



British Geriatrics Society Best Practice Guide

Palliative and End of Life Care for Older People

(Best Practice Guide 4.8 Reviewed February 2009)

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1. Executive Summary

- An End of Life Care Strategy has been published in England (2008) (1) and similar initiatives are being produced in the other 3 nations of the UK
- End of life care for older people is often suboptimal
- Comprehensive geriatric assessment plays an important part in enabling older people (especially the frailest with complex co-morbidity) to live well until they die
- Comprehensive geriatric assessment, along with enhanced communication and honest prognostication are important factors in identifying treatment priorities as part of effective clinical decision making
- The principles of palliative care can be embedded in this approach
- Advanced planning and integrated care pathways enhance the quality of end of life care
- Older people should have access to specialist palliative care teams where appropriate regardless of diagnosis or place of care

2. Introduction

1. Good end of life care is an important component in the care of older people. Palliative care seeks to influence improvement in the quality of life of patients with incurable disease by advocating a holistic, problem-orientated approach, including symptom control.
2. Cancer patients were traditionally viewed as the primary recipients of palliative care, but it is increasingly recognised that good end of life care is important in the management of patients with any incurable disease, whatever the diagnosis (dementia, chronic chest or heart disease, Parkinson's disease, frail older people with several long term conditions, to cite only a few examples).
3. Since the majority of people die at an older age, very few people die unexpectedly and many people die of long term conditions this is particularly relevant to those caring for older people.
4. Although most people would prefer to die at home relatively few currently do so; most die in hospital
5. Thus hospital based staff caring for older people (often geriatricians and their teams) are the group providing end of life care for the majority of people who are dying

3. Definitions

- **Palliative Care** - is the active care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. It may be delivered by any health care professional.
- **Terminal Care** - is the care of a person in the last days or weeks before they die (ie. the final part of palliative care).
- **Specialist Palliative Care** - Palliative care delivered by those with specialist training in palliative care (McMillan nurses/ Consultants in palliative medicine). Usually for more difficult/complex cases.

4. Issues in end-of-life care of older people

Research studies have identified inadequacies in the end-of-life care of older patients.

1. Dying patients frequently do not receive basic nursing care or assistance with eating and drinking(2)
2. Alternatively staff may focus on meeting physical needs at the expense of psychological and spiritual care
3. Older people are less likely to receive appropriate pain control than their younger counterparts. This is especially so for patients with dementia. They are less likely to take opioids for pain due to cultural beliefs
4. Older people are less likely to receive hospice care
5. In care homes end of life care may be impeded by inadequate staff training, poor symptom control and lack of psychological and emotional support
6. Comorbidity and drug reactions make symptom control more difficult(3)

5. What constitutes a good death?

Age Concern have highlighted 12 principles constituting a 'good death' (Appendix 1). Understanding these precepts allows end-of-life care to be planned in an effective manner. Important elements of this planning are:

1. Open communication between all involved in the patient's care to promote symptom control, discuss treatment decisions and place of ongoing care or death.
2. Honest prognostication: Although accurate prognostication is difficult, especially for non-cancer patients, an indication of time left (e.g. days, weeks or months) may be very helpful to those patients and their relatives who wish to know. Doctors are known to be frequently over-optimistic in estimating prognosis.
3. Symptom control: Staff involved in the palliative care of older people need to have adequate training in symptom control and to be able to access specialist advice and support from palliative care teams both in hospital and in the community. Common symptoms requiring treatment include pain, breathlessness, nausea and vomiting, anorexia, constipation, depression, cough, delirium, dysphagia, insomnia, incontinence and anxiety.

6. Improving end of life care

The National End of Life Care Strategy has been published in England (2008) and similar initiatives are being taken forward in Wales, Scotland and Northern Ireland, with the aim of improving end of life care.

1. **Improved Education**
Palliative care teams may provide education to supplement the skills of those caring for patients at the end of their lives. This may include training in holistic assessment, symptom management, both physical and psychological, and communication skills.
2. **Improved communication with the palliative care team**
3. **Integrated Care Pathways**
An integrated care pathway for the dying patient has been developed (5) ("the Liverpool care pathway"). This is being increasingly used to improve care for patients dying both in hospital and at home. The pathway is designed for patients with a known diagnosis who have deteriorated to such an extent that death appears inevitable. Symptoms are monitored and treated expectantly with an emphasis on comfort, communication and preparation for death with spiritual support.

