Care of the dying: how do we replace the Liverpool Care Pathway?

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Abstract

Introduction: Death is an inescapable certainty of life. Variability in care for dying persons, however, is present. The Liverpool Care Pathway (LCP) sought to guide care for the last days of life but was phased out after intense scrutiny.

Sources of data: A governmental report and rapid review of evidence were considered alongside mass and social media reporting. An evidence review of end-of-life care was undertaken.

Areas of agreement: Any person’s death is inherently challenging. Much consideration must be given to holistic needs when approaching death. Communication skills may be lacking for professional and patient alike.

Areas of controversy: The LCP became flawed in use rather than intention or principle. Seeming financial gains from death were concerning to all.

Growing points: We have responsibility for making choices prospectively in order for them to influence our care when we are dying. Normalization of death is key on both micro- and macro communication levels.

Areas timely for developing research: Perceptions of relevant terminology; review of the definition of dying; improved recognition of the dying process and measuring the impact of communication skills training.

The evil that men do lives after them
The good is oft interred with their bones
Julius Caesar, Act III Scene ii

Introduction/background

To suggest that the death of a person is ‘an important life event’ is an understatement. As the English poet John Donne recognized over 400 years ago, no one’s
death occurs in isolation.\textsuperscript{2} We are all interconnected, particularly those we consider ‘nearest and dearest’. A family member’s death affects the newly bereaved in a myriad of ways.\textsuperscript{3} Not only is the act itself of profound significance, but the manner in which we die may be remembered years later.\textsuperscript{4} It comes as no surprise that a previous Dying Matters campaign and the more recent Leadership Alliance for the Care of Dying People (LACDP) publication were both entitled ‘One Chance to Get it Right’.\textsuperscript{5,6}

Whilst evidence suggests that the previous century was somewhat death denying there is a body of work which supports our current society as death-defying.\textsuperscript{7,8} Although death is a natural consequence of life we are increasingly living in a post-modern age where the preoccupation of medicine with curative efforts has caused some, perhaps ironically, to regard death as ‘physically-optional’. This reductionist view, however, fails to consider a person’s death as loss of being in addition to the loss of a being. As the close of life approaches an individual’s needs become increasingly multifaceted. Healthcare professionals are not exempt from the emotion and challenge that caring for someone at the end of life brings.

In the 1990s the management of dying patients was more formally addressed by the launch of the Liverpool Care Pathway (LCP).\textsuperscript{9} Having a basis in well-established principles of end-of-life care, the LCP aimed to transfer the excellence of hospice-based care of the dying into other healthcare contexts, including the acute hospital. It facilitated comprehensive recognition of patients’ needs in addition to symptom management. The needs of a person and his or her family are not limited to physical, but comprise profound psychological, emotional, social, sexual and spiritual components. The interventions that the LCP suggested were pertinent to both patients and the healthcare professionals caring for them. In addition the LCP provided a framework for robust documentation, an often overlooked ingredient of high-quality end-of-life care.

The LCP was hailed by the Royal College of Physicians and championed by generalist teams because of the standards of excellence it set.\textsuperscript{10} It was soon adopted widely throughout the UK. Credence was gained in national audits of care of the dying and this led to endorsement by the Department of Health itself.\textsuperscript{11} For these reasons it was surprising that by the second decade of this century, despite the noble intentions of the LCP as a tool to aid patients and professionals, things soon began to unravel.

Over a course of several months from late 2012 care of the dying in the UK became the target of intense media scrutiny. What was once considered the most sacred space in the human life cycle became prey to tabloid sensationalism.\textsuperscript{12–14} The LCP was lambasted in the process. The media considered it as little more than a ‘money-making tool’ for acute trusts to reduce length of stay figures.\textsuperscript{15} Entwined with this conviction were emotionally charged reports of the incorrect implementation of a pathway designed to be applicable only to the last hours or days of life. To summarily dismiss all the charges levied against the LCP as heinous, however, would be erroneous. For example, it was during this same frenzy when failures in communication about death and dying became startlingly apparent. Likewise, inappropriate use of the pathway as a surrogate for clinical responsibility came to light. Whilst the raised public profile of death and dying was welcomed, the emotionally fuelled finger-pointing at the LCP often weighted chaos above rational discourse.

