Palliative Care & Symptom Management for Patients with End Stage Dementia

Indicators of late stage dementia include:

| Unable to walk without assistance AND | Plus any of the following: |
| Urinary & faecal incontinence AND | Weight loss |
| No consistently meaningful conversation AND | Urinary Tract Infection |
| Unable to do Activities of Daily Living | Stage 3 / 4 pressure sores |
| Barthel score >3 | Recurrent fever |
| | Reduced oral intake |
| | Aspiration pneumonia |

GSF 2011

General guidance for the last few weeks:

- Assess each patient individually, including checks such as urinalysis
- Check for any Advanced Care Plans, Advanced Directives to Refuse Treatment, Preferred Place of Care.
- Discuss plans with patient (if capacity) or, Lasting Power of Attorney for Health & Welfare, close family/friend (and staff if in Care Home) and explain the need to avoid inappropriate hospital admission & CPR – complete DNACPR form as required.
- Encourage eating and drinking by mouth for as long as possible. Access specialist assessment & advice about swallowing if necessary. Apply ethical principles to decisions about artificial nutrition; it is unlikely to be helpful in advanced dementia but this should not be a blanket policy (NICE 2013, Pace et al 2011)
- Review all medication, reduce polypharmacy. Continue Acetylcholinesterase Inhibitors and Memantine if able and willing to swallow as the evidence for discontinuation is limited and contradictory (Cruz-Jentoft et al 2012, Parsons et al 2010).
- Prescribe injectable prn drugs in anticipation of unsafe swallow.
- Promote non-pharmacological approaches to symptom management where effective.

Pain/Discomfort:

- Pain in people with dementia is frequently poorly recognized and undertreated.
- It commonly presents as altered behaviour and agitation which is attributed to the dementia and at risk of being treated with psychotrophic drugs.
• Uncontrolled pain seriously impacts the person’s quality of life and physical function. Assessment can be challenging, even using an appropriate assessment tool (e.g. Abbey Pain Score).
• Check for reversible causes, e.g. constipation, full bladder, blocked catheter
• Initiate an analgesic trial over 3-4 days to check for the presence of pain by optimising paracetamol (1g qds)
• If opioids required – start with low dose e.g. BuTrans 5mcg and titrate following usual palliative care principles. Monitor for adverse side-effects.
• Transdermal analgesics are useful if oral medication is burdensome but immediate release analgesics are required for breakthrough pain e.g. Oramorph
• Consider Dantrolene starting at 25mg daily as a muscle relaxant if pain due to contractures or muscle spasm
• Don’t sedate pain!

Agitation & restlessness:

• Check possible (and reversible) causes

<table>
<thead>
<tr>
<th>Drug</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Risperidone – start 0.5mg bd and titrate up to 1mg bd</td>
<td>Licensed in UK for short-term (6 weeks) treatment of agitation in dementia but if beneficial, may be continued following advice from psychiatrist. Risk of insomnia, postural hypotension</td>
</tr>
<tr>
<td>Quetiapine 25mg bd and titrate up to 100mg bd</td>
<td>Risk of sedation Decreased risk of Parkinsonism and mortality (Huybrechts et al 2012, PCF 4 2011)</td>
</tr>
<tr>
<td>Olanzapine – start at 5mg daily, increase up to 10mg daily</td>
<td>Risk of hyperglycaemia, nausea &amp; vomiting, sedation, increased appetite</td>
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Avoid all anti-psychotics for people with Lewy body dementia as they may exacerbate behavioural symptoms

Nausea & vomiting:

• Select anti-emetic according to probable cause except in Lewy Body Dementia

| Cyclizine | Acts on vomiting centre. Motion sickness, raised ICP |
| Haloperidol | Acts on CTZ e.g. biochemical abnormalities, drug related |
| Metoclopramide | Prokinetic. Gastric stasis or compression |
| Levomepromazine | 2nd line, broad spectrum |
Lewy Body Dementia– prescribe oral Domperidone 10-20mg qds, Ondansetron 4mg bd or Cyclizine 50mg tds orally or s/c

General guidance for the last few days:

- Ensure family are aware that the patient is probably dying
- Ensure anticipatory injectable drugs for prn and syringe pump use are prescribed
- Ensure DNACPR form completed

Pain/Discomfort:

- If opioids required – start with low dose (e.g morphine sulphate 5 – 10mg s/c over 24 hours) and titrate following usual palliative care principles. Avoid starting transdermal analgesics at this late stage as slow to reach therapeutic levels and difficult to titrate.
- If transdermal analgesic patch already in situ, continue with patch and add additional medication as required to a syringe pump
- Ensure immediate release analgesics prescribed and available

Agitation & restlessness:

- Check possible (and reversible) causes
- Avoid all anti-psychotics for people with Lewy Body dementia

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<th>Medicine</th>
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<tr>
<td>Midazolam - start at 5 - 10mg s/c over 24 hours in syringe pump</td>
<td>If syringe pump not available or impractical, consider buccal or prn s/c injections High dose (30+mg over 24hrs) if replacing anticonvulsants</td>
</tr>
<tr>
<td>Haloperidol – start at 0.5mg s/c prn</td>
<td>Use to replace antipsychotics but NOT if Lewy bodies or Parkinson’s disease Increased dose-related risk of mortality (mostly circulatory disorders)</td>
</tr>
<tr>
<td>Levomepromazine – start at 6.25mg s/c prn</td>
<td>If no response to the above (Pace et al 2011)</td>
</tr>
<tr>
<td>Phenobarbitone</td>
<td>Last resort (Pace et al 2011). Seek Specialist Palliative Care Advice</td>
</tr>
</tbody>
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Nausea & vomiting:

- Select anti-emetic according to probable cause except in Dementia with Lewy Bodies – see previous page
Respiratory secretions:

- Glycopyrronium 200 - 400mcg s/c prn OR 1.2mg s/c over 24hrs via syringe pump

References:


Cruz-Jentoft A J, Boland B, Rexach L (2012) Drug therapy Optimization at the End of Life *Drugs Aging* 29 (6) 511-521


National End of Life Care Programme (2010) *Care towards the end of life for people with dementia.* [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

