Dementia end of life toolkit

Standardised evidence-based approach to dementia in palliative care.

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Why create this document?

Patients with dementia who are end of life have different care needs compared to those without dementia. The European Association for Palliative Care included Dementia Palliative Care as an emerging speciality area in its review of standards and norms for Palliative Care in Europe in 2022.

Dementia is the leading cause of death in the UK with 11.4% of deaths in 2022, this figure is only set to increase as the number of people living with dementia is increasing, it is estimated that 1 million people will be living with dementia in the UK by 2025 and this increases to 2 million by 2050 (Office for National Statistics, ONS, 2023a) Deaths registered in England and Wales - Office for National Statistics (ons.gov.uk) It is likely then as the prevalence of dementia increases that the number of those being supported by palliative care teams with dementia will also increase**.**

It is hoped this toolkit will a useful resource for clinicians working in the Community Palliative Care services working with patient who have dementia or cognitive impairment. Providing evidence based advice and guidance on delirium screening and management, symptom assessment in cognitive impairment/dementia, behavioural and psychological symptoms in dementia, mapping out of other services to signpost to and guidance on prescribing in dementia. It is to provide a resource to use in practice with patients but also a reference point to return to for further learning and understanding for clinicians providing end of life care to those with dementia.

As part of the formation of this toolkit focus groups were held with interested stakeholders who included Palliative Care Clinical Nurse Specialists, Palliative Care Registrars, Registered Mental Health Nurses, Mental Health Care Assistants and Occupational Therapists within Community Mental Health Teams. These helped to establish the common themes of difficulties experienced by both specialities when working with patients who were end of life with dementia and identify topics to include in the toolkit to help address some of these issues.

The issues that were highlighted in the focus groups can be thought of in these broad themes:

- Treatments- pharmacological and non-pharmacological
- Presentation and symptom recognition
- Prognostication
- Other services to involve for best care for that individual
- Advance care planning
- Capacity and legal considerations

What is dementia vs cognitive impairment?

Dementia is a permanent, progressive clinical syndrome with a range of cognitive and behavioural symptoms including memory loss, problems with reasoning and communication, change in personality, impacting on the person's ability to carry activities of daily living (National Institute for Health and Care Excellence, NICE,2024a) Definition | Background information | Dementia | CKS | NICE It is not a normal part of aging.

For a diagnosis of dementia to be made, the person must have impairment:

- in at least two of the following cognitive domains: memory, language, behaviour, visuospatial or executive function;
- which causes a significant functional decline in usual activities or work and is not explained by delirium or other major psychiatric disorder;
- there must be functional impairment as a direct consequence of the cognitive impairment for a diagnosis of dementia to be made;
- this is different to Mild Cognitive Impairment where there is only one cognitive domain affected or no functional impairment seen.

Subtypes of dementia

Dementia is the umbrella term for a clinician syndrome observed in individuals with different underlying pathophysiology leading to permanent, progressive cognitive decline with associated functional impairment. There are many different types is dementia disease processes. In both those aged over 65 years old and under 65, Alzheimer's disease is the commonest type of dementia. Accounting for 50-75% of the diagnoses of dementia in the UK. It commonly co-exists with other forms like vascular dementia – known as mixed dementia. Vascular dementia is second commonest type (20%). Dementia with Lewy bodies is the third most common type (10-15%) of dementia.
Then Frontotemporal dementia with 2% of the diagnoses (NICE, 2024b) Dementia | Health topics A to Z | CKS | NICE).

Alzheimer's dementia

The presenting symptom is usually loss of recent memory first, and often difficulty with executive function and/or nominal dysphasia. There is also loss of episodic memory — this may include memory loss for recent events, repeated questioning, and difficulty learning new information (NICE, 2024c) Clinical features | Diagnosis | Dementia | CKS | NICE

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 are more likely to be observed by others. The person may miss an appointments 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 being 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 are seen.

The A's of Alzheimer's dementia:

Amnesia Forgetfulness (amnesia) is universal and characteristically said to be for recent memories. Relatives often 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 impairment in language, including understanding and expressing language and grammar (aphasia) usually occur later, and are often a mixture of receptive and expressive problems.

Apraxia impairment 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 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.

(North West Coast Strategic Clinical Network, 2018)
https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf

Vascular dementia

Typically, a stepwise worsening in the severity of symptoms is described. However, depending on the area of the brain affected this may differ e.g. in subcortical ischaemic vascular dementia may present insidiously with gait and attention problems and changes in personality. Focal neurological signs (such as hemiparesis or visual field defects) may be present (NICE, 2024c) [Clinical features | Diagnosis | Dementia | CKS | NICE]()

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 vascular 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. (North West Coast Strategic Clinical Network, 2018)

https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf

Dementia in Parkinson`s disease (PDD)/ Dementia with Lewy bodies (LBD)

Core clinical features are fluctuating cognition; recurrent visual hallucinations; REM sleep behaviour disorder and one or more symptoms of Parkinsonism: disorder; bradykinesia, rest tremor, or rigidity. Memory impairment may not be apparent in early stages (NICE, 2024c) Clinical features | Diagnosis | Dementia | CKS | NICE

Parkinson's Disease dementia and Dementia with Lewy bodies are thought to be a part of the same spectrum disorder and the differentiation in regard to diagnosis is made by the chronology of symptoms emerging- if movement and memory symptoms appear within 12 months of each other the diagnosis is typically that of Dementia with Lewy bodies, if the memory symptoms develop > 12 months after the motor symptoms then the diagnosis is that of Parkinson's disease dementia.

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. 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 and Parkinson's disease dementia are very sensitive to antipsychotics, which can considerably worsen the Parkinsonian symptoms.

(North West Coast Strategic Clinical Network, 2018)

https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf

Frontotemporal dementia

Personality change and behavioural disturbance (such as apathy or social/sexual disinhibition) may develop insidiously. Other cognitive functions (such as memory and perception) may be relatively preserved in the initial stages of the disease.

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. 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 cases <65 y/o 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.

(North West Coast Strategic Clinical Network, 2018)

https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf

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. (North West Coast Strategic Clinical Network, 2018)

https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf

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 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 (National Institute for Neurological Disorders and Stroke) Dementias | National Institute of Neurological Disorders and Stroke (nih.gov)

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. There is spongiform degeneration in the brain seen. (North West Coast Strategic Clinical Network, 2018) https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf

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 (North West Coast Strategic Clinical Network, 2018) https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf

Dementia in people with Down's syndrome

Those with Down's syndrome are at higher risk than the general population to develop dementia. The detection and diagnosis of this condition are particularly important, given its effect on cognitive and functional abilities. It is thought the higher rates of dementia in those with Down's syndrome is due to the triploid of the gene coding for Amyloid precursor protein (the protein linked to plaque deposition in Alzheimer's) on Chromosome 21 which leads to increase amounts of protein deposition in the brain at an earlier age in those with the condition, 30% of those with Down's syndrome will have Alzheimer's dementia in their 50's which increases to around 50% of those in their 60's. In those with Down's syndrome the presentation of dementia can be different and functional, personality and behavioural changes may be the initial things noticed rather than memory loss. Early symptoms may include:

- Reduced interest in being sociable, conversing or expressing thoughts.
- Decreased enthusiasm for usual activities.
- Decline in ability to pay attention.
- Sadness, fearfulness or anxiety.

- Irritability, uncooperativeness or aggression.
- Restlessness or sleep disturbances.
- Seizures that begin in adulthood.
- Changes in coordination and walking.
- Increased noisiness or excitability.

(North West Coast Strategic Clinical Network, 2018) https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf ; (Alzheimer's Association) Down Syndrome and Alzheimer's | Symptoms & Treatments | alz.org

Alcohol related Brain Damage (Dementia) ARBD

Alcohol related dementia is an alcohol related brain damage, this differs from alcohol related brain injury-which is a reversible condition that the cognitive and functional impairment is observed to improve with cessation of alcohol consumption. Alcohol related brain damage is a permanent cognitive and functional impairment secondary to alcohol consumption.

Symptoms include difficulties with:

- staying focused on a task without becoming distracted
- solving problems, planning and organising
- setting goals, making judgements and making decisions
- being motivated to do tasks or activities (even essential ones like eating or drinking) controlling their emotions – they may become irritable or have outbursts
- understanding how other people are thinking or feeling (their behaviour may seem insensitive or uncaring).

The symptoms can vary from person to person due to the area of the brain most damaged. Typically on neuroimaging you see frontal predilection to brain atrophy associated with alcohol. When there is frontal lobe dysfunction symptoms seen include unusual behaviours (including disinhibition), emotional problems, trouble communicating, difficulty problem solving and planning, or difficulty with walking. (Alzheimer's Society a) Alcohol-related brain damage (ARBD): what is it and who gets it? | Alzheimer's Society (alzheimers.org.uk)

Unlike other forms of dementia ARBD is not necessarily progressive, if a person stops drinking and receives thiamine treatment the cognitive impairment may be halted. There is a related condition known as Alcohol related brain injury (ARBI) when the cognitive and functional impairment observed improves with abstinence from alcohol.

However should the person affected continue to drink when diagnosed with ARBD their cognitive and functional impairment will worsen or it may progress if there is another underlying dementia process occurring concurrently e.g. Alzheimer's or vascular dementia in which case they would be experiencing a mixed dementia.

Wernick Korsakoff Syndrome

Is brain damage caused by Vitamin B1 (Thiamine) deficiency, typically associated with excess alcohol consumption, although there are other dietary or absorption problems leading to Thiamine deficiency.

This syndrome has two stages the acute stage- Wernicke's encephalopathy- this is a medical emergency and if treated with parental thiamine permanent cognitive and functional impairment can be prevented.

Korsakoff's syndrome 'dementia' is the long-term condition resultant from untreated or delayed treatment of Wernicke 's Encephalopathy.

The main symptoms of Korsakoff's syndrome are confusion and memory loss – particularly memory of events that happened after the person developed the condition.

Because the person is less able to form new memories, they may also repeat the same question several times. For some people with the condition, memories of the more distant past can also become lost or distorted.

Other symptoms of Korsakoff's syndrome can include:

- difficulty understanding new information or learning new skills
- changes in personality – the person may become apathetic (lacking emotional reactions), become very talkative, or do the same things over and over
- lack of insight into the condition – even a person with large gaps in their memory may believe their memory is working normally
- confabulation – a person's brain may fill in the gaps in their memory with things that didn't happen. For example, a person who has been in hospital for several weeks may talk about having just visited a person or a place earlier that day (this is more common in the early stages of the condition). It is important to remember that the person thinks this is a real memory. It may seem as if they are purposefully lying – but often this isn't the case
- problems with concentration, planning, making decisions or solving problems.

(Alzheimer's Society b) Wernicke–Korsakoff syndrome | Alzheimer's Society (alzheimers.org.uk)

Psychiatric symptoms common in dementia

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.

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.

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).

(North West Coast Strategic Clinical Network, 2018)

https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/palliative-care-guidelines-in-dementia.pdf

Progression of dementia

Dementia is a life-limiting condition and there is no treatment available to cure dementia or to alter its progressive course (Dementia: key facts. World Health Organization. https://www.who.int).

There is progressive deterioration that can be considered as three stages, although the rate of deterioration varies between individuals (World Health Organisation, WHO, 2012) Dementia: a public health priority

Early stage (mild) — lasts years 1–2. This stage may be overlooked. Onset is gradual, and features include becoming forgetful, communication difficulty, losing track of time, difficulty making decisions.

Middle stage (moderate) — lasts years 2–5.Limitations become clearer and more restricting. Features include becoming very forgetful, increasing communication difficulty, help needed with personal care, unable to prepare food, behaviour changes.

Late stage (severe) — from year 5 and later. Near-total dependence and inactivity. Features include very serious memory disturbances, more obvious physical features, unaware of time or place, difficulty understanding what is happening around them, unable to recognize relatives and friends, unable to eat without assistance and may become non-verbal.

Of all deaths registered in 2022 in England and Wales, 65,967 (11.4%) were due to dementia and Alzheimer's disease. This makes Dementia and Alzheimer's disease are the leading cause of death in England and Wales. It is the leading cause of death in females with 15% of death in females and second most common cause of death in males with 8% of deaths in England and Wales in 2022 (ONS,2023b) Death registration summary statistics, England and Wales - Office for National Statistics

One of the most difficult aspects of caring for those with dementia and for families and carers is the considerable variation in the time from presentation to death. This big prognostic variability is in part due to variability of the disease progression between individuals. Generally people diagnosed in their late 60s to early 70s have a median lifespan of 7–10 years, this reduces to 3 years for those diagnosed in their 90s (Schott, J.M, 2020)

A longitudinal population-based study (the Kungsholmen project) found that Women survive longer in the severe stage of dementia than men (2.1 years for women aged 75–84 years compared to 0.5 years for men of the same age (Rizzuto et al, 2012)

Dementia has been found to progress more rapidly following an episode of delirium (Fong et al, 2009; Young et al, 2011).

