Care of the dying: priorities for the future

Care of the dying is core business for acute hospitals. As doctors go on their ward rounds they should reflect that 29% of the patients they see will be in their last year of life, 16% will be within 3 months of death and 9% will die during this admission (Clark et al, 2014). This should colour the way doctors approach the care of these patients. It is important to consider how these hospital admissions give opportunities for discussions about prognosis and future care planning that may avoid future admissions. But when patients are admitted to die in hospital clinicians should be excellent at providing the care they need – after all it is something clinicians do every day.

How do we care for the dying?

The *National Care of the Dying Audit for Hospitals, England* (Royal College of Physicians and Marie Curie Cancer Care, 2014) showed a mixed picture. Sixty-eight per cent of bereaved carers were likely or extremely likely to recommend the trust which had cared for their loved one to friends and family, suggesting that the care their loved one received had been good. However, 12% said they were unlikely or extremely unlikely to do so.

How did the doctors rate in the eyes of the bereaved? In the majority of cases doctors were rated fairly well but 3% felt they were never treated with dignity by doctors and 8% only some of the time. A total of 14% felt that the doctors did not have time to listen and discuss their loved one's conditions with them; 6% had no confidence in any of the doctors and 25% only had confidence in some of the doctors. Nearly a quarter (24%) did not feel involved in decisions about care. Some of these may seem like small percentages but for each of these individuals this was the one chance to get it right. The death of a loved one lives in our memories for ever. Clinicians should be as intolerant of failures in care for the dying as they are of failures in care causing patient's deaths.

Fifty per cent of bereaved carers were not talked to about whether clinically assisted hydration would be appropriate. Some may feel this is a clinical decision, believing fluids are simply not appropriate in the last days of life and they would only discuss if asked. However, there is inadequate evidence in most cases for fluids to be contraindicated and General Medical Council (2010) guidance is clear that 'when the benefits, burdens and risks are finely balanced, patient's wishes will usually be the deciding factor'. Of the carers with whom this was not discussed 55% said they would have found such discussion helpful.

Casenote audit showed that doctors were poor at recording discussions with patients and families about key issues such as hydration, nutrition, spiritual needs and telling patients who could understand that they were dying. This begs the question: was this ever done? The organizational audit identifies that care of the dying was not given enough attention at board level, not given high enough priority in training, and specialist support was not universally available when it was needed.

This is not to say that there were failings everywhere. Some trusts were doing far better than others, demonstrating that high quality care of the dying can be achieved within current NHS resources. The publication of *One Chance to Get it Right*, the system-wide response to the More Care Less Pathway report, is welcome, particularly the sections on 'Duties and Responsibilities of Health and Care Staff' and the 'Implementation Guidance for Service Providers and Commissioners' (Leadership Alliance for the Care of Dying People, 2014). These sections both start with five priorities for care, as outlined in *Table 1*.

These priorities may seem to some like simple good care but they are areas where failings in care have been documented, not only in the national audit but in the numerous responses to the Leadership Alliance public engagement exercise which informed their response. *One Chance to Get it Right* clearly sets out where responsibility lies for improving the quality of care for dying patients. It is important that all play their part.

Making the change

Sometimes, focussing on the simple things in many ways across a whole organization – infection control, thromboembolic prophylaxis – makes a big difference. But we have learnt from these areas that simply producing guidance does not work. It needs organizational investment of leadership, time, energy, education and training. It needs systems and processes and it needs

Table 1. Five priorities for care when it is thought that a person may die within the next few days or hours

1.	This possibility is recognized and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly
2.	Sensitive communication takes place between staff and the dying person, and those identified as important to them
3.	The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants
4.	The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
5.	An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion

From Leadership Alliance for the Care of Dying People (2014)

© 2014 MA Healthcare Ltd

support on the coalface, audit and monitoring – real time quality control. Some may say the Liverpool Care Pathway provided that and in some organizations maybe it did because it was implemented with all the above in place. But there is no point in continuing to mourn the loss of this pathway. Rather this should be seen as an opportunity to develop something even better.

