

14 January 2014

Joint statement by the Leadership Alliance for the Care of Dying People, ie:

Care Quality Commission (CQC); College of Healthcare 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); NICE (National Institute for Health and Care Excellence); 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; 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 interim statement is an update on work being carried out by the Leadership Alliance for the Care of Dying People (LACDP) following the report of the independent panel on the Liverpool Care Pathway (LCP). The LACDP is a coalition of the national organisations to which the panel addressed its recommendations, joined by charities with a strong interest in care for dying people. LACDP members are committed not only to taking forward the panel's recommendations, but also to implementing a consistent approach to caring for dying people across England, to ensure that everyone who is in the last days and hours of life, and their families, receive high quality care, tailored to their needs and wishes and delivered with compassion and competence.

The alliance believes that the starting point for ensuring excellent care for everyone in the last days and hours of life should be a common understanding, between professionals, dying people and their families and between professionals themselves, about what such care should look like. The alliance aspires to a shared vision for care and is currently engaging with families, and professionals and organisations on draft outcomes and guiding principles, which would help create that shared vision.

The alliance recognises the continuing challenges faced by those caring for dying people, including following the review panel's report. We understand that professionals

are looking for further guidance and direction. The independent review panel concluded that many of the issues around the LCP were that it had come to be regarded and used as a generic protocol – and sometimes as a tick box exercise - which is the wrong approach. The alliance will not produce a replacement for the LCP. Instead, we want to see the way in which a dying person is cared for, including the goals and other key aspects of their care, focused around the individual, in line with their needs and preferences; and developed and delivered in consultation with them, wherever possible and/or their family, and in line with the final version of the outcomes and guiding principles.

The alliance is currently engaging on the draft outcomes and guiding principles. The intentions behind them are generally supported. There has been extensive comment to date on the detail of the guiding principles, which the alliance will consider. The alliance continues to engage widely on the outcomes and guiding principles and is particularly keen to hear from dying people and their families and carers. We will carry out dedicated engagement events with them over the next few weeks, in addition to workshops we ran during November 2013. The alliance will seek views from families from a range of cultural backgrounds, as part of ensuring that the final version of the outcomes and guiding principles will support high quality and responsive care for all dying people, in all societal contexts and taking account of the dying person's religious, spiritual or other beliefs.

All care for dying people should be based on the final version of the outcomes and guiding principles. To support individual organisations and professionals who deliver such care, alliance members will use or support the use of the final version to inform, amongst other things:

- further work on education and training, including in relation to communicating with dying people and their families;
- further work on developing the evidence base in this area;
- the forthcoming reviews of professional standards by the Nursing and Midwifery Council, the Health and Care Professions Council and the General Pharmaceutical Council;
- the new Care Quality Commission (CQC) approach to hospital inspections, under which end of life care will be one of eight core service areas to be inspected;

- CQC inspections of end of life care in adult social care, hospices, community health services and general practice;
- CQC's themed inspection focussing on end of life care, planned for 2014/15;
- the way in which the NHS Trust Development Authority supports NHS trusts to deliver high quality care; and
- the development of a new NICE (National Institute for Health and Care Excellence) guideline on the care of dying adults, which it expects to publish in final form in summer 2016.

The alliance will set out what competences individual groups of professionals who care for dying people need in order to deliver good care; and show how existing provision can help them develop and sustain those competences. We will produce a prompt sheet to help professionals who care for dying people to consider the important elements of care. We will produce a list of recommended core components for training on caring for people in the last days and hours of life, to inform those who fund and procure such training. The alliance will also make existing advice, including on caring for dying people with specific conditions, more easily available.

On 16 July 2013, NHS England issued interim guidance for doctors and nurses caring for people in the last days of life (Gateway 00264). That guidance stands, but the final outcomes and guiding principles will supersede it and professionals and organisations will want to begin considering now how they will implement them. The end-date for phasing out the Liverpool Care Pathway is 14 July 2014. In future, the focus of care for dying people, in whatever setting, should be ensuring the delivery of the fundamentals of good care, as set out in the outcomes and guiding principles. It will not be sufficient to demonstrate the delivery of particular processes or protocols.

The alliance's aspiration is consistent, high quality care for everyone in the last days and hours of life in England, irrespective of where they are being cared for. Much of this is about achieving the culture change that Sir Robert Francis' report on the events at Mid Staffordshire NHS Foundation Trust identified; namely to ensure high-quality, compassionate care, focused on the needs of patients. The system-wide programme of action that is being taken in response to the reports of the Francis Inquiry and the Berwick Report into patient safety is part of improving overall standards of care for dying people. But specific actions are also needed. National organisations are committed to

making the final version of the outcomes and guiding principles a reality for all dying people and their families. But this is not enough. There needs to be the same commitment from every organisation providing health and social care and their Boards, as well as from individual professionals, who, as a minimum, need to reflect on their personal professional practice and how it might be improved.

Individual alliance members will, as appropriate, provide specific support as provider organisations and professionals consider over the coming weeks how they will implement and take forward the outcomes and guiding principles.

Notes:

The draft outcomes and guiding principles are available at:

<http://www.england.nhs.uk/wp-content/uploads/2013/12/lacdp-engage.pdf>

The on-line engagement on the draft outcomes and guiding principles continues until 31 January 2014. To take part, please go to:

<https://www.engage.england.nhs.uk/consultation/care-dying-ppl-engage>

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