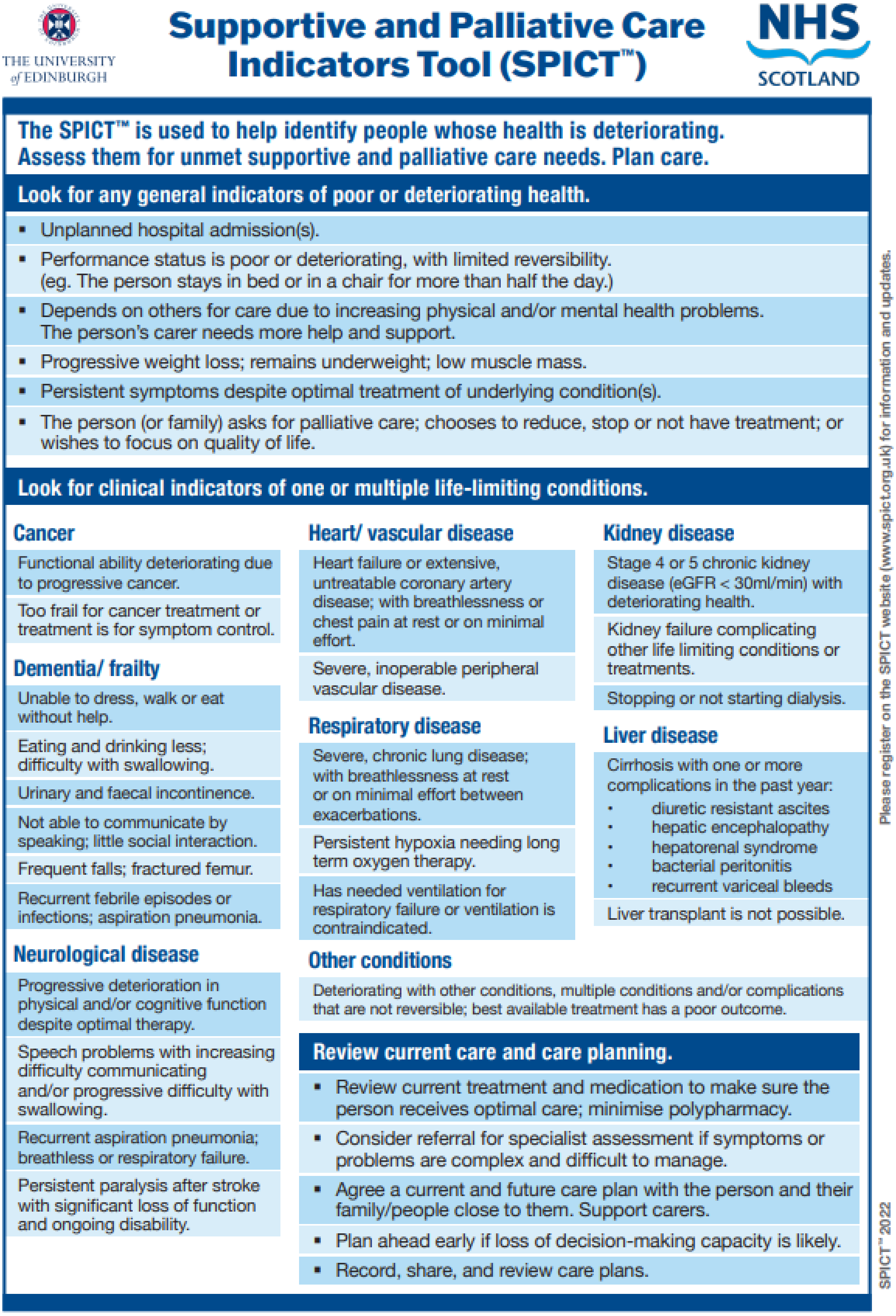
Prognostication tools

Due to the sometimes protracted and unpredictable decline in the disease trajectory, recognising the terminal phase is a challenge for patients with Dementia and therefore it can be difficult to accurately identify people in need of end-of-life care.

However some identification tools have been developed and research has demonstrated that tools that rely on a chronological disease trajectory are less useful for people with advanced dementia, and recent research has identified lack of consistency in how end of life in dementia is defined, and therefore there is a call to move beyond prognostication to a needs-based approach to identify those who are end of life and in need of palliative care intervention.

One such need based tool is the Supportive Palliative Care Indicators Tool (SPICT™) (University of Edinburgh, 2022) which can support the identification of people with advanced health conditions who are at risk of deteriorating and dying. It lists general indicators of deteriorating health to look for, and advises looking for clinical indicators of one or more advanced conditions The SPICT™ – SPICT

Supportive and Palliative Care Indicator Tool (SPICT)



THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS SCOTLAND

**The SPICT™ is used to help identify people whose health is deteriorating.
Assess them for unmet supportive and palliative care needs. Plan care.**

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems. The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Urinary and faecal incontinence.

Not able to communicate by speaking; little social interaction.

Frequent falls; fractured femur.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with breathlessness at rest or on minimal effort between exacerbations.

Persistent hypoxia needing long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping or not starting dialysis.

Liver disease

Cirrhosis with one or more complications in the past year:
- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is not possible.

Other conditions

Deteriorating with other conditions, multiple conditions and/or complications that are not reversible; best available treatment has a poor outcome.

Review current care and care planning.

- Review current treatment and medication to make sure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family/people close to them. Support carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, share, and review care plans.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™ 2022

The Necesidades Paliativas NECPAL CCOMS-ICO© tool The Necesidades Paliativas NECPAL CCOMS-ICO© tool (WHO, 2011) Microsoft Word - NECPAL TOOL_ENG_VF (gencat.cat) This has been developed to identify patients with chronic advanced diseases who would benefit from a palliative approach to their care. It has the following sections, comprising yes or no questions:

- *The Surprise Question: would you be surprised if this person dies within the next twelve months?*
- *Choice/request or need: has the patient or caregiver requested palliative care, or do you consider that the patient requires palliative care at this moment?*
- *General clinical indicators of severity and progression, covering nutritional markers, functional markers, other markers of severity and extreme frailty, use of resources and co-morbidity.*
- *Specific indicators of severity and progression for the following diseases: cancer, COPD, chronic heart disease, chronic neurological diseases, serious chronic liver disease, serious chronic renal disease, dementia*

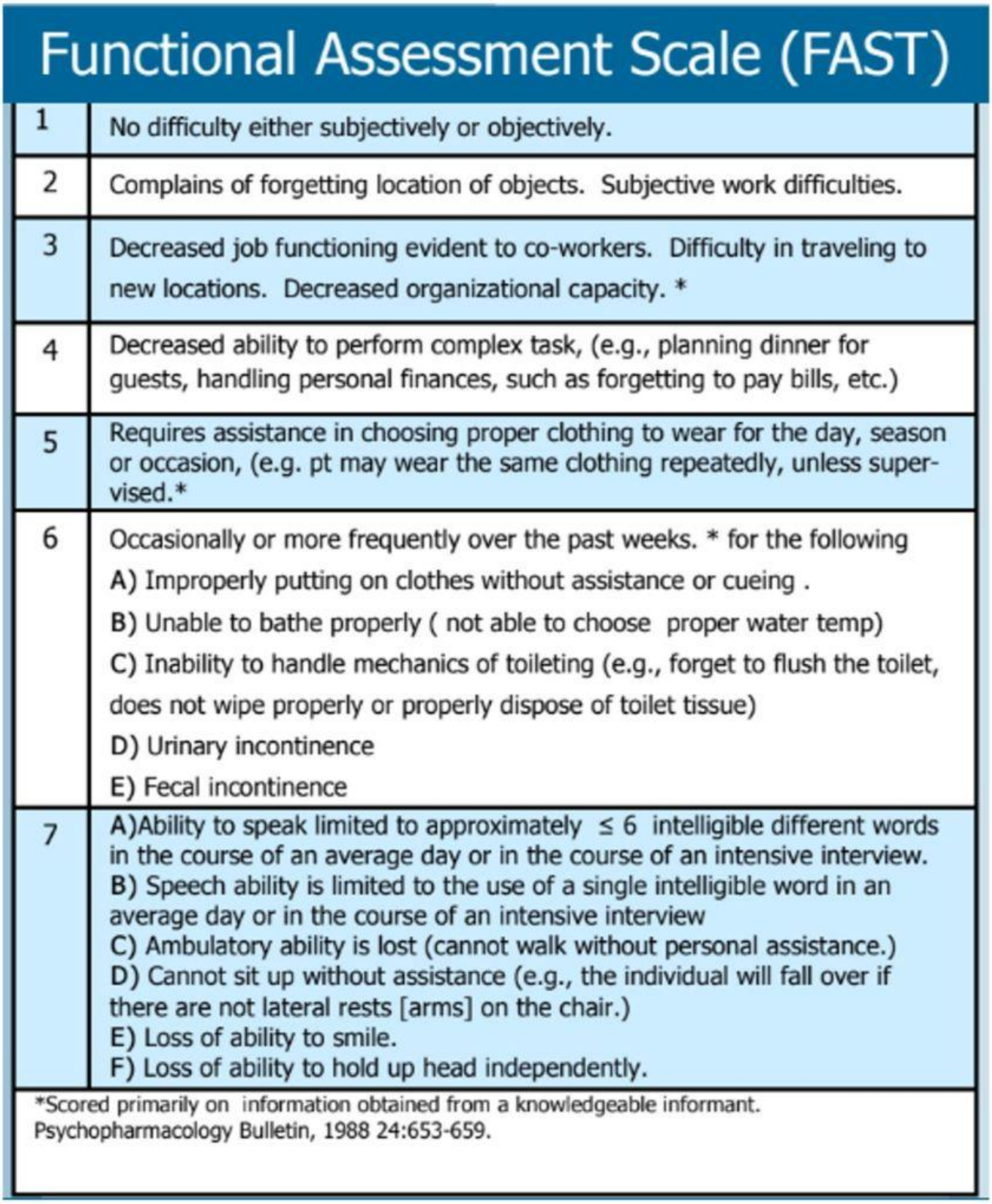
A person is identified as requiring palliative care if the answer to the first question is no, and the answer to at least one other question is yes. It is based on SPICT™ (University of Edinburgh, 2022) and the Gold Standards Framework Prognostic Indicator Guidance © (National Gold Standards Framework Centre in End of Life Care, 2016).

The FAST scale is a functional scale (Rush, B, 2023)
Has been designed to assess people at the more moderate to severe stages of dementia when cognitive testing can no longer indicate changes in a meaningful clinical way. A person in the earlier stages of dementia may be able to participate in the assessment, but usually the information should be collected from someone who knows the individual very well, or, if the person is a care home resident, from the care home staff.

The scale has seven stages:

1. normal adult with no cognitive decline
2. normal older adult with very mild memory loss
3. early dementia
4. mild dementia
5. moderate dementia
6. moderately severe dementia
7. severe dementia

A study of the reliability, validity, and progressive ordinality of FAST found that is a reliable and valid assessment technique for evaluating functional deterioration in people with Alzheimer's disease throughout the entire course of the illness both in community and hospital/hospice settings.
(© Healthcare Improvement Scotland, 2018) palliative-care-identification-tools-comparator.pdf (ihub.scot)



Functional Assessment Scale (FAST)

1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless supervised.*
6	Occasionally or more frequently over the past weeks. * for the following A) Improperly putting on clothes without assistance or cueing . B) Unable to bathe properly (not able to choose proper water temp) C) Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) D) Urinary incontinence E) Fecal incontinence
7	A)Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. B) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview C) Ambulatory ability is lost (cannot walk without personal assistance.) D) Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) E) Loss of ability to smile. F) Loss of ability to hold up head independently.

*Scored primarily on information obtained from a knowledgeable informant.
Psychopharmacology Bulletin, 1988 24:653-659.

Delirium

Dementia is the biggest single risk factor for developing delirium

What is delirium?

Delirium is an acute confusional state that presents typically as a fluctuating syndrome of encephalopathy leading to altered levels of consciousness, disturbances in attention, cognition and perception (NICE,2023a) Delirium | Health topics A to Z | CKS | NICE

It generally develops over a period of hours or days and causes changes in the person's behaviour, personality, mood and risk to themselves and others. Psychotic symptoms may occur quite commonly without a past history of functional psychotic disorder (NICE, 2024a) (Definition | Background information | Dementia | CKS | NICE).

It is triggered by medical illness, surgery, trauma or drugs, but typically its cause is multifactorial (Marcantonio, 2017). There are many predisposing factors for developing delirium, these include older age, dementia, frailty, the presence of multiple comorbidities, male, sensory impairments, a history of depression, a history of delirium, and alcohol misuse. (Marcantonio, 2017; Persico et al, 2018).

There are three subtypes of delirium;

Hyperactive:

- restlessness or agitation, such as being unable to stay still or pacing;
- resist or respond aggressively to personal care;
- not understand where they are, or what time or day it is;
- seem unusually wary of other people;
- have delusions, such as thinking that people are trying to harm them;
- have hallucinations, such as seeing someone next to the bed who isn't really there.

Hypoactive:

- withdrawn, sluggish or tired;
- move around less;
- interact less with people around them;
- be unusually sleepy;
- struggle to stay focused when they're awake;
- eat or drink less than usual.

Mixed: combination of the two above observed in the same individual. This can vary day to day and even within the same day (Alzheimer's Society c) Delirium - symptoms, diagnosis and treatment | Alzheimer's Society

The hyperactive subtype is most easily recognizable for obvious reasons, but it is in fact hypoactive delirium that is the most common subtype and is often times overlooked.

Delirium is common both in palliative care patients but also patients with dementia and it may be a case that a patient who has dementia is presenting with a delirium on the background of dementia progression to end stages of dementia with reducing oral intake in the weeks to months prior to your assessment, and this episode may therefore be their terminal event.

However, there are some patients in end stages of dementia who experience delirium with a poor prognosis who do improve and can continue to live for weeks to months after the episode.

It can be difficult to identify which of these outcomes will be the case for your patients and this makes prognostication difficult, it may be case that for some patients they are diagnosed as dying who do improve and others who don't. This is when your excellent communication skills in having difficult conversations about the "grey areas" and the unknown with families and carers comes in. It is so important to open and honest in the difficulties in predicting death for those with dementia. It can be helpful to advise that the patient's situation will be reviewed regularly and dying can be undiagnosed if appropriate and syringe drivers can be stopped in these instances, but all the while reinforcing that important and primary focus of the care of the individual being that of maintaining comfort and dignity whatever the outcome is.

Why is delirium identification important?

Delirium is important due to the significant morbidity and mortality associated with it. Delirium can double a patient's risk of dying compared to that of a patient with the same medical condition without co-morbid delirium, this risk remains at being twice as likely to die up to 12 months post hospital discharge (NICE,2023) Delirium | Health topics A to Z | CKS | NICE

Delirium can lead to the following complications:

- Increased mortality
- Increase length of stay in hospital
- Increased rates of healthcare associated infections
- Increase readmission rates, increased rates of discharge to 24-hour care
- Increased incidence of dementia- it is possible that those who experience frequent or prolonged deliriums have an underlying neurodegenerative change as seen in dementia. The delirium can "unmask" this, rather than the delirium causing dementia.
- Falls
- Pressure sores
- Continence issues
- Malnutrition
- Functional impairment
- Distress for the individual, carers and families.

Not only are these complications significant in themselves but they have wider implications for health and social care when you consider the prevalence of delirium in health care settings.