Improving care planning

Clinicians should not just focus their efforts on the 9% of inpatients who will die in that admission but on identifying and working with the other 20% who will die that year. As the Minister for Care and Families, Norman Lamb said in launching the response: 'It's also important that, where possible, planning for dying should start well before the last few days and hours of someone's life, where they want to have those discussions'. An inpatient admission can provide an ideal opportunity for starting that discussion. It is not that the whole plan needs to be signed, sealed and delivered but starting the conversation that the end of life is approaching, and discussing the limits of acute care in delaying death, can lead onto further discussions with GPs and district nurses to put in place plans that support patients at home and reduce use of acute care. These plans need to be reviewed and updated as the condition progresses.

This might also include referral to palliative care services. Seow et al (2014) demonstrated that community-based specialist palliative care teams were effective at reducing acute care use and hospital deaths at the end of life. Temel et al (2010) showed that for patients with metastatic non-small-cell lung cancer, early palliative care was associated with significant improvements in both quality of life and mood. Compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but survived longer.

The *National Care of the Dying Audit for Hospitals, England* (Royal College of Physicians and Marie Curie Cancer Care, 2014) showed wide variance in palliative care provision in hospitals. Only 21% of palliative care teams were available to see patients at weekends and only 2% were available to see patients 24 hours a day, 7 days a week. Shockingly, 9% of hospitals did not even have access to palliative care telephone advice out of hours.

One Chance to Get it Right (Leadership Alliance for the Care of Dying People, 2014) makes clear that service providers and commissioners are expected to ensure provision of specialist palliative medical and nursing cover routinely 9am–5pm 7 days a week and a 24-hour telephone advice service, including face-to-face assessment at any time in the exceptional circumstances where this is necessary.

Conclusions

The challenge for all clinicians is to ensure that *One Chance to Get it Right* (Leadership Alliance for the Care of Dying People, 2014) does not become yet another document lying on the shelf collecting dust but leads to system-wide improvement of care of those in the last year of their lives. Those who are tempted to put it on the 'too difficult' pile should beware – the Care Quality Commission have committed to make end of life care a focus of their future inspections. BJHM

David Brooks
Macmillan Consultant in Palliative Medicine
Chesterfield Royal Hospital and Ashgate Hospice
Chesterfield Royal Hospital NHS Trust
Calow
Chesterfield S44 5BL
(davidbrooks@nhs.net)

Clark D, Armstrong M, Allan A, Graham F, Carnon A, Isles C (2014) Imminence of death among hospital inpatients: Prevalent cohort study. *Palliat Med* **28**(6): 474–9

General Medical Council (2010) *Treatment and care towards the end of life.* General Medical Council, London

Leadership Alliance for the Care of Dying People (2014) One Chance to Get It Right. www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf (annex D and E) (accessed 26 June 2014)

Royal College of Physicians and Marie Curie Cancer Care (2014) National Care of the Dying Audit for Hospitals, England. www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals (accessed 26 June 2014)

Seow H, Brazil K, Sussman J et al (2014) Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis. *BMJ* **348**: g3496 (doi: 10.1136/bmj.g3496)

Temel JS, Greer JA, Muzikansky A et al (2010) Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* **363**: 733–42 (doi: 10.1056/NEJMoa1000678)

KEY POINTS

- Care for the dying is core business for acute hospitals.
- *One Chance to Get it Right* mandates a system-wide approach to improving end of life care.
- All have a responsibilty to play their part.
- Hospital admissions should be seen as an opportunity to improve care beyond hospital.
- Early involvement of palliative care teams reduces hospital attendances and improves quality of life.

CORRESPONDENCE

If you would like to comment on any of the articles in *British Journal of Hospital Medicine,* please write in no more than 250 words to:

Professor Rob Miller, Editor-in-Chief, BJHM, c/o Rebecca Linssen, MA Healthcare, St Jude's Church, Dulwich Road, London SE24 0PB

email: rebecca.linssen@markallengroup.com fax: 020 7978 8316

© 2014 MA Healthcare Ltd