Dying in hospital: what are the priorities for care?

The care of people dying in hospital has come under intense scrutiny in recent years. Serious concerns were raised about a 'tick box' approach without due consideration of the individual's needs and preferences (Neuberger, 2013). In response to the Neuberger report, quality care in the last days of life was clearly described in *One Chance To Get It Right* (Leadership Alliance for the Care of Dying People, 2014). Through compassionate and considerate care, supported by skills and knowledge, and clear, timely and sensitive communication, all hospital staff can contribute to the best possible experience of people and their families at this difficult and distressing time.

> **'Partly as a consequence of being able to postpone the inevitable so successfully in so many instances, a timely death remains difficult to discuss and therefore perhaps less well managed than it might be' (Professor T Treasure, National Confidential Enquiry into Patient Outcome and Death, 2009).**

Caring for dying people in hospital

The proportion of people dying in hospital has fallen steadily over the past decade. Currently nearly half of the UK population die in hospital. Most people, if asked, express a wish to die at home (Dying Matters, 2016). For those aware that their death is expected soon, and who wish to be cared for at home, this is usually possible if the necessary community support is available. However, crises occur, symptoms may prove difficult to manage, and people may change their minds about their plan of care. Caring for dying people in the highly pressurised acute hospital setting is challenging but, done well, it is possible to enable the best possible ending for an individual's life, and to provide support for the bereaved.

Dr Suzanne Kite, Consultant/Clinical Lead in Palliative Medicine, Department of Palliative Care, The Leeds Teaching Hospitals NHS Trust, Leeds LS9 7TF
(suzanne.kite@nhs.net)

What does good care of the dying look like?

One Chance To Get It Right (Leadership Alliance for the Care of Dying People, 2014) describes quality care in the last days of life, focusing on 'five priorities for care'. Grounded in compassionate and sensitive health care, the five priorities are considered under the headings:

1. Recognize
2. Communicate
3. Involve
4. Support
5. Plan and do.

The aims are:

- To provide clear, honest communication at a suitable pace
- To enable informed choice based on an assessment of the needs and wishes of the individual and those close to them
- To develop a personalised plan of care that is reviewed and amended in light of changing circumstances and patient wishes
- To ensure comfort.

Specialist palliative care teams are available to support ward teams in caring for dying people. However, realizing such care for all patients requires that end of life care be 'everyone's business' – a point elaborated in this issue by Enguell and Harwood (https://doi.org/10.12968/hmed.2019.80.2.86).

The five priorities, along with clinical guidance on end of life care (General Medical Council, 2010; National Institute for Health and Care Excellence, 2017; Royal College of Physicians, 2018; Royal College of Surgeons, 2018), provide a standard for good end of life care, and set expectations for the public, professionals, organizations and regulators. End of life care in hospital is a core NHS service (Care Quality Commission, 2016), subject to regular national audit (Royal College of Physicians, 2016; NHS Benchmarking, 2019).

What do we need to do?

The sooner it is recognized and communicated that death may be approaching, the more likely that the dying person can be involved in planning his/her end of life care, and achieving his/her preferences and goals. However, for people dying in acute hospitals, the recognition that death may be imminent comes late – a median of 1–2 days before death (Royal College of Physicians, 2016). Prognostication can be difficult, particularly for those whose recovery is uncertain and in whom a focus on potentially life-prolonging treatment may be appropriate.

Doctors have a key role in improving the initiation and development of end of life care conversations with people who they recognize may die soon, and in developing care plans with them. Prompts that someone may be entering the last phase of life are available (e.g. Supportive & Palliative Care Tools Indicator – https://www.spict.org.uk/, Gold Standards Framework – www.goldstandardsframework.org.uk). These can act as triggers to 'start the conversation' and to record and share treatment options and preferences (e.g. via the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) https://www.respectprocess.org.uk/), and to link the person into general practice, community and palliative care services close to home. Applying the principles of the five priorities to the care of people whose recovery is uncertain can facilitate good individualized care for those who subsequently do not recover. The Amber Care Bundle (Guys and St Thomas' NHS Foundation Trust, 2019) is a useful tool for this.

Sensitive, skilled communication and shared decision making with dying people and those close to them builds upon skills learned earlier in training. Doctors need to be able to discuss uncertainty of recovery, prognosis, and what people can expect to experience, sensitively and with attentiveness to people's concerns. Fatigue and delirium are often present at the very end of life, limiting the capacity of the dying person to participate directly. If such a delay in initiating discussion is unavoidable, then drawing on the person's prior expressed wishes is invaluable. Few people have formal advance care plans, but many more will have had discussions with those close to them, and may also have recorded their wishes in various ways (e.g. ReSPECT).