Despite the well documented and researched area of rates of delirium. Delirium is frequently missed in routine clinical care and lack of detection is associated with poorer outcomes. (LaMantia et al, 2014; Neto et al, 2012).

Delirium detection and identification should ideally be undertaken at the earliest opportunity. Numerous assessment tools have been developed to help identify probable delirium in patients in a variety of settings, which can then prompt a more accurate diagnosis and consideration of underlying causes. For practical reasons like implementation and acceptability to patients and practitioners, assessment tools should be brief, require little or no training and be appropriate to the clinical setting (Hendry et al, 2016). The sensitivity of the tool is very important, as it is vital not to miss delirium as ultimately prompt recognition improves patient safety and reduced morbidity and mortality (NICE,2023b) Overview | Delirium: prevention, diagnosis and management in hospital and long-term care | Guidance | NICE

Delirium Assessment Tools-4AT

(MacLullich, Ryan, Cash) 4AT - Rapid Clinical Test for Delirium Detection

Alertness	Normal	0
	Mild sleepiness for <10 seconds after waking, then normal	0
	Clearly abnormal	4
AMT 4 Age, date of birth, place (name of hospital or building), current year	No mistakes	0
	1 mistake	1
	≥2 mistakes or untestable	2
Attention*	Lists ≥7 months correctly	0
	Starts but lists <7 months, or refuses to start	1
	Untestable (cannot start because unwell, drowsy, inattentive)	2
Acute change or fluctuating course**	No	0
	Yes	4

*Instruct patient to list months in reverse order, starting at December.

**Evidence of significant change or fluctuation in mental status within the last 2 weeks and still persisting in the last 24 hours.

4AT Score	**Level of impairment**
≥4	Possible delirium and/or cognitive impairment
1–3	Possible cognitive impairment
0	Delirium or severe cognitive impairment unlikely (but delirium still possible if "acute change or fluctuating course" information is incomplete)

MD+CALC 4 A's Test for Delirium Screening (mdcalc.com)

An inability to engage with cognitive testing indicates severe inattention – this is diagnostic of delirium.

A score of 4 or more suggests delirium but is not diagnostic: more detailed assessment of mental status may be required to reach a diagnosis.

A score of 1-3 suggests cognitive impairment and more detailed cognitive testing and informant history-taking are required.

Items 1-3 are rated solely on observation of the patient at the time of assessment.

Item 4 requires information from one or more source(s), e.g. your own knowledge of the patient, other staff who know the patient (e.g. ward nurses), GP letter, case notes, carers.

The tester should take account of communication difficulties (hearing impairment, dysphasia, lack of common language) when carrying out the test and interpreting the score.

Alertness: Altered level of alertness is very likely to be delirium in general hospital settings. If the patient shows significant altered alertness during the bedside assessment, score 4 for this item. AMT4 (Abbreviated Mental Test - 4): This score can be extracted from items in the full AMT if done immediately before.

Acute Change or Fluctuating Course: Fluctuation can occur without delirium in some cases of dementia, but marked fluctuation usually indicates delirium.

To help elicit any hallucinations and/or paranoid thoughts: ask the patient questions such as, "Are you concerned about anything going on here?"; "Do you feel frightened by anything or anyone?"; "Have you been seeing or hearing anything unusual?" In general, new psychotic symptoms most often reflect delirium rather than functional psychosis (such as schizophrenia) in patients with dementia, palliative care or in acute hospital settings, unless there is a previous history of functional psychotic illness (MacLullich, Ryan, Cash) 4AT - Rapid Clinical Test for Delirium Detection

The 4 'A's test is a screening tool for delirium that can also be used to identify pre-existing cognitive impairment. The tool was developed in 2010 after a review of screening tools available in this area. (NICE, 2020) 2020 exceptional surveillance of delirium: prevention, diagnosis and management (NICE guideline CG103)

Treatment for delirium

There are no pharmacological treatments that hasten a patient's recovery from delirium, the mainstay of delirium management is to address the underlying reversible factors and non-pharmacological approaches to reduce distress, agitation and support engagement with nutrition, hydration and cares.

There are however times when the level of distress the patient is experiencing, and or the risks they are posing to themselves or others are such that the use of medications to manage the symptoms of the delirium is warranted based on a risk versus benefits decision, which should always be discussed with the family or carers of the patient.

Psychotic symptoms- hallucination/delusions in delirium are common and their presence alone does not mean that the patient should receive medication management, instead a risk versus benefit assessment of the impact the psychotic symptoms are having on the patient should be carried out, looking at the following:

- nutrition and hydration-are they paranoid about staff poisoning them and therefore not eating and drinking;
- concordance with medications- again is their paranoia leading them to refuse medications;
- do they pose a risk to themselves (unintentional harm to self-due to severe confusion, deliberate self-harming behaviours, suicidal ideation) or
- do they pose a risk to others- do they feel they need to protect themselves from others be that staff, family members or other patients/residents;
- are they very distressed by their experiences

If on balance it is felt that impact of these symptoms in any of the above areas is such that the safety, comfort, dignity and quality of life of the patient is compromised then it may be that a decision to prescribe medications is made in the knowledge that these too come with risks which should be communicated with the families and carers.

These medications should be prescribed at the lowest effective dose and for the shortest duration. They should be reviewed regularly and stopped as soon as no longer clinically indicated or if it is felt the risks versus benefit balance has changed.

If it is proving difficult to assess a patient's level of agitation, or if there are any doubts as to whether a patient's agitation is severe enough to warrant use of medication, then The SGH Delirium guidelines advocate the use of the Richmond Agitation Sedation Score modified for palliative care patients (RASS-PAL) can prove a useful tool.

Richmond Agitation Sedation Scale – Palliative Version (RASS-PAL) (Bush et al, 2014)

If the patient's RASS-PAL score is +3 or more then pharmacological treatment may be appropriate. The RASS-PAL can also be used to monitor response to any medication used by repeating the score 1 hour after medication is administered.

Score	**Term**	**Description**	
+4	Combative	Overtly combative, violent, immediate danger to staff (e.g. throwing items); +/- attempting to get out of bed or chair	
+3	Very agitated	Pulls or removes lines (e.g. IV/SQ/Oxygen tubing) or catheter(s); aggressive, +/- attempting to get out of bed or chair	
+2	Agitated	Frequent non-purposeful movement, +/- attempting to get out of bed or chair	
+1	Restless	Occasional non-purposeful movement, but movements not aggressive or vigorous	
0	Alert and calm		
-1	Drowsy	Not fully alert, but has sustained awakening (eye-opening/eye contact) to *voice* **(10 seconds or longer)**	Verbal stimulation
-2	Light sedation	Briefly awakens with eye contact to *voice* **(less than 10 seconds)**	
-3	Moderate sedation	Any movement (eye or body) or eye opening to *voice* **(but no eye contact)**	
-4	Deep sedation	No response to voice , but any movement (eye or body) or eye opening to *stimulation by light touch*	Gentle Physical stimulation
-5	Not rousable	No response to *voice or stimulation by light touch*	

Procedure for RASS-PAL Assessment

1. Observe patient for **20 seconds.**	Score 0 to +4
a. Patient is alert, restless, or agitated **for more than 10 seconds**	
NOTE: If patient is alert, restless, or agitated for less than 10 seconds and is otherwise drowsy, then score patient according to your assessment for the majority of the observation period	
2. If not alert, greet patient and call patient by name and *say* to open eyes and look at speaker.	
b. Patient awakens with sustained eye opening and eye contact **(10 seconds or longer).**	Score -1
c. Patient awakens with eye opening and eye contact, but not sustained **(less than 10 seconds).**	Score -2
d. Patient has any eye or body movement in response to voice but no eye contact.	Score -3
3. When no response to verbal stimulation, physically stimulate patient by light touch e.g. gently shake shoulder.	
e. Patient has any eye or body movement to gentle physical stimulation.	Score -4
f. Patient has no response to any stimulation.	Score -5

Cognitive assessment tools to assess longer term cognitive impairment.

You will likely come across patients who you note have cognitive impairment or upon carrying out a 4AT- score 1-3 which indicates possible underlying cognitive impairment but not delirium.

For these individuals they may not necessarily have a diagnosed dementia already and it can be of benefit to carry out objective cognitive testing to determine whether there is a cognitive impairment present which can provide a good baseline test for when you either are discussing with liaison psychiatry, GPs for consideration of memory service referral/ DiaDEM diagnosis (see p.28 for further details on this) or referral to community mental health teams.

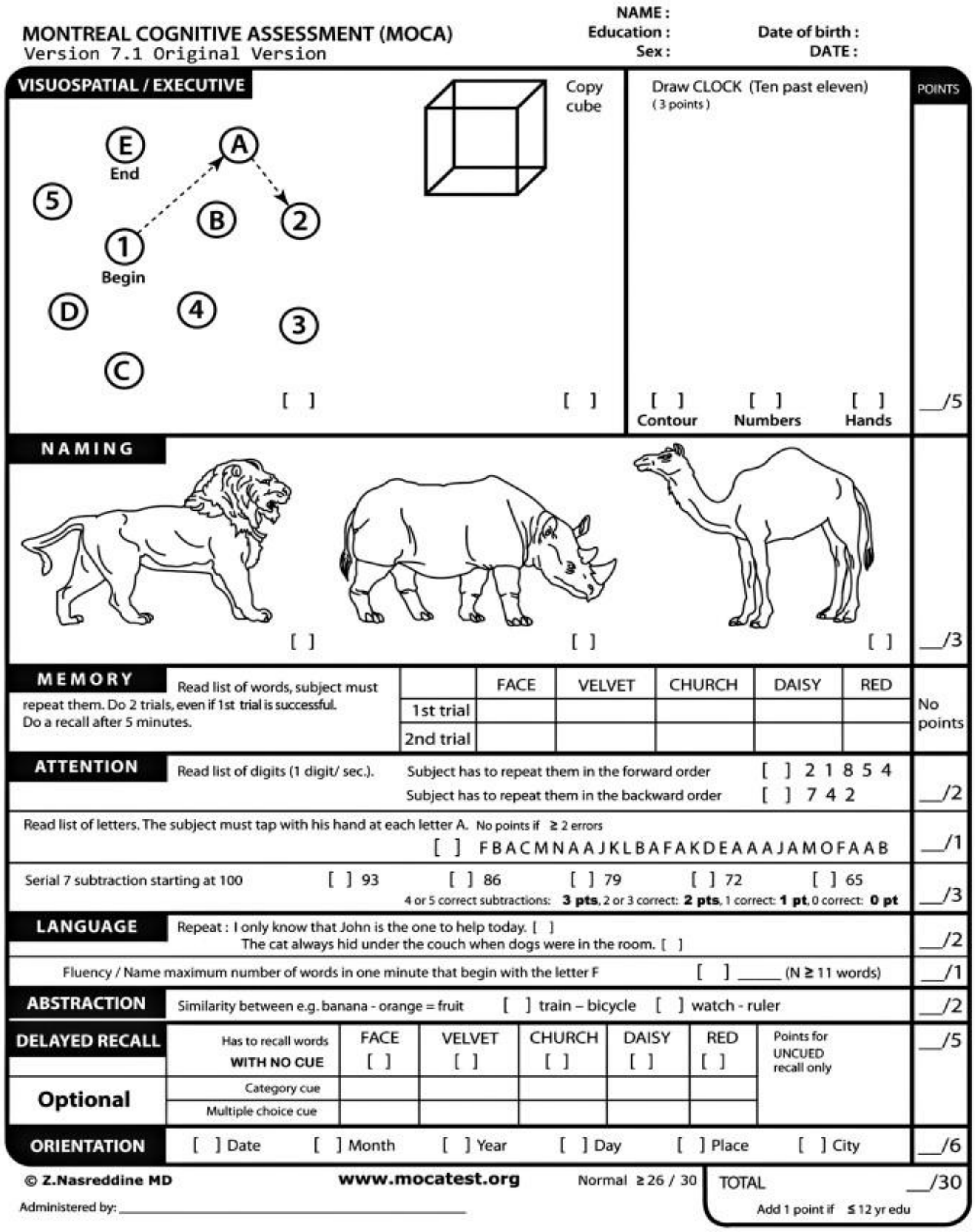
Montreal Cognitive Assessment- (MoCA) mocacognition.com

Montreal Cognitive assessment is an objective cognitive assessment tool that can identify cognitive impairment, it is not specific to dementia.

It tests multiple areas of cognitive ability and is available in multiple languages, in deaf and blind versions as well as versions designed for those with lower educational attainment levels.

MoCAs can be completed by many different health professionals, however interpretation of the meaning of results is advised to be done by those with expertise in the cognitive field as it is not specific to dementia, there may be other causes for a low MOCA score.

Montreal Cognitive Assessment- (MoCA)



MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME :
Education :
Sex :
Date of birth :
DATE :

		POINTS
VISUOSPATIAL / EXECUTIVE [ ]	Copy cube [ ]	Draw CLOCK (Ten past eleven) (3 points) [ ] Contour [ ] Numbers [ ] Hands	___/5

NAMING [ ] [ ] [ ] ___/3

MEMORY Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED	
1st trial						No points
2nd trial						

ATTENTION Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4
Subject has to repeat them in the backward order [ ] 7 4 2 ___/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B ___/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65 ___/3
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**

LANGUAGE Repeat : I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ] ___/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words) ___/1

ABSTRACTION Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler ___/2

		FACE	VELVET	CHURCH	DAISY	RED		
DELAYED RECALL	Has to recall words **WITH NO CUE**	[ ]	[ ]	[ ]	[ ]	[ ]	Points for UNCUED recall only	___/5
Optional	Category cue							
	Multiple choice cue							

ORIENTATION [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City ___/6

© Z.Nasreddine MD **www.mocatest.org** Normal ≥26 / 30 TOTAL ___/30
Add 1 point if ≤ 12 yr edu

Administered by: ________________________________

19-25 = mild cognitive impairment,

10-17= moderate cognitive impairment

less than 10= severe cognitive impairment.