In early 2013, public outrage over poor practice in end-of-life care prompted governmental response. The government commissioned Baroness Neuberger to chair an independent review of the LCP. It was not initially certain what the outcome would be, yet it came as no surprise to anyone that the death knell of the LCP soon sounded. It was to be phased out within 12 months of the July 2013 publication of ‘More Care, Less Pathway’.\textsuperscript{16} The 43 other recommendations addressed a wide range of issues, from improving basic communication skills to encouraging a more informative public debate on end-of-life care in the UK.

In response to the Neuberger report the LACDP was formed in October 2013, joining major public and benevolent organizations through NHS England. Among more than 20 national stakeholders represented are charities involved with end-of-life issues as well as regulatory bodies of both healthcare professionals and national strategy. A principal aim was
to consider the needs of dying persons and guide professionals towards a standard of the highest quality of compassionate care. To facilitate this pursuit a national consultation was opened. Both public and professional contributions were not only welcomed, but wanted. In addition to targeting specific expertise by means of direct appeals to individuals, persons from all walks of life were encouraged to attend a series of open workshops held throughout the UK. The LCP was to be phased out by July 2014, 1 month after the LACDP released its ‘One Chance to Get it Right’ in June 2014. Unlike the media fervour during the demise of the LCP, this publication was received into comparative media silence.

The report by the LACDP uses five priorities of care to consider why we are doing what we are doing, not just what we are doing (Table 1). Guidance on how to achieve these priorities with each patient is given to the entire care hierarchy, from individual patient right through to parliament. This is no small task and it will be of great interest to see how these recommendations are fulfilled. Those caring for persons at the end of life are further asked to pledge a collaborative approach between patients and professionals. From this the process of care will be tailored. Compliance with these priorities of care will be judged by the Care Quality Commission. This new approach, the authors maintain, serves to remove tick-box, protocol-led and task-based end-of-life care. Person-centred care is promoted instead and subsequent documentation for communications and care is left to local providers. This aims to represent the variation in service and cultural needs. Such localism will likely lead to many different written versions of care plans at the end of life; it remains to be seen whether or not this is beneficial. National guidance, however, is given on having a named consultant responsible for overall care of a patient, continuation of oral intake and communication regarding the appropriate use of sedation with or without a syringe driver.

Beyond the bedside the LACDP report advocates the need for further national guidance and an evidence base. In 2015 the National Institute for Health and Care Excellence is scheduled to publish specific guidance on caring for the dying adult. The James Lind Alliance Priority Setting Partnership aims to target funding for research in this area. These efforts will be enhanced by a mapping review by the National Institute of Health Research. These strategic academic aims are welcome but the delay in translating research into clinical excellence should not be the burden of those who are dying. For those dying without this prospective evidence base, governmental funding will be needed for the recommended provision of face-to-face specialist palliative care during office hours as well as 24-h advice 7 days per week.

Any personal end-of-life care plan may well take on a different structure from the LCP. For example, it may not lend itself to being documented in a similar manner, but will amalgamate the principles of holistic care for persons approaching death and those important to them. The plan will also need to be practical and possibly even instructional. For example, it will need to guide non-specialists through the prescription of medications for symptoms commonly experienced by dying persons. Implementation and rehabilitation of a locally influenced national scheme for the care of the dying is essential to regain trust in our ability to care for those who are dying. This will necessitate education for both public and professionals alike. End-of-life care offers a privileged opportunity to bear witness

Table 1 Five priorities of care from the LACDP document ‘One Chance to Get it Right’

| 1. | The possibility that a person may die within the coming days and hours is recognized and communicated clearly, decisions about care are made in accordance with the person’s needs and wishes and these are reviewed and revised regularly |
| 2. | Sensitive communication takes place between staff and the person who is dying and those important to them |
| 3. | The dying person, and those identified as important to them, are involved in decisions about treatment and care |
| 4. | The people important to the dying person are listened to and their needs are respected |
| 5. | Care is tailored to the individual and delivered with compassion—with an individual care plan in place |
to the dignity of an individual. This is true for family and professionals alike. Disappointingly, during the dissolution of the LCP there has been a distinct lack of dignity for both the principles of the care it espoused as well for those involved in its use.

