gill et al. 2007). Antipsychotic use may be associated with an increased risk of venous thromboembolism and currently there are insufficient data to determine any difference in risk between atypical and conventional antipsychotics or for individual drugs (MHRA, 2009). In addition elderly people are susceptible to postural hypotension and to hyper- and hypothermia.

Risperidone is licensed for short term treatment (up to 6 weeks) of persistent aggression in patients with moderate to severe Alzheimer’s dementia unresponsive to non-pharmacological interventions and where there is a risk of harm to self or others (British National Formulary 72, September 2016 – March 2017, section 4.3.6 p 369). The current position is that risperidone or any other anti-psychotic medication should only be prescribed after careful consideration of benefits and risks.

Prescribers of any antipsychotic medication should consider carefully the risk of cerebrovascular events before treating any person with a previous history of stroke or TIA. Consideration should also be given to other risk factors for cerebrovascular disease including hypertension, diabetes, current smoking and atrial fibrillation.

Antipsychotic drugs may be considered for severe non-cognitive symptoms (such as psychosis and/or agitation causing significant distress) only if:

- The risks and benefits of using the drugs have been discussed by the team and with the carers of the patient and legal proxies if appointed.
- Changes in cognition are regularly assessed and recorded. If there are differences, a change in medication should be considered.
- Target symptoms have been identified and recorded and changes are regularly monitored.
- Other conditions, such as depression, have been taken into account.
- The drug is chosen after an individual risk-benefit analysis.
- The dose is started low and titrated upwards.

The treatment is time-limited and regularly reviewed (every three months or according to clinical need). If there is no clear benefit, then it should be discontinued or altered. People on longer term antipsychotic medication should be specifically reviewed at regular intervals to see if the medication may be reduced or stopped.

In people with dementia with Lewy bodies, severe adverse reactions, such as development or worsening of extrapyramidal features such as tremor, stiff gait and falls, or acute severe physical deterioration should be monitored for.

Antidepressants such as citalopram and trazadone can be helpful, as well as mood stabilisers (also known as antiepileptics) such as sodium valproate. There is also a role for benzodiazepines such as lorazepam for acute problems, and diazepam for more chronic problems but their use must be time-limited and carefully monitored in terms of sedation, falls and tolerance of their effects.

Challenging behaviour

Any factors that increase the likelihood of challenging behaviour should be addressed, as this can be caused by, for example the person's physical environment, psychosocial factors or physical health. Relevant factors include: overcrowding; lack of privacy; lack of activities; inadequate staff attention; conflicts between staff and carers; and weak clinical leadership.

Immediate management of such behaviour should take place in a low-stimulation environment, away from others. Drugs (benzodiazepines or antipsychotics) should be used to calm the person and reduce the risk of violence and harm rather than to treat any underlying psychiatric conditions.

The aim should be to reduce agitation or aggression without sedation. The lowest effective dose should be used and combinations of drugs should be avoided. Typically this should be an oral medication.

Drugs to control behaviour should be used with caution owing to risks of loss of consciousness, over-sedation, damage to relationships between the person with dementia, carers and the care team, and specific issues related to age and physical/mental health.

Co-morbid disorders

People with dementia are more likely than the general population to have depression (Robert et al, 2005) and anxiety is also common. Therefore staff should carry out assessments for co-morbid disorders.

Psychosocial interventions for co-morbid depression and/or anxiety include cognitive behavioural therapy and a range of tailored interventions such as reminiscence therapy, multisensory stimulation and exercise.

People with co-morbid depression should be offered antidepressant medication after a risk-benefit analysis. Generally a Selective Serotonin Reuptake Inhibitor would be the first-line anti-depressant considered. Anti-depressants with anticholinergic effects, such as tricyclic antidepressants, should be avoided because they may adversely affect cognition. Similarly procyclidine (an antimuscarinic drug used in Parkinsonism) would need using with care.

See Chapter 6 'General considerations for medicines management in people with dementia'.

Interventions for carers

Carers often need support themselves, particularly if the person they are caring for experiences severe non-cognitive symptoms (Donaldson et al, 1997). Compared with other carers, those supporting people with dementia are among the most vulnerable to stress, depression, feelings of guilt and other psychological difficulties.

See Chapter 17 'Carers' Health and Wellbeing' for more information on support for carers and further resources available.

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6. General Considerations for Medicines Management in People with Dementia

General recommendations

Generally for people with dementia and in need of palliative medicines consider:

- It is possible the person has received some of these groups of medicines already in managing their dementia symptoms so consider how they responded previously.
- Using the minimum number of medicines, which can cause increased confusion as people with dementia are particularly susceptible to central nervous system adverse effects.
- Increase doses cautiously and try to only change one medication at a time.

If people have difficulty swallowing medications or tolerating particular formulations it is advisable to contact pharmacy for advice regarding alternative formulations and whether capsules can be opened or tablets crushed. Once a medication is crushed it becomes an unlicensed medication and if medication is to be given this way permission should be sought from the prescriber.

The appropriate source of pharmacy advice will depend on the care setting in which the person with dementia is being cared for:

- For a person with dementia at home, within a care home or in another community setting contact the local community pharmacist.
- For a person with dementia who is an inpatient contact the appropriate pharmacist or medicines information service

Further information regarding whether or not a medication can be crushed is available from: http://www.formulary.cht.nhs.uk/Guidelines/MMC/105b_MedEnt_IndivDrugs.htm [Last accessed 31/07/2017]

Further information about whether medication can be given via an enteral feeding tube is available in the following references:

White R, Bradnam B. *Handbook of Drug Administration via Enteral Feeding Tubes*. British Pharmaceutical Nutrition Group. Pharmaceutical Press; 2006.
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[Last accessed 11/08/17]

Smyth JA (editor). *The NEWT Guidelines for administration of medication to patients with enteral feeding tubes or swallowing difficulties.* 3rd edition. Published by North East Wales NHS Trust ; 2015.The online version of these guidelines is available on http://newtguidelines.com/
[Last accessed 31/07/2017]

Specific recommendations about medications commonly used in palliative care

Some medications which are commonly used in palliative care should be used with caution or avoided in people with dementia.

Medicines with anticholinergic side-effects

Medicines which can cause anticholinergic side-effects e.g. hyoscine hydrobromide, cyclizine, levomepromazine and amitriptyline can cause increased confusion so should be used with caution. Those which do not cross the blood brain barrier to the same degree, such as glycopyrronium and hyoscine butylbromide, are less likely to do so although still have such side-effects as dry mouth.