Tools to diagnose Dementia

Dementia is a clinical syndrome characterized by permeant and progression cognitive impairment that affects a person's ability to function day to day. As such the diagnosis is a clinical one, made based upon clinical history including collateral history, clinical presentation, objective cognitive testing and neuroradiological findings- the purpose of neuroimaging is to help determine the subtype of dementia. All dementia diagnoses are clinical, as there is no definite test to confirm dementia. So, in fact all diagnosis of Dementia are probable, the only definitive test is through brain biopsy and that will only determine presence of underlying neurological pathophysiology not the clinical syndrome during life.

Typically, dementia diagnoses are made by memory services and are made by Old Age Psychiatrist. This is due to the funding for the assessment diagnosis and initial treatment of dementia being provided to mental health services nationally. However, there are times when Neurologists may make this diagnosis, as well as Geriatricians.

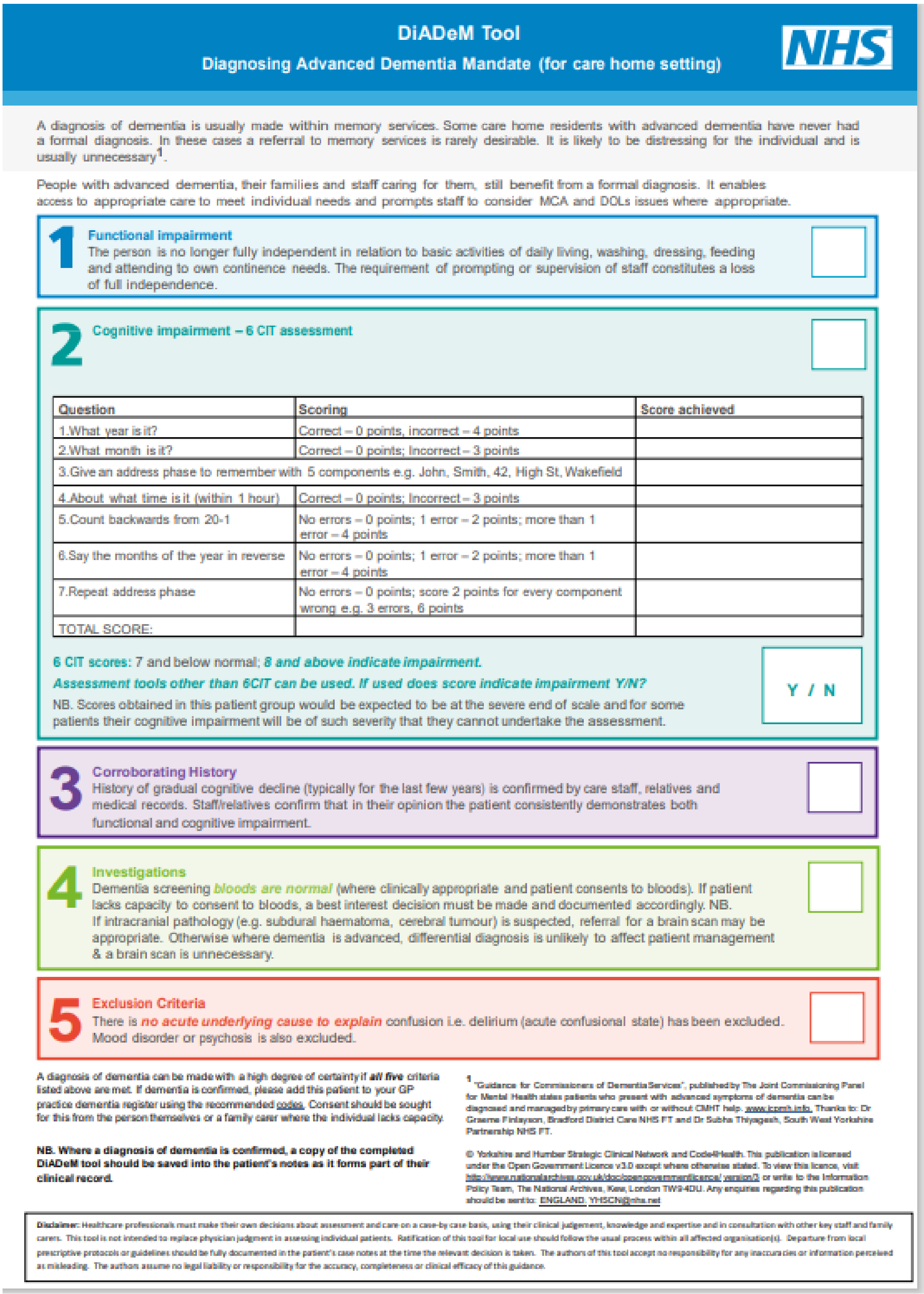
It is important to note that memory services are purely diagnostic services, they do not retain a caseload of patients to regularly review and monitor the progression of the syndrome. This is due to their capacity to meet the demand for diagnostic assessments preventing long term follow up. Therefore, a patient will receive a diagnosis of dementia and initiate medications as applicable and typically be discharged to GP care if there are no issues with the medications or problems warranting a Community Mental Health team referral. So, you may come across patients who had not been seen regarding their dementia by secondary level Mental Health Services since their diagnosis and have been receiving their annual dementia review in primary care.

In saying this there are occasions when people may not be seen by secondary levels services (Psychiatry/Neurology/Elderly Medicine) to receive a dementia diagnosis. This is usually those patients who have been living in 24-hour care environment for some time and have cognitive impairment that has been corroborated by care staff as being progressive over the time they have been caring for the individual. In these instances, a referral to memory services for a diagnosis is not always required. In Leeds GPs can review the patient with the use of the DiaDem tool and make a diagnosis of probable dementia.

It may be that if you have a patient who you are seeing, and they fit the above description, and it would be of benefit liaising with their GP to request they review their cognitive impairment with the DiaDem tool/framework in mind.

Even in advance stages of cognitive impairment it is important to seek a formal diagnosis of dementia for your patients as it can enable them in accessing appropriate care to meet to their needs, as it can help those involved in their care understand their needs and difficulties and this in turn leads to person centred care. It will also prompt those involved in the patient's care to keep the Mental Capacity Act and Deprivation of Liberty Safeguards in mind.

Diagnosing Advanced Dementia- DIADem Tool (Yorkshire & Humber Dementia Clinical Network, 2015)



DiADeM Tool

Diagnosing Advanced Dementia Mandate (for care home setting)

NHS

A diagnosis of dementia is usually made within memory services. Some care home residents with advanced dementia have never had a formal diagnosis. In these cases a referral to memory services is rarely desirable. It is likely to be distressing for the individual and is usually unnecessary[1].

People with advanced dementia, their families and staff caring for them, still benefit from a formal diagnosis. It enables access to appropriate care to meet individual needs and prompts staff to consider MCA and DOLs issues where appropriate.

1 Functional impairment
The person is no longer fully independent in relation to basic activities of daily living, washing, dressing, feeding and attending to own continence needs. The requirement of prompting or supervision of staff constitutes a loss of full independence. ☐

2 Cognitive impairment – 6 CIT assessment ☐

Question	Scoring	Score achieved
1.What year is it?	Correct – 0 points, incorrect – 4 points	
2.What month is it?	Correct – 0 points; Incorrect – 3 points	
3.Give an address phase to remember with 5 components e.g. John, Smith, 42, High St, Wakefield		
4.About what time is it (within 1 hour)	Correct – 0 points; Incorrect – 3 points	
5.Count backwards from 20-1	No errors – 0 points; 1 error – 2 points; more than 1 error – 4 points	
6.Say the months of the year in reverse	No errors – 0 points; 1 error – 2 points; more than 1 error – 4 points	
7.Repeat address phase	No errors – 0 points; score 2 points for every component wrong e.g. 3 errors, 6 points	
TOTAL SCORE:		

6 CIT scores: 7 and below normal; ***8 and above indicate impairment.***

Assessment tools other than 6CIT can be used. If used does score indicate impairment Y/N? Y / N

NB. Scores obtained in this patient group would be expected to be at the severe end of scale and for some patients their cognitive impairment will be of such severity that they cannot undertake the assessment.

3 Corroborating History
History of gradual cognitive decline (typically for the last few years) is confirmed by care staff, relatives and medical records. Staff/relatives confirm that in their opinion the patient consistently demonstrates both functional and cognitive impairment. ☐

4 Investigations
Dementia screening ***bloods are normal*** (where clinically appropriate and patient consents to bloods). If patient lacks capacity to consent to bloods, a best interest decision must be made and documented accordingly. NB. If intracranial pathology (e.g. subdural haematoma, cerebral tumour) is suspected, referral for a brain scan may be appropriate. Otherwise where dementia is advanced, differential diagnosis is unlikely to affect patient management & a brain scan is unnecessary. ☐

5 Exclusion Criteria
There is ***no acute underlying cause to explain*** confusion i.e. delirium (acute confusional state) has been excluded. Mood disorder or psychosis is also excluded. ☐

A diagnosis of dementia can be made with a high degree of certainty if ***all five*** criteria listed above are met. If dementia is confirmed, please add this patient to your GP practice dementia register using the recommended codes. Consent should be sought for this from the person themselves or a family carer where the individual lacks capacity.

NB. Where a diagnosis of dementia is confirmed, a copy of the completed DiADeM tool should be saved into the patient's notes as it forms part of their clinical record.

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[1] "Guidance for Commissioners of Dementia Services", published by The Joint Commissioning Panel for Mental Health states patients who present with advanced symptoms of dementia can be diagnosed and managed by primary care with or without CMHT help. www.jcpmh.info. Thanks to: Dr Graeme Finlayson, Bradford District Care NHS FT and Dr Subha Thiyagesh, South West Yorkshire Partnership NHS FT.

Disclaimer: Healthcare professionals must make their own decisions about assessment and care on a case-by case basis, using their clinical judgement, knowledge and expertise and in consultation with other key staff and family carers. This tool is not intended to replace physician judgment in assessing individual patients. Ratification of this tool for local use should follow the usual process within all affected organisation(s). Departure from local prescriptive protocols or guidelines should be fully documented in the patient's case notes at the time the relevant decision is taken. The authors of this tool accept no responsibility for any inaccuracies or information perceived as misleading. The authors assume no legal liability or responsibility for the accuracy, completeness or clinical efficacy of this guidance.

DiADeM-Tool.pdf (oxfordhealth.nhs.uk)

Symptom assessment in dementia

Communication difficulties are a prominent feature in dementia, this includes both expressive and receptive (understanding) communication difficulties. Not only do patients with dementia experience communication difficulties they also experience changes in pain processing. These factors combine to create problems when the standard means of assessing pain or symptoms in medicine are attempted with patients with dementia.

Therefore, a different approach is needed when assessing symptoms in patients with dementia, we cannot solely rely on their self-reported experiences. Some patients particularly in the earlier stages will be able to accurately describe what they are experiencing or feeling, however others may not and the likelihood of an accurate self-description in later to end stages of dementia is low.

We will look at some means to assess symptoms in dementia in this section- these include symptoms assessment tools, non-medical person information leaflets (This Is Me/Understanding Me) and a systematic approach to assessing change in behaviour that is used in Psychiatry and is applicable for use in those who are end of life with dementia.

Recognising distress tools: Dis DAT (Regnard et al, 2007)

Symptoms assessment tools in dementia are difficult in terms certainty of their reliability and sensitivity in identifying the cause of agitation or distress- which is the thing that most often observed, and it is then a case of working backwards from this point to try and identify a cause for this distress/agitation or aggression that is observed.

The Distress and Discomfort tool is intended to help identify distress cues in individuals who have severely limited communication. It can be helpful to individuals assessing the patient who have not met them before or if there are times when more subtle signs of an individual's distress may not be picked up by those who do not know them well. It is a helpful tool to fill in with carers or family who know the person with dementia well and ideally in advance of an acute episode of agitation/distress, as this can provide a Baseline assessment document and enables good transfer of information helpful to other teams/people involved in the patient's care.

- If the patient is distressed and a DisDAT has been completed it can be used to compare the current signs and behaviours with those previously and provide a baseline to monitor changes.
- If the patient is distressed and a DisDAT has not been completed, if the patient is well known you can complete one with collateral from carers/family to document previous signs and behaviours and compare to those currently observed.
- If one has not been completed and the patient is unknown or collateral history is not available, it can be used to document current signs and behaviours to act as a baseline to monitor changes following interventions.

