One Chance to Get it Right: understanding the new guidance for care of the dying person

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Abstract

Background: Following criticism of the Liverpool Care of the Dying Pathway (LCP), widely used to guide care of dying people in British health-care settings, the UK Government set up an independent review which in 2013 recommended that use of the LCP be discontinued. In response, the Leadership Alliance for the Care of Dying People, a coalition of a wide range of stakeholders, recently published guidance entitled One Chance to Get it Right. This guidance contains five Priorities of Care for the dying person that are intended to guide clinical staff and will inform Care Quality Commission inspections of health-care providers. This article summarizes the background to One Chance to Get it Right and the guidance it contains.

Sources of data: One Chance to Get it Right, More Care, Less Pathway and related guidance documents.

Areas of agreement: The need to improve the standard of end-of-life care in every clinical setting.

Areas of controversy: The value of a pathway-based approach to end-of-life care in a context where well-implemented programmes of staff education in the subject are lacking.

Growing points: Public concern with, and scrutiny of, the quality of dying in the UK health-care system, particularly in hospitals but also the ability of patients to die well at home where that is their place of choice.

Areas timely for developing research: Effective methods of teaching end of life care to all clinical staff; the effect upon families of caring for a dying relative at home; the optimum type, quantity and source of external support to informal carers that is perceived by them as adequate and enables the ill person to die well in in their own home; fuller understanding of the physiology of dying.
Introduction

One Chance to Get it Right was published in June 2014. Intended to provide guidance to clinicians everywhere in the care of dying people, it was drafted by the Leadership Alliance for the Care of Dying People. This is a group of 23 individuals representing between them a wide range of stakeholders, from National Health Service (NHS) England to regulatory bodies such as the General Medical Council and the Care Quality Commission (CQC), by way of others such as the medical Royal Colleges, Health Education England, cancer support charities and the care home sector.

Before One Chance to Get it Right, the tool that guided end-of-life care for generalists was the Liverpool Care of the Dying Pathway (LCP). The LCP, first developed nearly two decades ago, encapsulated the principles of good end-of-life care that had been developed in hospices. It offered a tick box approach to care at the very end of life, both an aide memoire and a checklist to assist staff who infrequently looked after dying patients. A series of studies based largely on the opinions of health-care professionals found that the pathway was generally viewed as beneficial to patient care, with one study also concluding that use of the LCP reduced the quantity of potentially life-shortening medication given to patients. Anecdotally, the pathway improved the last days and hours of life for many thousands of people, but the lack of research evidence to distinguish between the effectiveness of different therapeutic approaches to this stage of life, not least with regard to the place of clinically assisted nutrition and hydration, attracted criticism.

However, between 2009 and 2012, media reports raised concerns that the LCP was bringing about the end of life rather than facilitating care for it. This was particularly due to a perception that the pathway banned the use of clinically assisted nutrition and hydration, with the result that dehydration accelerated the patients’ death. The government responded by appointing Dame Julia Neuberger to head an independent review of the LCP. Under the title More Care, Less Pathway, this reported in July 2013.

The Neuberger Commission heard a number of examples of poor practice associated with the use of the LCP on hospital wards. Some of these revealed a lack of understanding of what the LCP actually said, notably in regard to the administration of food and fluids. Instances were reported of intravenous infusions being stopped when the LCP was initiated; but at the same time, the patient being declared nil by mouth. The aim of the LCP was to prompt re-evaluation of therapies, of whatever kind, so that any that were now redundant—or even counterproductive—in view of the patient’s deterioration could be withdrawn. Although intravenous fluids might no longer serve a therapeutic purpose in someone who was starting to die, it was never stated or intended that a patient who wished to receive oral fluids should be denied them. The apparent abandonment of patients to dehydration revealed a serious lack of the staff education necessary to underpin use of the LCP.

From public submissions made to the Commission, it also appeared that communication with families about the patient’s condition and the objectives of treatment had on occasion been poor. Coupled with inadequate review of changes in the patient’s condition over time, these deficiencies encouraged an impression in some families that the LCP was covertly intended to bring about death rather than being a response to the natural onset of dying. This mistrust was compounded by revelations that just over half of NHS Trusts had received financial inducements to implement the pathway.

