

Clinical review

Care of the dying patient: the last hours or days of life

John Ellershaw, Chris Ward

Evidence based guidelines on symptom control, psychological support, and bereavement are available to facilitate a “good death”

Marie Curie Centre
Liverpool, Speke
Road, Liverpool
L25 8QA

John Ellershaw
consultant in
palliative medicine

Department of
Clinical
Pharmacology,
Ninewells Hospital
and Medical School,
Dundee DD2 9SY

Chris Ward
consultant
cardiologist

Correspondence to:
J Ellershaw
jellershaw@
mariecurie.org.uk

BMJ 2003;326:30–4

The impact of death in our society is easily underestimated. National events sometimes provide a timely reminder of the power and influence of a dignified death and the profound effect it has on the family and those close to the person who has died. Evidence based guidelines now exist to help with the care of people who are dying, including guidelines for symptom control, psychosocial support, and bereavement care.^{1–3} None the less, highly publicised cases continue to occur of patients dying in distress with uncontrolled symptoms and relatives being unsupported at this vulnerable time in their lives.⁴ Ensuring a good death for all is therefore a major challenge not only for healthcare professionals but also for society.

Mortality data for the United Kingdom show that 608 000 people died in 2000; 25% of these deaths were from cancer, 17% from respiratory disease, and 26% from heart disease.⁵ The table gives a breakdown of place of death for all dying patients and those dying from cancer. The modern hospice movement was established in response to the poor quality of care of the dying patient.⁶ The hospice model of care is now espoused as a model of excellence and has led to a worldwide hospice movement aspiring to deliver high quality care to dying patients. Palliative care services deliver direct patient care and also have an advisory and educational role to influence the quality of care in the community and in hospitals. The major challenge is to transfer best practice from a hospice setting to other care settings and to non-cancer patients.

Sources and selection criteria

We searched Medline from January 2000 to March 2002 in the English language by using the terms “palliative care” and “terminal care.” The search yielded 253 references, but only a limited number of articles were directly related to the care of dying patients. Recent books, review articles in specialist journals, and abstracts from conferences have also contributed to this review. The review is also based on personal experience gained by JE as a consultant in palliative medicine based in a hospice and a university teaching hospital over eight years and by CW as a consultant cardiologist over 23 years, including more than 10 years in charge of a heart failure clinic in a large tertiary centre.

Summary points

Too many patients die an undignified death with uncontrolled symptoms

Transfer of best practice from a hospice setting to other care settings, including for non-cancer patients, is a major challenge

Diagnosing dying is an important clinical skill

One of the key aims of specialist palliative care is to empower generic healthcare workers to care for dying patients

Core education objectives related to the care of dying patients should be incorporated in the training of all relevant healthcare professionals

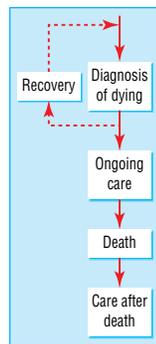
Resources should be made available to enable patients to die with dignity in a setting of their choice

National indicators for care of the dying patient should be identified and monitored

Diagnosing dying (the last hours or days of life)

In order to care for dying patients it is essential to “diagnose dying” (figure).⁷ However, diagnosing dying is often a complex process. In a hospital setting, where the culture is often focused on “cure,” continuation of invasive procedures, investigations, and treatments may be pursued at the expense of the comfort of the patient. There is sometimes a reluctance to make the diagnosis of dying if any hope of improvement exists and even more so if no definitive diagnosis has been made. When recovery is uncertain it is better to discuss this rather than giving false hope to the patient and family. This is generally perceived as a strength in the doctor-patient relationship and helps to build trust.

Recognising the key signs and symptoms is an important clinical skill in diagnosing dying. The dying phase for cancer patients can sometimes be precipitous—for example, massive haemorrhage—but



Clinical trajectory of care of dying patients



Additional material
is available on
bmj.com

United Kingdom data on place of death, 2000⁵

Place of death	All deaths (%)	Malignant neoplasm (%)
Hospital	66.5	55.5
Hospice	4.3	16.5
Other communal establishments	7.8	3.4
Home	19.0	23.0
Other private houses	2.4	1.6

is usually preceded by a gradual deterioration in functional status. In cancer patients, the following signs are often associated with the dying phase:

- The patient becomes bedbound
- The patient is semicomatose
- The patient is able to take only sips of fluid
- The patient is no longer able to take oral drugs.