Antiemetics

Antiemetics which can cause extrapyramidal side-effects, such as haloperidol, levomepromazine and metoclopramide, should be avoided in people with Lewy body type dementia as they may cause a rapid decline which may not recover with cessation of the drug. They should be used in caution in people with other types of dementia and the potential risks and benefits considered. Cyclizine should also be used with caution in people with any type of dementia due to its anticholinergic side-effects, as noted above. It may be advisable to use an alternative antiemetic if possible. The most appropriate antiemetic and route will depend on the cause of the nausea and vomiting.

For further information about management of nausea and vomiting and specific antiemetics please refer to:

Greater Manchester Strategic Clinical Networks. *Pain and Symptom Control Guidelines. Palliative Care. 4th Edition* 2015. Available online at Cheshire e-paige [Last accessed 27/07/17].

Cheshire & Merseyside Palliative and End of Life Care Network Audit Group. Standards and Guidelines. http://www.nwcscnsenate.nhs.uk/strategic-clinical-network/our-networks/palliative-and-end-life-care/audit-group/clinical_standards_and_guidelines/ [Last accessed 27/07/17].

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Opioids

Opioid analgesics can increase confusion and so doses should be started low and increased slowly. Morphine is still the first-line strong opioid of choice. Opioids such as buprenorphine and fentanyl are associated with a lower incidence of sedation, delirium and hallucinations and are available in transdermal patch formulations which may be more convenient for use in people with moderate to severe cognitive impairment especially if they have swallowing difficulties or if there are concerns about compliance.

- Buprenorphine is a weak opioid and the lowest dose (BuTrans 5) is equivalent to 12mg oral morphine or approximately 120mg Codeine over 24 hours.
- Transdermal fentanyl is not suitable for unstable or rapidly changing pain due to the long half-life. The lowest dose of transdermal fentanyl patch of 12mcg/hr every 3 days is equivalent to 30mg oral morphine over 24 hours which may be too high a starting dose in opiate naïve people.
- Cheshire & Merseyside Palliative and End of Life Care Network Audit Group. Standards and Guidelines for guidance on symptom control medication and pain management. http://www.nwcscnsenate.nhs.uk/strategic-clinical-network/our-networks/palliative-and-end-life-care/audit-group/clinical_standards_and_guidelines/

Benzodiazepines

Midazolam and other benzodiazepines should be used cautiously as they could increase confusion or agitation.

Please also see Chapter 5 ‘Therapeutic interventions in dementia’.

On occasions it may be appropriate to consider covert administration of medication in the best interests of a person with dementia who lacks capacity. The following guidance concerning covert administration of medication is adapted from the Cheshire and Wirral Partnership NHS Foundation Trust Medicines Policy (Issue 9, section 8.13 Implementation date October 2012).

Principles of covert administration

When is it necessary and legal considerations?

Treatment may be given to adults who lack mental capacity to consent to treatment if it is considered to be in their best interests under the Common Law Doctrine of Necessity which is now codified in sections 5 and 6 of the Mental Capacity Act 2005.Treatment must be:

- Necessary to save life or prevent a deterioration or ensure an improvement in the person`s physical or mental health;
- In accordance with the practice accepted at the time by a reasonable body of medical opinion skilled in that particular form of treatment in question and Part IV of the Mental Health Act 1983 (see Code of Practice); https://www.gov.uk/government/news/new-mental-health-act-code-of-practice [Last accessed 11/08/17]
- Although there is legal support under certain circumstances to prescribe medication to adults who mentally cannot consent to treatment there are no nationally agreed protocols or standards for the administration of such medication in food or drink. It is left to local services to develop their own protocols and standards.

It is clear that offering medication in food or drink could still be perceived as being deceitful and could be open to abuse and requires particular guidelines to be established locally to ensure that when this practice happens it has been properly considered, proper consultations have been made and that the practice is transparent and open to public scrutiny and audit.

Principles of covert administration

- These principles apply to the administration of medication to patients who cannot give consent to treatment who are refusing to take tablets or syrup when openly presented to them and for whom administration of medicine disguised in food or drink is then considered. The decision to administer covertly should not be considered routine;
- Covert administration should not be confused with the administration of medicines against someone’s consent. Administering medicines covertly to clients should be carefully considered;
- The capacity of the person in relation to medicines should be assessed. If the person has capacity to consent and refuses medication it cannot then be given covertly. If a person has not got capacity to consent and refuses medicines then it may be appropriate to administer some medicines covertly;
- People who are refusing or unable to take treatment because they:
    - Find it difficult to swallow the size or shape of the tablet / capsule;
    - Find the taste of the liquid is unpalatable;
    - Have swallowing difficulties;

  should be discussed with the clinical pharmacist as a different formulation that is suitable may be available. These people may not be actively refusing to take treatment but find the treatment difficult to swallow and if presented with medication in the appropriate form will consent to take it.
- It is important to remember that the Mental Health Act only applies to those medicines used in treatment of mental illness. Other medicines, even though their administration may be considered in the patient’s best interests cannot be given against the patient’s consent under the Mental Health Act. The Mental Health Act does not give guidance on administering medication covertly. If the person is detained under a section of the Mental Health Act then the use of covert administration should be discussed with the Second Opinion Appointed Doctor (SOAD). A second opinion should be sought for informal patients for whom covert administration is being considered, as a principle of good practice;
- A review of the importance of the medication and whether it is essential to continue with it

should also be made. A judgment about the importance of the treatment to the person`s quality of life and general health should be formulated to decide whether to give the treatment or to discontinue it;

- Although it is acknowledged that nobody can consent for another adult the views of the nearest relative/carer or a person's advocate should be sought;
- The decision to use covert medication must be made by the Multidisciplinary Team (including the clinical pharmacist) including the views of the relatives and carers and any advance statement/directive made by the patient. The pharmacist will consider ethical, cultural or religious beliefs that could affect the choice of medicines. The method of administration should clearly be recorded on drug prescription and administration chart. The second opinion should be sought before this discussion is held.