In response, More Care, Less Pathway in July 2013 recommended the strengthening of palliative care teams, programmes of education in end-of-life care and the replacement of the LCP by programmes of individualized care planning. The Government accepted the report’s findings and ruled that the LCP
should be phased out by July 2014. During the intervening year, the Leadership Alliance for the Care of Dying People was formed and developed five Priorities of Care for Dying People, described in One Chance to Get it Right, together with extensive guidance relating not only to the implementation of the Priorities themselves but also other issues concerning the best care of dying people, notably professional education, research and the use of terminology.

The five Priorities of Care

The five Priorities of Care represent an approach, which is ‘universal’, to be applied irrespective of the place in which someone is dying and regardless of whether those providers concerned were previously using the Liverpool Care Pathway. It, therefore, applies to all settings where a dying person is being cared for, whether this be a hospital, their own home, a care home or a hospice. The aim is to ensure a high-quality, consistent care for people in the last few days and hours of life. It is important to understand that One Chance to Get it Right lays responsibility for implementation of the Five Priorities widely: all clinical staff members, wherever they work and whatever their profession or grade, who are involved in caring for a dying person must contribute to making that care of the highest quality. This expectation is not new, but it is now fully explicit. Furthermore, doing the right clinical thing is no longer the sole responsibility of care providers. In addition, the role of contracting and resources is recognized through an explicit expectation that Commissioners of care will share the responsibility for effective end-of-life care, while previous training deficiencies are acknowledged through placing this responsibility also with Commissioners of education and training as well as the medical and nursing Royal Colleges. The priorities are shaped predominantly by the 44 recommendations of the independent review of the LCP.

Priority one

‘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.’

This priority is less about making a ‘diagnosis of dying’, which proved a contentious issue with the LCP, but about recognizing a ‘possibility’ of dying. As critics of the LCP pointed out, it is often difficult to be sure that someone is dying and when, particularly if the principal diagnosis is not cancer and may involve disorders of several systems. Instead, the emphasis has shifted to recognizing patients who are clinically unstable and may not recover despite medical treatment. Such an assessment must be carried out on a person whose condition has deteriorated by a doctor competent to judge whether this change is potentially reversible or whether the death is likely to result in the next few hours or days. The results of this judgement—including the likelihood of dying—need sensitively to be communicated to the patient (if possible) and to those important to them, explaining why this conclusion has been reached, acknowledging that there is always prognostic uncertainty and giving opportunity to ask questions. These conclusions must be reviewed by a senior clinician who has the skills to assess whether the person is dying and should also be influenced by the views of the wider multiprofessional team. Here, the language of the guidance changes, and although a doctor is required to make the initial assessment, it is not explicit that continuing review has to be by a doctor. It would seem appropriate that a senior nurse or other member of the multiprofessional team could also carry out this function, the key point being that whoever it is has to have the skills necessary to judge the progression of the dying process. This is particularly so given that the review process is envisaged as being carried out at least daily, something that in the community will require involvement of district or care home nurses as well as the general practitioner (GP). However, reflecting concerns expressed in the LCP report, whoever has done the review it must be clear who is responsible for the patient’s care. It is that person who should be directing the overall strategy of care and seeking specialist opinion if there is uncertainty whether or not the person is dying.
The conversation with the patient should encompass what goals of treatment and care are now appropriate and who else they would wish to be involved in discussions or to be informed. Once decided, these goals and wishes should be recorded in a way that is accessible to everyone who is contributing to the person’s care. If the assessment reveals that the person lacks mental capacity to make the necessary decisions, the goals must be decided on a best interests basis in accordance with the Mental Capacity Act 2005, a point that will be considered further during discussion of the third priority of care. Those whom the person has identified as important to them need to be kept updated about changes in their condition and how the caring team intends to respond.

Priority two

‘Sensitive communication takes place between staff and the dying person, and those identified as important to them.’