**Sources of data**

A variety of sources were employed during the preparation of this paper. The issues surrounding death and dying in the UK are today much more frequently addressed in the professional literature. Extensive mass media coverage cannot be ignored. The LCP, in particular, has been featured on a dedicated prime time television programme,\(^{17}\) receives on-going newspaper coverage and continues to provoke sometimes inflammatory reviews on various social media platforms.\(^{18}\) In contrast, when the British government entered into dialogue, it did so in the form of a rapid review of evidence\(^{19}\) for the use of a pathway in end-of-life care. This was quickly followed by the Neuberger report and the birth of the LACDP. Hence, the actions of the mass media may have partly prompted formal governmental response and appreciation of the need for a critical analysis of the LCP, its principles and its evidence base. For the purposes of this paper, a literature review of care at the end of life was performed and consideration was paid to how the needs of care of the dying might change in the future. At present the evidence base for palliative and end-of-life care is growing, but is still relatively small. End-of-life care research has numerous associated challenges, ranging from ethical considerations to difficulties with randomization.

**Areas of agreement**

We are all going to die. In the face of this truth high-quality end-of-life care seeks to affirm life until death. Since each person’s life is inimitable, however, why should this individuality end as the close of life nears? We believe families and loved ones recognize this, as do most healthcare professionals, but the frenetic pace and staffing ratios of an average NHS hospital do not readily permit comparable personal care as achieved in a hospice inpatient unit. Sadly, the LCP in some places was perceived as a generic assembly-line process, the so-called ‘one-way trip’ for patients that could not be reversed once it was started. We agree instead with a philosophy of care where medical input at the close of life is but one facet in the treatment of symptoms. Symptoms, however, may not be solely physical. Death has become an increasingly medicalized issue despite the fact that no person will be spared. Another role for care workers is to help prepare patients and families for loss, particularly essential for those that live on.

Symptom control may be of profound importance at any point along the illness trajectory, perhaps even more so as a life is ending. Efforts to relieve suffering shape the experience of the dying person and that of his or her family as well as the professionals involved in care. In light of this the prescribing of as-required anticipatory medications, tailored to a patient’s needs and disease state, is an essential step to facilitate relief of physical suffering. Although the intention is to minimize suffering their appropriate and safe use is vital. Guidance on basic prescribing of commonly required medicines at the end of life will be needed to ensure patients have timely access to drugs. It is, however, imperative that drug availability does not supplant healthcare professionals’ skills in timing of, as well as reasoning and communicating about, appropriate interventions at the end of life. Prescribing in end-of-life care should not only consider common symptoms such as pain, distress, nausea or secretions, but must be safe holistically speaking. For example, the use of drug therapy in end-of-life care should be measured not only in effective symptom relief, but also in the memories of the effects of drugs used in proximity to the death of a loved one.

A building is only as tall as its foundation is strong enough to build on. Likewise, the principles of good end-of-life care must underpin whatever system is destined to succeed the LCP. Some form of written document should be employed to help crystallize these principles lest they remain ambiguous and ephemeral rather than practical and helpful to those providing care. A document acts as a resource to prompt excellent care rather than a series of commandments to absolve the wielder of professional
responsibility. It is not possible to create a nationwide instrument which will govern every individual’s needs at the end of his or her life in every conceivable circumstance. No tool, irrespective of how well created or intended, could or should replace a values-based practice attending to a person and the needs of his or her personhood (see Fig. 1).