This predictability of the dying phase is not always as clear in other chronic incurable diseases. Patients with heart failure highlight some of the complexities of diagnosing dying. Heart failure is the most common single cause of death in many hospital medical wards. The palliative care needs of these patients have, until recently, been largely ignored. However, the national service framework for coronary heart disease specifically requires cardiologists and others involved in the management of patients with heart failure to work with palliative care staff to use or adapt palliative care practices for their needs (see quotes on bmj.com).⁸

Diagnosing dying in heart failure

The distress of patients dying from heart failure was identified almost 40 years ago.⁹ A more recent account of their plight clearly shows that they would benefit from strategies developed in palliative care.¹⁰ Approximately 60 000 heart failure patients die annually in the United Kingdom. Most have poorly controlled symptoms—notably breathlessness and chest pain but also mental distress and a range of non-cardiac symptoms that are helped very little by conventional hospital care.¹¹ Patients' wishes to have just symptom control rather than invasive treatments during their last days of life are often ignored.¹²

Predicting when death is imminent is particularly difficult in patients with heart failure for several reasons. Worsening heart failure is not always the result of an inexorable progression of the underlying pathology. In many cases a reversible cause exists (for example, a chest infection, anaemia, an arrhythmia, or suboptimal or inappropriate heart failure drugs), the correction of which may induce a worthwhile symptomatic remission. Furthermore, the use of standard diuretics, inotropes, and vasodilators in varied combinations may produce an improvement, albeit only temporary. The variable effects on outcome of these clinical and iatrogenic scenarios may partly explain the failure of many attempts to identify sensitive biochemical or haemodynamic markers of the end of life in individual patients.

Experienced clinicians will recognise a subgroup of patients, admitted to hospital because of worsening heart failure, whose prognosis seems to be particularly poor. In our experience, currently the subject of a prospective review, these patients are often characterised by:

- Previous admissions with worsening heart failure
- No identifiable reversible precipitant
- Receiving optimum tolerated conventional drugs

- Deteriorating renal function
- Failure to respond within two or three days to appropriate changes in diuretic or vasodilator drugs.

While others steadily improve, such patients often continue to worsen, although they may survive for a week or more. Before this point is reached, the likelihood of recovery and the justification for continuing invasive treatments or monitoring should be reviewed and discussed with patients and carers.

Diagnosing dying—decision making

The most important element in diagnosing dying is that the members of the multiprofessional team caring for the patient agree that the patient is likely to die. If the team members are in disagreement then mixed messages together with opposed goals of care can lead to poor patient management and confused communication. If the patient is thought by the healthcare team to be in the dying phase (that is, having only hours or days to live), then this should be communicated to the patient, if appropriate, and to the relatives. Once dying has been diagnosed the team can then refocus care appropriately for the patient (box 1).

Box 1: Overcoming barriers to caring for dying patients

Barriers to “diagnosing dying”

1. Hope that the patient may get better
2. No definitive diagnosis
3. Pursuance of unrealistic or futile interventions
4. Disagreement about the patient's condition
5. Failure to recognise key symptoms and signs
6. Lack of knowledge about how to prescribe
7. Poor ability to communicate with the family and patient
8. Concerns about withdrawing or withholding treatment
9. Fear of foreshortening life
10. Concerns about resuscitation
11. Cultural and spiritual barriers
12. Medicolegal issues

Effects on patient and family if diagnosis of dying is not made

1. Patient and family are unaware that death is imminent
 2. Patient loses trust in doctor as his or her condition deteriorates without acknowledgment that this is happening
 3. Patient and relatives get conflicting messages from the multiprofessional team
 4. Patient dies with uncontrolled symptoms, leading to a distressing and undignified death
 5. Patient and family feel dissatisfied
 6. At death, cardiopulmonary resuscitation may be inappropriately initiated
 7. Cultural and spiritual needs not met
- All the above can lead to complex bereavement problems and formal complaints about care

Educational objectives for overcoming barriers to diagnosing dying

1. Communicate sensitively on issues related to death and dying
2. Work as a member of a multiprofessional team
3. Prescribe appropriately for dying patients to:
 - discontinue inappropriate drugs
 - convert oral to subcutaneous drugs
 - prescribe as required drugs appropriately, including for pain and agitation
 - prescribe subcutaneous drugs for delivery by a syringe driver
4. Use a syringe driver competently
5. Recognise key signs and symptoms of the dying patient
6. Describe an ethical framework that deals with issues related to the dying patient, including resuscitation, withholding and withdrawing treatment, foreshortening life, and futility
7. Appreciate cultural and religious traditions related to the dying phase
8. Be aware of medicolegal issues
9. Refer appropriately to a specialist palliative care team

