

Guidelines for Healthcare Professionals: Symptom Management in End of Life Care for People with Dementia

These guidelines are intended to support Healthcare Professionals who do not specialise in dementia care to assess and manage symptoms likely to be present in people with dementia during the end of life stage. They supplement the Guidelines for Symptom Management in Palliative Care available to download [here](#) by providing additional information specific to the assessment and management of people with dementia, delirium and/or other cognitive impairment.

Pre-Assessment

A prognostic indicator tool maybe helpful to assess whether a patient is in the end of life stage e.g. **SPICT** <http://www.spict.org.uk/the-spict/> or

GSF <http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>.

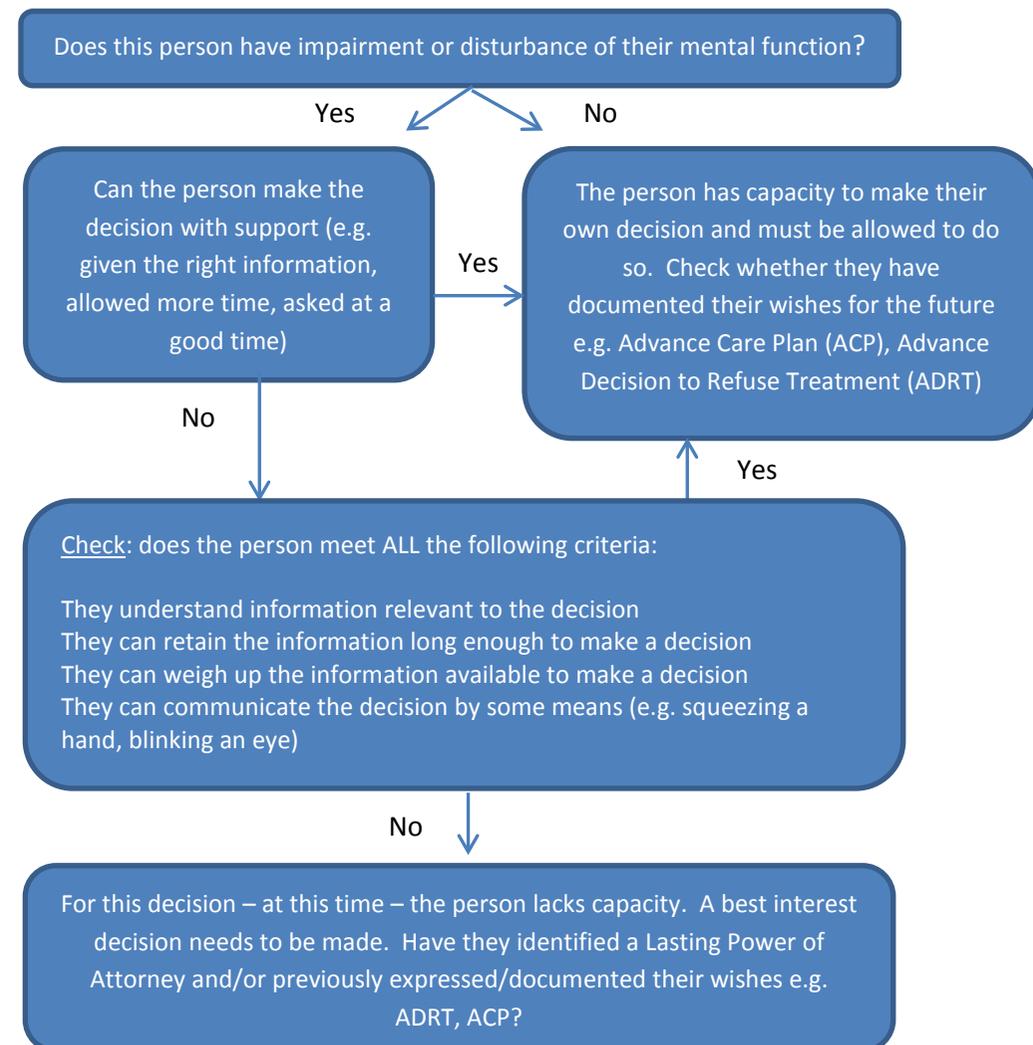
Assessment

A comprehensive, holistic assessment is an essential cornerstone in meeting an individual's needs and managing their symptoms effectively. The following considerations are particularly important when assessing a person with dementia:

- Is the individual able to self-report symptoms including pain?
- Involve other people who know the individual. This may include family members, professional carers, other clinicians. This is vital for understanding the person's 'normal state' so that changes in behaviour can be identified & understood in context to help identify underlying cause (e.g. breakthrough pain) in apparently distressed individuals.
- Consider using "This Is Me" or similar to ensure individual's history and preferences are recorded and shared with staff
- Use supportive communication strategies: ask short questions and allow additional response time; use gestures; minimise distractions and external noise; address any sensory impairments; seek confirmation of any assumptions made; consider use of first language
- Is the person compliant with medication?
- Consider sub-type of dementia (where known) as this may affect presentation of symptoms and management
- Consider the carer's needs including their support needs and coping strategies

- Does the individual have capacity to consent (with support) to examination/ investigation/ taking medications? Will investigation really alter management or can you treat on presumed diagnosis?