Communication with the dying person should have certain key characteristics. It must first of all be comprehensible. Medical staff still too frequently use medical terms, initials or acronyms without explaining them to patients or families. Equally unhelpful to clear communication is the use of euphemisms other than as staging posts on the way to more explicit, but still sensitive, descriptions of the clinical situation. However, sensitivity also includes respecting a patient’s wish not to have open conversations about their condition or what is happening to them. Good communication is a dialogue, not a monologue: it entails listening to what the dying person wants to know and what their principal concerns are in order to tailor the conversation to meet their needs. If any additional support is required for the dying person to understand the information, communicate their wishes or make decisions, this must be provided. Clinical staff should confirm the understanding that has been gained at the end of a discussion.

Communication should be regular so that people both know they have an opportunity to ask questions and also when those opportunities will arise. The frequency of communication that is acceptable should be checked with the dying person and those important to them. Opportunities for discussion should be offered spontaneously by the staff rather than the patient and the family having to seek them out. There can be a reluctance to ask questions of busy nurses and doctors for fear of unnecessarily taking up their time, and clinicians should not make the mistake of assuming that if no questions are asked, patients and families are satisfied with the information they have.

Communication should show a concern for privacy and confidentiality, including finding out what the person would wish to be communicated to whom. However, families have needs for information and where there is no record to say otherwise and the dying person does not have capacity to consent, it is reasonable to assume that they would want their family and those important to them to be informed about their condition and prognosis. The content and outcome of all discussions must be documented and accessible to everyone involved in the person’s care. This applies particularly to any concerns that the person, their family and friends may have expressed.

For people dying at home, the named GP or nurse must ensure that families and carers know how to seek urgent help at any time of day and night. It is also valuable for family members to have guidance as to what key information they should be ready to provide when calling in order to ensure that they obtain the most effective response. As soon as possible after the death of the person, and with the family’s agreement, a health-care professional should attend to make sure that the body is cared for appropriately and to look after the immediate practical and emotional needs of those present.

Priority three

‘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.’

People vary in their desire to be involved in treatment decisions, but this priority focusses on the importance of the caring team sensitively exploring with each individual the degree of involvement they
want at each stage as the illness progresses. But for this to happen, the patient and those close to them must be able to recognize the clinical staff heading their care. Therefore, in both hospital and in the community, patients need to know the names of the lead doctor and nurse responsible for their clinical management including who will be standing in for them at times of absence.

In making any decision the potential benefits, burdens and risks of either having a treatment or, alternatively, of not having it for this particular patient must be discussed to the extent that is wanted. The dying person’s family and those important to them should be involved in decisions to the degree that the patient is comfortable with. As a person approaches death, it is likely that their mental capacity to make decisions will diminish, so clinical staff should be familiar with the provisions of the Mental Capacity Act 2005, starting with the requirement to offer all practicable support to enable patients to make informed decisions as much as they want to. Capacity is specific to the decision in question and depends on the patient’s ability to understand, retain and weigh information about the matter to be decided.

If capacity is judged to be lacking, decisions must be taken on their behalf in their best interests in the light of any valid, relevant advance directive that may exist and other information that may be available as to their past preferences. Family members and friends might contribute to this knowledge, but staff must understand the basis on which any conversation is being had. Are members of the family and friends:

- Being informed regarding a decision about care and treatment? This is appropriate if the patient has capacity and has indicated that they would like those close to them to be kept in the picture about their condition and treatment.
- Being consulted regarding a decision about care and treatment? This is the situation where a best interests decision has to be made in the absence of an appointed proxy under a Lasting Power of Attorney for Personal Welfare. Family, whether or not labelled as ‘next of kin’ do not have the legal right or responsibility to make decisions on behalf of the patient, but clinicians must find out from them if they know of any relevant preferences the patients has expressed in the past.

- Taking a decision about care and treatment? This is only the case where a family member or friend has been appointed under a Lasting Power of Attorney for Personal Welfare that has been registered and gives authority to make the type of decision currently needed.

In the case of persistent disagreement about what constitutes a patient’s best interests, efforts must be made to facilitate discussion among the concerned parties, for instance, by involvement of a social worker or spiritual care lead. A second opinion should be sought if differences persist, and if disagreement really cannot be resolved, staff should take advice about applying to the court for an independent ruling, a move about which the dying person and those important to them must be informed as promptly as possible.