Box 2: Goals of care for patients in the dying phase

Comfort measures

Goal 1—Current medication assessed and non-essentials discontinued

Goal 2—As required subcutaneous drugs written up according to protocol (pain, agitation, respiratory tract secretions, nausea, vomiting)

Goal 3—Discontinue inappropriate interventions (blood tests, antibiotics, intravenous fluids or drugs, turning regimens, vital signs); document not for cardiopulmonary resuscitation

Psychological and insight issues

Goal 4—Ability to communicate in English assessed as adequate (translator not needed)

Goal 5—Insight into condition assessed

Religious and spiritual support

Goal 6—Religious and spiritual needs assessed with patient and family

Communication with family or others

Goal 7—Identify how family or other people involved are to be informed of patient's impending death

Goal 8—Family or other people involved given relevant hospital information

Communication with primary healthcare team

Goal 9—General practitioner is aware of patient's condition

Summary

Goal 10—Plan of care explained and discussed with patient and family

Goal 11—Family or other people involved express understanding of plan of care

(Adapted from the Liverpool care pathway for the dying patient—initial assessment)

Care of the dying patient

Healthcare professionals are sometimes reluctant to diagnose dying, as they have not been trained to care for dying patients and therefore feel helpless. One example of this is the practice of transferring the patient to a side room and withdrawing from the patient and family, a strategy that has been used for many years, particularly in hospitals. However, this is the very moment when the hospice model of "intensive palliative care" should come into action, providing physical, psychological, social, and spiritual care for the patient and the relatives (box 2).

Physical care

As patients become weaker they find it increasingly difficult to take oral drugs. Non-essential drugs should be discontinued. Drugs that need to be continued, such as opioids, anxiolytics, and antiemetics, should be converted to the subcutaneous route and a syringe driver used for continuous infusion if appropriate. As required subcutaneous drugs should be prescribed according to an agreed protocol (including those for pain and agitation). Inappropriate interventions, including blood tests and measurement of vital signs, should be discontinued. Evidence is limited but suggests that continuing artificial fluids in the dying patient is of limited benefit and should in most cases be discontinued.¹³ Patients who are in the dying phase should not be subjected to "cardiopulmonary resuscitation," as this constitutes a futile and

inappropriate medical treatment.¹⁴ The patient may have an advance directive that can be used to facilitate discussion about care at this sensitive time.¹⁵

Regular observations should be made and good symptom control maintained, including control of pain and agitation (box 3). Attention to mouth care is essential in the dying patient, and the family can be encouraged to give sips of water or moisten the patient's mouth with a sponge. If urinary incontinence or retention is a problem, catheterisation may be needed. Invasive procedures for bowel care are rarely needed in the dying phase.

In the community, as required drugs need to be readily accessible in the patient's home. Twenty four hour district nursing services should be made available, and with the development of general practitioner cooperative out of hours services the continuity of patient care must be ensured. To this end, innovative models are being developed in the community to support patients dying at home and to prevent inappropriate admission to hospital.¹⁶

Psychological care

Patients' insight into their condition should be assessed. Issues relating to dying and death should be explored appropriately and sensitively.¹⁷

Social care

The family's insight into the patient's condition should be assessed and issues relating to dying and death explored appropriately and sensitively. The family should be told that the clinical expectation is that the patient is dying and will die. Use of ambiguous language such as "may not get better" can lead to misinterpretation and confusion. A constant source of frustration and anger voiced by bereaved relatives is that no one sat down and discussed the fact that their loved one was dying. If relatives are told clearly that the patient is dying they have the opportunity to ask questions, stay with the patient, say their goodbyes, contact relevant people, and prepare themselves for the death. Relatives of patients dying in the community should be given contact telephone numbers so that they have access to help and advice on a 24 hour basis.