People often have questions about what they might feel and see as death draws nearer. Dying people and those close to them value discussions with doctors on the potential benefits of starting, stopping or continuing treatments, including medication, food, fluid, and observations and monitoring (Leadership Alliance for the Care of Dying People, 2014; National Institute for Health and Care Excellence, 2017). Background knowledge, supported by a suitable vocabulary, is needed to support shared decision making and to dispel any misapprehensions or fears. An overview of nutrition and hydration is provided in this issue (https://doi.org/10.12968/hmed.2019.80.2.78), as is a practical guide to breathlessness – a symptom all junior doctors will encounter regularly (https://doi.org/10.12968/hmed.2019.80.2.72). The e-Learning for Healthcare (2019) suite of online learning provides a wide range of topical and up to date learning bursts.

Patient priorities inform discussion on place of care. If the need to be comfortable and in familiar surroundings with those one wants near is already being met, people may decide against the upheaval of a further move. However, others prefer to die at home, and many hospitals and localities have mechanisms in place to facilitate rapid discharge. Again, the earlier this wish is recognized, the more likely it will be realized.

The individualized care plan and relevant discussions must be clearly documented, and accessible to the whole care team.

Maintaining a regular presence is really important, to review the dying person's plan of care, being attentive to changes, and to address new and ongoing concerns for the person and those close to the person. All staff can contribute to a culture and atmosphere where care of the dying is highly valued, where the dignity and privacy of those who are dying are prioritised, and their loved ones supported. At this time, the little things can have a lasting impact – some quiet moments by the bedside, a listening ear, vigilance in conversations outside the curtain or door. Timely completion of death certificates is always appreciated.

Conclusions

Palliative and end of life care are core services provided by hospitals. Through compassionate and considerate care, supported by skills and knowledge, and clear, timely and sensitive communication, all hospital staff can contribute to the best possible experience of people and their families at this difficult and distressing time. **BJHM**

KEY POINTS

- Care of the dying is 'everyone's business'.
- The 'five priorities for care' are recognize, communicate, involve, support, and plan and do.
- Hospital doctors have a vital role in recognizing and communicating when death may be imminent, supporting individualized care planning.
- Resources to support development of knowledge and skills are accessible.
- Specialist palliative care is available to support ward teams.

Care Quality Commission. 2016. A different ending: addressing inequalities in end of life care. Newcastle-upon-Tyne: Care Quality Commission.

Dying Matters. 2016. Key Facts. https://www.dyingmatters.org/page/key-facts (accessed 28 January 2019)

e-Learning for Healthcare. 2019. About the End of Life Care programme. (accessed 2 January 2019) https://www.e-lfh.org.uk/programmes/end-of-life-care/

General Medical Council. 2010. Treatment and care towards the end of life. London: General Medical Council.

Guys and St Thomas' NHS Foundation Trust. 2019. Amber Care Bundle. (accessed 8 January 2019) https://www.ambercarebundle.org/homepage.aspx

Leadership Alliance for the Care of Dying People. 2014. One Chance to Get It Right. Publications Gateway Reference 01509. (accessed 29 January 2019) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

National Confidential Enquiry into Patient Outcome and Death. 2009. Caring to the End? A review of the care of patients who died in hospital within four days of admission. London: National Confidential Enquiry into Patient Outcome and Death.

National Institute for Health and Care Excellence. 2017. Care of dying adults in the last days of life. Quality standard [QS144]. (accessed 29 January 2019) https://www.nice.org.uk/guidance/qs144

Neuberger J. 2013. More Care, Less Pathway. A Review of the Liverpool Care Pathway. (accessed 29 January 2019) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

NHS Benchmarking. 2019. National Audit of Care at the End of Life. (accessed 28 January 2019) https://www.nhsbenchmarking.nhs.uk/nacel/

Royal College of Physicians. 2016. End of Life Care Audit - Dying in Hospital. Executive summary. London: Royal College of Physicians.

Royal College of Physicians. 2018. Talking about dying: How to begin honest conversations about what lies ahead. London: Royal College of Physicians.

Royal College of Surgeons. 2018. Caring for People Nearing the End of Life: a guide to good practice. London: Royal College of Surgeons.