Decision Making/Assessment of Mental Capacity



Distress and Pain Assessment

People with dementia may not report their pain so it is always important to ask them. They may not associate their experience with the word pain, so use alternative words such as aching, hurting, sore, and uncomfortable. Focus on current pain and ensure assessment is made during both periods of activity and of rest.

Visual tools in the form of rating scales (numerical rating scale, verbal rating scale, pain thermometer), body diagram, descriptive words and pictures may support people with communication difficulties to self-report their pain.

When a person is not able to accurately report how they feel, observing their behaviour can indicate when they are distressed.

The following behaviours are likely to be a sign of distress which may be an indication of pain, discomfort or an emotional need: Agitation, walking around more than usual, withdrawal, night-time waking, not eating/drinking or any behaviour that signals a change from the person's normal behaviour.

Knowing about a person, their routines, habits and life story and the context in which the distressed behaviour occurs, can help to distinguish pain and other causes of distress such as hunger, anxiety, boredom.

If a person is unable to say whether they have pain it is important to look to rule out other potential causes of distress before assuming it is pain.

There are several tools available to support pain assessment in people with dementia, including **PAIN-AD** <https://www.healthcare.uiowa.edu/igec/tools/pain/PAINAD.pdf> and **Abbey Pain Scale** http://prc.coh.org/PainNOA/Abbey_Tool.pdf. When using these tools, watch for over-identification of pain. Is distress due to another cause?

Disability Distress Assessment Tool helps healthcare professionals and carers record a person's behaviour and recognise signs they are distressed. It also has a clinical decision check list to help determine the possible cause of their distress.

http://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf

Medication use – general considerations

- Consider non-drug management options first
- Take a full drug history
- Optimise current medications: consider concordance, patient specific factors, consider use of e.g. Dosette box
- People with dementia are particularly vulnerable to the side effects of drugs that exacerbate confusion e.g. anticholinergics, amitriptyline.
- In Parkinson's Dementia and Lewy Body Dementia, be aware of side effects of dopamine agonists (confusion, hallucinations and delusions).
- Use oral medication as **first line** wherever possible.
- If the person is unhappy taking oral medications, consider: switching from tablets to syrup/liquids; giving tablets with jam/yoghurt; oro-dispersible preparations; change to a one daily/slow release preparation if available. Liaise with

pharmacist. NB. Administration of covert medication for patients who lack capacity will require a best interest decision.

- Prioritise essential medications (in dying phase, symptom management is priority)
- If needed, sub-cutaneous injections can be given regularly or prn.
- A syringe pump enables a combination of drugs to be administered subcutaneously in one infusion over a continuous period. It can be particularly useful for patients unable or unwilling to take oral medication and in patients with intractable nausea and vomiting. If a person is likely to move about and forget to take the syringe pump or to pull at the infusion line, a syringe pump is unlikely to be appropriate.

Pain Management

- Identify and, where possible, treat any contributing causes e.g. constipation, pressure sores
- If unclear if patient has pain, consider a trial of regular analgesia
- Start with regular paracetamol, consider stronger analgesia if necessary.
- If unable to swallow oral medications and patient not obviously in last days of life, consider transdermal route.

Transdermal patches

A number of different continuous release preparations are available to treat moderate to severe pain including BuTrans® (buprenorphine) patches (lowest strength 5mcg/hr lasts 7 days and is equivalent to 90mg oral codeine/24hr. Conversion charts are available in, "[A Guide to Symptom Management in Palliative Care](#)". All patients using continuous release preparations should also be prescribed an immediate release preparation for breakthrough pain such as codeine or morphine (dose dependent on patch strength)

Topical preparations

Topical preparations such as non-steroidal anti-inflammatory gels can be effective in mild-moderate localised pain in acute and chronic musculoskeletal conditions such as arthritis. Heat pads and warm baths can relax muscles, reduce joint stiffness and help relieve aches and pains. Ice packs can help relieve pain where there is inflammation and swelling. Care should always be taken to protect the skin from burns when using heat pads and ice packs.