Spiritual care

Sensitivity to the patient's cultural and religious background is essential. Formal religious traditions

Box 3: Use of subcutaneous diamorphine for pain control in dying patients

Continuous subcutaneous infusion over 24 hours

To convert a patient from oral morphine to a 24 hour subcutaneous infusion of diamorphine, divide the total daily dose of morphine by three. For example, MST 30 mg twice daily orally = diamorphine 20 mg via subcutaneous infusion over 24 hours

As required diamorphine

Patient on subcutaneous infusion of opioid—dose of diamorphine should be one sixth of 24 hour dose in syringe driver. For example, patient on diamorphine 30 mg subcutaneously via driver will need 5 mg subcutaneous diamorphine every four hours as required

Patient not on regular opioid—diamorphine 2.5-5 mg subcutaneously every four hours as required

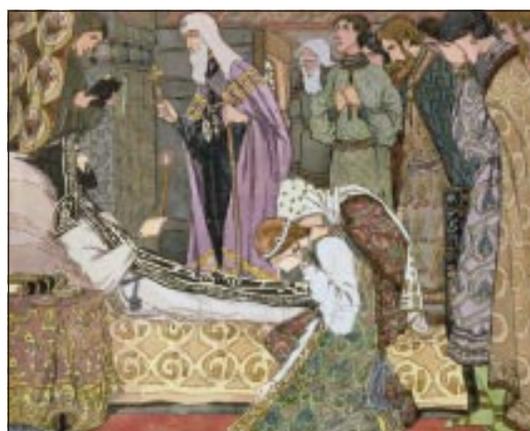
may have to be observed in the dying phase and may also influence care of the body after death. After the patient's death, relatives should be dealt with in a compassionate manner. A leaflet explaining issues related to grieving can be helpful.

Education and empowerment

One of the key aims of specialist palliative care is to disseminate this approach to dying patients among all healthcare professionals. It is important that educational programmes lead to empowerment of generic healthcare workers. This education needs to be targeted at both undergraduate and postgraduate educational levels. *Tomorrow's Doctors* identifies palliative care, including care of terminally ill patients, as one of the core content areas for undergraduate medical education.¹⁸ Indeed, the palliative care component is increasing in medical schools across the United Kingdom; the mean number of taught hours in a recent survey was 20.¹⁹ The educational objectives in box 1 should be incorporated in the training of all healthcare professionals who care for dying patients.

The Liverpool integrated care pathway for the dying patient (see example extract on bmj.com) developed by the Royal Liverpool University Hospitals Trust and the Marie Curie Centre Liverpool, has been recognised as a model of good care²⁰ and is now incorporated into the cancer collaborative programme. It is an innovative model that translates best practice for care of the dying patient from the hospice to a hospital setting. The document is multiprofessional and provides a template outlining best practice for the care of dying patients.²¹ It is initiated when the multiprofessional team members agree that a patient is in the dying phase. It is split into three sections: initial assessment and care, ongoing care, and care after death.²² Patients with heart failure and other terminally ill patients will benefit as much from the Liverpool model as do the cancer patients for whom it was primarily developed.

The development of the Liverpool care pathway has led to measurable outcomes of care. After its implementation, patients dying in a hospital setting had standards of care at a level almost comparable to those reached in a hospice setting. More than 100 cen-



Relatives and friends should be enabled to go through the death of someone they love feeling that they are experiencing a "good death"

Additional educational resources

Books

Maguire P. *Communication skills for doctors*. London: Arnold, 1997

Twycross R, Wilcock A, Thorp S. *Palliative care formulary*. Oxford: Radcliffe Medical Press, 1998

Fallon M, O'Neill B, eds. *ABC of palliative care*. London: BMJ Books, 1998

Kearney M. *Mortally wounded: stories of soul pain, death and healing*. London: Touchstone Books, 1997

Neuberger J. *Caring for dying people of different faiths*. London: Lisa Sainsbury Foundation, 1987

Websites

Bandolier (www.jr2.ox.ac.uk/bandolier/kb.html)—an authoritative evidence based healthcare site, with a large palliative care section

National Hospice Council (www.hospice-spc-council.org.uk/index.htm)—offers educational material and information guidelines about hospices throughout the United Kingdom

Pain.com (www.pain.com/)—covers pain in an educational way and has sections on opioid myths and a library of articles on cancer pain

Palliative drugs (www.palliativedrugs.com)—the palliative care formulary on a website; offers a choice of information about all drugs used in palliative care; also has a section on the use of syringe drivers, with a drug compatibility grid