**Priority four**

‘The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.’

Care of the dying is a public health measure, with families’ experience of a loved one’s final illness and death shaping their own responses to serious illness and health care in the future. Accordingly, staff need regularly to assess and, as far as possible, address the needs of families and others important to the dying person, including directing them to other sources of help and support. Inpatient facilities need to welcome families and enable them to spend time with the dying person to the extent that they and the dying person wish. The knowledge that these groups might have about the ill person’s preferences and their experience of caring for them should be taken into account in planning care, and they should be enabled to be involved in giving care if this is what they and the dying person wish.

The needs of the dying person and those important to them may differ, between individuals and between generations, and these differences need to be acknowledged and sensitively accommodated in
the care and support that are provided. Although some families do not wish to talk openly about death and dying, staff nevertheless should seek a sensitive way in which to remain clear in their communications and prepare them for the death that is shortly to occur, whether this is happening in an institution or at home. In particular, when death is very close, staff should check with the family and others accompanying the dying person how they wish to be supported, for instance, whether they wish to be left alone or to have regular visits from the nursing team on duty, and, in any case, ensure that they know where the staff are or can be contacted.

When the death occurs, the immediate support that family and friends need must be provided, and if they wish to spend time with the deceased person, this should be allowed without a feeling of pressure. They must have a chance to ask questions and to be given guidance about death certification and registration procedures. This is particularly so if the death has occurred unexpectedly or after only a short period of deterioration, when it may also become necessary to give them help in understanding the role and working of the coroner.

Priority five

‘An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.’

Priority five addresses some of the most significant findings of the Neuberger report, through the requirement that a plan of care should be drawn up that is individualized to each dying person and that careful thought should be given to symptom control and issues of hydration and nutrition.

The plan of care must be responsive to the needs and wishes of the dying person and evolve according to changing requirements. Its existence and content should be transparent, and mechanisms should be in place to make it accessible across professional boundaries, e.g. by an Electronic Palliative Care Co-ordination System. Ideally, the care planning should have started earlier in the illness and subsequently been updated, rather than only commencing as a response to the onset of dying. The extent to which the dying person wishes to be involved in such planning must be respected, as must their wishes as to who else should be involved in the planning discussions. When the dying patient lacks capacity to make the relevant decisions, these must be made in their best interests following appropriate consultation as outlined in connection with Priority three.

As part of care planning, the dying person’s physical, emotional, psychological, spiritual, cultural and religious needs must be assessed and then reviewed as appropriate. The outcome of assessments should be explained to the patient insofar as this is wanted and possible and to their family and others important to them. Disagreements about the outcome of assessments ought to be acknowledged and acted upon through discussion, reflection and seeking alternative opinions.

Most of the complaints about the LCP concerned hydration or nutrition, and One Chance to Get it Right makes clear that patients must be assisted to eat and drink as they wish unless there is a ‘serious’ risk of choking. If this is in doubt pending a swallowing assessment, alternative forms of hydration must be considered and discussed with the person; but where their informed choice is to eat or drink despite the risk of aspiration, this has to be respected. Alternative modes of hydration are clearly easier to implement in inpatient hospital or hospice settings than elsewhere, but subcutaneous administration of fluid can be carried out safely in the community without continuous professional supervision. Clinical records should contain an assessment of the patient’s intake. For patients unable to swallow, decisions about clinically assisted nutrition and hydration must comply with the General Medical Council 2010 guidance Treatment and Care Towards the End of Life: Good Practice in Decision-Making. Whatever decision is taken in this area staff must pay attention to the dying person’s mouth care and other personal care needs in order to ensure their comfort and dignity.

