

Among patients with dementia, episode of pneumonia cause significant symptoms, including dyspnoea (shortness of breath) and discomfort (Steen et al, 2002). However, there is evidence to indicate that patients on long-stay wards who are dying at the end stage of dementia have not always received appropriate palliative care. For example, in a study undertaken in New York in which the outcomes of patients with end-stage dementia who had hip fracture or pneumonia were compared with the outcomes among cognitively intact patients who had also suffered a hip fracture or pneumonia (Morrison and Siu, 2000). In comparison with the cognitively intact patients, a higher proportion of those with end stage dementia died within six months of the fracture (55% vs 12%) or episode of pneumonia (53% vs 13%), although the patients with dementia were as likely to receive antibiotics as those who did not have dementia. Furthermore, patients with dementia received less opiate analgesia than other patients even though they had similar physical problems and underwent the same surgical and other procedures. The authors of this study concluded that increased attention needs to be directed to relieving pain and other distressing symptoms in hospitalised patients with end stage dementia.

In a study undertaken in a long-stay psychogeriatric unit in England, patients with end stage dementia were found to have many symptoms, including pain, dyspnoea and pyrexia for which no palliative treatment was given. Instead, there was widespread use of parenteral antibiotics and infrequent use of analgesia in the last few days of life (Lloyd-Williams 1996). In a follow-up to this study, guidelines on palliative care in end stage dementia were developed, and an increase in the use of analgesics including opiates occurred (Lloyd-Williams and Payne, 2002). The data collected after the implementation of the guidelines related to the deaths of 27 patients, of whom 13 (48%) were prescribed 4-hourly morphine for the palliation of pain of dyspnoea (caused by pneumonia). Two patients who were unable to take oral medication were commenced on syringe drivers.

Nurses working in long-term institutions for elderly patients tend to regard the avoidance of clinical interventions such as resuscitation, major surgery or antibiotics as more appropriate among patients who are more cognitively impaired (Gillick and Mendes, 1996). Communication between professionals (nurses and doctors), and between professionals and relatives or dying elderly patients is sometimes poor (Costello, 2001). There is evidence that decisions on whether resuscitation would be appropriate ('do not resuscitate' or DNR orders) may not be fully discussed, although they are based on what is judged to be in the patient's best interests (Costello, 2002).

### **Guidelines**

Two clinical guidelines are summarised here in order to illustrate current professional opinion about the care of people in the terminal phase of dementia. The first guideline was developed in a long-stay hospital in England (Lloyd-Williams and Payne, 2002), and was concerned with the palliative care of patients with end stage dementia. It is summarised in Box 1.

**Box 1. Guidelines for the management of patients with end stage dementia  
(from: Lloyd-Williams and Payne, 2002)**

Consider treatable causes of pain (e.g. pressure sores, full bladder); use oral medication when possible, and administer on a regular basis; use co-proxamol initially; if still in pain, consider a non-steroidal anti-inflammatory drug.

When opiates are used, start with a low dose and increase as needed to control pain; always prescribe diamorphine 2-5-10mg for injection on an as required basis so that analgesia can still be given if the oral route is not available.

When converting from oral subcutaneous opiates, remember to divide the total oral dose by three e.g. 60mg oral morphine in 24 hours = 20mg diamorphine in syringe driver.

In the event of agitation, think of full bladder; midazolam 2.5mg-10mg subcutaneously or oral haloperidol or thioridazine may be used.

The most common cause of dyspnoea is bronchopneumonia. There is no evidence that using antibiotics in end stage dementia is helpful or improves patients' comfort or prolongs the quality of life. Oral morphine 5mg 4-hourly can reduce sensation of breathlessness and improve patient's comfort.

A guideline to help physicians decide whether to forgo curative treatment of pneumonia in patients with dementia resident in nursing homes has been developed by a research group in the Netherlands (Steen et al, 2000). The guidelines were based on a literature review, discussion papers prepared by Dutch medical associations, and consensus procedures with experienced nursing-home physicians and international experts in the fields of nursing-home medicine, ethics and law. The guidelines were subsequently authorized by the Dutch professional organisation of nursing home physicians. The guidelines were presented in the form of a checklist for use by physicians in nursing homes (see Box 2).

***Box 2. Checklist on decision for starting or not starting a curative treatment of pneumonia in a patient with dementia (Steen et al, 2000).***

The key factors to consider are:

1. the expected effect of a curative treatment from the medical perspective
2. the patient's wish: a living will, or the reconstruction of the wish
3. the patient's best interest in the case the wish of the patient is not clear, or remains unknown.

The checklist considerations:

1. Is an intentionally curative treatment indicated for this patient?
2. How physically and/or psychiatrically burdensome would the total curative treatment – antibiotics and (re)hydration – be for the patient?
3. Is the patient sufficiently mentally competent, and is so, what treatment does the patient want?
4. What is the purport of the written will?
5. What is the purport of the reconstruction of the patient's will according to the representative(s)?
6. What is the purport of the reconstructed patient's wishes according to the other involved professional carers?
7. Which treatment seems to be in the patient's best interests (not certain, intentionally curative treatment, or palliative treatment)?

Development and adoption of an integrated care pathway has been suggested as one strategy to improve the care of dying patients in hospitals (Edmonds and Rogers,

2003). The proposed criteria for starting an integrated care pathway for dying patients are shown in Box 2.

***Box 3. Criteria for starting an integrated care pathway for patients dying in hospital (from Edmonds and Rogers, 2003)***

Patients who have a known diagnosis and have deteriorated despite appropriate medical intervention. The multiprofessional team have agreed the patient is dying and at least two of the following apply:

The patient:

1. is bedbound
2. is only able to take sips of fluids
3. has impaired concentration
4. is semi-comatose
5. is no longer able to take tablets

## **References**

Costello J (2001). Nursing older dying patients: findings from an ethnographic study of death and dying in elderly care wards. *J Advanced Nursing* 35:59-68.

Costello J (2002). Do not resuscitate orders and older patients: findings from an ethnographic study of hospital wards for older people. *J Advanced Nursing* 39:491-9.

Edmonds P, Rogers A (2003). 'If only someone had told me ...' A review of the care of patients dying in hospital. *Clinical Medicine* 3:149-52.

Gillick MR, Mendes ML (1996). Medical care in old age: what do nurses in long-term care consider appropriate? *J Am Geriatr Soc* 44:1322-5.

Lloyd-Williams M (1996). An audit of palliative care in dementia. *Eur J Cancer Care* 5:53-5

Lloyd-Williams M, Payne S (2002). Can multidisciplinary guidelines improve palliation of symptoms in the terminal phase of dementia? *Int J Palliative Nursing* 8:370-5.

Morrison RS, Siu AL (2000). Survival in end-stage dementia following acute illness. *JAMA* 284:47-52.

Steen JT van der, Graas T de, Ooms ME, (2000). When should physicians forgo curative treatment of pneumonia in patients with dementia? *West J Med* 173:274-7.

Steen T van der, Ooms ME, Wal G van der, Ribbe MW (2002). Pneumonia: the demented patient's best friend? Discomfort after starting of withholding antibiotic treatment. *J Am Geriatr Soc* 50:1681-8.