Helpful Essential Links to Palliative Care (HELP) (www.dundee.ac.uk/meded/help/welcome.htm)—discusses pain, communication, distressing symptoms, and context of care

Information for patients

CancerBACUP (www.cancerbacup.org.uk/info/living-with-cancer.htm); freephone: 0800 18 11 99 and 0808 800 1234—provides information and support by letter, telephone, or email. Information booklets are also available

Cancerlink (www.cancerlink.org); freephone support link service: 0808 808 000; telephone: 020 7840 7840—provides information and emotional support, as well as financial help for patients

Carers National Association (www.carersonline.org.uk/carersuk/); carers line: 0808 808 7777 Mon-Fri 10-12 noon, 2-4 pm—provides support and information for carers of cancer patients

Crossroads: caring for carers (www.crossroads.org.uk/); telephone: 01788 573 653—provides a range of services for carers, including care in the home to enable carers to have a break

Cruse Bereavement Care (www.crusebereavementcare.org.uk/); helpline: 0870 167 1677—offers help to bereaved people. Free counselling service and opportunities for contact with others through support groups

Marie Curie Cancer Care (www.mariecurie.org.uk); telephone: 020 7599 7777—national charity that provides care at 10 specialist palliative care centres and hands-on palliative nursing care in the community

Macmillan Cancer Relief (www.macmillan.org.uk/); information line: 0845 601 6161—national charity that provides information and support for people with cancer and their families

National electronic Library (<http://www.nelh.nhs.uk/>)—designed to be accessible to professionals and members of the public. It offers reliable, up to date information with links to Bandolier and the Cochrane Library

tres across the United Kingdom are involved in work related to the pathway, including implementation in community and nursing home settings. Randomised and blinded research methods are often inappropriate in the care of dying patients, but use of the care pathway results in the production of data for audit and research purposes.²³

Conclusion

The hospice movement, supported by charitable funding, has challenged the prevailing death-denying

attitude of our healthcare system and championed a positive attitude to caring for vulnerable and dying patients that resonates with society. To disseminate this model of care a greater focus needs to be given to the educational issues related to diagnosing dying. Expertise in the care of dying cancer patients needs to be disseminated widely and to include the non-cancer population. A clear structure for care is needed to empower generic workers if we are to achieve the requirement of the NHS cancer plan that “the care of all dying patients must improve to the level of the best.”²⁴

Competing interests: None declared.

- 1 Working Party on Clinical Guidelines in Palliative Care. *Changing gear: guidelines for managing the last days of life: the research evidence*. London: National Council for Hospice and Specialist Palliative Care Services, 1997.
- 2 Twycross R, Lichter I. The terminal phase. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford book of palliative medicine*. 2nd ed. Oxford: Oxford University Press, 1998;chapter 17.
- 3 Expert Working Group of the European Association for Palliative Care. Morphine in cancer pain: modes of administration. *BMJ* 1996;312:823-6
- 4 Dyer C. GMC tempers justice with mercy—Cox case. *BMJ* 1992;305:1311.
- 5 Office of National Statistics. Annual review of the Registrar General on deaths in England and Wales, 2000. www.statistics.gov.uk/downloads/theme_health/DH1_33/Table17.xls (accessed 22 Nov 2002).
- 6 Clark D. Between hope and acceptance: the medicalisation of dying. *BMJ* 2002;324:905-7.
- 7 Higgs R. The diagnosis of dying. *J R Coll Physicians Lond* 1999;33:110-2.
- 8 Department of Health. *National service framework for coronary heart disease*. London: Stationery Office, 2000;chapter 6, para 18.
- 9 Hinton JM. The physical and mental distress of the dying. *QJM* 1963;32:1-20.
- 10 Anderson H, Ward C, Eardley A, Gomm SA, Connolly M, Coppinger T, et

