

20 March 2014

Joint statement by the Leadership Alliance for the Care of Dying People, i.e.: Care Quality Commission (CQC); College of Health Care Chaplains (CHCC); Department of Health (DH); General Medical Council (GMC); General Pharmaceutical Council (GPhC); Health and Care Professions Council (HCPC); Health Education England (HEE); Macmillan Cancer Support (also representing the Richmond Group of Charities); Marie Curie Cancer Care (also representing Help the Hospices and the National Council for Palliative Care); Monitor; National Institute for Health Research (NIHR); National Institute for Health and Care Excellence (NICE); NHS England; NHS Trust Development Authority (NTDA); NHS Improving Quality (NHS IQ); Nursing and Midwifery Council (NMC); Public Health England (PHE); Royal College of GPs (RCGP); Royal College of Nursing (RCN); Royal College of Physicians (RCP); and Sue Ryder (also representing the National Care Forum and the Voluntary Organisations Disability Group).

Care for people in the last days and hours of life

This statement provides an update on the work being carried out by the Leadership Alliance for the Care of Dying People (the Alliance)¹ since its last statement on 14 January 2014. Alliance members are committed to ensuring that everyone who is in the last days and hours of life², and those important to them, receive high quality care, tailored to their needs and wishes and delivered with compassion and competence.

From late October 2013 to 31 January 2014, the Alliance carried out extensive public engagement, including engagement with families and professionals, on proposed outcomes for the care of dying people, and on guiding principles for professionals. There was strong feedback from the people who took part in the engagement that the proposed ten outcomes were too many and needed to be simplified. The Alliance has therefore developed the outcomes into five priority areas, which cover:

- The possibility that a person may die within the next few days or hours is recognised 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.
- Sensitive communication takes place between staff and the person who is dying, and those identified as important to them.
- 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.
- The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
- 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.

¹ The Alliance is a coalition of the national organisations to which the Liverpool Care Pathway for the Dying Patient review panel addressed its recommendations, joined by charities and others with a strong interest in care for dying people.

² The scope of the Alliance's work is England.

There is no hierarchy within the priority areas: they are all equally important to achieving good care in the last few days and hours of life.

The Alliance is finalising detailed wording for each of these priority areas, along with a version that sets out what dying people and those who are important to them should expect; and a statement of the responsibilities of health and care staff for delivering the priority areas. (This is a development of the “guiding principles for professionals” on which the Alliance engaged and will take account of views and comments from the engagement.) There will also be implementation guidance for commissioners and service providers.

The Alliance’s approach to the care of dying people focuses on what that care should be like, as defined by the five priority areas, rather than the delivery of particular protocols or processes. Where it is currently used, the Liverpool Care Pathway for the Dying Patient (LCP) must be phased out by 14 July 2014. There will not be a ‘national tool’ to replace the LCP. Instead professionals will be expected to demonstrate attention to these priority areas. Service providers and commissioners will be expected to create and support the systems and learning and development opportunities that enable this to happen. The priority areas will inform the inspection by CQC of end of life care in acute hospitals, hospices, adult social care, community health services and general practice and the development of a new NICE Clinical Guideline on the care of dying adults.

The Alliance expects to publish more detailed descriptions of the five priority areas, as well as the supporting documents, in late spring / early summer 2014, along with the system wide response to the recommendations made by the independent panel that reviewed the LCP. The Alliance will not publish detailed clinical guidelines, as these should already exist in each region. In the meantime, organisations and professionals will, as part of best practice, be expected to review the care they deliver for dying people against these five priority areas, including considering how they will demonstrate delivery of each of them for individual dying people and those important to them. Alliance members will, as appropriate, provide specific support to organisations and professionals as they review their arrangements for ensuring that they continue to deliver good care for dying people.

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