The centrality of communication to this discussion must not be underestimated. There are challenges on both sides of the patient–professional divide. These include the acceptance of an approaching-yet-unavoidable death, the hopefulness of ‘curing’ death and the willingness to broach a subject still widely regarded as taboo. Remarkably, there continues to be a lack of a common vocabulary within end-of-life care.20 The phrase ‘LCP’ is not a descriptor of its function in end-of-life care. Euphemisms and stock phrases persist to protect professional and lay person alike. Given such collusion, it becomes easy to eschew conversations which may cause distress, but are nonetheless required as a matter of professional responsibility. Whilst all communication must respect the wishes of the dying person with regard to disclosure, it should also consider the differing needs within his or her family so far as the patient is willing to allow.21

Sharing information with patients as they approach the close of life may best be appreciated as a process unfolding over time rather than a single episode. Continuity of staff and communication is essential. This is no mean feat in modern healthcare. Nonetheless the education of all professionals caring for those at life’s end is vital to ensure the constancy of approach. Good communication, however, is not just a latent property of the communicator. Professionals need to cultivate communication skills which encourage other parties, such as patients and their loved ones, to themselves facilitate productive information exchange. This expertise may promote mutual understanding and trust.22 Moreover, it is not solely based on any single or small group of professionals. Rather, it rests within an overarching paradigm of communication followed by appropriately trained care personnel.

Communication skills training must be available to all. The discrepancy that has arisen in communication training between cancer and non-cancer services has notably excluded the majority of professionals who care for the majority of dying patients. Most persons in the UK do not die from cancer, its treatment or its complications. In 2013, of those who died with a medical cause, 75% did not have a cancer diagnosis.23 A values-based approach to communication skills training would utilize nurtured or learnt methods rather than rote process. There is synergy between the classical tenets of medicine and

![Fig. 1 Facets of personhood to be considered at end of life.](https://academic.oup.com/cmb/article-abstract/112/1/5/2747684/6)
good clinical care. For instance, the dictum of ‘do no harm’ is typically associated with the prospect of physical injury. There are many types of injury, though, not least of which are emotional and psychological. Presumptions such as these should be reconsidered in the light of some 3–7% of NHS complaints which have to do with poor care at life’s end. Education about communication with dying persons and their loved ones, ranging from undergraduate to public levels, will be an integral component to any sustained improvement in caring for the dying.

The UK can justifiably lay claim to be the preeminent founding nation of the modern hospice movement. It was consequently quite unanticipated that such controversy emerged over the LCP. One reason may be the emotional tariff poor end-of-life care exacts. As a result, small numbers of substandard experiences are magnified and overshadow the otherwise potentially larger majority of patients who died on the LCP and who died well. Moreover, there is evidence that the LCP approach did not cause harm. As an intervention in care the LCP had a modest, but growing, evidence base which could not be expanded in time to meet protracted and growing scrutiny. Furthermore, the standard of the available evidence did not approach the present-day gold standard of the randomized control trial. On the other hand, this evidence could not possibly have taken into account the unreported negative effects of poor end-of-life care where the LCP was neither adopted nor used. Likewise it is not possible to prove that the absence of the LCP has led to any decline in patient experiences of care at the end of life. Of note is the absence of similar media furores regarding poor end-of-life care without the use of the LCP—an interesting subtext to the much needed debate around our care as we are dying. It is unreasonable to assume that all care has been exemplary since it was recommended that LCP use be ceased yet little evidence, including even single case reports, has arisen from the vacuum which replaced the LCP.

Areas of controversy

Given the choice, most people would rather not die. Whilst patients and their families do not like hearing bad news, professionals dislike delivering it. Those who are ‘diagnosed’ as dying may feel abandoned by healthcare professionals and superfluous within a contemporary hospital system designed to investigate and treat abnormality. This biomedical enthusiasm has, in recent years, been tempered by the advent of care bundles such as AMBER. These tools serve to inject a dose of realism into modern healthcare by helping professionals to confront the limitations of a person’s body as well as medical therapy, even with intensive organ support. The acknowledgement of uncertain recovery creates a space, both physiologically and psychologically, to prepare for the prospect of death. This buffer zone between present physical difficulty and possible harsh reality may encourage healthcare teams to help patients consider realistic goals of care whilst supporting both in accepting death as a possibility.