Eating and Swallowing Problems

Nutritional problems, loss of appetite, swallowing problems and weight loss are common issues in dementia, especially as the severity of illness increases. Overall there is no conclusive evidence that tube feeding provides benefit for people with advanced dementia, either in terms of prolonging life or improving quality of life for people with dementia. <http://www.ncbi.nlm.nih.gov/pubmed/19370678>

- Exclude reversible causes for not eating eg thrush. Ensure good mouth care.
- Consider if appropriate to refer to SALT for assessment.
- Comfort feeding small amounts of appropriately thickened fluids/soft food may provide enjoyment of eating and result in perceived alleviation of hunger or thirst. <http://www.airedale-trust.nhs.uk/services/dietetics/leaflets-for-patients-with-dementia/>

Nausea and Vomiting

- Treat reversible causes where appropriate (e.g. infection, constipation, review current medications).
- Are environmental factors contributing? Can they be minimised? (e.g. reduce noxious odours, strong food smells etc., reduce overwhelming food portion sizes).
- Non-pharmacological interventions may be useful (e.g. Peppermint tea, ginger biscuits).
- Consider longer acting anti-emetics to reduce tablet burden e.g. Levomepromazine.

If unable to take medications orally consider:

Subcutaneous injections

Most anti-emetics are available in injectable preparations and can be used as subcutaneous injections or via syringe pump as continuous infusion.

Patches

Hyoscine Hydrobromide is available as Scopoderm TTS patch and can be useful for motion sickness (1mg patch applied to hairless area behind ear every 72hours). Use with caution; can cause confusion, dry mouth, skin reaction, urinary retention. Granisetron (5HT antagonist) is available as a patch lasting up to 7 days but is only licensed for use with chemotherapy and can cause severe constipation. Seek specialist advice before using.

Constipation

Ensure regular assessment of bowel habit and early intervention where appropriate.

- Increase fluid intake and review diet to include fibre if possible
- Review medication which may be causing constipation
- Non-pharmacological measures may help: abdominal massage and use of heat pack, assist patient to adopt correct posture for defecation, ensure privacy
- Combination of stool softener and stimulant laxative is usually required
- Preparations containing dantron can cause contact dermatitis; avoid in incontinent patients
- In the dying phase it may be unnecessary to intervene unless constipation is causing distress

Anxiety and Agitation

Neuropsychiatric symptoms are nearly universal in dementia and agitation is among the most distressing for patients and family carers.

Consider specific causes: Physical (eg pain), side effect of medication, emotional, activity (eg dressing) or environment (eg lighting, unfamiliar surroundings)

Address where possible by person-centred non-drug approaches.

NHS Managing Behavioural and Psychological Disturbance in Dementia -

<http://www.leeds.gov.uk/docs/Leeds%20guideline%20-%20Behavioural%20and%20Psychological%20Needs%20in%20Dementia.pdf> .

Occasionally in severe anxiety/agitation at the end of life a trial of a benzodiazepine or antipsychotic may be appropriate, weighing up the risks and benefits. Antipsychotics should be avoided if possible in Lewy Body dementia as these patients are more prone to severe side effects.

Delirium and confusion

Delirium is extremely common in patients with advanced dementia where dehydration is a common problem. It is often unrecognised or misdiagnosed as worsening dementia, depression, anxiety or psychosis.

Clinical features

- A. Disturbance of consciousness (i.e. reduced clarity of awareness of the environment) with reduced ability to focus, sustain, or shift attention.
- B. A change in cognition or the development of a perceptual disturbance that is not better accounted for by a pre-existing, established, or evolving dementia.
- C. The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day.

Assessment

Obtain a thorough history to determine the patient's pre-morbid level of functioning, the onset of changes in their mental state and any potential cause e.g. infection, medication.

Management

Non-pharmacological measures are the mainstay and include:

- Assessing thoroughly for reversible causes and treating where possible
- Managing the patient's environment to reduce confusion and distress e.g. Visible clock to aid orientation, good lighting during daytime
- Encourage family to visit and provide them with a full explanation
- Consistent nursing

Pharmacological interventions

- Consider using haloperidol if patient is distressed

- Olanzapine Velotabs can be useful if patient can't swallow tablet or liquid

- If oral route not possible consider Haloperidol 500 micrograms – 1.5mg subcut, observe for 30-60 minutes and repeat if necessary. Titrate cautiously according to symptoms, usual maximum dose 5mg over 24hrs. Review every 24 hours, monitor for adverse effects & seek further advice if not working.

- Lorazepam (sublingual or IM) or Midazolam (SC) may be useful, particularly in Lewy Body Dementia (LBD), and where the prime therapeutic aim is to sedate and/ or reduce agitation.