- al. The concerns of patients under palliative care and a heart failure clinic are not being met. *Palliat Med* 2001;15:279-86.
- 11 McCarthy M, Lay N, Addington-Hall J. Dying from heart disease. *J R Coll Physicians Lond* 1996;30:325-8.
- 12 The SUPPORT Investigators. A controlled trial to improve care for seriously ill hospitalised patients. *JAMA* 1995;274:1591-8.
- 13 Joint Working Party between the National Council for Hospice and Specialist Palliative Care Services and the Ethics Committee of the Association for Palliative Medicine of Great Britain and Ireland. Ethical decision making in palliative care: artificial hydration for people who are terminally ill. *J Eur Assoc Palliative Care* 1997;4:203-7.
- 14 Joint Working Party between the National Council for Hospice and Specialist Palliative Care Services and the Ethics Committee of the Association for Palliative Medicine of Great Britain and Ireland. *Ethical decision making in palliative care: cardiopulmonary resuscitation for people who are terminally ill*. London: National Council for Hospice and Specialist Palliative Care Services, 2002.
- 15 British Medical Association. *Advance statements about medical treatment: code of practice with explanatory notes*. London: BMJ Publishing Group, 1995.
- 16 Thomas K. *Caring for the dying at home: companions on the journey*. Oxford: Radcliffe Medical Press, 2003.
- 17 Fallowfield LJ, Jenkins VA, Beveridge HA. Truth may hurt but deceit hurts more: communication in palliative care. *Palliat Med* 2002;16:297-303.
- 18 *Tomorrow's doctors: recommendations on undergraduate medical education*. London: General Medical Council, 2002.
- 19 Field D. Preparation for palliative care: teaching about death, dying and bereavement in UK medical schools 2000-2001. *Medical Education* (in press).
- 20 NHS Beacon Programme. *NHS Beacons learning handbook : spreading good practice across the NHS*. Volume 4: 2001/2002. Petersfield: NHS Beacon Programme, 2001:128.
- 21 Campbell H, Hotchkiss R, Bradford N, Porteous M. Integrated care pathways. *BMJ* 1998;316:133-7.
- 22 Ellershaw JE, Murphy D, Shea T, Foster A, Overill S. Development of a multiprofessional care pathway for the dying patient. *Eur J Palliative Care* 1997;4:203-8.
- 23 Ellershaw JE, Smith C, Overill S, Walker SE, Aldridge J. Care of the dying: setting standards for symptom control in the last 48 hours of life. *J Pain Symptom Manage* 2001;21:12-7.
- 24 Department of Health. *The NHS cancer plan: a plan for investment, a plan for reform*. London: Stationery Office, 2000;chapter 7, para 21.

Commentary: a “good death” is possible in the NHS

Julia Neuberger

King's Fund,
London W1M 0AN
Rabbi Julia
Neuberger
chief executive

Despite the fact that hospices are fashionable, we still discuss caring for a dying person relatively little in this country. Yet any district nurse will tell you that much of that care takes place quite adequately in the community, although it needs a level of coordination and sharing of knowledge and experience that is not always easy to achieve.

In recent years both my parents and my father-in-law have died in their own homes. Our experience was of district nurses of incredible kindness and professionalism working with the general practitioners and palliative care service, as well as community health services providing home loans and pharmacists ready to dispense at the drop of a hat. But this does not always happen. All too often healthcare professionals still regard death as a failure or simply fail to recognise that a patient is actually dying. As a congregational rabbi I often saw unnecessary suffering and terrible distress for family members and friends who loved the person concerned. For people dying of something other than cancer, care was often patchy, poor, and ill coordinated.

Ellershaw and Ward make an eloquent plea for the best care to be available for everyone—not only for cancer patients and not only for patients who are under the care of a specialist palliative care team. That must be right. My father, after a long history of coronary disease, had precisely the heart failure that this paper discusses. He was lucky; the care was superb, both in hospital and at home. We were supported

throughout, as the health professionals carried out a mixture of tasks, irrespective of their personal roles, so that my father could be as comfortable and as happy as possible.

Nothing can prepare a young doctor, nurse, or rabbi for facing people whose death is imminent, and their families, and realising that it is in their power to make a huge difference. Nor can professional education convey adequately just how important it is for individuals, both at the time and afterwards, to go through the death of someone they love feeling that they are experiencing a “good death.” My personal experience of the past few years has taught me that those last few days colour one’s memories permanently. The pain of loss is still immense, but to feel that everything that could have been done was done, that those who cared did so with knowledge, professionalism, devotion, and even love, and that the person died without pain, comfortably, with those they loved around them, is to feel immense gratitude and a curious humility. I now know that superb care is possible within our often stretched NHS. What I do not understand is why it is not available for everybody alike, at home or in a hospice, nursing home, or hospital. Nor do I understand why we do not celebrate the fact that we can, at best, provide a “good death” wonderfully well in this country, perhaps better than anywhere else.

Competing interests: None declared.