A buffer zone may also nurture the growth of candour amongst healthcare professionals, patients and their loved ones, as well as the public. This could, in turn, help families avoid the ‘gear change’ experienced by many when a patient’s treatment has ostensibly stopped abruptly. In the absence of adequate warning, let alone sensitive communication, it is little wonder why some people felt abandoned to a seemingly rigid pathway. It was not difficult to make the leap to assuming the pathway was a one-way railroad with no detour or reversal. Such a sudden change in emphasis was experienced by many and rightly caused concern. Who would not express anger and resentment under these conditions? Any new approach must recognize the uncertainty of recovery earlier in an illness trajectory. This may circumvent some of the difficulties encountered when the LCP was regarded as a ‘death pathway’.

Patients and families need to be assured that whilst specific treatments may be discontinued from time to time, care is never ‘switched off’. How any new approach to end-of-life care is portrayed to the public will, in large part, determine its fate. How it is received, interpreted and considered is critical to any chance it has at being taken up across the nation. We recognize that the success or failure of the next formal approach, even at local level, to end-of-life care may well rest upon future public
acceptance of the issue of death as a normal part of life. Public discourse to engage with the notion of death in the context of an increasingly commodity-driven culture is needed. Death may ironically even have to be ‘sold’ to the public consciousness as normal, natural and inevitable. Such transactions do not come cheaply and the currency of this purchase will likely come in the denomination of emotion for public and professionals alike. It follows that, rightly or wrongly, future end-of-life conversations will take place both at the bedside and through the national media. It is hence unavoidable that any care plan for a dying person will come under intense scrutiny and any errors found amplified exponentially. In contrast, any successes are unlikely to garner much fanfare. The task is not straightforward. Every health professional caring for patients should be asked to recognize their own role in the undertaking, including beliefs surrounding death and dying. Although challenging to consider, each of us has a responsibility to contemplate our own demise in order to claim any right to our own version of a good death.

As the sun sets on medical paternalism, it is the dawning of a new day for professionalism. The literature on medical professionalism is blossoming and includes significant contributions on issues such as shared decision-making. Lamentably, this professionalism was not always evident when the LCP was used. The bond of trust between the public and healthcare professionals can be rescinded much more easily by the former than forged by the latter. The affair of the LCP clearly articulates the need for doctors, in particular, to regain this trust. We submit, however, that all is not lost. For example, the early outcomes of the Francis report show learning from adverse past experiences.

The collapse of the LCP resonated with palliative medicine professionals all over the world, let alone in the UK. The charges laid by the mass media, as well as the Neuberger report, against the LCP more properly addressed general care issues rather than specialist palliative care ones. The LCP aimed to enhance generalist end-of-life care by incorporating the principles of the supposed gold standard of hospice end-of-life care. Simultaneously, it sought to do so in a setting where professional guidance for nurses and doctors favours patient safety and choice. Remarkably, in some areas the use of the LCP actually facilitated the opposite of the intended outcome; disengaging healthcare professionals from person-centred care. Work will need to continue to prevent palliative care, be it in specialist or generalist hands, from becoming defined by this single issue. End-of-life care is every health professional’s business rather than an amorphous entity couched behind side room doors or palliative care referrals.

All care costs and financial constraints provide a distinct challenge. These translate into a risk of care being considered purely on a task basis, measured against time, rather than being person centred. Task-based care may disconnect carer and patient which may permit the timely and expedient completion of tasks, but at the expense of holistic care. A document neatly filled out with all boxes ticked is no guarantee of adequate care, let alone patient or family satisfaction. Nor should it ever be. Basic record keeping and standard setting both have roles in governance, but can also promote minimum care undertaken in minimum time. The LCP undoubtedly suffered from this approach. Care plans should guide excellent care in practice and avoid a tick-box protocol of what should be nothing less than personalized care.

One major area of concern identified by the media has been the performance-related payments to hospitals for the number of patients cared for using the LCP. These reports prompted speculation of financial coercion whenever the LCP was started, particularly inappropriately. Costing and measuring outcomes of palliative care have long been subject to much debate in the NHS. Third sector institutions, such as hospices, cloud the true NHS financial cost of dying. Nonetheless to use the LCP as a surrogate for costing good end-of-life care was faulty.

The LCP approach did not guarantee any kind of outcome and only the deceased would know for sure whether or not he or she experienced a ‘good’ death. Although this approach has obvious limitations, it is still worth exploring. Patient feedback at the time of death could be approximated by having each patient consider in advance the aspects of dying most
important to him or her. Subsequent assessments of concordance with this advanced plan would promote tailored care. When we consider our future priorities, however, there is inherent difficulty in knowing precisely what we will want. We base decisions on the factors at play now and those we think may be present at a future time. Advanced priorities for end-of-life care may nevertheless change in response to our thoughts, feelings and physical symptoms as we die. It is therefore essential that any plan can be updated to account for the holistic changes each person may experience as they approach death. This is challenging, particularly when faced with an uncertain disease trajectory alongside patient- and/or professional-held hopelessness that the outcome, death, can be avoided. In this situation it is unlikely future care plans would address end-of-life priorities. An alternate means of evaluating end-of-life care is to consider the experience of family after death. Retrospective analysis from family reported outcomes may be clouded by grief, but their experiences of both care and approach will undoubtedly help improve future care of the dying. Professional satisfaction in the quality of end-of-life care provided should also be considered to ensure dissatisfaction does not lead to poor care.

Care of the dying must be open to rigorous scientific scrutiny. Undeniably, this will raise many practical and ethical challenges. All the same, the need to undertake this work stems from calls to evidence our practice proactively rather than considering negative consequences of actions retrospectively. Additionally, in order to properly assess any new intervention we will first need to adopt a standard of holistic care. This is challenging as holistic care is personalized and anything but static. Each individual may require personalized ‘gold standards’ unique to him or her. Research into which basic interventions suit most will likely produce the most gain. By applying basic priorities of care with an individual we will hopefully facilitate person reported outcome measures which show satisfaction. The needs of patients and families may be very different and this should be considered when designing any study on complex interventions at the end of life. Correspondingly, future study design must also consider the needs of practitioners who are caring for those who are dying. Involvement and a sense of common purpose around a good death for each person are paramount.

**Growing points**

How is personalized care to be given at the end-of-life if we do not know what the specific personal care needs of an individual are? The challenge is enormous and will require communication on both macro- and micro levels. Examples of the former include the work of the National Council for Palliative Care through Dying Matters, whereas the latter efforts converge on the professional–patient relationship. The particular needs of each person are unique and it could even be argued that each of us has a responsibility to consider our own death if we desire access to the right of personalized care at our life’s end. Delivery of said care will require a new end-of-life vocabulary. Already there exists a multiplicity of meanings for words such as ‘hospice’. A common language for patients and professionals will minimize ambiguities as well as aid future expectations. Managing expectations during the final journey of a person towards a natural, dignified death will enhance the experience, in general, and coping, in particular, for all those involved.

As we suggested earlier, the new approach to end-of-life care might include a helpful document of some sort. The LACDP purposefully shied away from this. It will hence again be incumbent upon individual practitioners to ensure that basic prescribing measures to relieve physical symptoms are not overlooked. Whilst this practice should always respect patient wishes this is not possible if a dying patient loses the ability to communicate. We have a responsibility to explore patient preferences prior to the dying phase. Births in the UK benefit from pro-active planning in the form of shared obstetric records. Such a normalization of facets of life’s end could include plans for excellent personalized care at end of life. After death there should be a debriefing of those involved in the deceased’s care while he or she was alive. One way of doing this could be through a Schwartz round. Schwartz rounds are a
non-clinical, multidisciplinary professional forum to consider the personal, social and emotional effects of caring for patients. They serve to support staff and improve patient outcomes. Professionals’ insight into their own needs is nurtured to sustain delivery of compassionate, whole person care.\(^{37}\)

Any society can be measured in many different ways. As Mahatma Gandhi considered, ‘A nation’s greatness is measured by how it treats its weakest members’. The maltreatment of those who are dying should be re-examined within a sociological context rather than a tabloid-moderated case-by-case basis. High-quality end-of-life care should be within the skill set of all healthcare professionals. This, however, is not the case. For this reason we support a national conversation starting with a consideration of how to address the core issue of human-to-human contact. If we start from this most basic concept we may be better positioned to learn about and appreciate the values of appropriate disclosure, trust and understanding what dignity is to each of us. Working towards each and every one of these is vital in end-of-life care. Unsatisfactory care becomes acceptable only in the absence of honest feedback.

In our final analysis we suggest that the pursuit of a patient’s personhood is a key to excellence in end-of-life care. The value of looking our dying patients in the eye and seeing them as persons is vastly underrated. We propose the best therapy for end-of-life care arises from our shared being rather than a document or drugs cabinet. Our deaths will not be that of our neighbour. Nor will they be your death. Such variability in needs will pose a staggering challenge for any tool or document to consider. Medical professionals will need prompts and prescribing advice, but the principles of good care should always be present. The unwritten aspects of caring for fellow humans who are dying in a holistic sense are in great need of consideration. This requires improvement in willingness and skill base for each and every person involved in caring for others. The LACDP’s efforts appear to be a step in the right direction and we look forward to seeing how the five priorities are translated into good medical practice and improved patient care.

### Areas timely for research

1. At present there are no nationally agreed definitions of terms used in caring for the dying. Accordingly, the potential for miscommunication between healthcare professionals is very high, let alone between healthcare professionals and members of the public. For this reason we would initially suggest that the terms ‘palliative’, ‘terminal’, ‘end of life care’ and ‘dying’ be explored systematically. A comparison of specialist, non-specialist professional and public perceptions of these terms may be very useful.

2. Review of the definition of dying. Loss of functionality and the inability to sustain one’s self are used as markers for approaching death. A major concern is that these criteria could be fulfilled by a person with dementia or a neurodegenerative condition some months, or even years, before death.

3. Improved recognition of dying persons, particularly those dying of non-malignant diseases or conditions. The majority of research to date has been exclusive to cancer patients. Work is ongoing with validation of the ‘surprise question’ which seeks to attune professional and then patient to the possibility of approaching death. This is done by asking ‘Would you be surprised if this patient died within the next 12 months?’\(^{38}\) Other tools, such as the Supportive and Palliative Care Indicators Tool (SPICT) are validated to identify palliative care patients rather than those who are suitable for end-of-life care.\(^{39}\) Another prognostic tool (Prognosis in Palliative care Study – PiPs) only gives valid guidance for 2 week or 2 month prognosis.\(^{40}\) Prognostication within the last days and hours of life remains challenging. Palliative care can no longer base itself on a cancer trajectory model of deterioration towards death.

4. Consider how and when communication regarding the process of dying should take place? We must find an effective way to train professionals communicating with families who are seeing a loved one die. This will also need to be considered in different disease states and settings. Various communication skills courses can
provide this training for professionals. If this is mandated for all it should be proven that this enhances patient care.

5. Consideration of trial methodology hierarchy with regard to palliative care. Randomized controlled trials of end-of-life interventions may just not be possible. Some interventions may not be amenable to, for example, ethical blinding or placebo. Cluster randomization with comparative interventions may give an opportunity to undertake research with a dying person as the subject. This does not denigrate good quality research being done. How research involving the dying person is undertaken may need to become a subject of academic pursuit in its own right.

6. Current funding for end-of-life care research is abysmal. It is obvious the 0.24% of the total 2010 UK National Cancer Research budget is insufficient to meet the needs for an evidence base for the replacement of the LCP.41

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