Care plan discussion and actions required

The discussion and actions taken as a result of deciding to use covert administration should include the following:

- Which medicines are considered essential? Remembering that treatment with the medication must be in the person`s best interest and necessary to save life or prevent deterioration or ensure an improvement in the person`s physical or mental health;
- Considerations to the taste of the medicines as some are so unpleasant tasting as to be impossible to disguise;
- The stability of the medicine when mixed with food (e.g. available in solution, crushing of tablets, effects of temperature). You must ask the pharmacist regarding mixing any medication in food or drink;
- Limit the number of medicines given covertly to one or two or food will taste unpleasant and be refused. Other medicines can still be offered in the conventional manner;
- Clarification of the aims of giving a particular medication covertly. If aims not met then the medication and its covert use should be reviewed;
- Medicines should be offered in the conventional manner on a regular basis. With covert administration the person may come to accept medication and it is well known that mental state and therefore consent can fluctuate;
- Consider the kind of food the person favours;
- Best to mix medication in a small amount of food e.g. jam, yogurt (some medication is bitter tasting) rather than whole dinner in case it isn't eaten;
- Administration needs to be closely supervised so that only the intended person gets the medicated food, should be cleared away and disposed of immediately the patient has finished eating;
- The prescribing doctor must mark the medicines chart 'for covert administration' in the Additional Instructions box;
- The decision should be documented in a care plan including all parties involved in discussions. See example care plan (page 35);
- A decision to administer medication in food or drink must be clearly entered into the case notes. Details of the condition being treated and the likely benefits of treatment, results of assessments indicating the nature of the person`s difficulty in taking medication openly, and indicating who else has been consulted, particularly referring to consultations with the Multidisciplinary Team and nearest relatives / carers.

Cheshire and Wirral Partnership NHS
NHS Foundation Trust

Example care plan

Cheshire and Wirral Partnership NHS Foundation Trust Older Peoples Mental Health

Care plan for	………………….has been prescribed medication but he/she has not been able to accept medication consistently. The importance of taking medication on a regular basis has been explained to………….. but he/she lacks the capacity to fully understand, their ability fluctuates, he/she is not always able to process or retain information given to him/her, which would then allow him/her to make an informed decision. Therefore a decision has been made in the best interest of…………………….to proceed with the use of covert administration of medication if he/she will not accept it voluntarily.	Care plan No.
Goal	To ensure that policy for covert administration of medicines is followed. To aid compliance and ensure medication is taken as prescribed. To ensure the safety of other patients to prevent them from unintentionally taking the wrong medication.	Sign
Core plan	Second opinion has been sought. MDTM meeting was held with Consultant, Family, Nursing staff, Pharmacist to discuss the need for covert administration of medication. This issue will have to be reviewed regularly at MDTM. ……………….compliance fluctuates so medication to be first offered in the conventional way at the prescribed times. If he/she refuses then medication, which has been endorsed 'For covert administration' by the doctor, can be given in a small amount of food or drink. Staff to observe……………..during covert administration and ensure that food/drink containing medication is taken and cleared away to prevent other patients unintentionally taking the wrong medication. To liaise with the Pharmacist as to availability of liquid or soluble formulation or suitability of crushing tablets. Ascertain the most suitable medication on the basis of taste and possibility of disguising this in food/drink	
Date	**Additional information for individualised care planning**	**Sign**

Patient name
Patient Number
Ward / hospital name
Primary nurse signature
Relative / carer signature
Consultant signature
Pharmacist signature

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7. Living with Dementia: A guide to the Care Act 2014 and the Impact on Local Authority Provision, Continuing Health Care and Finances

The Care Act 2014 has replaced nearly all the old legislation and supporting guidance covering the care needs and rights to support of both adults with social care needs and their carers. Most of it came into force in England from April 2015, but the planned new developments in paying for care will not now take effect until April 2020.

As well as the Care Act 2014 itself, there are 21 sets of new regulations that set out the law in more detail and almost 500 pages of new statutory guidance available from www.gov.uk/government/publications .

Wellbeing

One of the most significant changes is the duty placed on local authorities to carry out their work in a way that promotes "wellbeing". This applies whether the person is someone with dementia or a carer looking after another adult.

Wellbeing, as defined by the Act, includes:

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

This applies to all stages of adult social care involvement and is set out at the beginning of the Act because it is an important principle that adult social care did not have to consider under the old law. At the heart of this reformed system there 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 may need 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 (LA) 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:

a. Managing and maintaining nutrition

b. Maintaining personal hygiene
c. Managing toilet needs
d. Being appropriately clothed (includes being able to get dressed)
e. Being able to make use of the adult's home safely
f. Maintaining a habitable home environment
g. Developing and maintaining family or other personal relationships
h. Accessing and engaging in work, training, education or volunteering
i. Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services
j. 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:

a. Unable to achieve it without assistance
b. Able to achieve it without assistance but doing so causes significant pain, distress or anxiety
c. 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
d. Able to achieve it without assistance but takes significantly longer than would normally be expected

For Carers you will meet the eligibility threshold if:

a. The carer has needs connected with providing necessary care; and
b. 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
c. That results in a significant impact on the carer's wellbeing

Listed outcomes in the regulations are:

a. Carrying out any caring responsibilities the carer has for a child
b. Providing care to other persons for whom the carer provides care
c. Maintaining a habitable home environment in the carer's home (whether or not this is also the home of the adult needing care)
d. Managing and maintaining nutrition
e. Developing and maintaining family or other personal relationships
f. Engaging in work, training, education or volunteering
g. Making use of necessary facilities or services in the local community, including recreational facilities or services
h. Engaging in recreational activities

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

a. Unable to achieve it without assistance
b. Able to achieve it without assistance but doing so causes the carer significant pain, distress or anxiety or
c. 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, the carer provides.

Care and support planning

If eligibility criteria are met, the next stage is for adult social care to work closely with the person to plan how to support the person to meet eligible needs. 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 is wanted 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 interests 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 person’s wishes
- as a managed account held by a third party with care and support purchased and provided in line with the person’s wishes
- as a direct payment

Further advice can be found in Factsheet 24, a free information sheet published by Age UK.

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. Nursing homes offering permanent residential care can be found on the internet from the Care Quality Commission on http://www.cqc.org.uk

The 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 DH Care and Support statutory guidance Annex A https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#AnnexA [Last accessed 11/08/17]

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. However, from April 2016 a cap was planned, meaning that no-one would have to pay any more for their eligible care needs once a total of £72,000 had been spent. This has now been delayed until April 2020 at which time this figure may be different. Another important development will be the introduction of an accommodation charge for residential care, referred to as the "hotel costs". It will cover accommodation and ordinary living costs, but not social care and is set at £12,000 a year (or £230 pw), but again this figure may change due to the delay in implementation.