It may not be possible to complete it all at once and may need to be returned to over a period of time. It is vital that the patient is reassessed to observe the response to interventions trialled. If subtle signs are picked up early and interventions implemented crisis situations may be averted.

v22

DisDAT

Distress and Discomfort Assessment Tool

Individual's name:
DoB: **Gender:**

NHS No:

Your name:
Date completed:
Names of others who helped complete this form:

THE DISTRESS PASSPORT

Summary of signs and behaviours when content and when distressed

	When CONTENT	When DISTRESSED
Face Jaw & tongue Eyes		
Vocal sounds Speech		
Habits & mannerisms Comfortable distance		
Body posture Body observations		

Known triggers of distress (write here any actions or situations that usually cause or worsen distress)

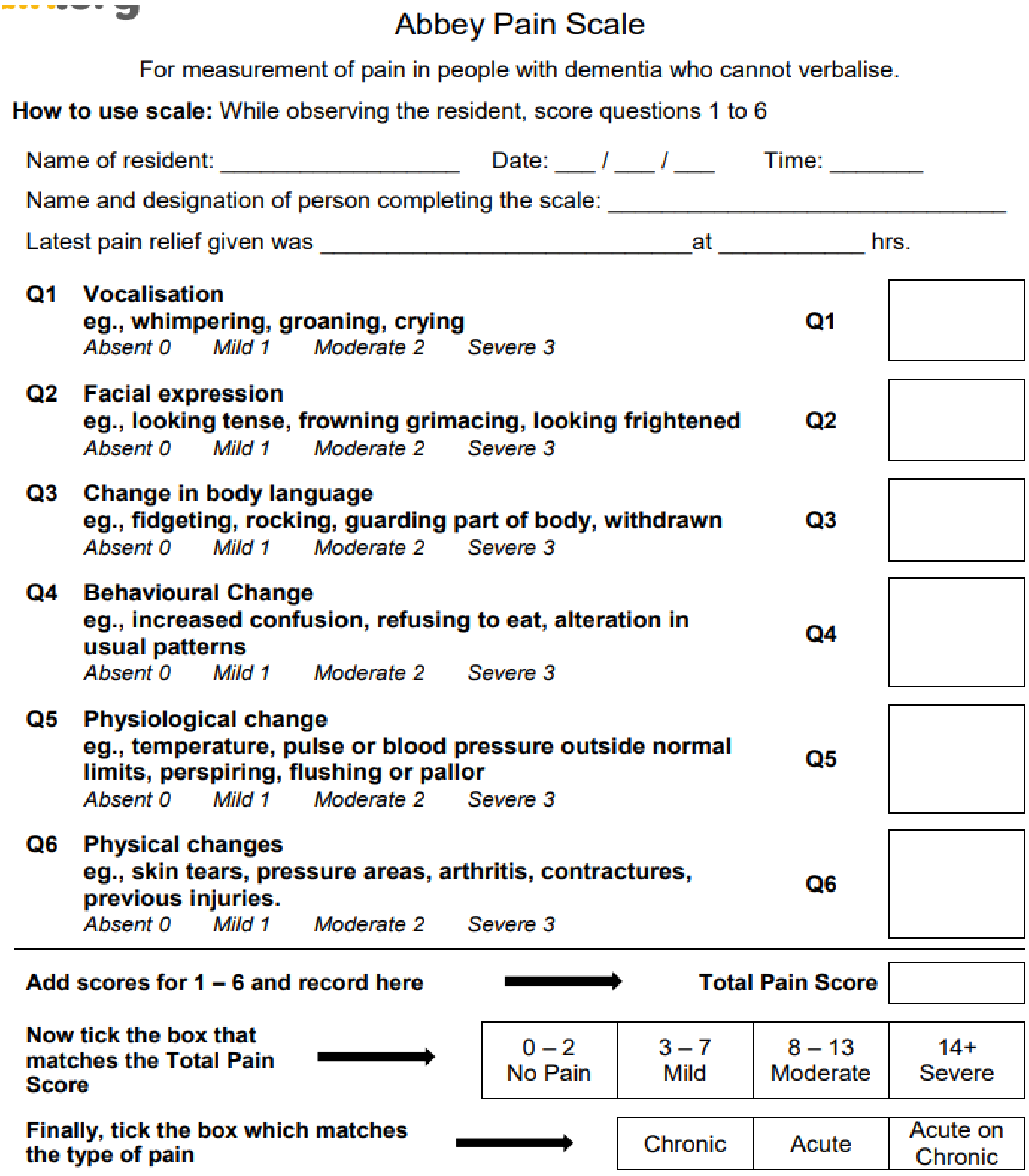
Disability (stoswaldsuk.org)

Assessing pain in dementia – Abby Pain scale: A validate pain scale that forms part of an overall assessment of pain.

It is important to note that the scale does not differentiate between pain and distress caused by other reasons. Therefore, it is important to measure the effectiveness of pain-relieving interventions as to whether an improvement or response has been achieved. The creators have recommended that it is a movement-based assessment and therefore the scale should be carried out during movement of the patient for example during pressure area care, personal cares or continence care.

The scale should be carried out immediately after the movement and document any intervention provided like analgesia, it should then be repeated one hour later to monitor the effectiveness of the intervention if no improvement further interventions should be carried out and the pain scale should be carried out hourly until the patient is comfortable.

If the distress persists despite adequate analgesia a holistic look at all facets of the patient's needs and care should be carried out and other potential causes of the distress investigated.



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: ___________________ Date: ___ / ___ / ___ Time: ________

Name and designation of person completing the scale: ________________________________

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 et al, 2004) Abbey Scale with logo.pdf (geriatricpain.org)

Cornell Scale for Depression in Dementia.(Alexopolous et al, 1998) Cornell Scale fro Depression in Dementia

Depression diagnosis in the context of dementia can be difficult. This is due to overlapping presentations at times and particularly as the disease progresses individuals may struggle to understand discussions around their feelings and internal experiences.Many symptoms that are seen in depression are also common in dementia e.g.
Apathy;
Loss of interest in previous enjoyed activities;
Social withdrawal;
Isolation;
Difficulties concentrating;
Problems thinking.

As with other end of life patients when diagnosing or recognising depression there needs to be less focus of the physical symptoms associated with depression and more consideration taken to the psychological symptoms/manifestations observed e.g. feelings of guilt, worthlessness, thoughts centring on negative things likes past traumas, losses etc.
The Cornell Scale for depression is a screening tool that can be used to identify those individuals who have dementia and may have a comorbid depression requiring further assessment. It is a caregiver rating scale and should be used in conjunction with clinician discussion with the patient.

This is me booklet

The 'This is me' booklet that is advocated by Alzheimer's Society d. This is me | Alzheimer's Society can be useful in providing clinicians with a baseline for a patient's presentation and behaviours. It helpfully includes sections on things that distress and agitate patients as well at behaviours that are observed to indicate these feelings, as well as including things that are known to have been of benefit in the past.

Similar to the DisDAT tool this is a resource that should be completed with family and carers who know the patient well.

Change in behaviour assessment:

Distress in those with dementia can manifest in many ways and many different behaviours. The communication difficulties associated with dementia can make identification of this and the cause difficult through discussion with the patient. Therefore, it can be extremely valuable to carry out a change in behaviour assessment when families or carers have highlighted changes or you yourself have noted changes.

Getting a really clear idea of what the behaviour is and gathering as much information about the behaviour and the events around it is key to trying to identify the unmet need that is driving the change in behaviour in the person with dementia.

Behaviour Diaries can be used by both formal and informal carers. They are to be used when it is unclear what the causes of distress are. Use for at least 48 hours – longer if able, 7 days can give a good overview- however this may not always be possible depending of the severity of the distress or risks associated with the behaviour or the burden on informal carers/family.

They support establishing:
- Pattern recognition for the behaviour
- Effectiveness of interventions
- Impact of the distress

It is not possible to measure the intensity of distress, but the number of distressed episodes is an indication of the impact on the person. A reduction of the number of distressed behaviours in a day would be an indication of an improved outcome.

History – what is the behaviour, when did it start, how long does it last for, how often, any triggers identifiable?

These behaviour diaries usually take the format below of looking at the behaviour and circumstances around it.

Date and Time	Environment/setting	Antecedent- what happened directly before the behaviour occurred	Behaviour- described that behaviour objectively	Consequence- what happened directly after	Possible function-
Any other notes: (e.g. wider context such as general noise level, particular people present, disruptions at home, medications)					

Whist also taking a look at the behaviours, you need to try and identify if there have been any changes that may have precipitated these.

A helpful way to try and identified reversible causes of change in behaviour in dementia can be to look at the following areas; **PPE.**

Physical health: this includes looking at the possible reversible causes in the context of Delirium using the PINCH ME mnemonic (Pain, Infection, Nutrition, Constipation, Hydration, Medication, and Environment) (British Geriatric Society, 2020)

Psychiatric health: Any concerns about mood, anxiety, delusions, hallucinations

Environment: Have there been any changes in the patient's immediate environment- this includes them moving somewhere new, new carers, noise levels, over stimulation by environment, family not visiting as regularly, the list can be endless.

Mapping out of other services, who to contact for what:

Mental Health Services: Non urgent referrals

The usual time from referral to initial assessment by a community mental health team is 14 days, they work to this as a target, it can happen earlier- however depending on staff availability/patient need it may take 14 days.

If your patient is in their own home- you would be making a referral to OPS CMHT (65+)

If your patient is in a care home- you would be making referral to the Care Homes Team.

Older People's Community Mental Health Team provide home-based care to older people experiencing complex, severe and enduring mental health problems including mood disorders, psychosis and dementia. They provide individualised assessment and treatment plans for those with Complex Mental Health Needs including those with dementia who have behavioural and psychological symptoms of dementia. Referrals are made via the single point of access forms which can be found by following this link; Leeds and York Partnership NHS Foundation Trust -Referrals to mental health services (leedsandyorkpft.nhs.uk)- depending on the urgency of the referral there are different ways to refer detailed on the web page.

On the referral it is helpful to present the referral in the SBAR framework, detailing the behaviours (e.g. agitation, aggression, wandering, disinhibition or sleep disturbance) symptoms (anxiety, depression, hallucinations or delusions) or concerns in regards to the patient's mental state that are prompting the referral or the input and advice required in relation to medication commencement or ongoing monitoring- particularly if a patient has been started on an antipsychotic. The referral should include details of risks, to the patient, to others or from others as applicable in the individual cases.

It would also be helpful to detail the reason for palliative care teams' involvement and as far as is possible outline the prognosis, as often times triage teams may see a referral coming from palliative care and wrongly assume that the patient is imminently dying and therefore surmise that there is not role of Mental Health Service input.

It is important to bear in mind that the referrals are initially sent to a single of point of access who then redirects to the appropriate Community Mental Health Team in the patient's area, the referral is then triaged by a clinician and this may involve calling the referrer or family/carers for collateral history to help understand the situation and determining the most appropriate input needed.

Some patients may have previously been known to Mental Health Services, a referral for them will be triaged again to gain understanding of current reason for referral and any significant changes to presentation. Following discussion with the MDT, consideration should then be given to either offer a review assessment, allocation to care co-ordination or signposting to an alternative service e.g., third sector organisations or Adult Social Care.

Mental Health Services: Urgent referrals

If you have urgent concerns regarding the patient's risks to themselves or others or level of distress experienced, you can make an urgent professionals' referral to The Crisis Resolution Service, they are available 24 hours a day, seven days a week.

To make an urgent referral with a same day response please contact the team by telephone on Freephone **0800 183 1485**.

You will be able to speak to a clinician who will take the referral details.

Within the urgent referral pathway the patient may be referred on to Home Based Treatment Team- a hospital at home team or Intensive Care Homes Team- these services can visit a patient daily if not multiple times a day to prevent hospital admission. They may also be referred on for a Mental Health Act assessment to assess need and appropriateness of admission to a psychiatric inpatient unit.

Palliative Liaison Service:

Any cases can be discussed with the Liaison Psychiatry Team who can provide advice or onward signposting. The result of this discussion may be an assessment by Liaison Psychiatry. They offer home visits as well as outpatient or virtual appointments.

Memory Support Workers;

Are provided through Alzheimer's UK, in Leeds referrals can be made through memory services, CMHT or GP practices, as well as contacting 0113 231 1727 memorysupport.lypft@nhs.net

They give personalised help and advice face to face or over the phone. Depending on the individual's needs, they can offer information and signposting or ongoing support regardless of whether you are worried about the patient's memory, they have a diagnosis of dementia or you can signpost carers, family or friends to access their service.

Carers Leeds:

Provide support to unpaid carers in Leeds regardless of the origin of the care need. Advice line 0113 380 4300, advice@carersleeds.org.uk

Mon-Thurs 9am- 5pm and Friday 9am to 4;40pm

They also provide drop-in session Monday-Friday 10am to 4pm at Mill 6, Ground Floor A, Mabgate Mills, Mabgate, Leeds, LS9 7DZ

Dementia UK – Admiral Nurses:

Dementia specialist nurses; provide a free telephone advice service for carers and families.

0800 888 6678, helpline@dementiauk.org or online form at this website Admiral Nurse Dementia Helpline - Dementia UK

As well as the Helpline, they offer phone or video call appointments in virtual clinics. These are available Monday to Friday between 9am and 4pm. They last 45 minutes.

Admiral Nurses can also guide and empower other health and social care professionals to support people living with dementia and their families. However, please note they **cannot** make contact directly with that person or family (unless they contact the Helpline themselves) or take third party referrals from statutory or third sector organisations. So you may need to provide the carers/families with the contact details in order for them to access Admiral Nurse support.

Dementia Specialist Admiral Nurse Service- Transition of Care service, St James's University Hospital – In collaboration with Leeds and York Partnership NHS Foundation Trust

The St James's University Hospital Transition of Care Admiral Nurse service is available to people with dementia who are experiencing complex needs, and their carers who are inpatients at St James's University Hospital Leeds or Leeds General Infirmary.

Carers of a person living with dementia who is an inpatient can refer themselves to the Admiral Nurse service by email, or can be referred by their GP or another health or social care professional working in dementia care and support. People living with dementia who are an inpatient can be referred via email by any member of the multi-disciplinary team (MDT) involved in their care.

Contact admiralnurseteam.lypft@nhs.net

service-leaflet-online-Admiral-Nurses.pdf

Dementia Mental Health Liaison Practitioners:

There are 3 working across the city. They cover the three sectors of the city: ENE, South and WNW

They work with adults over the age of 65 presenting with symptoms of mental ill health and adults with a diagnosis of dementia or cognitive deficits of any age

Patients need to be under the care of the neighbourhood teams either with the nursing team, therapy team, pharmacy or adult social care.

They are currently in the process of defining the service and what they can offer, so can't be more specific currently.

If people meet the above criteria or you wish to discuss someone with them, they can be contacted by email or phone;

Vikki McGeorge - Dementia and Mental Health Liaison Practitioner

- Beeston, Kippax, Middleton and Morley Neighbourhood Teams
- Mobile – 07980969443
- Email – vmcgeorge@nhs.net

Manvir Flora- Dementia and Mental Health Liaison Practitioner, Registered Occupational Therapist

- Chapeltown, Meanwood, Seacroft and Wetherby Neighbourhood Teams
- Tel: 07989 415658
- Working hours are: Tues – Thurs: 08:00 – 18:00, Fri: 08:00 – 17:30
-

Fiona Monier- Dementia and Mental Liaison Practitioner

- Woodsley, Yeadon, Pudsey, Armley and Holt Park Neighbourhood Teams
- Email – fiona.monier@nhs.net

- Tel: 07980957406
- Working hours: Mon – Wed: 08.00 -18.00, Thurs: 08.00 – 17.30

Adult social care:

- For initial care needs assessments,
- Reviews to look at increases in care package already in place or looking for 24 hours care placements if this is required and patient are not self-funding
- Organising planned respite care,
- Safeguarding concerns,
- Carers assessments
- 0113 222 4401

Emergency respite as an alternative to hospice or hospital admission:

Arranged through Adult social care, you need to contact in hours 0113 222 4401

Out of hours the Emergency Duty Team 0113 378 0644 edt.ss@leeds.gov.uk

The emergency duty team are available for the following;

- immediate protection from abuse, neglect, domestic violence or exploitation (safeguarding concerns)
- urgent care and they cannot wait until the next working day
- urgent help because their care arrangements have broken down, for example if their carer is not available or their equipment is broken
- an urgent assessment under the Mental Health Act

Speech and language therapists:

For swallow assessments, patients with dementia can develop unsafe swallows for many reasons, some of these are reversible, other times it may be as consequence of disease progression and is non reversible. It can be helpful to arrange a swallow assessment and review of appropriate diet particularly if the patient is not imminently dying and we want to reduce the risk of aspiration pneumonia.