7. Ethical and legal aspects of end of life care

1. Advance directives are becoming more common and provide helpful information for the clinician in making difficult decisions in the interests of the patient who is otherwise unable to give consent. Such directives may be of limited value as they often do not describe the precise clinical situation in advance. A living will cannot force a doctor to carry out treatment which he feels is inappropriate. The BGS, RCP and x in partnership have produced guidance on Advance care Planning (6)
2. The mental capacity act which came into force in 2007 allows patients to nominate a "health advocate" to assist in decision making about treatment.
3. Legal distinctions between allowing death and assisting death are difficult to define, and while patients have the right to determine treatment while capacity is retained, there is no legal right to die. (7)
4. Issues concerning feeding and hydration are covered in the BGS guidance on "Nutritional advice in common clinical situations" (part of the BGS Good Practice Guide of Guidelines, Policy Statements and Statements of Good Practice)

8. End of life care and the geriatrician

1. The current training curricula for trainees in Geriatric Medicine (SpR and StR) stipulates the need for geriatricians to undergo formal training in Palliative Medicine and less formal education in ethical and legal issues concerning end of life care and treatment decisions.
2. These skills will need to be employed in acute and continuing care settings and community situations. There is some evidence that older people are denied access to palliative care teams by being admitted to nursing homes or NHS continuing care facilities (8), but with knowledge of local palliative care facilities, this should be avoided. The End of Life Care Strategy dictates a move for services to be provided to the patient in all settings.
3. Geriatricians should access specialist palliative care teams for advice and support on management of symptoms, communication, psychological and spiritual support if necessary. Training for geriatricians should emphasise these areas. It is good practice to take time to discuss with patients and carers the likely sequence of events in the late stages of illness in order to anticipate the wishes of patients and carers. Tools such as the "Gold Standards Framework" (9) used in primary care can be very useful in discussions and planning in this area. Integrated care pathways (such as the Liverpool Care Pathway) for the dying patient may be a valuable way of improving quality of care at the very end of life.
4. Within a community setting tools such as "Gold Standards for Care homes" (10) may be used. Care homes which wish to use this tool to enhance their care of dying patients are provided with training as well as the tool itself. The aim of this work (led by the Department of Health's "Gold Standard Framework" group) is to aid high quality end of life care for care home residents with the remit of helping residents to "lie well until you die". The use of such tools prompts such matters as open and honest communication with residents or their families about preferences for place of care and other aspects of end of life care.

9. References

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2. Edmonds P., Rogers A. If only someone had told me. A review of patients dying in hospital. Clin Med 2003 3, 149-152.
3. Sutton L.M.: Denmark-Wahnefried W., Clipp E.C. Management of terminal cancer in elderly patients. Lancet oncology, 2003, 4, 149-157.
4. Pincombe J., Brown M., Thorne D., Ballantyne A., McCutcheon ? Care of Dying Patients in the Acute Hospital. Prog Palliative Care 2000, 8, 71-7.
5. Ellershaw J., Foster A., Murphy D., Shea T. and Overhill S.: Developing an integrated care pathway for the dying patient. Eur J Pall Care, 1997, 4 (6) 203-207.
6. Conroy S et al Advanced care planning BGS publications 2009 (in press)
7. Hale B., A Pretpass: When is there a right to die? Clin Med 2003, 3, 142-8.

8. Cleary J.F., Carhone P.P. Palliative Medicine in the Elderly. Cancer 1997, 80, 1335-1347.
9. www.goldstandardsframework.nhs.uk
10. www.goldstandardsframework.nhs.uk/care_homes.php

APPENDIX 1

Principles of a good death as Identified by Age Concern

1. To know when death is coming and to understand what can be expected
2. To be able to retain control of what happens
3. To be afforded dignity and privacy
4. To have control over pain relief and other symptoms
5. To have choice and control over where death occurs (i.e. at home or elsewhere)
6. To have access to any spiritual and emotional support required
7. To have access to hospice care in any location, not only in hospital
8. To have control over who is present and who shares the end
9. To be able to issue advance directives which ensure wishes are respected
10. To have time to say goodbye and control over other aspects of timing
11. To be able to leave when it is time to go and not have life prolonged pointlessly

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