Once adult social care has decided that eligibility criteria have been met, there will be a detailed financial assessment looking at both capital and income to decide a person's contribution. Upper and lower capital limits are currently set at £23,250 and £14, 250. 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, known as the tariff income from their capital, 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. 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

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 871 11 11

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 £110 each to register, a procedure which normally takes 6 to 8 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 be either completed on line or downloaded from the Office of Public Guardian (http://www.publicguardian.gov.uk/) as can more 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 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 LA 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 the Citizen's Advice Bureau (www.adviceguide.org.uk), Carers UK (email: advice@carersuk.org) and the DWP (www.gov.uk/browse/benefits) and (www.gov.uk/browse/working/state-pension)

PERSONAL INDEPENDENCE PAYMENT (PIPS) 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. For more information contact www.gov.uk/pip-checker.

Attendance Allowance (AA)

Again this is a non-means tested benefit for those people at or over the age of 65, 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. More advice can be found on DWP websites www.dwp.gov.uk/contact-us/contact-a-z/)

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 PIPS 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 Job Centre Plus for advice or the website https://www.gov.uk/carers-allowance

Universal Credit

Is a new benefit available mainly to people who are unemployed or earn less than £338 a month. In a Universal Credit area it replaces existing benefits like Jobseeker's Allowance, Employment and Support Allowance and Housing Benefit or Tax Credits. Eligibility can be complicated to work out, it might be easier to call the Universal Credit helpline on 0345 600 0723 or contact the local Citizens Advice.

You cannot get Universal Credit if you cannot work because of illness or disability or if you have caring responsibilities for a disabled person. In these cases you should look at other benefits and a useful guide is the Turn2us benefits checker to see what you can apply for. https://www.turn2us.org.uk

8. Spirituality and People with Advanced Dementia

There have been many difficulties in defining spirituality due to its complexity and subjective nature. Spirituality and religion are two terms that are often used interchangeably, but have different meanings for an individual. Religion could be identified as 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 a very poor evidence base to understand what that means, with the “extraordinarily sparse” research mainly limited to those who are still able to communicate (Kevern, 2013). When research studies have been carried out, it has tended to be restricted to people with early stage dementia who have fairly intact cognitive skills. Unsurprisingly, this cohort has been found to have similar beliefs and needs to any 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 has been identified as being as important as the physical and psychological support a person with dementia is offered. 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

These seem broadly accepted as dimensions of spiritual care and therefore consideration of how to integrate these within dementia care are significant.

Good spiritual care for people with dementia requires an impeccable holistic assessment. Assessment needs to be individualised and sensitive in order to identify aspects of the individual‘s spiritual being or religious beliefs. A 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 a detailed biography can be taken from family members or 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. These activities have been used as underpinning principles and related to a person with dementia, but their impact on the person with dementia needs to be carefully gauged as we may unknowingly provoke emotions or memories that are not positive ones:

Life review / life history
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 book, which can include photos and pictures, can be an enjoyable and empowering activity for a person with dementia.

The Alzheimer's Society produces a very useful guide that can be downloaded at www.alzheimers.org.uk [Last accessed on 27/07/17)

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 done as individuals or within group or family sessions. For those who have difficulty communicating, finding other ways to stimulate memories, such as visually (photographs, paintings, pictures or objects), using smell or taste, or touching items and different textures may be more appropriate.

Music / song
The positive effects of music and singing on wellbeing are becoming increasingly acknowledged and the power of music, especially singing, to unlock memories and kick-start the grey matter is an increasingly key feature of dementia care. Music can be provided by drawing on music that is 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.

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 on the basis of what the person needs rather than the predilections of the person 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, e.g. some Christians would react very badly indeed 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 etc. 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/frustrated response. We must remember that even where individuals share a religious faith, their interpretation of beliefs can be different.

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.

The Namaste Care Programme

The Namaste Care programme was developed by Professor Joyce Simard in the USA in 2003 and means ‘to honour the spirit within’. The care programme was developed to meet the needs of people with advanced dementia for 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. [Last accessed 17/05/17]

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. Further information can be found at: www.themindfulnessinitiative.org.uk/professional-networks/interest-areas/10-professional-networks/33-dementia [Last accessed 17/05/17]

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The practice of spiritual care for older people (The Institute for Research and Innovation in Social Services (IRISS) 2013 http://www.iriss.org.uk/resources/spirituality-and-ageing-implications-care-and-support-older-people [Last accessed 17/05/17]

9. The Mental Capacity Act 2005

The Mental Capacity Act 2005 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
- 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
- Least restrictive intervention – anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms

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 (CCG or Local Authority) for authorisation. Six assessments are undertaken by a Best Interests Assessor to assess Age, No Refusals (e.g. 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 public.

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 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

If a person meets the above tests 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 a 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.

Deprivation of Liberty Safeguards (DoLS) – 3rd April 2017 onwards: [last accessed 20/03/18]
https://www.judiciary.gov.uk/wp-content/uploads/2013/10/guidance-no-16a-deprivation-of-liberty-safeguards-3-april-2017-onwards.pdf

The Deprivation of Liberty Safeguards 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