Dietician

For advice regarding changes to diet and increasing calorific intake when eating patterns and preferences change as a result of dementia. It is a normal part of aging for appetite to change as people age, and this is even more noticeable in dementia, particularly patient's preferring sweeter foods than previous, as well as struggling to eat full meals, or difficulties utilising cutlery. Dieticians can help with reviewing the calorific intake needed and provide advice regarding smaller more regular meals and providing finger foods, which the patient can still eat without needing to use cutlery.

Evidence based prescribing for dementia

Acetylcholinesterase Inhibitors

These medications prevent the breakdown of the neurotransmitter Acetylcholine which improves the communication between neuronal pathways, the aim of which is to treat cognitive and behavioural symptoms of mild to moderate Alzheimer's dementia, Parkinson's disease dementia and Lewy Body dementia. (Marucci, et al, 2021).

You may also find that some patients with mixed dementia prescribed acetylcholinesterase inhibitors. These medications are only started on the advice of specialists trained in diagnosing and treating dementia.

There are three main medications in this class;

1. Donepezil- this is the most commonly prescribed medication of this class for Alzheimer's dementia and Lewy Body Dementia (off license use).
2. Rivastigmine- this is available in patch form; it is also licensed to be used in Parkinson's disease dementia and Lewy body Dementia. Sometimes this can help with the delusions/hallucinations typical if Lewy Body Dementia and avoid the need for antipsychotic prescription.
3. Galantamine- this is rarely prescribed in the UK and there is no evidence in being effective in Lewy body dementia or Parkinson's disease dementia.

It is not recommended that these are stopped purely based on progression of the disease, if there are no side effects that warrants cessation or issues around loss of swallow.

However there may come a time in the patient is no longer able to swallow these tablets and particularly if they are end of life, de-prescribing would be appropriate, ideally these should be tapered over a number of weeks however situations may mean this is not possible and you may need to warn about and observe for possible discontinuation symptoms typically these are neuropsychiatric- hallucinations, delusions, agitation, insomnia and lability of mood. If pharmacological management is required in this circumstance these symptoms may be able to be managed by alternative medications in the patient's syringe driver typically used for delirium management in end of life e.g. Haloperidol or Midazolam (Portlock, et al, 2023).

Memantine

Is a glutamate receptor antagonist, that is licensed for use in moderate dementia for those intolerant to acetylcholinesterase inhibitors or for those with severe dementia.

This can also be used in combination with an Acetylcholinesterase inhibitor for those with moderate to severe dementia (NICE, 2018) Dementia: assessment, management and support for people living with dementia and their carers

It can be prescribed to those with Lewy body dementia if Acetylcholinesterase inhibitors are not tolerated or contraindicated.

You may also come across patients with vascular dementia prescribed Memantine, and this likely will have been prescribed either because they have a mixed dementia with a vascular component or for Behavioural and Psychological symptoms of Dementia BPSDS (See below) and this decision is usually made by an Old Age Psychiatrist based on assessment and clinical decision regarding risk versus benefits for pharmacological management. There is however limited evidence to support Memantine's efficacy in management of BPSDs, and in practice it is usually trialled in an attempt to avoid antipsychotic prescription which carry a more significant risk profile.

There is limited research or evidence on the appropriate way to discontinue Memantine, but as you would when deprescribing other medications, a taper may be of benefit if possible, if not and the patient is NBM and requiring a syringe driver for symptoms management, it would be prudent to warn about possible discontinuation side effects, and monitor for these and as with Acetylcholinesterase inhibitors if pharmacological management is required management these symptoms through alternative medications typically used in delirium management in end if life. (Parsons et al 2021).

Neither Acetylcholinesterase inhibitors nor Memantine are prescribed for those with Frontotemporal dementia, as these can exacerbate behaviour symptoms associated with this dementia subtype, if disinhibition is problematic for these patients a trial of a Selective Serotonin Reuptake Inhibitors (SSRI) can be made, this would usually be done under the guidance of a psychiatrist.

Evidence based prescribing for Behavioural and Psychological Symptoms of Dementia (BPSDS)/non- cognitive symptoms:

Agitation, aggression, distress. Psychotic symptoms- hallucinations or delusions

People with dementia experience a range of symptoms. Some can affect their behaviour, others are personal, inner experiences. These include agitation, aggression, hallucinations and delusions. More than 90 per cent of people with dementia will experience BPSD as part of their illness and nearly two thirds of people with dementia living in care homes are experiencing these symptoms at any one time. Good practice recommendations, such as the NICE dementia guidelines, recommend psychosocial interventions as the first line approach and emphasise the importance of assessing medical conditions and pain, which often underpin the development of these symptoms. The value of not rushing into treatment is also important, as many people with BPSD will experience significant improvement or resolution of symptoms over a 4–6 week period (Alzheimer's Society,2011) Optimising treatment and care for behavioural and psychological symptoms of dementia: A best practice guide. Full colour version

After carrying out an assessment of the change in behaviour as detailed earlier in the toolkit. If there have been no reversible causes for a change in behaviour identified, for example pain which is the most common cause of acute behaviour change in those with dementia, who struggle to communicate their internal experiences to others. Or depending on the risks these behaviours pose to the patient or others you may have to consider pharmacological options for managing the behaviours.

Pharmacological management is only advised when non-pharmacological interventions alone have not been successful or when the risks posed to the patient or others is such that a combination of non-pharmacological and pharmacological intervention are required. (NICE, 2018) Dementia: assessment, management and support for people living with dementia and their carers

Pharmacological management options:

Acetylcholinesterase inhibitors or Memantine may be started in certain patients for BPSDs if they were not already prescribed these, however the there is no evidence that these improve agitation but may be effective through improving cognitive problems that may be driving the agitation. They are generally not trialled if the risks to the patient or others are acute.

Benzodiazepines

There is no evidence that the use of benzodiazepines carry significant benefit in the management of BPSD and their risks may more often outweigh their sedating benefits. (Alzheimer's Society, 2011) Optimising treatment and care for behavioural and psychological symptoms of dementia: A best practice guide. Full colour version

However you may see short acting benzodiazepines like Lorazepam being utilised to manage behaviours that challenge in patients with dementia who the risks of antipsychotic use greatly outweighs their benefits even in a quality of life decision, this may more common in the earlier stages of dementia rather than in the end stages or when a patient is end of life.

Benzodiazepines may also be seen to be used when the behaviours are predictable, for example a behaviour chart has been carried out and a theme has been established that certain interventions lead to increased agitation and or aggression which is not observed at other times. If the interventions are unavoidable like basic nursing care and personal care, then Lorazepam may be prescribed on as required basis to be utilised at least 30 minutes before the intervention.

Antipsychotics

These medications are to only be considered in those patients with dementia (any subtype) who are a risk to harming themselves or others, or they are experiencing agitation, hallucinations or delusions that are causing them significant distress (NICE, 2018) Dementia: assessment, management and support for people living with dementia and their carers They should only be initiated under specialist supervision.

Haloperidol and Risperidone are the only antipsychotics licensed in the UK for treating non-cognitive symptoms of dementia (NICE, 2024d) Antipsychotics | Prescribing information | Dementia | CKS | NICE

It is important to note that patients with Lewy Body dementia and Parkinson's disease dementia (PDD) are highly sensitive to extrapyramidal side effects of antipsychotic medications, causing a worsening of their motor symptoms. If antipsychotics are required for these patients, they will usually be prescribed Quetiapine and occasionally Clozapine, this is because both of these antipsychotics have less extrapyramidal side effects compared to others.

Best practice for prescribing antipsychotics in dementia is to prescribe at the lowest dose for the shortest length of time, and they must be reviewed regularly (NICE guidance is at least every 6 weeks) as to whether they are effective and need to be continued.

When antipsychotics are prescribed in dementia you are not treating the underlying cause of the agitation, hallucinations or psychosis but you are utilising the sedating effectives of these medications. As such they come with serious risks that need to be discussed thoroughly with the patient if able, families and carers in order to come to a risks vs benefit decision. These risks include falls, sedation, and reduced oral intake as a consequence of sedation; stroke and death as a direct result of being on an antipsychotic. These discussions usually involve consideration of quality of life.

A helpful decision aid for patients and their carers can be found here (NICE, 2018); NG97 Patient decision aid on antipsychotic medicines for treating agitation, aggression and distress in people living with dementia

Non-pharmacological approach to BPSD

Soothing and creative therapies

Although there is not necessarily a robust evidence base to support them, aromatherapy and massage can help to soothe, as can warm towels or smells of cooking, or having one's hair brushed or a manicure. Music can help improve a person's mood. Music from the past can bring back good memories. Singing and dancing can energise people and lift spirits. It may be helpful to try these if they are available in the care setting.

Simple non-drug treatments- These might include:

- developing a life story book
- frequent, short conversations (as little as 30 seconds has proven effective)
- using personal care as an opportunity for positive social interaction.

Sleep hygiene-It may help to consider:

- reducing daytime napping
- increasing activities during the day
- agreeing realistic expectations for sleep duration

Improving social interactions

Brief psychosocial therapies help to engage people in ways that they find interesting and enjoyable. These should generally include 10–30 minutes of daily one-to-one conversation or activity based on the person's interests, hobbies, history and ability, and feedback from their carer and/or family. Promoting positive activities and exercise. Evidence indicates that exercise and promotion of pleasant events improves physical function, cognition and mood. A range of ideas for this are presented in the Seattle Protocols

Some options include:

- exercises – gentle stretching, strength training, balance and endurance
- pleasant activities – build an understanding of the person's likes and interests to engage them in the exercise or activity
- problem solving – asking the person to suggest ways to make their exercise activity more enjoyable or effective.

Personalised activities.

Create a menu of pleasant activities that are tailored to the person and that can be completed with care staff. For example:

- looking at photographs or pictures from their past
- playing specific games or doing puzzles
- creating a scrap book or similar simple craft project
- going for a walk.

(Alzheimer's Society, 2011) Optimising treatment and care for behavioural and psychological symptoms of dementia: A best practice guide. Full colour version

Terminal agitation in dementia

There is limited research into terminal agitation specifically in dementia. Signs that typically indicate terminal agitation are:

- distressed behaviour;
- not being able to get settled;
- confusion;
- calling out, moaning, shouting or screaming;
- hallucinations;
- trying to get out of bed or wandering;
- being sleepy during the day but active at night;
- becoming harder to rouse from sleep;
- being unable to concentrate or relax, or getting easily distracted;
- rambling conversation or switching topics often;
- sometimes angry and aggressive behaviour;
- facial cues, like frowning, grimacing, and looking less peaceful;
- fidgeting, including repeatedly picking at clothes or bed sheets.

(MarieCurie, 2022) Terminal agitation at the end of life | Information for professionals

These can be remarkably similar to non-cognitive symptoms of dementia i.e. BPSDs (which are usually transient but are more common and frequent in later stages of dementia) that a person with severe dementia can experience, this is another reason why diagnosing dying in patients with dementia can be difficult.

This situation is when it is invaluable to gain a clear history from family or carer of the patient functioning and presentation prior to this point. If the general picture is one of progressive decline in functional abilities, swallowing problems, limited speech, urinary and faecal incontinence and difficulties mobilising and effectively becoming bed bound, there is a high chance that the patient is end of life and the agitation observed is that of terminal agitation and should be managed as such through both non-pharmacological and pharmacological means as needed.

Patients may require a syringe driver with medications for management of agitation, there is limited evidence on which medication is the one of choice for managing terminal agitation in dementia and this is where discussions within the MDT and with family and carers are important to devise a plan to trial a medication with the intention of improving the patient's comfort and dignity in dying.

This may mean trialling Midazolam first line or Haloperidol/ Levomepromazine depending on the patient's individual situation. As discussed above first generation antipsychotics like Haloperidol/Levomepromazine are generally advised to be avoided in Lewy body dementia/Parkinson's disease dementia due to the extrapyramidal side effects however in the end stages it may be after a trial of midazolam or on discussion with family/carers that it is felt that Haloperidol/Levomepromazine would be worth trialling, based on clinical decision and a risks versus benefits discussion with all those involved there is no reason these cannot be prescribed. But as with all patient's this will need to be review regularly to ensure that any possible extrapyramidal side effects is not worsening to a patient's pain or discomfort in their last days.

There will be some patients who present with what may appear to be terminal agitation in dementia and are started on a syringe driver, who do improve and no longer required subcutaneous medications and begin to eat and drink again and what was observed was actually reversible like a delirium or severe BPSDs.

However, at the time the diagnosis of dying was made and the syringe driver was commenced, this was not the wrong decision based upon the clinical picture and the information that was available. This is why it is important as with all patients to review the situation and any changes carefully daily and not to be afraid to 'undiagnose' dying.

This difficult area of prognostication is a time when your great communication skills as clinicians when discussing the 'grey' and uncertainties around the situation come into their own.

Legal considerations

Capacity in context of dementia and capacity assessments

In those with dementia as with all adults capacity is assumed until proven otherwise.

The Mental Capacity Act sets out a 2-stage test of capacity

1. Is there an impairment of the mind or brain, either as a result of illness or external factors e.g. alcohol or drug use?

If yes, then proceed to the next question

2. Does the impairment mean that the person is unable to make a specific decisions when they need to?

Capacity is time and decision specific; one cannot simply lack capacity generally. The conclusion regarding one's capacity must relate to a specific decision.

Capacity assessments require consideration of the following four facets:

- Is the person able to understand all the relevant information needed to make a decision
- Are they able to retain this long enough to make a decision
- Can the use or weigh up this information as part of the process- this includes both the positive and negative consequences of their decision
- Can they communicate their decision is some way.