Sedatives and analgesic drugs appear sometimes to have been given as a matter of course to patients placed on the LCP rather for a specific symptom control need. Accordingly, as part of Priority five, all medications must be targeted at specific symptoms,
have a clinical rationale for the starting dose, be regularly reviewed and the dose adjusted as needed for effect. The dying person should, if at all possible, be given an explanation as to why any intervention is needed prior to it being started. This also applies to the potential side effects of interventions, especially where a drug might make the patient sleepy, and this explanation should also be given to those important to the person unless the patient does not wish this to happen. At all times, staff must ensure that medications and equipment necessary for the dying person’s comfort are available as soon as needed or, in the community, that they are obtained in anticipation. Treatment and care must be fully and accurately documented.

Where assessment has identified the need for specialist spiritual or religious support, staff must make sure that the dying person and those important to them can access available chaplaincy or spiritual care provision, whose members must hold information about and be able to contact local faith leaders. As part of care planning, staff must discover from the dying person and their family any specific religious or cultural requirements that are important to them, including how they would wish the body to be treated after death.

Clinical teams must refer to specialist palliative care for advice or assessment when the needs of the person or those close to them are beyond their competence to meet or when initial measures have failed to provide adequate relief within 24 h at most. For their part, Commissioners must ensure adequate access to specialist palliative care. As a minimum, this comprises the ability to visit between 9 am and 5 pm, every day of the week and 24/7 access to telephone advice.

Should there be inadequate time to determine the dying person’s wishes about, or suitability for, cardiopulmonary resuscitation, DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) documentation from another care setting or care provider should be taken into account and followed, where the clinician making the decision is sure that they have enough information about the person to judge that the DNACPR is valid and applicable. This includes ambulance personnel who might be called to a dying person at home or in a care home because they have new symptoms. In addition to the question of CPR, ambulance staff are expected to manage symptoms or decide whether to transfer the patient to hospital or another care facility in accordance with the patient’s previously expressed wishes and agreed care plans. Where there is doubt, help should be sought from senior ambulance clinical advisors, the GP or out of hours primary care provider or (if involved) the community specialist palliative care team.

**Conclusion**

*One Chance to Get it Right* is a highly significant document in the breadth both of those who have contributed to it and of its reach. It applies to all clinicians everywhere who have care of a dying person and expects a consistent quality of professional response that to date has not always been present. It recognizes the support that clinicians need if they are to live up to the behaviours required by the Priorities of Care: accordingly, it expects Clinical Commissioning Groups to include compliance with the Priorities, and the education necessary to underpin them, in their contracts and service specifications. Within provider organizations, there should be prioritization of the care of dying people, incorporated into Clinical Governance, with Board level accountability. Education to enable staff to acquire and maintain the competences necessary to complying with the Priorities of Care must be made available and accessible; in an Annex, the document describes currently available educational resources. Regulators are included as well: *One Chance to Get it Right* will inform the CQC inspections of end-of-life care in hospices, adult social care, community health services and general practice. The CQC will also take it into account as it undertakes a themed inspection focussing on end-of-life care in 2014/2015.

However, *One Chance to Get it Right* does not stand alone but is only one of a series of documents and initiatives that are intended to improve the way in which the health service meets the needs of dying people. *Actions for End of Life Care: 2014–16* sets out NHS England’s commitments for adults and children; it is one component of a wider ambition to develop a vision for end-of-life care beyond 2015.
National Institute for Health and Care Excellence expects to publish a new clinical guideline on the care of dying adults in 2015, while Health Education England and others will initiate work to guide in the use of the ‘e-ELCA’ e-learning programme as a resource to support education and training.

Research in palliative and end-of-life care is meagre and poorly resourced. The National Institute for Health Research (NIHR) has commissioned updates of Cochrane Reviews of evidence on medically assisted nutrition and on medically assisted hydration for palliative care patients, as well as underpinning One Chance to Get it Right by mapping evidence requirements from the five Priorities for Care. The results of the NIHR mapping and the recently established James Lind Alliance Priority Setting Partnership will inform a programme of future research around care for people in the last few days and hours of life.

The independent review of the LCP commented that ‘Dying is not only a physical event—it is the conclusion of a life defined in its nature, content and connections within a society and its cultures that are every bit as important as the mechanism of how dying happens.’ The Leadership Alliance fully agrees with this view, whose influence permeates all five Priorities of Care.

Conflict of interest statement
The author has no potential conflicts of interest.

References