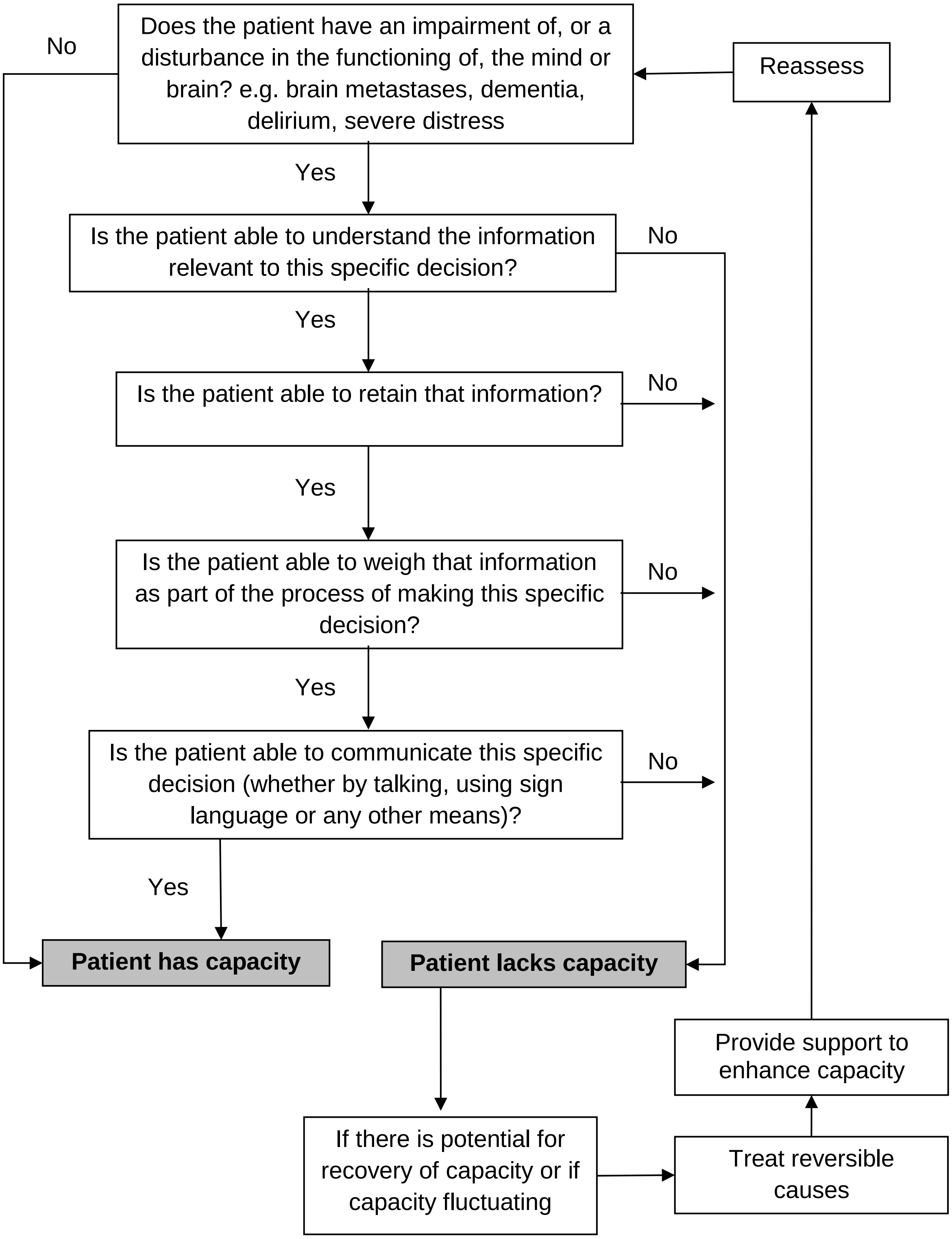
Good Practice in Decision-Making

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 interests decision-making and care planning at the end of life with practical examples and case studies.

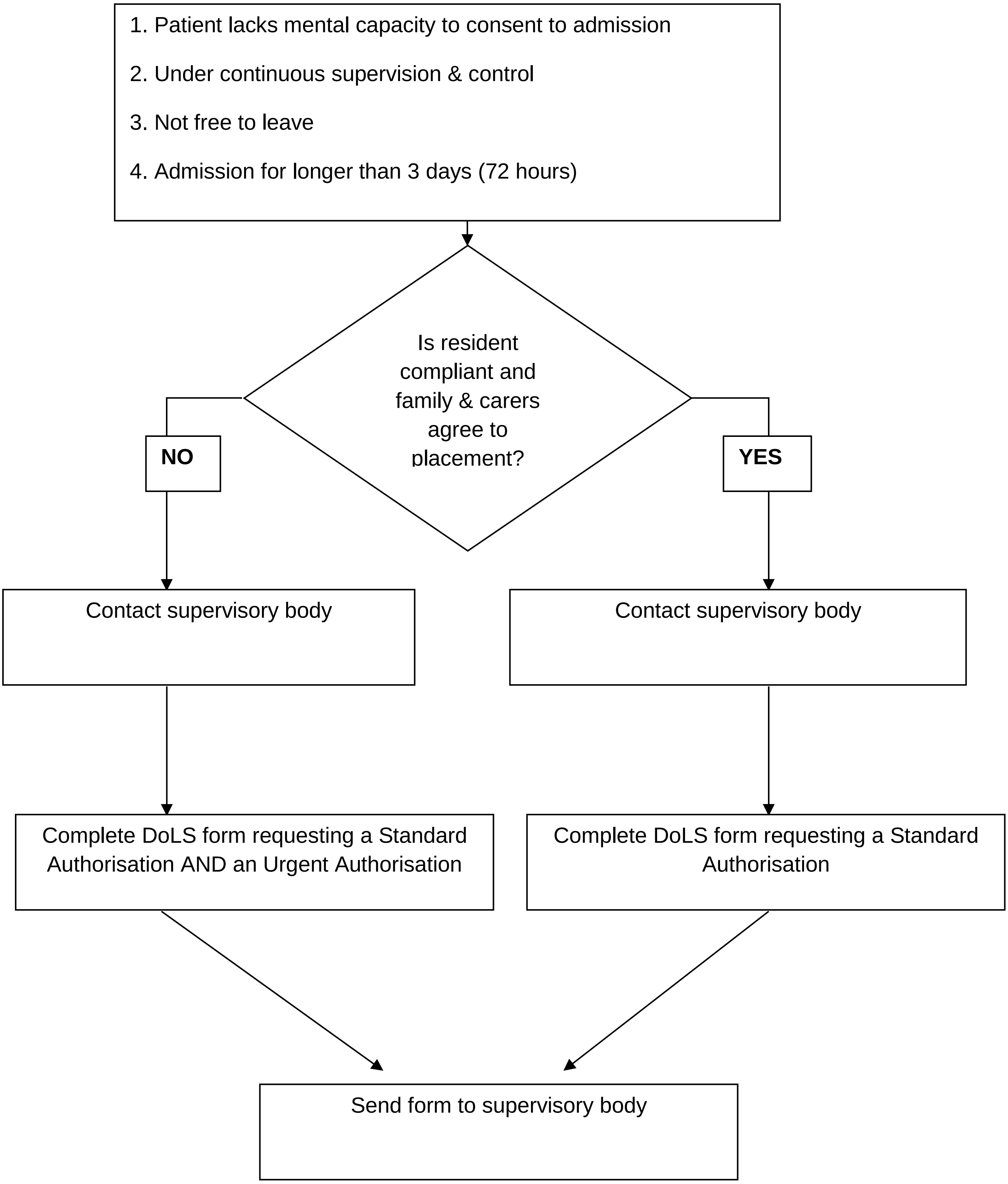
Mental Health Act 1983

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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10. Advance Care Planning

Advance Care Planning (ACP) is a voluntary 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.

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.