People must be supported to make capacitous decisions and information needs to be provided in appropriate means to their communication requirements, consideration of better times of day or locations for the assessment to take place and can the decision be delayed until a time when they may be better able to make a decision. Not all of these adaptions are appropriate for people with dementia as we know that it is unlikely that their cognitive function will improve with time, however it may be a case of them experiencing an episode of delirium and their cognition may improve from the acute confusional state.

If someone lacks capacity the decision being made for them MUST be in their best interest and the following should be considered

- encourage participation – do whatever's possible to permit or encourage the person to take part
- identify all relevant circumstances – try to identify the things the person lacking capacity would take into account if they were making the decision themselves
- find out the person's views – including their past and present wishes and feelings, and any beliefs or values
- avoid discrimination – do not make assumptions on the basis of age, appearance, condition or behaviour
- Assess whether the person might regain capacity – if they might, could the decision be postponed?
- It's vital to consult with others for their views about the person's best interests.

In particular, try to consult:

- anyone previously named by the person
- anyone engaged in caring for them
- close relatives and friends
- any attorney appointed under a Lasting Power of Attorney or Enduring Power of Attorney
- any deputy appointed by the Court of Protection to make decisions for the person

Alongside the above you must also consider whether there is a least restrictive alternative, i.e. one that interferes less with their basic rights and freedoms as a human. This will involve consideration of whether there is even a need to make a decision or act at all.

Sometimes it may not be possible to choose the least restrictive option if this goes against what is in the patient's best interests.

(NHS, 2024a) Mental Capacity Act - Social care and support guide - NHS

Advance Decisions

An Advance Decision to Refuse Treatment (ADRT) can be made while you have mental capacity. It lets you choose and explain which medical treatments you do not want doctors to give you, if a time comes when you lack capacity and cannot make the decision or communicate your wishes. If you want to refuse life-sustaining treatment, you must put this in writing, sign and date it in the presence of a witness.

An ADRT is time and decision specific. It is only acted upon if it is decided, following Mental Capacity Act principles, that you lack capacity to make a specific decision at the time it needs to be made. It is legally binding if it complies with the Act, is valid and applicable.

You may hear the term 'Living Will' but it is not a legally recognised term.

To make an advance decision, you must:

- be aged 18 or over, and
- have mental capacity to make the advance decision.

In an advance decision you **cannot:**

- choose to refuse basic care that is essential to keep you comfortable, for example nursing care, pain relief, or keeping you warm;
- state you are not to be offered food or drink by mouth;
- ask for anything unlawful e.g. euthanasia or help to take your own life;
- demand specific treatment, healthcare professionals do not have to give treatment they consider clinically unnecessary, futile, or inappropriate;
- refuse treatment for a mental disorder if you meet relevant criteria to be detained under the Mental Health Act 1983.

To be valid, you must have been aged 18 or over and had mental capacity at the time you made it. Doctors must be sure you have not withdrawn it, or clearly said or done something that goes against it which would suggest you have changed your mind. They must be sure that since you made it, you have not created a Lasting Power of Attorney (LPA) for health and care decisions that gives your attorney the power to make the same treatment decisions described in the advance decision.

To be applicable, it must apply to the situation in question and in current circumstances. Doctors should consider whether there are new developments you did not anticipate at the time, which could have affected your decision, for example new developments in medical treatment, or changes in your personal circumstances. If there is doubt over the existence, validity or applicability of an advance decision, doctors can provide treatment they believe is in your 'best interests' while seeking clarification

(Age UK, 2024) Advance decisions, advance statements and living wills

Advance statement

An advance statement lets you make general statements, describing your wishes and preferences about future care, should you be unable to make or communicate a decision or express your preferences at the time. You may want it to reflect religious or other beliefs and important aspects of your life. You can include things such as food and drink preferences; type of clothes you like to wear; music, TV preferences, or whether you prefer a bath or a shower. You can say who you would like to visit you, or to be consulted about your care.

An advance statement is not legally binding but those making a 'best interests' decision on your behalf should take its contents into account when you cannot tell them what you would like.

(Age UK, 2024) Advance decisions, advance statements and living wills

Lasting power of attorney

The Mental Capacity Act 2005 introduced the system of Lasting Powers of Attorney (LPA) which replaced the Enduring Power of Attorney (EPA). Under the Act you can make an:

- LPA for financial decisions, and
- LPA for health and care decisions.

Advance decision created after LPA:

If you create an advance decision after creating an LPA for health and care, your attorney cannot consent to any treatment refused in the advance decision, if it is decided the advance decision is valid and applicable.

Advance decision created before LPA:

If you create an LPA for health and care after creating an advance decision, the advance decision will be invalid if the attorney has been given authority to make decisions about the same treatment.

(NHS, 2024b) Giving someone power of attorney - Social care and support guide - NHS; (Age UK, 2024) Advance decisions, advance statements and living wills

Ethical considerations at the end of life

Eating and swallowing difficulties

What if the person isn't eating, is having difficulty swallowing, or choking?

A judgement needs to be made as to whether this is an emergency or not. If it's considered to be an emergency, for example if the person is choking, then apply the principles of first aid and call for help. This may include calling 999- depending on where you are. If the person's difficulties with swallowing aren't acute, then you'll need to assess whether they're due to the progression of dementia and they are end of life. To make this assessment, you may consider whether to consult Speech and Language Therapist (SALT). Alongside this, you will need to carry out a medication review and look to de-prescribe if appropriate or look to alternate preparations.

Is this being caused by dementia?

If it's judged that these difficulties are due to the progression of dementia, or if it isn't considered to be reversible, then you can offer comfort feeding (see below). If the person's difficulties with eating and swallowing aren't due to the progression of dementia, stop feeding them and assess whether the difficulties are reversible.

What should I do if there's a reversible cause?

Discuss options with the MDT e.g. a period of a time limited nasogastric tube (NG) for feeding. Conversations with family members or advocates should clearly specify that there's a defined time period for which NG feeding will be trialled, during which the response to the treatment will be monitored. If it seems not to be working, or brings other problems, tell the family or advocate that NG feeding is likely to be withdrawn at the end of this trial period.

What's comfort feeding?

Comfort feeding means eating for pleasure. It involves providing the person with small amounts of food or drink that the person likes. Comfort feeding can carry associated risks, such as aspiration. In some settings it's referred to as 'risk feeding'. You'll need to balance the risks of feeding and have these important discussions with families and carers.

How to comfort feed;

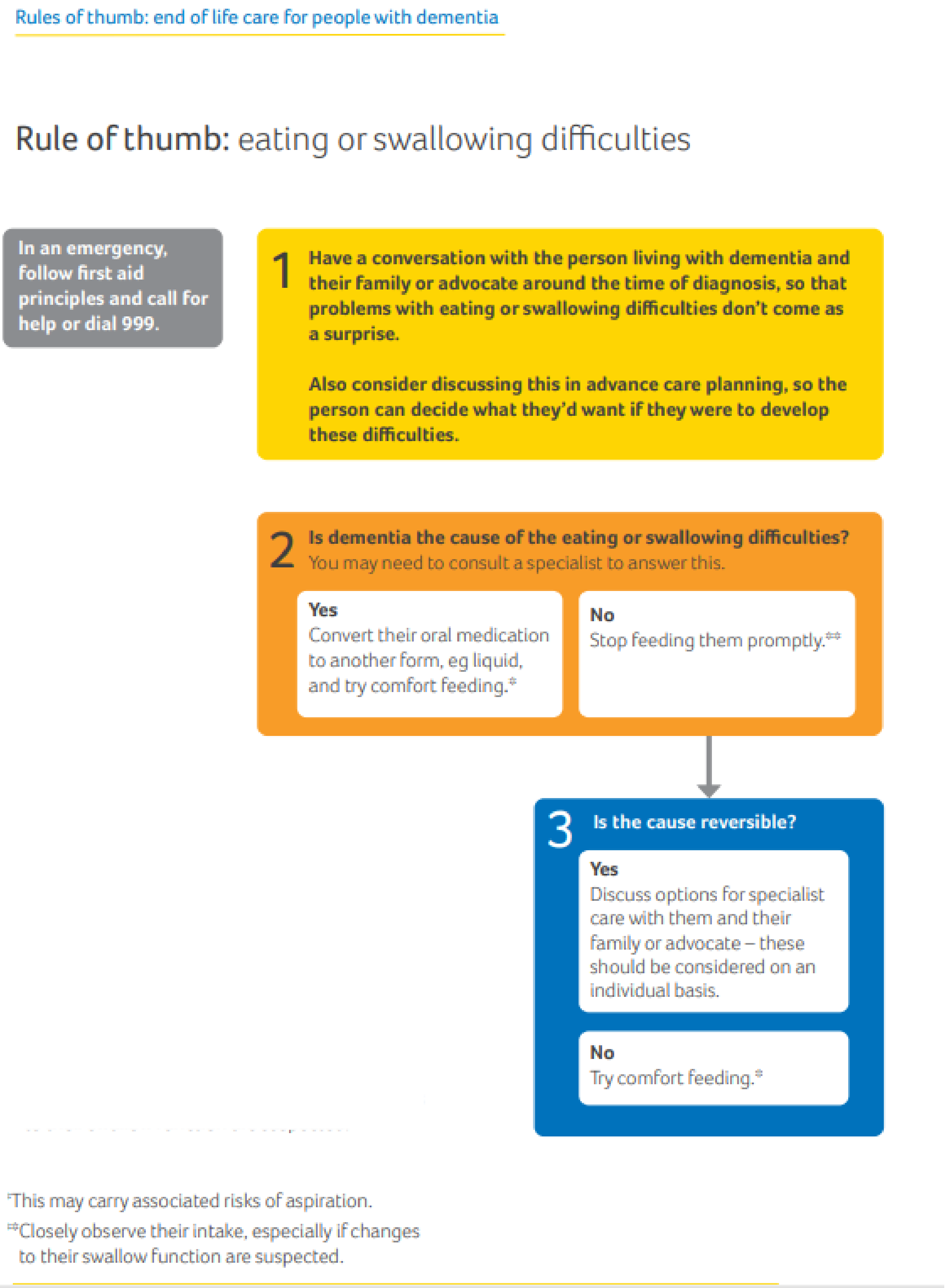
To begin comfort feeding, you should:

- Identify the person's favourite foods and drinks – and what they don't like – to create a food passport. You can include information like how many sugars they prefer in tea or coffee.
- Assess how much assistance the person will need with feeding.
- Follow any recommendations from the Speech and Language Therapist, e.g. the texture, consistency or quantity of food, or specific strategies for feeding. Seek clarification if these no longer seem appropriate.
- Allow for flexibility in the person's eating patterns.
- Check that the person is sufficiently awake and alert enough to be offered food and drink.
- Support the person to sit as upright as possible, preferably out of bed and in a chair.
- Follow the person's pace to make sure they're relaxed when you're feeding them and check their mouth for residue at the end of meals.
- Reduce distractions or background noise so the person can focus on eating and drinking.
- Consider asking someone the person knows to help feed them.

- Make sure the person gets regular, thorough mouth care to maintain oral hygiene.
- Closely observe all their intake, particularly if changes to their swallow function are suspected.
- If swallowing difficulties persist or worsen, seek guidance from specialist colleagues.

Enteral Feeding

Enteral feeding is not routinely recommended for patient with severe dementia unless the indication is an alternative reversible co-morbidity, a helpful decision aid to support this discussion with patients, families and carers can be found here; NICE (2018c) NG97 Patient decision aid on enteral (tube) feeding for people living with severe dementia



Rules of thumb: end of life care for people with dementia

Rule of thumb: eating or swallowing difficulties

In an emergency, follow first aid principles and call for help or dial 999.

1 **Have a conversation with the person living with dementia and their family or advocate around the time of diagnosis, so that problems with eating or swallowing difficulties don't come as a surprise.**

Also consider discussing this in advance care planning, so the person can decide what they'd want if they were to develop these difficulties.

2 **Is dementia the cause of the eating or swallowing difficulties?**
You may need to consult a specialist to answer this.

Yes
Convert their oral medication to another form, eg liquid, and try comfort feeding.*

No
Stop feeding them promptly.**

3 **Is the cause reversible?**

Yes
Discuss options for specialist care with them and their family or advocate – these should be considered on an individual basis.

No
Try comfort feeding.*

*This may carry associated risks of aspiration.

**Closely observe their intake, especially if changes to their swallow function are suspected.

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Agitation and Restlessness

Agitation isn't necessarily caused by dementia. There could be several reasons why someone with dementia is agitated.

You should look for an underlying cause. Ask yourself this question:

Has there been a change for this person? Whilst considering the following three areas and checklists:

Is there an environmental or social cause?

- The temperature or noise may not be comfortable for them.
- It may be a result of unfamiliarity with their surroundings.
- They may be bored.
- Their cultural values, beliefs or spiritual needs may not be being met.

Is there a physical cause?

