

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



This is a single page summary of the Symptom Management Guidelines. The full version is available to download at: <http://www.yhscn.nhs.uk/media/PDFs/mhnd/Dementia/Documents%20and%20links/Guidelines%20for%20Healthcare%20Professionals%20FINAL.pdf>

Disclaimer: This guidance is not intended to take the place of physician judgment in assessing individual patients nor is it intended to be a prescriptive direction defining a single course of management. Variations, taking individual circumstances into account, will be appropriate. 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 authors accept no responsibility for any inaccuracies or information perceived as misleading. In addition the authors assume no legal liability or responsibility for the accuracy, completeness or clinical efficacy of this guidance.

Yorkshire and the Humber
Clinical Networks

ASSESSMENT	A prognostic indicator tool can help to assess whether a person is in the end of life stage.	INVOLVE OTHERS who know the person to help understand their 'normal state'. Use "This Is Me" or similar to ensure the person's history & preferences are recorded & shared with staff.	ASK short questions & allow additional response time; use gestures; minimise distractions and external noise.	Consider PAIN . Is the individual able to self-report symptoms including pain? It is important to ask about pain, using words such as aching, hurting, sore, and uncomfortable and/or visual tools in the form of rating scales.	OBSERVE behaviour. When a person is not able to accurately report how they feel, observing their behaviour can indicate when they are distressed. Signs of distress can include: 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. Distressed behaviour can indicate pain, discomfort or an emotional need.	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?				
MEDICATION	OPTIMISE current medications: consider CONCORDANCE , person specific factors, consider use of e.g. Doseette box.	PRIORITISE essential medications (in dying phase, symptom management is priority).	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.	If needed, sub-cutaneous injections can be given regularly or prn.				
MANAGING PAIN	Identify and, where possible, treat any CONTRIBUTING CAUSES e.g. constipation, pressure sores.	People with dementia frequently UNDER-REPORT PAIN . If unclear if person 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.	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 approximately equivalent to 90mg oral codeine or 10mg oral morphine/24hr). Conversion charts are available in "A Guide to Symptom Management in Palliative Care" ¹	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 such as non-steroidal anti-inflammatory gels can be effective in mild-moderate localised pain in acute and chronic musculoskeletal conditions such as arthritis.				
EATING	NUTRITIONAL AND SWALLOWING PROBLEMS including loss of appetite and weight loss are common issues for people with dementia, especially as the severity of illness increases.	Ensure good MOUTH CARE .	Exclude REVERSIBLE CAUSES for not eating eg thrush.	COMFORT FEEDING small amounts of appropriately thickened fluids/soft food may provide enjoyment of eating and result in perceived alleviation of hunger or thirst.	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 http://www.ncbi.nlm.nih.gov/pubmed/19370678 .					
AGITATION	Neuropsychiatric symptoms are nearly universal in dementia and AGITATION is among the most DISTRESSING for the person and family carers.	Consider SPECIFIC CAUSES : Physical (eg pain), side effect of medication, emotional, activity (eg dressing) or environment (eg lighting, unfamiliar surroundings).		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 people with Lewy Body dementia and Parkinson's Disease as they are more prone to severe side effects.					
DELIRIUM	Delirium is EXTREMELY COMMON in people with advanced dementia where dehydration is a common problem.	It is OFTEN UNRECOGNISED or misdiagnosed as worsening dementia, depression, anxiety or psychosis.	Assess thoroughly for REVERSIBLE CAUSES and treat where possible. Provide consistent nursing.	Manage the person'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.	Consider haloperidol if the person is distressed; Olanzapine Velotabs can be used if they can't swallow tablets 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 and where the prime therapeutic aim is to sedate and/ or reduce agitation.
OTHERS	NAUSEA & VOMITING : Assess for REVERSIBLE CAUSES and consider if environmental factors are contributing	Simple measures eg ginger biscuits, peppermint tea may be useful	If tablet burden is an issue, consider LONGER ACTING antiemetics eg. Levomepromazine.	Most anti-emetics are available in injectable preparations and can be used as sub-cutaneous injections or via syringe pump as continuous infusion.	Hyoscine is also available as a patch formulation. However use with CAUTION ; can cause confusion, dry mouth, skin reaction, urinary retention.	CONSTIPATION : Combination of stool softener and stimulant laxative is usually required.				

NB. All antipsychotics (including Benzodiazepines) can increase confusion and should be used with caution, weighing up the risks & benefits. Seek advice if there are concerns.

¹ "A Guide to Symptom Management in Palliative Care" is available to download at: <http://www.yhscn.nhs.uk/common-themes/end-of-life-care/EOLDocuments.php>. An app version of this guidance is also available.