Examples of ACP 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 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'**).
- A Do-Not-Attempt Cardiopulmonary Resuscitation (DNA-CPR) decision refers only to withholding CPR and is completed by a clinician with responsibility for the person.

Gold Standards Framework/Palliative Care Meetings

The inclusion of patients with a dementia diagnosis within Primary Care -led palliative care meetings can facilitate a more holistic and coordinated approach to care during the last 6-12months of life. Having proactive discussions as a multi-professional team when someone with dementia is thought to be nearing the last few months of life will enable the early recognition of advance care planning processes that have already taken place, thereby assisting the proactive management of care in accordance with an individual's previously expressed wishes.

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11. Clinically Assisted Nutrition and Hydration in People with Dementia

Clinically assisted nutrition and hydration refers 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, Nasogastric (NG) 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 changes in appetite, difficulty coordinating movements which can make it difficult for them to feed themselves and difficulty swallowing. 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 and 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 NG 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 NG 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 and oedema. 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, 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 an NG tube in the interim with a nasal loop to prevent 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, NG 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 diarrhoea, 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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12. Treating Infection in End Stage Dementia

The National Council for Palliative Care (2006) recognises the prevalence of infections amongst people with a diagnosis of end-stage dementia and they also acknowledge that this group of people are particularly vulnerable to infection.

Patients at the end stages of 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). These may present as aggression, withdrawal or resistance to care/interventions.

The use of antibiotics can be controversial as it may provide comfort measures and symptomatic relief (Morrison & Sui, 2006). Others argue that it is reasonable to treat infections such as urinary tract infections, but that treating pneumonia is often ineffective (Van der Steen et al, 2002). It is also argued that not treating pneumonia would almost certainly lead to a less protracted dying phase (Heerema, 2016). Often the decision to treat can be clouded by the lack of recognition that dementia is a terminal disease (Van der Steen et al, 2009).

However the effectiveness of repeated antibiotic treatment for pneumonia may be limited and decisions to treat should therefore be made on an individual basis, weighing up all of the pros and cons of each situation (General Medical Council, 2010). Consideration should be given to any Advance Decisions to Refuse Treatment (ADRTs), any advance statements that the person may have made and the views of family and carers where appropriate.

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 straight forward if the patient is able to take oral medication and is able to remain in their place of care. Consideration should be given to the distress to the client that may be caused should hospitalisation be required for intravenous therapy (Ouslander et al, 2000).

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

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13. Identifying Dying in Advanced Dementia

Introduction

Advanced dementia is an incurable, progressive condition. With time, palliation becomes the primary goal 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. The duration from diagnosis to death ranges on average from 1.1 years to 8.5 years (Brodaty et al, 2012). For some individuals, it may be much longer.

There are two principal stages of advancing dementia that it is beneficial to try to predict and recognise. The first stage involves the period when the person is enters 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’.

Benefits to the 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 (Johnson et al, 2013)
- 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 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 survival reports of other dementia types by more than a 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 severity of the illness, including 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). Some general guidance and indicators have been developed. Such indicators may be used routinely to assess 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 care services that a person may be in need of palliative/supportive care. Two examples are The Gold Standards Framework (2011) and SPICT (2010). Both have indicators specifically relating to dementia.

Gold Standards Framework (GSF) - Proactive Identification Guidance

These general and specific clinical 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 for Dementia (NB There are other Specific Clinical Indicators for other disease groups)

There are many underlying conditions which may lead to degrees of dementia and these should be taken into account. 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://mh4ot.files.wordpress.com/2012/05/barthel.pdf)

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 two or more indicators of deteriorating health, plus any of the clinical indicators from a list related to dementia. (See http://www.spict.org.uk/the-spict/ for the full guidance).

Due to the difficulties of in prognostication the National Council for Palliative Care (NCPC, 2009) suggested that a needs based criterion may be simpler.

(1) Does the patient have moderately severe or severe dementia? [1]

(2) Does the patient also have:

a. Severe distress (mental or physical) which is not easily amenable to treatment?
b. *Or* severe physical frailty which is not easily amenable to treatment?
c. *Or* another condition (e.g. comorbid cancer) which merits palliative care services in its own right?

If criteria 1 or 2 co-exist, then the patient ought to have a full assessment of need and a focused analysis of why they are in distress and how best their symptoms can be improved and distress reduced.

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 stages of life phase of life is only part of the challenge. However, discussing these issues is difficult. Even when professionals are able to identify these stages, 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, 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 can 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 increase.

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[1] Stages of progressive dementias

- Mild – some cognitive impairment, limited ADL (e.g. cooking, shopping), but still independent in basic activities, e.g. washing, dressing
- Moderate – more confused, apraxic, needs help with basic activities; may engage in unsafe activities; able to feed self and ambulate independently
- Severe – unable to walk independently (may with assistance), feed self; still able to communicate
- Terminal stage – unable to ambulate; unable to communicate; able to perceive pain, discomfort

Chapter 6: Dementias. Volicer L. In *Palliative care in Neurology. Voltz R, Bernat JL, Domenico et al. Pages 59-67. Oxford University Press, Oxford, 2004.*

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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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 usually 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: needs assistance with dressing, bathing and incontinence; developing diminished vocabulary; then loss of ambulatory ability and beyond. Individuals differ in their disease progression and needs, and all decisions must be individualized.

Acetylcholinesterase inhibitors and Memantine

- These are of questionable efficacy in advanced dementia
- NICE guidance states that acetylcholinesterase inhibitors should be withdrawn when the MMSE score is less than 10; however, clinical judgement should be used for those with pre-existing learning difficulties or communication problems
- The guidance on when to stop memantine is less clear
- However, when the person is bed-bound and has a minimal vocabulary, this is well past the point at which acetylcholinesterase inhibitor or memantine could provide benefit
- The decision to withdraw medication must be made in the patient`s best interests, incorporating the view of the family, carers and professionals involved
- When the medication is withdrawn, it should preferably be tapered off to reduce the risk of a withdrawal reaction

Antipsychotic drugs

- 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, so the benefit of treatment must be balanced with this
- Consider tapering off antipsychotic medication once the condition has been stabilized
- 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, and the balance of benefit versus the risk of myopathy diminishes
- There is no evidence of any benefit of statins in people with advanced 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')

- There is limited evidence of effectiveness in advanced dementia
- It may be useful to reduce specific symptoms – e.g. dysuria with a urinary tract infection; production of mucopurulent sputum in a chest infection
- 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
- The use of antibacterials should be limited to relieve symptoms; 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

Diabetes mellitus medications
The goal is to keep the person asymptomatic. Tight blood sugar control, mainly needed to reduce the risk of long-term effects of diabetes, is no longer relevant, and runs an increasing risk of hypoglycaemia.

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.

Type 2 diabetes

- Drug therapy here is generally not life-sustaining. The risk of ketoacidosis is low
- Irregular feeding in a person on sulphonylureas 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)
- 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 sugar 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 hyperglycaemia

Type 1 diabetes

- There is less consensus here. More careful individual assessment is needed. Advice from a Diabetes Specialist may be helpful
- Problems include
    - resistance to finger pricking for capillary blood glucose checks
    - irregular and variable feeding
    - hypoglycaemia may be masked by the dementia, or be a cause of BPSD

    - intercurrent infections are more common if the glucose is running high
- 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 sugars are consistently above 15 mmol/l then a simplified insulin regimen may be considered – e.g. insulin glargine once daily. Advice from a Diabetes Specialist may be helpful
- If blood sugar 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

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 or other medication used (e.g. opioid analgesia, antimuscarinic drugs); 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 oral anticoagulants is more risky as dementia develops. Irregular taking of coumarins means that monitoring by INR is not sound. The effect of weight loss, impaired nutrition, other medication and falling albumin increase the risk of under or over coagulation
- Most with advanced dementia should have their anticoagulation stopped. If it is essential to continue anticoagulation to prevent serious morbidity, then a switch to once daily low molecular weight heparin injections should be considered

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, 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
- 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
- Refer to the BNF for individual entries for the relevant drugs
- In people towards the end of life, the need for blood 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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15. Caring for a person with dementia in the final days of life

As highlighted earlier in this guidance prognostication in dementia care is difficult. This chapter refers specifically to care for a person with dementia who is in the final days of their life. This in itself can be challenging as it can be difficult to recognise when a person with dementia is dying 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 5 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 that when it is though 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 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 often the case 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 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 recognized and shared. Reassessment 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 about 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 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 patient being transported to the local hospital. If the wish not to be resuscitated is part of an established ADRT then it should 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 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 wish. 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 patient 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:

- there are complex symptom control issues
- advice is needed about medication
- there are complex aspects to the support needed by the family

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 which affects an individual`s cognition or psychology such as dementia as they may experience feelings of loss and grief and the associated emotions throughout the different stages of the illness, including when it is recognized that they are in the final hours and days of life.

See also Chapter 18 'Carers Health and Wellbeing' and Chapter 16 '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, hospital admissions
- Avoidance of interventions and investigations that will not help the patient's current or future condition
- Help to support relatives and others close to the patient, 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 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 rationalized as time goes on, taking into account the patient’s needs (see chapter 15 - 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 driver may be needed for continuous subcutaneous medication, and knowledge of how to obtain one should be sought in anticipation. Non-essential 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.

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 patient is deeply unconscious, and it is appropriate to reassure those at the bedside that, although they may be disconcerting to witness, the patient themselves would not be aware or suffering due to them. The person`s skin may become pale and clammy and their fingers and feet may be 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.

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 patient. If in doubt, ask the family for specific wishes, and ensure contact with appropriate religious representatives is enabled, if desired.

Patients 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).

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 patient? 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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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 Europe, 2009). 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 may 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 of 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 again.

Anticipatory grief is normal and may 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.

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. Thune-Boyle et al (2010) states that families are often unaware of the terminal nature of dementia, what to expect at the end of life and what palliative care entails. 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. The majority of people (87-90%) will have an unproblematic bereavement. It is estimated that 7-10% of bereaved people need additional psychosocial support other than information and 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 National Institute for Clinical Excellence (NICE,2004) about bereavement care recommends a three component model of bereavement support and points out 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).

NICE (2004) highlights that bereavement can cause a wide range of needs, including practical, financial, social, emotional and spiritual. The assessment of a carer's bereavement risks should enable an appropriate plan to be put in place to meet their identified needs (Cruse bereavement care, 2014). Relf et al (2010) recommend an approach that encourages consideration of how people are likely to cope and focusses on resilience as well as vulnerability, and includes social processes, trying to understand the adequacy of an individual's coping response for the demands of their 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 (Relf et al, 2010) 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 and more formalised psychological interventions such as counselling, aiming to meet the needs of those with complicated grief reactions and those needing low-intensity support.

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 (NICE, 2011).

Useful websites

- Age UK: http://www.ageuk.org.uk/
- Alzheimer`s Society: https://www.alzheimers.org.uk/
- Cruse Bereavement Care: https://www.cruse.org.uk/

Useful contact telephone numbers

- Age UK advice line 0800 169 2081
- Cruse helpline: 0844 4779400
- National Dementia Helpline 0300 222 11 22

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17. Carers’ Health and Wellbeing

Caring can have a significant impact on your mental and physical health and wellbeing. Therefore, it is important to look after your own health to support you in your caring role.

It is important to look after yourself and keep fit, so that you do not become unwell, and can continue to support the person you care for. Maintaining good health and emotional wellbeing will help you in your caring role and in continuing your relationship with the person you care for. The type of support that each carer needs will vary depending on the individual circumstances and help should always be sought preferably before difficulties arise.

The advice below will help you to look after your own wellbeing to help you in your role as carer.

- Research the ailment and expectations of the person for whom you are caring, know their limitations and adapt to suit. Try to eat a well-balanced diet, with at least five portions of fruit and vegetables every day. A healthy diet will be beneficial for the person you care for too.
- Taking regular exercise is good for the physical and mental health of both of you, if practical. You could try going for a walk or taking up an exercise class. Whatever you choose it should be fun and something that you want to do.
- Having hobbies and interests is also good for your mental and physical health.
- Try to get enough sleep. Sleep is very important as it helps the brain and body recover from fatigue. It can be difficult if the person you care for has disturbed nights. You may find it easier to sleep when the person you care for is sleeping, and you may be able to take advantage of 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 that can help.
- Register with your GP, and the GP of the ‘patient’, that you are a carer. Ask for regular check-ups.
- If you have a physical disability or a sensory impairment then these will affect your caring role. It is important to make sure you are receiving all the support you are entitled to. Speak to your GP or social services department.
- If you have to help the person move around, be careful of your back. Provided trained, use any provided specialist equipment in your tasks. Speak to your GP for advice; they may be able to refer you to a physiotherapist or an occupational therapist. Some local carers' organisations provide training sessions on moving and handling. Contact your local carers organisation, GP or social services to find out what is available in your area.
- If you are struggling to cope or feel depressed, anxious or stressed, talk to your GP. There are options available such as counselling and extra support services, and these problems are easier to manage at an early stage.

A comprehensive list of organisations is included below where you will be able to access advice, support and further information. Please also visit Chapter 17: Useful Resources for further information on access to carer support.

Organisation	**Website**	**Telephone**	**Area**
Age UK	www.ageuk.org.uk	0800 169 2081	Head office
	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.ageconcernliverpoolandsefton.org.uk	0151 330 5678	Liverpool
		01704 542 993	Sefton
	www.ageuk.org.uk/midmersey	01744 454530	St Helens
		0151 559 3061	Knowsley
		01928 575400	Halton
		01925 244645	Warrington
Alzheimer's Society	www.alzheimers.org.uk	0300 222 1122	National helpline
	www.alzheimers.org.uk/northwest	01925 572 239	Area office
		0151 426 4433	Knowsley
		0151 298 2444	Liverpool
		01625 503 302	Macclesfield (Cheshire East)
		01606 781 110	Northwich (Vale Royal and Cheshire West)
		01704 539 967	Sefton
		0151 420 8010	St Helens / Widnes
		0151 650 5505	Wirral
Alzheimer's Research UK	http://www.alzheimersresearchuk.org/	0300 111 5555	Helpline
British Association of Counselling & Psychotherapy	www.itsgoodtotalk.org.uk	01455 883300	Head office
Care Choices	www.carechoices.co.uk	0800 389 2077	Helpline
Carers Trust / Crossroads	www.carerstrust4all.org.uk	01260 292850	Head office
		0800 085 0307	Cheshire and Warrington
		01260 292 850	Cheshire East
		0151 230 1137	Cheshire West, Chester and Wirral
		0845 601 1990	Liverpool, Knowsley, Sefton and Warrington
		0151 230 1137	Cheshire West, Wirral and Shropshire
		0151 343 1960	Wirral
	www.haltoncarers.co.uk	01928 580 182	Runcorn
		0151 257 9673	Widnes
	www.knowsleycarers.co.uk/	0151 549 1412	Kirby Office
		0151 482 6279	Huyton Office
		0151 448 9771	Halewood Office
	www.sefton-carers.org.uk	0151 288 6060	Sefton Office
		0151 288 6890	Southport Office
	www.sthelenscarers.org.uk	01744 675 615	St Helens Office (Adults)
		01744 677279	St Helens Office (Young Carers)

Cruse Bereavement Care	www.cruse.org.uk	0808 808 1677	Helpline
Citizens Advice Bureau	www.citizensadvice.org.uk	03444 111 444	National helpline
Dementia UK	www.dementiauk.org	0800 888 6678	Admiral Nurse Dementia Helpline
		0207 697 4160	Head Office
Department of Work and Pensions	www.direct.gov.uk/disability	0345 608 4321	General
	www.direct.gov.uk/carers		
	www.direct.gov.uk/carerscredit		
	Carers Allowance		
Healthwatch	www.healthwatch.co.uk	01625 838 394	Cheshire East
		0845 340 2859	Cheshire West
		0300 777 6543	Halton
		0151 449 3954	Knowsley
		0300 777 7007	Liverpool
		0800 206 1304	Sefton
		0300 111 0007	St Helens
		01925 246 892	Warrington
		0151 230 8957	Wirral
Housing Care (EAC First Stop)	www.housingcare.org	0800 377 7070	Head office
Local Authority	www.warrington.gov.uk	01925 443322	Warrington Borough Council
	www.halton.gov.uk	0303 333 4300	Halton
	www.cheshirewestandchester.gov.uk	0300 1238 123	Cheshire West and Chester
	www.cheshireeast.gov.uk	0300 123 5500	Cheshire East
	www.wirral.gov.uk/	0151 606 2002	Wirral
	www.sthelens.gov.uk	01744 676789	St Helens
	www.knowsley.gov.uk	0151 489 6000	Knowsley
	www.sefton.gov.uk	0345 140 0845	South Sefton
	www.liverpool.gov.uk	0151 233 3000	Liverpool
Live Well Liverpool	www.livewellliverpool.info	0300 777 7007	Liverpool CCG area
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	Helpline
MIND	www.mind.org.uk	020 8519 2122	Head office
	www.mindhalton.org.uk	01928 563 612	Runcorn
		0151 495 3991	Widnes
	macclesfield-mind	01625 430471	Macclesfield
	www.midcheshiremind.org.uk	01606 863 305	Winsford
	www.sthelensmind.org.uk	01744 647 089	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 *Dementia specialist*	www.cwp.nhs.uk	0800 195 4462	Patient Advice and Liaison
		01625 505666	Out of Hours - East Cheshire
		01244 397537	Out of Hours - West Cheshire
		0151 482 7639	Out of Hours - Wirral
		01244 397 300	Bowmere Hospital, Chester
		0151 334 4000	Springview, Clatterbridge Hospital
	www.merseycare.nhs.uk	0800 328 2941	Patient Advice and Liaison
		0151 473 0303	Mossley Hill
		0151 330 7200	Clock View Hospital
NHS Trusts	www.wuth.nhs.uk	0151 678 5111	Arrowe Park Hospital
		0151 334 4000	Clatterbridge Cancer Centre
	www.rlbuht.nhs.uk	0151 706 2000	Royal Liverpool University Hospital
		0151 282 6000	Broadgreen Hospital
	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.southportandormskirk.nhs.uk	01704 547 741	Southport and Formby District General
	www.whh.nhs.uk	01925 635 911	Warrington and Halton Hospitals NHS Foundation Trust
	www.sthk.nhs.uk	0151 426 1600	Whiston Site
		01744 646 461	St Helens Site
	www.coch.nhs.uk	01244 365 000	Countess of Chester
	www.mcht.nhs.uk	01270 255 141	Leighton Hospital
	www.eastcheshire.nhs.uk	01625 421 000	Macclesfield District General
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.wordpress.com	n/a	Part of Liverpool Dementia Action Alliance
TIDE Together in dementia	www.tide.uk.net	0151 237 2669	Carers network

18. Useful Resources

Cheshire & Merseyside Palliative Care Network Audit Group Clinical Standards and Guidelines. http://www.nwcscnsenate.nhs.uk/strategic-clinical-network/our-networks/palliative-and-end-life-care/audit-group/clinical_standards_and_guidelines/ [Last accessed 27/07/17]

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