The person living with dementia may:

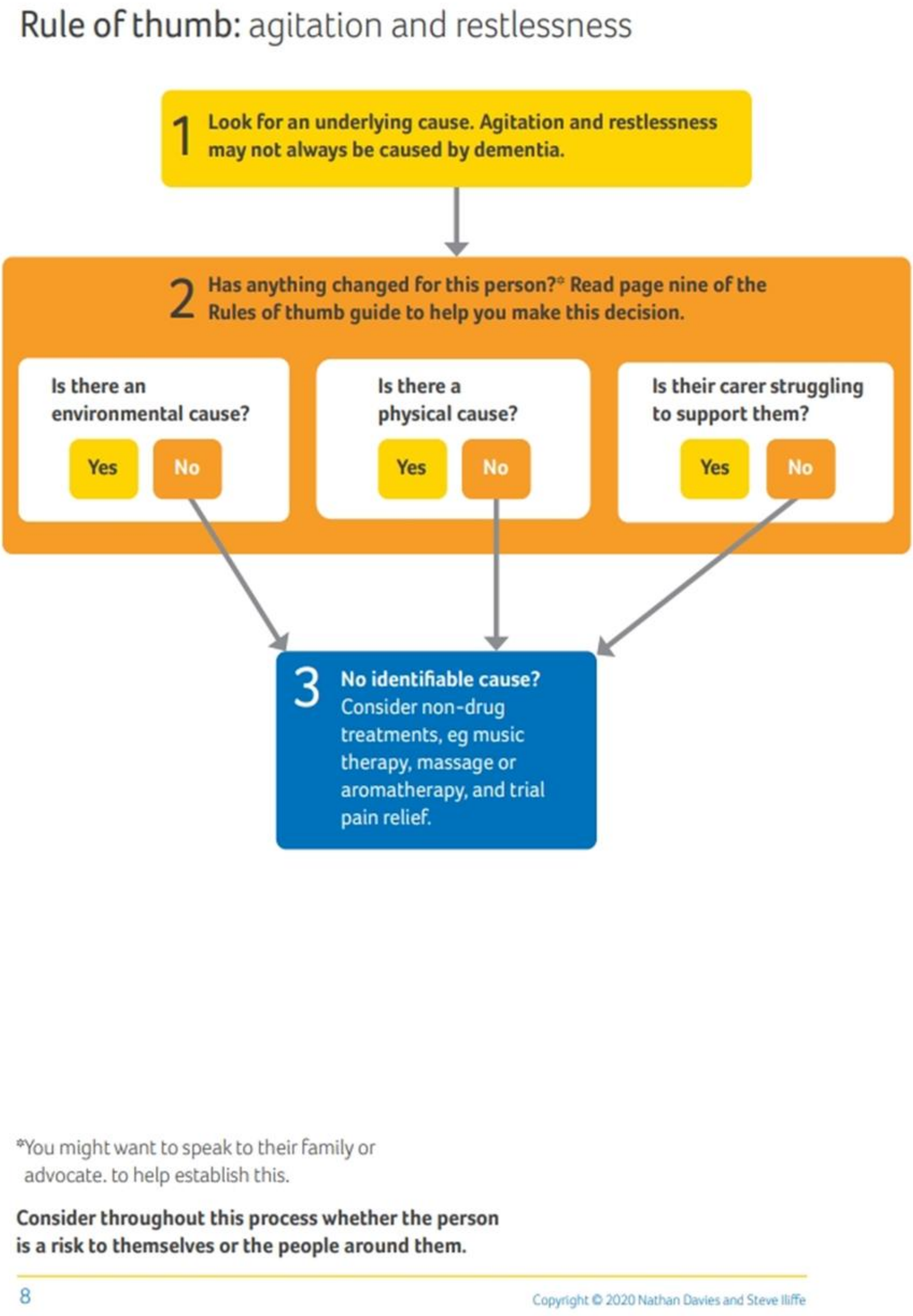
- be hungry or thirsty.
- be constipated – treat them with laxatives.
- have urinary retention – if so, consider catheterization.
- have a pressure sore or be uncomfortable in their position.
- have soiled underwear – address their personal hygiene.
- have an infection or other underlying illness – treat as appropriate or control the symptoms.
- be in pain. This could be because of arthritis, badly fitting dentures or something else.
- have alcohol, nicotine or drug withdrawal.
- have side effects from any drugs or medication they're taking.

Is it related to the health or wellbeing of their carer?

- If their carer is struggling to cope or is ill themselves, this may have an indirect effect on them.
- Do they have a new or existing condition which is making it harder for them to provide care?
- Do they feel supported? Do they have enough support?
- Are they experiencing side effects from any drugs or medication?
- Consider a carer assessment or review for the family member or advocate- through adult social care.

Providing care

Agitation may have several causes, which fall into different areas, so you should consider them all equally at any time. You may also have to return to all three areas. It's ok if you can't identify a cause for the agitation or restlessness. In this case, you should consider non-drug treatments first line, then a trial of pain relief. If these aren't effective, seek specialist help/advice and consider the use of medication. If the person with dementia remains agitated despite making these changes, then it may be part of the dying process. At all times, consider if the person is a risk to themselves or others around them and if so, how this can be managed.



Rule of thumb: agitation and restlessness

1 Look for an underlying cause. Agitation and restlessness may not always be caused by dementia.

2 Has anything changed for this person?* Read page nine of the Rules of thumb guide to help you make this decision.

Is there an environmental cause? Yes / No

Is there a physical cause? Yes / No

Is their carer struggling to support them? Yes / No

3 No identifiable cause? Consider non-drug treatments, eg music therapy, massage or aromatherapy, and trial pain relief.

*You might want to speak to their family or advocate. to help establish this.

Consider throughout this process whether the person is a risk to themselves or the people around them.

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Reviewing Treatment and Interventions

Advance care planning

When caring for those who are dying with dementia the model of care needs to be flexible due to the huge prognostic variability. It is ok and in fact encouraged that you review the diagnosis dying if the presentation changes. It is also best practice to review any prescribing, which may result in deprescribing, and re-prescribing as indicated and referring on to other services as required if the patient if not dying imminently but may be in the end stages of dementia and have ongoing needs that need addressing either through social, psychological or pharmacological interventions (see other services sections).

Due to the huge prognostic variability in patients with dementia and the added complications of additional co-morbidities including heart disease, frailty etc alongside increased rates and severity of delirium, diagnosing dying in a patient with dementia can be difficult and there are times when this may be incorrectly diagnosed, and they may live for weeks or months longer than predicted. This is why frequent review of the diagnosis of dying and the treatment plan is a vital component of good end of life care in dementia.

Reviewing treatment and interventions at the end of life

Interventions can include regular measurements, physical observations, blood tests, cannulation, blood pressure monitoring and other invasive processes.

Who should be involved in this decision?

Decisions to continue or stop treatment or interventions should be discussed in a MDT meeting. You'll need to take into account any decisions made in the person's advance care plan, if they have one, and consult the person who holds lasting power of attorney (LPA) or their deputy.

Any decisions to stop treatments or interventions should also involve frequent discussions with the person's nominated family member or advocate.

Reviewing current treatments

Consider whether the current treatment or intervention is still needed. Does this treatment or intervention help to maintain the person's quality of life?

Ensure that the family or advocate is aware that stopping intrusive treatment is not an indication of 'giving up' on the individual; we will just offer a different type of care that focusses on comfort or quality of life.

If the treatment or intervention is still considered to be needed, then continue with the current care.

Continually review comfort of the person and their quality of life. There may be occasions when a treatment needs to be re-started as it may be having a positive effect on their quality of life and/or the comfort

As their disease progresses, later in the course of the person's disease, you should review all treatments, including those that were originally thought of as symptomatic treatments.

Covert Medications Plans:

In the last days of life patients will stop being able to take medications orally and this is of course one of multiple times that there should be a review of their medications and deprescribing as appropriate. In some ways this is a time when it can be easier to make the decision on what medications to stop.

There are however times when patient with dementia may stop taking oral medications earlier in the disease course. At this point a consideration and review of treatment and medications is also indicated and deprescribing may also occur.

There may be some instances when it is appropriate to continue certain medications due to the prognosis being longer or the medications is needed for symptom management and the use of more restrictive means of administration- SC injections/ IM injections is not appropriate.

In these cases, it is essential to have discussions with the patient's GP, community pharmacist, family and carers regarding the situation and options available. A capacity assessment for the patient's refusal to take oral medications will need to be carried out by the patient's GP and if they are deemed to lack capacity in regard to this, a best interest decision in regard to whether a covert medication plan is to implement needs to be made with all those parties involved. If there is no family available for a patient an Independent Mental Capacity Advocate (IMCA) will need to be involved in these discussions.

(NICE, 2015) Quality statement 6: Covert medicines administration | Medicines management in care homes | Quality standards | NICE

Rules of thumb: end of life care for people with dementia

Rule of thumb: reviewing treatment and interventions

1 **Towards the end of a person's life, you should only continue medication or interventions that are likely to maintain their comfort and quality of life. The same goes for starting them on any new medication or interventions.**

2 **Is the current treatment or intervention contributing to their comfort or quality of life?**
You'll need to discuss this decision with the person's family or advocate.

Yes
Continue the current care.

No
Stop the treatment.

3 **Regularly review the person's comfort and quality of life after any change in treatment. Be prepared to restart treatments if necessary, as it's not always clear whether they're helping the person feel comfortable or improving their quality of life.**

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<u>Providing routine care at the end of life;</u>

These rules concerning routine care are to be used in the final hours to days of life.

What's routine care?

Routine care includes oral (mouth) care, washing and bathing, changing the person's bed sheets and turning them to prevent pressure sores or skin irritation.

Some types of routine care are essential, as they add to the comfort of the person, and shouldn't be stopped. This includes changing soiled or wet bed sheets or clothing and providing mouth care.

Who should decide the level of routine care that's provided?

An advance care plan should be taken into account if the person with dementia has one.

Other existing legal authorities should be documented and understood.

You should talk about routine care with the nominated family member or advocate in advance, before issues arise. Make sure you understand what they believe to be an acceptable level of care and how it should be provided.

If routine care does not cause distress, then continue to provide routine care to maintain the comfort and dignity of the individual, but let your colleagues know what you're doing and why.

What if routine care is causing distress?

For some people with dementia and their family or advocates, routine care may become distressing.

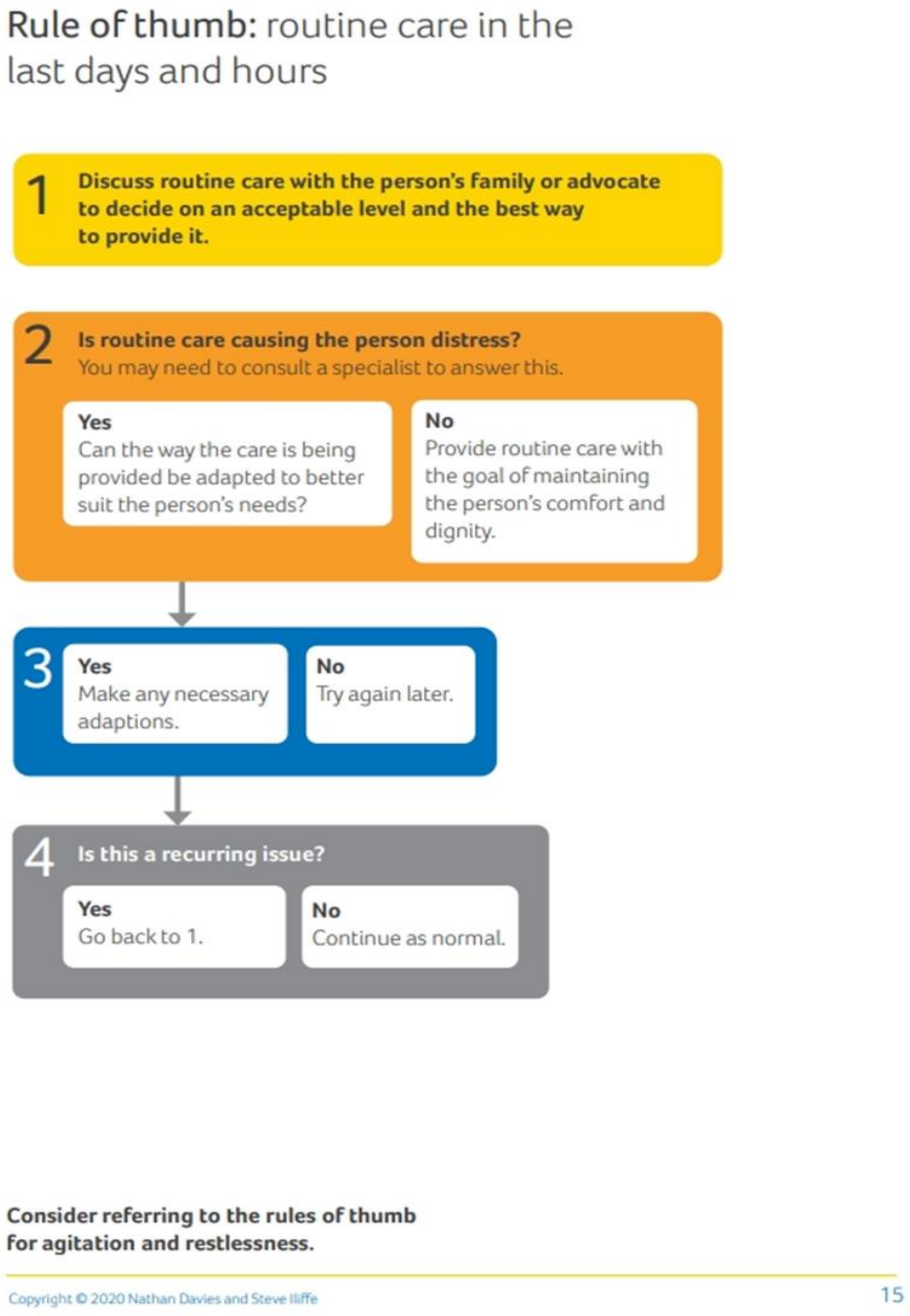
If routine care is causing distress for the person with dementia, see if the way it's being delivered can be adapted. For example, can you change the way you hold or touch the person when you move them?

Consider giving anticipatory pain relief to the person prior to providing essential care, if it's likely to cause them distress or discomfort.

If the adaptions don't help then try again later, when it may be possible to provide that care.

Distress from routine care may be a recurring issue. If this is the case, discuss it with the person's nominated family member or advocate and decide on an acceptable level of care.

Some family members or advocates may not prioritise routine care at the end of life, as it can also take away from the valuable and limited time they have left with their relative. This needs to be discussed. Minimum care may be a kindness to the person with dementia at the end of life, and their dignity should be maintained.



Rule of thumb: routine care in the last days and hours

1 **Discuss routine care with the person's family or advocate to decide on an acceptable level and the best way to provide it.**

2 **Is routine care causing the person distress?**
You may need to consult a specialist to answer this.

Yes
Can the way the care is being provided be adapted to better suit the person's needs?

No
Provide routine care with the goal of maintaining the person's comfort and dignity.

3 **Yes**
Make any necessary adaptions.

No
Try again later.

4 **Is this a recurring issue?**

Yes
Go back to 1.

No
Continue as normal.

Consider referring to the rules of thumb for agitation and restlessness.

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