NB Use with caution. All psychotropics (including Benzodiazepines) can increase confusion. Seek advice if concerns

Last Hours or Days of Life

Dying patients will manifest some or all of the following:

- Profound weakness - usually bedbound
- Drowsy or reduced cognition - semi-comatose
- Diminished intake of food and fluids - only able to take sips of fluid
- Difficulty in swallowing medication - no longer able to take tablets

Five priorities for Care have been identified by the Leadership Alliance of the Care of dying People: [Click here to access](#)

When it is recognised that a patient is entering the dying phase, it is recommended that a clear care plan for End of Life care is in place. This should include guidance on symptom management for patients unable to take oral medication including pain, breathlessness, terminal restlessness and retained secretions. Use contact details below for specialist advice.

Local Contacts:

How these guidelines were developed and how they should be used:

The Yorkshire and Humber Clinical Networks are part of NHS England. These guidelines were developed by clinicians experienced in the care of people with dementia, including at the end of life. They are intended as advisory and do not represent NHS England policy. Health care professionals should adhere to the policies of their own organisations. They should use their clinical judgment, working closely with patients and carers to

provide optimum care for patients. Organisations may wish to adopt these guidelines and will need to use their clinical governance processes to do so.

The authors of this guidance have made considerable efforts to ensure the information upon which they are based is accurate and up to date. However, the guidelines may be superseded by new evidence and the authors accept no responsibility for any inaccuracies or information perceived as misleading.

Appendix 1

Useful resources:

- **Triangle of care – Carers included (endorsed by RCN and Carers Trust)**
[https://professionals.carers.org/sites/default/files/the triangle of care carers included best practice in dementia care - final.pdf](https://professionals.carers.org/sites/default/files/the%20triangle%20of%20care%20carers%20included%20best%20practice%20in%20dementia%20care%20-%20final.pdf)
- **This is Me**
https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1604
- **Disability Distress Assessment Tool (DisDAT)**
[http://prc.coh.org/PainNOA/Dis%20DAT Tool.pdf](http://prc.coh.org/PainNOA/Dis%20DAT%20Tool.pdf)
- **PAIN-AD Tool**
<https://www.healthcare.uiowa.edu/igec/tools/pain/PAINAD.pdf>
- **My Name is Not Dementia (Alzheimer's Society)**
https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=418 –
- **Quality of life indicators and literature review**
Key Principles for Person Centred dementia Care – Statement of Best Practice (National Care Forum)
https://www.derbyshire.gov.uk/images/NCF%20%20Key%20principles%20of%20person-centred%20dementia%20care_tcm44-159567.pdf
- **EOLC Quality Markers for Dementia**
<http://www.ncpc.org.uk/sites/default/files/EndofLifeQualityMarkersForDementia.pdf>
- **Dementia UK - Overview (Alzheimer's society)**
https://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1491
- **National End of Life Care Intelligence Network report on Deaths from Alzheimer's disease, Dementia and Senility**
http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_alzheimers
- **NICE** <https://www.nice.org.uk/guidance/cg42> (guidance) and <https://www.nice.org.uk/guidance/qs1> (quality standard)
- **NHS Managing Behavioural and Psychological Disturbance in Dementia** <http://www.leeds.gov.uk/docs/Leeds%20guideline%20-%20Behavioural%20and%20Psychological%20Needs%20in%20Dementia.pdf>
- **National Council for Palliative Care – Achieving a good death for people with dementia**
www.ncpc.org.uk/dementia
- **PAIN – AD**
<https://www.healthcare.uiowa.edu/igec/tools/pain/PAINAD.pdf>
- **Abbey Pain Scale:**
http://prc.coh.org/PainNOA/Abbey_Tool.pdf
- **SPICT (Supportive and Palliative Care Indicators Tool)**
<http://www.spict.org.uk/the-spict/>
- **GSF (Gold Standards Framework)**
<http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>
- **NHS Managing Behavioural and Psychological Disturbance in Dementia -**
<http://www.leeds.gov.uk/docs/Leeds%20guideline%20-%20Behavioural%20and%20Psychological%20Needs%20in%20Dementia.pdf> .
- **Priorities of Care for the Dying Person**
[http://www.nhs.uk/media/2485900/duties_and_responsibilities_of_health_and_care_staff - with prompts for practice.pdf](http://www.nhs.uk/media/2485900/duties_and_responsibilities_of_health_and_care_staff_-_with_prompts_for_practice.pdf)
- **One Chance to Get it Right: Improving people's experience of Care in the last few days and hours of life**
[https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One chance to get it right.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf)