INDEPENDENT REVIEW OF THE LIVERPOOL CARE PATHWAY

MORE CARE, LESS PATHWAY

A REVIEW OF THE LIVERPOOL CARE PATHWAY

CONTENTS

FOREWORD

In Britain, although most people would prefer to die in their own home, around half end their days in hospital. The proportion dying at home will increase, but because of a rise in the death rate, the actual numbers dying in hospital will also increase. The Liverpool Care Pathway for the Dying Patient (LCP) is an approach to care, including a complex set of interventions, that resulted from a desire to replicate within the hospital sector the standard of care for the dying found in many hospices. It was in part a response to the belief of clinicians and others that care for the dying in the acute sector was deficient.

The introduction and widespread use of the LCP must be seen in the context of a number of developments in society itself. One of these is a substantial shift towards the idea of patient choice, with people increasingly likely to question treatment plans for themselves and their relatives, and to question the authority of clinicians. A second factor is that death and dying is now beginning to be debated more openly.

Nevertheless it seems still to be the case that, in practice, the discussion of death as an inevitable and, in some cases, imminent aspect of life is regarded as morbid and thus avoided. Even with patients suffering from terminal conditions, it is common for there to have been no discussion with patients, their consultants or GPs, relatives, and carers, about preparing for dying.

Whatever decisions are made about the LCP (our recommendations are listed on page 52), we believe there needs to be a proper National Conversation about dying. Otherwise doctors and nurses are likely to become the whipping-boys for an inadequate understanding of how we face our final days.

We were asked to conduct this Review following alarming stories in the press and broadcast media concerning the LCP. Some of these stories appeared to have much in common with the complaints that led to the Mid Staffordshire Public Inquiry, and with a spate of stories concerning the treatment of the elderly in acute hospitals.

Clinicians themselves expressed their own views that in their own last hours they would prefer to be treated under an approach such as the LCP, and we found that many relatives of people dying whilst being treated under the LCP had felt that their loved ones had had good deaths. It would seem that when the LCP is operated by well trained, well-resourced and sensitive clinical teams, it works well.

However it is clear to us, from written evidence we have received and what we have heard at relatives' and carers' events, that there have been repeated instances of patients dying on the LCP being treated with less than the respect that they deserve. It seems likely that similar poor practice may have taken place in the case of patients with no close relatives, carers or advocates to complain, or where families have not felt able or qualified to question what has taken place. This leads us to suspect this is a familiar pattern, particularly, but not exclusively, in acute hospitals. Reports of poor treatment in acute hospitals at night and weekends – uncaring, rushed, and ignorant – abound.

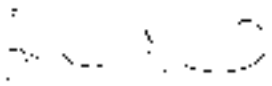
Where care is already poor, the LCP is sometimes used as a tick box exercise, and good care of the dying patient and their relatives or carers may be absent. Whether true or not, many families suspected that deaths had been hastened by the premature, or over-prescription of strong pain killing drugs or sedatives, and reported that these had sometimes been administered without discussion or consultation. There was a feeling that the drugs were being used as a "chemical cosh" which

diminished the patient's desire or ability to accept food or drink. The apparently unnecessary withholding or prohibition of oral fluids seemed to cause the greatest concern.

Preventable problems of communication between clinicians and carers accounted for a substantial part of the unhappiness reported to us. Relatives and carers felt that they had been "railroaded" into agreeing to put the patient on a one-way escalator.

We feel strongly that if acute hospitals are to deal with dying patients – and they will – whether or not they are using the LCP – they need to treat patients, their relatives and carers with more respect. Hospitals and other institutions need to make more time available to them at any hour of the day or any day of the week. We know that hospitals are often short staffed, and that senior staff may often not be present at night, over weekends, and on Bank Holidays. This is perceived by many as one major cause of poor levels of care and communication. In order that everyone dying in the acute sector – can do so with dignity, the present situation has to change.

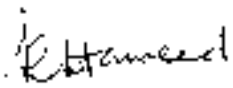
It is for this reason that we make our strong recommendations for change.



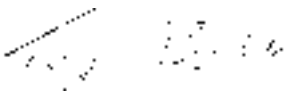
Baroness Julia Neuberger (chair)

Lord Charles Guthrie

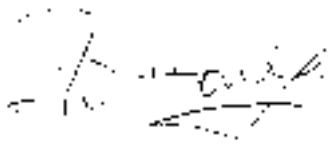
David Aaronovitch



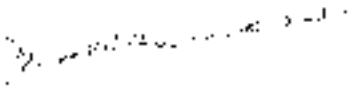
Lord Khalid Hameed



Tony Bonser



Professor Lord Harries of Pentregarth



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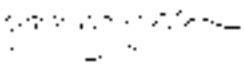

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EXECUTIVE SUMMARY

Developed from a model of care successfully used in hospices, the Liverpool Care Pathway for the Dying Patient (LCP) is a generic approach to care for the dying, intended to ensure that uniformly good care is given to everyone thought to be dying within hours or within two or three days, whether they are in hospitals, nursing homes, or in their own homes.

Because of substantial criticism of the LCP in the media and elsewhere, Norman Lamb MP, Minister of State for Care Support, asked Baroness Julia Neuberger to chair a panel to review of the use and experience of the LCP in England, to be kept independent of Government and the NHS. The Review considered evidence from many quarters: written submissions from members of the public and health professionals with experience of the LCP, as well as professional bodies and other organisations; a review of academic literature; a review of relevant hospital complaints; and surveys of health professionals. The panel also met members of the public at four sessions, to hear directly from them their experiences of the LCP.

TERMINOLOGY

To understand better how criticisms of the LCP were arising, the Review panel considered the LCP within its wider context. This gave rise to some underlying problems of definition and terminology. 'End of life' can mean any period between the last year of life of a person with a chronic and progressive disease to the last hours or days of life. Unless this lack of clarity is addressed, there is the very real risk that a person deemed to be at the 'end of their life' may be placed onto the LCP too early.

The term 'pathway' is clearly being misunderstood, being used to describe a very broad range of initiatives to provide care in the dying phase. It seems as though some doctors and nurses using the LCP are treating it as a set of instructions and prescriptions, which is not at all its aim. Furthermore, to the lay person, a pathway suggests a road leading somewhere. Some relatives and carers have reached the conclusion that 'the pathway' represents a decision on the part of clinicians, in effect, to kill their dying patients, when that is clearly not the case.

The term 'Liverpool Care Pathway' is extremely unhelpful and should be abandoned. Within the field of end of life care, the term "pathway" should also be avoided, the simple term 'end of life care plan' being the suggested alternative.

EVIDENCE

A rapid evidence review of integrated care 'pathways' for end of life showed there are specific gaps in evidence on the LCP, not least that independent, prospective testing of the LCP has not yet been carried out after nearly 10 years of its dissemination. Fully independent assessments of end of life care in England are required, focusing on the outcomes and experience of care, as reported by patients, their relatives and carers, as well as the quality of dying. Further research into the biology and experience of dying is needed.

LCP DOCUMENTATION

The LCP document is designed to replace the contemporaneous medical records written by the clinical staff. But because it exists as a separate record on top of the continuation notes, it seems it is

easy for staff (not least those who had had little or no training) to believe that both the LCP document and the continuation notes had to be completed, when they had not. The Review panel heard many reports of the form having been filled in wrongly, for example including observations that the relatives or carers believed had not been made. There may have been reasonable explanations for this, but it provided resonances with the Mid Staffordshire Public Inquiry's findings, and the Review panel recommends that the professional regulators must take stern action with individual doctors and nurses where there is evidence of the deliberate falsification of any document or clinical record, in order to deflect future criticism of a failure of care.

DIAGNOSIS OF DYING

There are no precise ways of telling accurately when a patient is in the last days of life, and the LCP document acknowledges this. Given the difficulty of diagnosing when a patient is actually going to die, placing patients on the LCP can lead to considerable distress in relatives or carers when the patient does not die with hours or days, or recovers. Doctors and nurses must communicate with patients and relatives far more honestly about these clinical uncertainties. More use of evidence-based prognostic tools and education and training in them is needed. More research is needed into improving the accuracy of these tools, where possible and where it is not, clear guidance and training is needed for doctors and MDTs on understanding and explaining the uncertain timings within the dying process.

Approaches like the LCP have made a valuable contribution to improve the timeliness and quality of clinical decisions in the care of dying patients, and plenty of evidence received by the Review shows that, when the LCP is used properly, patients die a peaceful and dignified death. But implementation of the LCP is sometimes associated with poor care. Although this report highlights significant difficulties with practice in care for the dying among some clinicians, those reading the conclusions of this Review should not respond, for fear of censure, by defaulting back to treating dying patients as though they are always curable.

DECISION MAKING

The Review panel heard many instances of both good and bad decision-making. Repeatedly, they heard stories of relatives or carers visiting a patient, only to discover that without any forewarning there had been a dramatic change in treatment. There now appeared to be no clinical care or palliative care, and the patient was unnecessarily or excessively sedated. Every patient diagnosed as dying should have a clearly identified senior responsible clinician accountable for their care during any 'out of hours' period. Unless it is unavoidable, urgent, and is clearly in the patient's best interests, the decision to withdraw or not to start a life-prolonging treatment should be taken in the cool light of day by the senior responsible clinician in consultation with the healthcare team. The practice of making such decisions in the middle of the night, at weekends or on Bank Holidays, by staff that do not have the requisite training and competence, should cease forthwith.

CONSENT

One of the central issues causing difficulty in the use of the LCP seems to be misunderstanding and uncertainty over whether deciding to implement the LCP is a treatment decision, requiring the patient's consent or requiring the decision to be taken in the patient's best interests if they lack capacity. In some cases, relatives and carers incorrectly consider they are entitled to decide whatever

treatment their relatives receive, and in others clinicians fail to seek consent from a patient or consult the relatives and carers in a 'best interests' assessment when treatment is being changed.

The LCP is not a single, simple medical procedure, and so there is no legal requirement for consent to be sought before it is used. Some aspects of the LCP do not concern treatment, but others, such as medication changes, do. Patients, relatives and carers are always entitled to explanations of how decisions have been made and a chance to understand them, but all too often they have not been afforded that opportunity. The LCP documentation is deficient in making distinct and clear where the need for consent and explanation exist.

INVOLVEMENT IN THE CARE PLAN

Contrary to the intentions of the LCP documentation, submissions to this review indicated that a significant number of relatives and carers do not feel that they were involved in discussions about the care plan, or even offered the chance to be involved. Some relatives and carers were handed a leaflet without any explanation. Others were not told that their loved one was dying, which clearly contributed to their distress. It appears that a conversation with relatives or carers to explain the diagnosis, prognosis and uncertainties clearly had simply not taken place. The GMC's guidance is clearly not always being followed in the care of the dying, and so the Royal Colleges need to review the effectiveness of training in shared decision-making that they provide to ensure competence is maintained across the education and training spectrum.

HYDRATION AND NUTRITION

Most of the submissions to the Review from relatives and carers that were critical of the LCP made reference to hydration and nutrition. Judging from these accounts, far too often the LCP advice on these is not being followed. The current version of the LCP does not go far enough to adjust the language of previous versions to advise that the default course of action should be that patients be supported with hydration and nutrition unless there is a strong reason not to do so.

At the end of life, a person may become overhydrated, and there is no moral or legal obligation to continue to administer and clinically assisted hydration or nutrition if they are having no beneficial effect. But there can be no clinical justification for denying a drink to a dying patient who wants one, unless doing so would cause them distress. In hospitals in particular, there appear to have been many instances demonstrating an inadequate understanding of the LCP's direction on oral hydration. Refusing food and drink is a decision for the patient, not clinical staff, to make.

The Review heard reports of patients being given drugs by a syringe driver so quickly that they rapidly became drowsy, and so unable to ask for something to drink. The offer of a drink was not discussed. The GMC has issued clear guidance on supporting artificial nutrition and hydration, but more is needed on supporting oral nutrition and hydration. The NMC, from which no equivalent guidance currently exists, needs to produce it for nurses as a matter of urgency.

SEDATION AND PAIN MANAGEMENT

The Review heard that, if a patient became more agitated or in greater pain as they died, they often became peaceful because the right drugs were given to them at the right time and in the right dose. But there were complaints that opiate pain killers and tranquillisers were being used inappropriately as soon as the LCP was initiated. Many hospital patients appear to be put on a syringe driver with morphine as the 'next step' on the LCP, even if morphine is not the right drug, or pain relief is not

what is needed. Some relatives and carers were unsure whether this meant that the death had occurred naturally or if it was directly attributable to the drugs administered. It seems that at least some of the distress experienced could have been mitigated by better communication. Before a syringe driver is commenced, this must be discussed as far as possible with the patient's relatives or carer, with the reasoning documented.

ATTEMPTS AT CARDIOPULMONARY RESUSCITATION

The Review received evidence of conversations about attempts at cardiopulmonary resuscitation that were held sensitively, patients and their families and carers having felt both consulted and involved in the decision making. However, it also heard of very vague, snatched conversations, in which relatives and carers felt pressurised to give an opinion, the implications which were not made clear to them. Many people recounted that agreement not to attempt cardiopulmonary resuscitation had been taken by the clinical staff as a proxy for agreement to start the LCP, which is clearly unacceptable.

ETHICAL ISSUES

Some people believe that to implement the LCP is a way of deliberately hastening someone's death, and this is understandable, given what the Review heard about poor communication between clinicians and patients, their relatives and carers about what was happening during the dying process. The Review panel is content, however, that the LCP entirely reflects the ethical principles that should provide the basis of good quality care in the last days and hours of a person's life. Any attempt deliberately to shorten a person's life is illegal, but there is no obligation, moral or legal, to preserve life at all costs. The Review considered the issue of local financial incentives being applied per patient on the LCP, and concluded that this sort of incentive must cease in relation to any approach to care of the dying. Not only has it given rise to fears about hastening death for financial gain, but there is a very real risk that providing a payment for each patient implemented on the LCP, or equivalent approach, looks like an incentive to do so, rather than a means of providing sufficient resources for good quality and compassionate care to be provided.

WIDER ISSUES

In reviewing use and experience of the LCP, the Review identified a number of important issues that impact on the ability of the LCP and similar approaches to support high quality care of the dying. If these wider issues are not addressed, no amount of changes to particular approaches to care of the dying will help.

ENVIRONMENT AND EQUIPMENT

The review received little evidence on the facilities and environments provided for patients that were dying, and their relatives and carers. When it was mentioned by respondents, however, it was often the case that rooms were not available where patients and families could talk privately or to meet and confer with staff. Similarly, facilities and support for those bereaved were not always available.

ACCOUNTABILITY

Patients, their relatives and carers need to know who the senior responsible doctor in their care is. Dying patients must have a named consultant or GP taking overall responsibility for their care. If a

medical practitioner is available, the responsible clinician role in the community could be held by a nurse, as long as he or she has the right competencies.

The responsible clinician is not only responsible for the care of the patient, but bears some responsibility for their relatives and carers too. The name of a registered nurse responsible for leading the nursing care of the dying patient in a hospital should be allocated at the beginning of each shift, and this nurse should also be responsible for communicating effectively with relatives and carers.

Organisations providing care for the dying, in particular acute hospitals, must ensure that the right systems are in place to ensure they deliver consistently good care, and so, as a matter of urgency, the boards of these providers should give responsibility to one of its members for leading on the interests of the dying patient, their relatives and carers.

CARE WITH COMPASSION

During this Review, the panel heard of far too many instances where the commencement of the LCP has led to a withdrawal of care, in some cases with relatives and carers left to do the caring themselves as much as they could. Caring with compassion for people at the end of their lives should be the aim of all doctors, nurses and healthcare staff. Good care for the dying is as important as good care at any other time of life.

DOCUMENTING AN END OF LIFE CARE PLAN

Many patients and their families felt as though they have lost control over what was happening to them. Involving patients, their relatives or carers in discussions about the care plan is an important way of restoring a sense of control. And good practice in documenting discussions and decisions is vital. Where a patient has no relatives or carers and so is unrepresented, the discussion about the care plan needs instead to involve a GP from their registered practice or their senior responsible community clinician, who may be a nurse. The panel recommends a system of shared care folders in hospitals, to which relatives and carers can contribute, as well as better integration of documentation in the community.

CARE OF THE ELDERLY

Evidence from relatives and carers strongly suggested that care of the dying elderly is of the greatest concern: the Review panel suspects that age discrimination is occurring, which is unlawful. Nor should old age be taken as a proxy for lack of mental capacity. Each patient lacking capacity, of whatever age, on the LCP or a similar approach, should be represented by an independent advocate.

AVAILABILITY OF STAFF AND EQUIPMENT

The availability of staff to care for the dying, both in terms of the number of staff and the level of competence, is of serious concern. The Review panel repeatedly heard stories of poor standards of basic care and a lack of staff and equipment over weekends and out of hours; this also prevented some people from being able to come home to die, as they wished. There were numerous reports of no access to the palliative care teams outside office hours and at weekends, both in acute hospitals and in the community. In some places there were separate teams for the community, the hospital and in hospices. Such fragmentation must not continue and, wherever possible, palliative care teams should combine to form integrated palliative care services.

About half of all deaths currently take place in hospital, making care of the dying a core duty of hospital trusts. Many of their patients would benefit from the skill and expertise offered by the palliative care team. Lack of funding may be the reason that patients report a lack of access to the hospital palliative care team in the weekends and evenings. Funding must be made available to make palliative care teams accessible at any time of the day or night, seven days a week, both in hospitals and in community settings.

COMMUNICATIONS

No matter how much effort is put into training clinicians in good communication skills, unless everyone in society – members of the public, the press, clinicians, public figures – is prepared to talk openly and honestly about dying, death and bereavement, accepting these as a normal part of life, the quality of care and the range of services for the dying, their relatives and carers will remain inconsistent. The Review panel strongly supports the work of organisations that promote public awareness of dying, death and bereavement.

Unless there has been good communication between staff and relatives or carers, unnecessary misunderstandings and distress can arise. Care of the dying requires not only substantial technical knowledge and clinical skill, but above all it needs excellent communication skills. Adequate training and continued support is the key to getting this aspect of care right.

TRAINING

Health Education England, the GMC, the NMC, the Royal Colleges and provider organisations should all play a part in improving the training and continuous professional development of clinicians involved in caring for dying patients. Clinicians should be required to demonstrate proficiency in caring for the dying, doctors as part of each five-year cycle of revalidation; the principle of setting requirements to demonstrate proficiency in caring for the dying should also apply to nurses. There is no specific NMC guidance for nurses caring for patients at end of life or who are dying, although such guidance from the GMC exists for doctors. This may explain, at least in part, why the Review panel heard so many examples of poor quality nursing of the dying. The NMC must provide such guidance as a matter of urgency.

AN END OF LIFE CARE PLAN FOR EVERY PATIENT

The LCP is not being applied properly in many cases. Generic protocols, as the LCP has come to be seen, are the wrong approach. The Review panel strongly recommends the development of a series of guides and alerts reflecting the common principles of good palliative care, supplemented by technical guidance specific to certain disease groups. These guidelines must be so designed that they are readily adapted for local use to meet the needs of individuals, in a similar way that examples already exist for the LCP.

Use of the Liverpool Care Pathway should be replaced over the next six to 12 months by an end of life care plan for each patient, backed up by condition-specific good practice guidance.

A SYSTEM-WIDE APPROACH TO IMPROVING END OF LIFE CARE

But adherence to guidelines cannot be enough: a system-wide approach to professional practice and institution provision, measurable and monitored, is required to bring about improvements in care for the dying. A strategic approach needs to be taken to the problem – a coalition of regulatory and professional bodies, NHS England and patient groups together setting clear expectations for a high

standard of care for dying patients, as well as their relatives and carers. Such a coalition could lead the way in creating and delivering the knowledge base, the education training and skills and the long term commitment needed to make high quality care for dying patients a reality.

Under this approach, the CQC would collaborate with the professional bodies and patient groups in defining what good quality end of life care services should look like and then inspect against those standards. End of life care should be incorporated urgently into the new hospital inspection programme that the Chief Inspector of Hospitals will run. The CQC should carry out a thematic review of how dying patients are treated in all settings within the next year.

NHS England must use its full powers to work with clinical commissioning groups to address what are considerable inconsistencies in the quality of care for the dying, to drive up quality by means of considerably better commissioning practices than persist at present. Hospital provision in particular must from now on be commissioned and prioritised according to local need, to ensure that properly constituted multidisciplinary specialist services are available for support around the clock as a hub of expertise, support and training.

Unsurprisingly, this Review has uncovered issues strongly echoing those raised in the Mid Staffordshire Public Inquiry: notable among the many similar themes arising were a lack of openness and candour among clinical staff; a lack of compassion; a need for improved skills and competencies in caring for the dying; and a need to put the patient, their relatives and carers first, treating them with dignity and respect.

In view of the Review panel's serious concerns about the current state of care for the dying, it strongly recommends that the Government set improved quality of care for the dying as a priority for NHS England in the next Mandate. Given the very strong links between the vulnerability of older people and the quality of care for the dying, the forthcoming Vulnerable Older People's Plan should include a strand on care for the dying, and NHS England's contribution to it should also be specified as a priority in the NHS Mandate.

Many of the problems in the care of the dying highlighted in this report are due to poor understanding among clinicians of existing guidance in care for the dying, and an unwillingness to discuss with patients, their relatives and carers the prospect of death and the clinical uncertainties that accompany it. The Government must therefore ensure that its arms-length bodies collaborate with the clinical professional bodies and other key players in the system, and inject considerable funding into the system, to ensure that guidance on care for the dying is properly understood and acted upon, and tick-box exercises are confined to the waste paper basket for ever.

The Review panel feels so strongly about this that it is going to continue to meet at its own expense and volition, to monitor closely what happens next in response to its recommendations.

CHAPTER 1

THE LIVERPOOL CARE PATHWAY

1.1 The trend over recent years has been for more deaths at home and fewer in hospital, but long term projections[1] indicate that institutional deaths will nevertheless increase by over 20%.

1.2 The Liverpool Care Pathway for the Dying Patient, commonly shortened to the LCP, was originally developed by the Royal Liverpool University Hospital and the Marie Curie Hospice in Liverpool for the care of terminally ill cancer patients. The Marie Curie Palliative Care Institute Liverpool (MCPCIL) has overseen the development and dissemination of the LCP since then, and the LCP now aims to ensure that uniformly good care is given to everyone, wherever they are – in hospitals, nursing homes, or in their own homes – when it is thought that they will die within hours or within two or three days.

1.3 Under the LCP, all care should be directed to comfort and maintaining the person's dignity, as well as providing information and support for families. The LCP is holistic: it alerts clinicians not only to physical problems, but also to the emotional, social and spiritual needs of dying patients and those close to them. It also aims to ensure that unnecessary and possibly harmful tests and treatments are at least reconsidered, if not stopped. As MCPCIL's own documentation makes clear,[2] responsibility for day to day implementation of the LCP lies with individual hospitals, GPs and care homes.

1.4 The LCP provides alerts, guidance and a structured, single record for doctors, nurses and multidisciplinary teams that are inexpert in palliative care. It has been put forward as a model of good practice by successive national policy frameworks,[3] the national End of life care strategy,[4] Quality Markers and Measures for End of Life Care,[5] General Medical Council guidance,[6] and the NICE quality standard for end of life care for adults.[7]

1.5 However, in recent months the LCP has been an object of substantial criticism in the media and elsewhere. English health Ministers had substantial concerns about the poor end of life care cited in accusations against the LCP. Accordingly, Norman Lamb, MP, Minister of State for Care Services, appointed a panel with a wide-ranging set of complementary interests and expertise in end of life care to review the use and experience of the LCP in England, and asked Baroness Julia Neuberger to chair it. The Review operated independently of Government and the NHS, and was asked to report its findings to the Government and NHS England by the summer of 2013. The panel was supported by an expert advisor and a secretariat, resourced by the Department of Health but operating independently of it. Neither panel members, nor its

1 Gomes B, Higginson IJ. Where people die (1974–2030): Past trends, future projections and implications for care. Palliative Medicine 2008; 22: 33–41.
2 Liverpool Care Pathway for the Dying Patient (LCP) – FAQ – see http://www.sii-mcpcil.org.uk/media/10846/LCP%20FAQ.pdf
3 Department of Health, 2003 and 2006
4 End of life care strategy. Fourth Annual Report. Department of Health, October 2012 (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136486/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf)
5 Department of Health, 2009 (http://webarchive.nationalarchives.gov.uk/20130107105354/http:/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681)
6 Treatment and care towards the end of life: good practice in decision making General Medical Council, 2010 (http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp)
7 National Institute for Health and Care Excellence, 2011 (http://guidance.nice.org.uk/QS13)

medical advisor, were paid for their time. The terms of reference of the Review and information on the panel members and their expert advisor, are set out on page 50.

1.6 Between February and June 2013, the Review panel met five times, with sub-groups meeting in between the full meetings to consider more specific issues and themes. In February 2013, the Review issued a general call for evidence, with a deadline for responses of 5 April. 483 submissions were received from members of the public, most of whom had experience of the LCP as relatives or carers, 91 from health and care professionals, some of whom also had experience of the LCP in their personal capacities, and 36 professional bodies and other organisations. Members of the Review panel made visits to health providers that use the LCP in a range of settings. They also held sessions between March and May 2013 in Leeds, London, Preston and Bristol, where they met 113 members of the public to hear directly from them their experiences, as relatives, carers, or indeed as individuals who had been on the LCP. The Review panel further took advice from a range of professionals in order to reach a view on particular aspects of use of the LCP. Short extracts from written and oral submissions to the panel have been anonymised and included in this report as representative examples.

1.7 The Review panel was also supplied with evidence from a rapid review of academic literature focused on the dying phase in end of life,[8] and a snapshot review of complaints to hospitals relating to end of life care.[9] Both of these were commissioned by the Department of Health's former End of Life Care Programme and approved by the panel, and the documents are published alongside this report.

1.8 The headline results of a survey of health professionals administered by the Association of Palliative Medicine[10] have also been taken into account,[11] as has an email survey on the LCP among doctors run jointly in February 2013 by the British Medical Journal and Channel 4 Dispatches,[12] to each of whom the Review was most grateful.

USE AND EXPERIENCE OF THE LIVERPOOL CARE PATHWAY

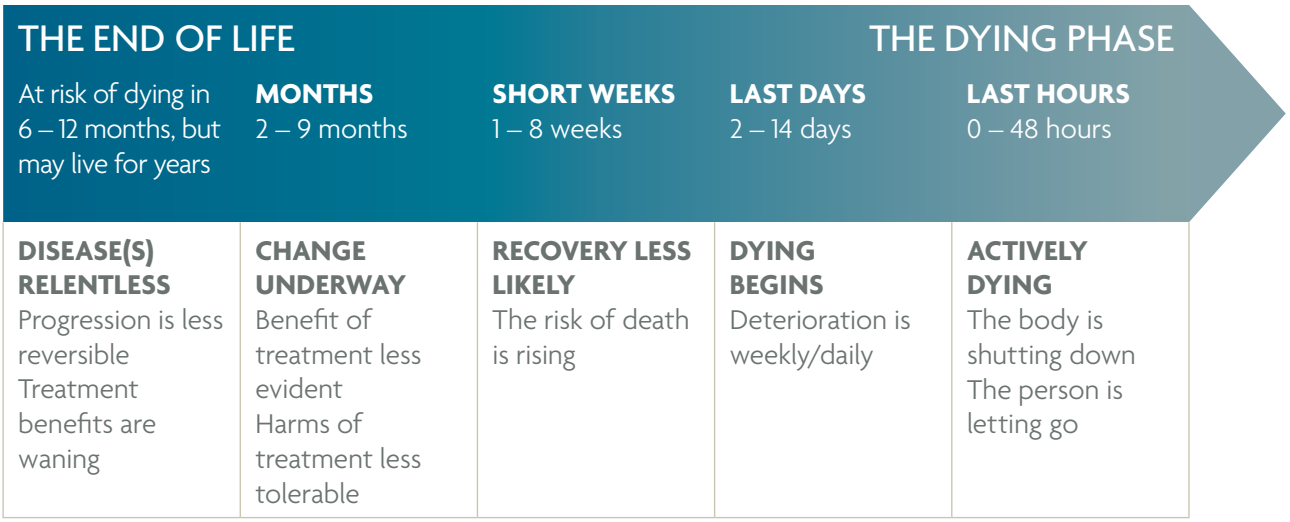
Plenty of evidence received by the Review shows that, when the LCP is used properly, patients die a peaceful and dignified death. But the Review panel is also convinced, from what it has both heard and read, that implementation of the LCP is not infrequently associated with poor care.

END OF LIFE CARE

1.9 The Review panel has identified that there is significant lack of clarity over the meaning of the term 'end of life.' Variously, 'end of life' covers the last year of life of a person with a chronic and progressive disease, the last months, the last weeks or – for the LCP – the last hours or days of life: in short, the dying process. Diagram 1 below sets out the distinctions.

8 Rapid Evidence Review: Pathways Focused on the Dying Phase In End Of Life Care and their Key Components, Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care, University of Nottingham, March 2013 (published alongside this report on www.gov.uk)
9 Snapshot Review of Complaints in End of Life Care Key findings, NHS Improving Quality, June 2013 (published alongside this report on www.gov.uk)
10 To be published by the APM on their website http://www.apmonline.org/
11 Full analysis of the results was not available in time for the Review panel to take them into account for the purposes of this report
12 see http://group.bmj.com/group/media/latest-news/criticism-and-apprehension-about-liverpool-care-pathway-201cputting-end-of-life-care-back-about-twenty-years201d-doctors-tell-joint-bmj-channel-4-dispatches-survey

Diagram 1: Timeframes in the dying process



'They spoke to us as a family in a sensitive way.... She died with my mother holding her hand, surrounded by the people she loved in the place where she wanted to be....I believe we could only do this, because the LCP provided staff with the guidance to prepare us for her death and also gave them the confidence to provide the right care at the right time.'

1.10 The Review panel is concerned that, in settings where there is little or no input from a specialist palliative team – whether in hospitals or the community – it might be all too easy to misinterpret a doctor's statement about the patient being now at the 'end of life' and for the LCP to be initiated inappropriately.

1.11 For these reasons, the Review panel **recommends** that NHS England should work speedily to issue clear definitions of time frames relating to end of life decision-making, and that these definitions be embedded firmly into the context of existing policies and programmes so that there is no room for doubt. Linked to this are levels of uncertainty in prognostication (see paragraph 1.33).

THE PLACE OF THE LCP IN THE DYING PROCESS

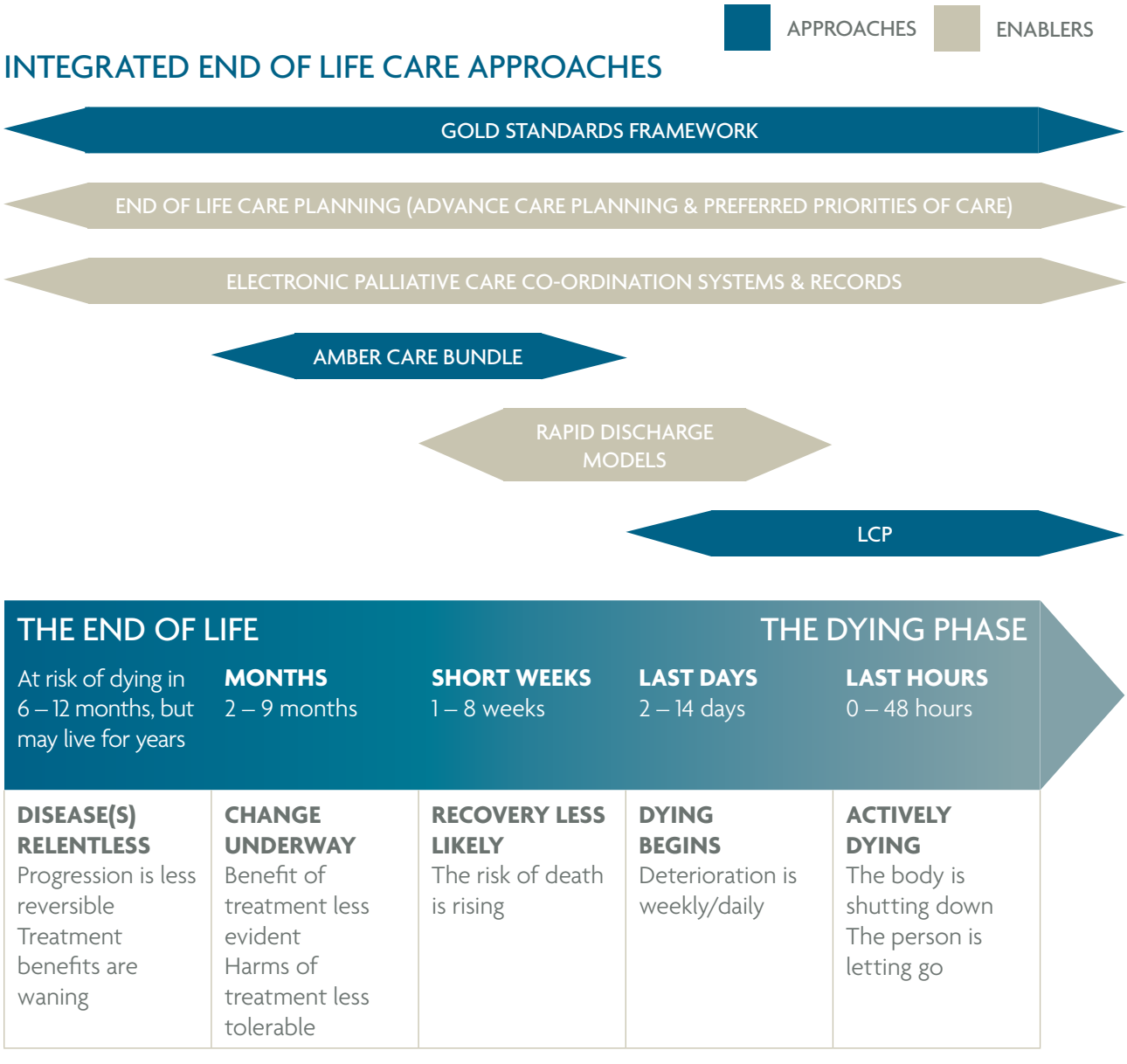
1.12 The LCP is not the only approach to care for people in the dying phase, but is one of a range of integrated care approaches for end of life. There are a number of locally or nationally developed end of life integrated care approaches developed according to these principles and covering the different timespans of end of life. Notable among them are the Gold Standards Framework,[13] the Amber Care Bundle,[14] and the All Wales Integrated Care Priorities for the Last Days of Life.[15] The LCP is one version of these generic approaches, distinct in being concerned specifically with the last days and hours of life. Local variations of the LCP and other approaches are based on its principles. Common to all of these approaches is that they must first be agreed by a multidisciplinary team, regardless of setting.

13 www.goldstandardsframework.org.uk
14 www.ambercarebundle.org
15 wales.pallcare.info/index.php?p=sections&sid=11

'Use of the LCP potentially exposes vulnerable patients to life threatening harm as current controls are very weak.'

1.13 Diagram 2 below illustrates how approaches to integrated end of life care relate to the end of life timeframes set out in Diagram 1. Integral to success in implementing approaches of this kind are the key elements of end of life care: planning at all stages of the dying process, rapid discharge models to enable patients who wish to die in the community to be discharged from hospital in good time; and electronic co-ordination systems, which enable clinicians to access and contribute to the patient's record online at any time and from any setting.[16]

Diagram 2: Timeframes in the dying process



16 For an example of such a system, see www.coordinatemycare.co.uk

THE LCP – AN INTEGRATED CARE PATHWAY

'I thought the LCP was some kind of external charity type organisation that helped care for seriously ill'

1.14 The LCP core documentation explains how the LCP complies with the key features of a pathway. However, the designation of 'pathway' is clearly, and understandably, being misunderstood by people at the bedside. As the rapid evidence review published alongside this report[17] states:

> 'The term 'care pathway' may be unhelpful because it is currently used to describe a very broad range of service initiatives. While these various initiatives are often underpinned by similar principles to pathways for the dying phase in end of life care, they involve very different procedures and have very different aims and outcomes'

1.15 The Department of Health's End of Life Care Strategy[18] states:

> "The LCP is a multi-professional, outcome-driven document that provides an evidence-based framework for the delivery of care in the last days or hours of life."

This appears to represent the LCP as a stand-alone document, rather than what it is intended to be: an approach to care in itself.

1.16 In contrast, the National Institute for Health and Care Excellence (NICE) describes its own web-based programme of pathways as follows:

> "Each pathway includes all relevant NICE guidance, including clinical guidelines, public health guidance, technology appraisals, interventional procedures, medical technology and diagnostics guidance, and quality standards, and accompanying tools produced by NICE to support implementation."[19]

The Review panel has noted that NICE itself has not yet produced a 'care pathway for the end of life', but it has recently issued two separate 'documents' relevant to this area: its quality standard for end of life care,[20] and a guideline for the use of opioids in palliative care.[21]

1.17 The Marie Curie Palliative Care Institute Liverpool (MCPCIL) describes care pathways as follows:

> "a care pathway is a complex intervention for the mutual decision making & organisation of care processes for a well defined group of patients during a well defined period."[22]

1.18 Due to this lack of clarity, the LCP is being perceived by some of its users – doctors and nurses – not as a document, nor as a guideline, but most frequently as a set of instructions and prescriptions, that is to say a protocol.

1.19 To remove this lack of clarity and the unintended consequences that appear to follow from it, the Review panel **recommends** that NHS England and NICE should review urgently the terms they are using to define clinical 'pathways',[23] distinguishing them from protocols, standard

17 Rapid Evidence Review: Pathways Focused on the Dying Phase in End of Life Care and their Key Components. University of Nottingham, March 2013
18 End of life care strategy. Fourth Annual Report. Department of Health, October 2012 (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136486/End-of-Life-Care-Strategy-Fourth-Annual-report-web-version-v2.pdf)
19 See http://pathways.nice.org.uk/about-us
20 NICE: Quality standard for end of life care (http://guidance.nice.org.uk/QS13)
21 NICE: Guideline for opioids in palliative care (http://www.nice.org.uk/cg140)
22 See www.liv.ac.uk/mcpcil/liverpool-care-pathway/
23 For the rest of the report, reference to 'pathway' will be in single quotes to denote the panel's reservation over its current usage in care of the dying.

operating procedures, guidelines, guidance, and best practice models. These must be intelligible to all, from clinicians to members of the public.

1.20 The Review panel has reluctantly concluded that the term 'Liverpool Care Pathway' is most unhelpful: anxious and upset relatives cannot be expected to understand what an 'integrated care pathway is, let alone what it has to do with Liverpool. A 'pathway' suggests to most people a road that leading somewhere. When someone is 'put on' a pathway, it sounds like, as one carer put it, they are being placed on "a conveyor belt to death". In the context of the debate about assisted dying and euthanasia, some carers have formed the impression that "the pathway" represents a decision on the part of clinicians, in effect, to kill their dying patients, when that is clearly not the case.

1.21 In respect of the name itself, therefore, the Review panel **recommends** that 'Liverpool Care Pathway' should be abandoned, and within the area of end of life care, the term "pathway" be avoided. An 'end of life care plan' should be sufficient for both professionals and lay people.

EVIDENCE BASE FOR THE LCP

The rapid evidence review commissioned for the Review concluded that there is no strong evidence on potential benefits or on potential adverse effects and risks of 'pathways' for managing the dying phase in end of life care. No research has yet produced evidence by robustly comparing these pathways with other forms of care.

1.22 There appear to the Review panel to be other significant gaps in evidence about the LCP. These include:

- The extent to which staff who decide upon and implement the 'pathways' in various settings, including acute hospitals, are competent to care for the dying, let alone to a sufficiently high standard.
- Evidence of which factors (such as training, on-going expert support, or the environment) result in good or poor implementation of the LCP and its underpinning principles.
- More information on incidence, features, trajectory and consequences of placing people on the LCP who then recover in that particular care episode.

1.23 Formal, independent, prospective testing of the LCP has not yet been carried out after nearly 10 years of its dissemination, which is a major cause for concern. The National Care of the Dying Audit – Hospitals (NCADH)[24] does provide some limited evaluation of the LCP.

1.24 In view of this lack of evidence on the LCP and end of life care more generally, the Review panel **recommends** that the CQC and the Health Quality Improvement Partnership (HQIP), should conduct fully independent assessments of the roles of the healthcare professions in end of life care in England. Rather than focusing on process, they should focus on the outcomes and experience of care, as reported by patients, their relatives and carers, as well as the quality of dying.

24 National Care of the Dying Audit – Hospitals (NCADH). Round 3. Generic Report 2011/2012. Marie Curie Palliative Care Institute in collaboration with the Royal College of Physicians.

1.25 Currently well below one per cent of research funding is devoted to end of life care.[25] To provide independently and rigorously gained evidence for good end of life care, the Review panel also **recommends** that the National Institute for Health Research (NIHR) fund research into the biology of dying. However, research funding should not stop there. 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. Patients, their relatives and carers see themselves as people, not as biological specimens in a laboratory.

1.26 The Review panel therefore also **recommends** that the NIHR fund research into the experience of dying, because there are critical and legitimate social and health objectives and benefits that must be understood, in how patients, their relatives or carers experience care at the end of life. Health service research can then help to develop and evaluate the best ways by which patients can be helped to approach, experience and orchestrate their dying and death. In the light of failings in communication between some clinicians and relatives or carers that this Review has identified, research priorities must extend also to systematic, qualitative and mixed methods research into communication in the patient and relative or carer experience.

LCP DOCUMENT

'The doctors told us that my mother would die within twenty four hours on being placed on the pathway yet it took her five days to die.'

'I asked her how she could possibly know that he was dying today. She replied "We are experts and we recognise the signs of dying.'

1.27 The Liverpool Care Pathway has its own generic document,[26] designed to replace the contemporaneous medical records written by the clinical staff. In some hospitals, training had been supplied for those tasked with filling in the forms. But the Review panel was told that this training can be as little as an hour-long lecture which it was considered acceptable to miss. It was also told that filling this form in could be delegated to the most junior doctor who was sometimes tasked with "completing it at 3 o'clock in the morning".

1.28 The design of the form allows clinicians to record plans and findings, and there is a separate section at the back for variations to the plans. Because it exists as a separate record on top of the continuation notes written by doctors and nurses, it was easy for staff to believe that both sets had to be completed. The Review panel was told that a lot of energy was initially put into completing the form, but after a while some clinicians tended to ignore it, and reverted to standard contemporaneous note keeping.

25 Analysis of UK research expenditure (charity and statutory) shows that less than 0.25% of the research budget in cancer is allocated to palliative or end of life care (Lancet 2012; 379(9815): 519)

26 The Liverpool Care Pathway for the Dying Patient (LCP) Core Documentation. Version 12. December 2009. Marie Curie Palliative Care Institute, Liverpool.

'The nurse announced that she was going on holiday for 2 weeks...as she left our home she told me she did not expect 'n' to be alive when she returned although no specific reasons were given.'

1.29 It is a complicated form; the Review panel was shown examples only partially completed, with the sections about relatives left blank. It was also consistently shown, and all too frequently told of, instances where the form had been filled in wrongly – recording discussions with relatives or carers which they denied had taken place, or including observations that the relatives or carers believed had not been made. The Review panel appreciates that a record can only summarise the perspective of its author, and that a claim of false recording may be made because of a lack of clear communication between the clinician and the patient, relative or carer at a very difficult time for them. Nevertheless, the duty remains with clinicians, so far as they are able, to overcome the challenge. In such situations, the record must openly reflect the difficulties at play, or, if the record is completed in retrospect due to a legitimately unavoidable delay, the reasons why. By reflecting with this openness, the clinician is demonstrating the willingness to be accountable.

'This was done simply by a community nurse who was visiting another resident. .... No examination was made, no diagnosis attempted.'

1.30 The reports of incomplete and wrongly completed forms that the Review received are of grave concern, reminding the Review panel of a key finding of the Mid Staffordshire Public Inquiry – insufficient openness, transparency and candour.[27] The Review Panel strongly supports Robert Francis QC's call for a duty of candour, and **recommends** that clinicians be reminded by their registration bodies that the deliberate falsification of any document or clinical record, in order to deflect future criticism of a failure of care, is contrary to GMC[28] and NMC guidelines[29] and therefore a disciplinary matter.

DIAGNOSIS OF DYING

As the LCP documentation acknowledges, diagnosing imminent death is a far more imprecise science than people realise. And accurate prediction in non-cancer patients is particularly difficult. There are no precise ways of telling accurately when a patient is in the last days of life.

1.31 The LCP document makes clear that the process of diagnosing dying includes a multidisciplinary team (MDT) assessment.[30] It rightly reminds the team that it should seek the advice and support of the specialist palliative care team when there are areas of difficulty or doubt, and states that 'once the clinical decision is taken, 'patient, relative or carer communication is focused on recognition & understanding that the patient is dying.'

27 Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry Volume 3, p.1441
28 Good medical practice (2013), General Medical Council, March 2013, Domain 1, 16-18
29 *Record keeping: Guidance for nurses and midwives*, Nursing and Midwifery Council, July 2009
30 The Liverpool Care Pathway for the Dying Patient (LCP) Core Documentation. Version 12. December 2009, page 2

1.32 The LCP document is accompanied by supporting core documentation[31] to help with its implementation, but without reference to wider material, the documentation offers insufficient advice to the non-specialist clinician on how to diagnose the final stages of dying. The Review panel understands that tools for improving the accuracy of prognosis do exist, but that these are not yet, or indeed may never be, sensitive enough to identify reliably those who will die within hours or days.

1.33 Uncertainty can never be removed from the dying process, as dying can be as much a social as a medical process. The timing of a patient's death may be less related to the physical processes, but more by symbolically meaningful occasions such as birthdays, anniversaries and festivals.[32]

1.34 Given the difficulty of predicting when a patient is actually going to die, placing patients on the LCP can lead to considerable upset in families expecting the patient to die sooner than they do or, if they recover, understanding what has happened. Families expect that, because a patient is placed on the LCP, they must be in the last hours or days of life; but the Review panel knows from the evidence it received that some patients then remain on the pathway for several days or longer. Relatives naturally become distressed, and this is heightened if pain relief is not effective, and 'normal' drugs, nutrition and, particularly, hydration are discontinued. Doctors and nurses need to communicate with patients and relatives or carers far more honestly about the difficulties in diagnosing the dying phase, admitting to, and being explicit about uncertainty and dealing in likelihoods, not certainties. The need for good communication at all times in end of life care is an issue that arose time and time again during this Review, and it is addressed elsewhere in this report.

1.35 In order to help address the problem of diagnosing dying, and avoid inappropriate use of the LCP, the Review panel **recommends** that NHS England and Health Education England collaborate to promote:

- the use of evidence-based prognostic tools, including awareness of their limitations; and
- evidence-based education and competency based training, with regular refresher modules, for all professionals working with the dying, both in the use of prognostic tools and in explanation to patients and relatives or carers of how they are used and the unavoidable uncertainties that accompany an individual's dying.

1.36 The Review panel also **recommends** that the NIHR should fund research on improving, where possible, the accuracy of prognostic tools for the last weeks to days of life. This would cover, for example, the accuracy of prognostication where that is possible, suitably configured, mixed method trials of different forms of care during dying, and trials of specific interventions, such as hydration and nutrition, and symptom control measures. It should also extend this as a matter of priority to the development and evaluation of education and training methods, their impact on clinical competence, and programmes addressing uncertainty and communication when caring for the dying.

1.37 The Review panel also **recommends** that the GMC should review whether adequate education and training is currently provided at undergraduate and postgraduate levels to ensure competence. It should also consider how, given its recently increased responsibilities for specialist training and enhanced role in continuing professional development, it can ensure that practising doctors maintain and improve their knowledge and skills in these areas.

31 LCP Model Pathway – UK Core Documentation, Marie Curie Palliative Care Institute Liverpool, October 2012
32 Dein S, George R, The time to die: Symbolic factors relating to the time of death, Mortality Vol 6, No 2, 2001

1.38 It also **recommends** that clear guidance be issued by the NICE on:

- diagnosis and who should ultimately be responsible for diagnosing that someone is beginning to die
- the necessity for multidisciplinary decision-making
- the usefulness or otherwise of laboratory and other biological evidence
- the importance of case notes review for diagnosis
- how any uncertainty about whether a patient is in the active process of dying should be taken into account in the clinical management of the patient, in different healthcare settings.

The Review panel fully recognises the valuable contribution that approaches like the LCP have made in improving the timeliness and quality of clinical decisions in the care of dying patients. It is therefore vital that the comments which follow below do not result in clinicians defaulting back to treating dying patients as though they are always curable, for fear of censure. However, the Review has heard far too many examples of sloppy and unmonitored clinical decision-making for the status quo to go unchallenged.

'The decision was made to not continue to treat Mum in ICU any more. It was explained to me how she had suffered extensive brain damage during the cardiac arrest and without the ventilator she would not survive, and that there was no hope of her making a recovery. She was moved from ICU to a single room on one of the wards and the LCP commenced. Suddenly there was a great feeling of calm...nurses came in and out to care for her, visitors came to say good bye, prayers were said and tears shed.'

'I did not feel involved, just a helpless onlooker.'

'As a family we were involved in the LCP and DNR decisions, we understood it, we agreed with it and we were willing passengers on my nan's final journey.'

MAKING THE LCP DECISION: THE INVOLVEMENT OF THE PATIENT, RELATIVES AND CARERS

1.39 The LCP document[33] states that the healthcare professional documenting the decision of the multidisciplinary team (MDT) 'will vary according to circumstances and local governance arrangements. In general this should be the most senior healthcare professional immediately available.' It goes on to stipulate that 'The decision must be endorsed by the most senior healthcare professional responsible for the patient's care at the earliest opportunity if different from above.'

1.40 There are later sections in the present LCP document to record what the 'doctor and the nurse' with responsibility for the care of the patient have decided. Whilst there is clear provision in section 2 for further review, it is unclear from the document whether the 'doctor' and 'nurse' jointly undertaking the initial and on-going assessments (in Sections 1 and 2) should be those that made the MDT assessment, or whether this falls to the clinicians of the day. It was the Review panel's view that this should be more explicit.

33 The Liverpool Care Pathway for the Dying Patient (LCP) Core Documentation. Version 12. December 2009 Page 3

'I am well aware that the LCP pathway should be initiated by a multi-professional team but often it is the doctors that make the initial decision with the family to start the LCP. The current document is confused and lacks direction for health care professionals with respect to who has responsibility for the various sections.' (pharmacist)

1.41 The Review panel heard many instances of both good and bad decision-making. Repeatedly, they heard stories of relatives or carers visiting a patient, only to discover that without any forewarning there had been a dramatic change in treatment. There now appeared to be no clinical care or palliative care, and the patient appeared to be unnecessarily or excessively sedated. As if caught in the midst of a perfect storm, relatives and carers would discover that a previously sentient person was now semi-comatose. They were told that, following an overnight decision by a relatively junior clinician, this patient had been 'placed on the pathway.' One senior consultant who gave evidence to the Review panel related how a surgical professor was apt to conclude discussions in MDT meetings about certain patients with 'this patient is unfit for surgery, so LCP.' This is entirely unacceptable.

1.42 The current GMC guidance sets out the circumstances under which a doctor must seek advice or a second opinion.[34] Equivalent requirements should apply to nurses, but it is of great concern that the NMC has not produced similar guidance for them. The Review panel **recommends** that the NMC rectifies this situation as a matter of urgency.

1.43 Every patient diagnosed as dying should have a clearly identified senior responsible clinician accountable for their care during any 'out of hours' period. Unless it is unavoidable, urgent, and is clearly in the patient's best interests, the decision to withdraw or not to start a life-prolonging treatment should be taken in the cool light of day by the senior responsible clinician in consultation with the healthcare team. The Review panel **recommends** that the practice of making such decisions in the middle of the night, at weekends or on Bank Holidays, by staff that do not have the requisite training and competence, should cease forthwith. The Review panel therefore **recommends** that the GMC, the Health and Care Professions Council (HCPC) and the NMC ensure their professional standards clearly place the responsibility for such decisions on the senior responsible clinician, and that they take steps to emphasise how clinicians will be held to account against these standards. Furthermore, NHS England must ensure that appropriate systems are in place, with adequate levels of staffing to deliver these arrangements in practice. And CQC and Monitor should ensure their inspection regimes focus on this important aspect of the patient experience.

1.44 If a patient has capacity,[35] they must give informed consent[36] to any treatment they receive. If a patient lacks capacity, the Mental Capacity Act 2005 (MCA) applies to any medical decision that is taken on their behalf. The decision-maker – who will normally be the treating clinician – is under a duty to make decisions in the patient's best interests. Crucially, the 'best interests' assessment under the MCA is not simply a clinical judgement about what the doctor thinks is

34 Treatment and Care towards the end of life: good practice in decision making, General Medical Council, May 2010, page 23 (http://www.gmc-uk.org/Treatment_and_care_towards_the_end_of_life_English_0513.pdf_48902105.pdf)

35 The ability to make personal decisions

36 The NHS Constitution supports this in its pledge: 'You have the right to accept or refuse treatment that is offered to you, and not to be given any physical examination or treatment unless you have given valid consent. If you do not have the capacity to do so, consent must be obtained from a person legally able to act on your behalf, or the treatment must be in your best interests (unless detained by the Mental Health Act 1983).'

clinically best for the patient. Instead the 'best interests checklist' in section 4 of the Act specifies that the doctor must also take into account the patient's past and present wishes and feelings, and his beliefs and values. The doctor must also – unless it is impracticable and inappropriate – consult people involved in caring for the patient in order to help elicit the patient's preferences and beliefs. The decision ultimately, however, remains with the clinician.

From the submissions of evidence that the Review panel has received, it is clear that one of the central issues causing difficulty seems to be some misunderstanding and uncertainty over whether deciding to implement the LCP is a treatment decision that requires the patient's consent (if the person has capacity) or requires the decision to be taken in the patient's best interests (if the person lacks capacity). In some cases, relatives and carers incorrectly consider they are entitled to decide what treatment their relatives receive, and in others clinicians fail to seek consent or consult the relatives and carers in a 'best interests' assessment when they should.

1.45 The LCP is not a single, simple medical procedure, and there is no legal requirement for consent to be sought before it is commenced. Some aspects of the LCP, for example making sure that the GP practice is notified that the patient is dying,[37] do not concern treatment, and so do not require patient consent or the application of the MCA to determine what is in the patient's best interests.

'They opened us a discussion regarding the Liverpool Care Pathway and welcomed us to actively participate. My aunts, mother and myself decided it was the best chance that Nanna had of experiencing a dignified death. The medical team explained the care pathway to us and provided us with information relating to all the aspects of Nanna's care. The family were given space and time to make the decision and felt that they were in partnership with the medical team.'

1.46 On the other hand, for aspects of the LCP that do involve medical treatment – for example, starting, continuing or stopping the use of strong analgesia or sedation, artificial nutrition or hydration – discussion and consent will be appropriate. But, while any planned treatment requires consent or a best interests assessment, no clinician can be compelled to act against their patient's best interests.

1.47 The Review panel concluded that the LCP document is deficient in making the distinction between treatment and non-treatment (to seek consent and/or to explain one's actions). The document should be clear about when consent or a decision taken under the MCA is required. This should be clearly set out in the information sheet for relatives, in the algorithm and under each of the relevant goals in sections 1 and 2, as a prompt to the lead doctor.

37 The Liverpool Care Pathway for the Dying Patient (LCP) Core Documentation. Version 12. December 2009 Page 6, Goal 9.4

Perfectly preventable problems of communication between clinicians, relatives and carers appear to account for a substantial part of the recent controversy and unhappiness surrounding the LCP.

'No one explained anything to us about what would take place once the Pathway was implemented, or what would happen otherwise. We weren't given anything to read and, as far as I can remember, the issue was raised so tentatively by the doctor and nurse that at the time we were simply unaware that we had taken such an important decision. Surely the circumstances where this situation arises require a high standard of communication, which does not vary from hospital to hospital and from staff member to staff member – and is clearly understood by family members whose individual powers of understanding will also vary.'

1.48 The LCP's information sheet for relatives and carers states that they "will be involved in the discussion regarding the plan of care," advising that, "There are information leaflets available for you as it is sometimes difficult to remember everything...." Submissions to this review, both written and oral, indicate that a significant number of relatives and carers do not feel that they were involved in discussions about the care plan, or even offered the chance to be involved. The relative or carer may well have been involved in the day-to-day care of the patient for some time, and feel a strong need to continue this involvement as a member of the whole end of life care team. They may also be much better informed than professional staff as to the wishes and needs of the patient. The responsible clinician or their recognised delegate should hold a discussion with the patient and their relative or carer, in which the clinician obtains significant information, including wishes and preferences, including any religious and cultural aspects of dying which are important to them, to identify the best means of meeting the needs of patient, relative and carer. The panel strongly endorses the Mid Staffordshire Public Inquiry's recommendation that 'each patient should be allocated for each shift a named key nurse responsible for coordinating the provision of the care needs for each allocated patient. The named key nurse on duty should, whenever possible, be present at every interaction between a doctor and an allocated patient and/ or their families.'[38]

1.49 There were many stories of relatives and carers being handed a leaflet with 'Liverpool Care Pathway' on the cover, without any explanation. A common theme among respondents was that they were simply not told that their loved one was dying; this clearly contributed to a failure to understand that the patient was dying, compounded their distress and subsequently their grief, after what they perceived to have been a sudden death. It appears in these cases that a conversation with relatives or carers to explain the diagnosis or prognosis had simply not taken place, or that doctors had used euphemisms such as "making comfortable". In other cases, discussions about the fact that the patient was regarded as dying took place hurriedly, and inappropriately, in corridors or while standing slightly away from the bedside. Equally

38 Mid Staffordshire NHS Foundation Trust Public Inquiry, Feb 2013, Recommendation 199 www.midstaffspublicinquiry.com

worrying, the Review panel heard instances of brutal or callous language being used. It heard several cases of relatives being asked by passing nurses or clinicians, "Oh, is X still with us?" or words to this effect. It is hard to imagine how this could ever be appropriate.

'After 2 days the doctors said they could not believe that she was still with us and that she would die in the next few hours. This situation continued for 16 days with the same assurance each day.'

'I asked that she be removed from the Liverpool Care Pathway and this was done'

'It seemed to us that once he was placed on this plan there was no further review. It seemed that he had simply been written off.'

'He managed over a few days to eat a little and joke with his grandchildren. I questioned whether he had been put on the Pathway too early but was told that it was too late to reverse because of the damage to his organs. He survived for nearly another week.'

'My mother's notes has the word 'futile' written in large letters, as if it seemed to justify the medical team's decision to let my mother die.'

1.50 As the GMC's guidance[39] makes clear, as a matter of good practice and respect, the clinician should explain their thinking, ensure it is understood, and offer referral for another opinion if appropriate. This is the proper process of joint decision-making. Failure to discuss the prognosis and the care plan with patients and their relatives or carers[40] is unacceptable practice, leading to untold levels of distress that severely impact relatives' and carers' experiences of the dying process and subsequently their bereavement. The Review panel is deeply concerned that the GMC guidance is clearly not always being followed in the care of the dying, and **recommends** that the Royal Colleges review the effectiveness of any training in shared decision-making that they provide, examining the extent to which it closely reflects the professional standards in GMC and NMC guidance and required competencies in this area, with a view to ensuring continued competence is maintained across the education and training spectrum from undergraduate teaching and learning through to continued professional development.

REVERSING THE LCP DECISION

1.51 The LCP document states that at least every three days the patient should be reviewed by an MDT. If a dying person's condition improves to the extent that the LCP is no longer applicable ("Improved conscious level, functional ability, oral intake, mobility, ability to perform self care"),[41] the LCP allows for the patient who stabilises or improves to return to standard interventional medical and nursing care. This concept of reversibility is well recognised by palliative care consultants, who regularly suspend the LCP because of an improvement in the patient's condition.

39 Treatment and Care towards the end of life: good practice in decision making, General Medical Council, May 2010, (http://www.gmc.uk.org/Treatment_and_care_towards_the_end_of_life___English_0513.pdf_48902105.pdf

40 unless the patient has expressly asked for their relative or carer not to be involved

41 The Liverpool Care Pathway for the Dying Patient (LCP) Core Documentation. Version 12. December 2009Section 2

The Review received evidence from relatives and carers which suggested that the patient's condition might be reversible, though without the necessary clinical information on individual cases, it was impossible to be sure. What did emerge, however, was that the LCP appears to be being used by some clinicians as a protocol to be followed, rather than as a set of alerts and guidelines for good practice, as it is intended. The risk from this is that insufficient attention is paid to signs of reversibility in the patient's condition.

HYDRATION AND NUTRITION

'On the LCP she died a peaceful and dignified death free from pain or distress which was a great comfort to us. She received food and fluids as she wished and was able to take, including ice cream the day before she died.'

1.52 As part of the process of dying, patients usually experience a reduced need for food. Not eating is often accepted to be the choice of a dying patient. It does not seem to have to same potential to cause distress to patients, relatives or carers as the withholding of hydration. If fluids are stopped without review over many days, death from dehydration will be inevitable, the lack of hydration having accelerated the dying process. Inadequate hydration is a real vulnerability for old and frail people, and may resemble dying.

1.53 Goal k in section 2 of the LCP document states:

> '**The patient receives fluids to support their individual needs**
>
> The patient is supported to take oral fluids/thickened fluids for as long as is tolerated. Monitor for signs of aspiration and or distress. If symptomatically dehydrated and not deemed futile, consider clinically assisted (artificial) hydration if in the patient's best interest. If in place, monitor and review rate and volume. Explain the plan of care with the patient and relative and carer.'

Most of the submissions to the Review from relatives and carers that were critical of the LCP made reference to hydration and nutrition. Judging from these accounts, far too often the LCP advice is not being followed. The Review panel considers that the current version of the LCP, version 12, does not go far enough to adjust the language of the previous version,[42] to advise that the default course of action should be that patients be supported with hydration and nutrition unless there is a strong reason not to do so.

'He was not given sufficient pain relief or sedation to ease his discomfort from what in effect was a slow death, attributable in part to dehydration and starvation.'

1.54 At the end of life, the kidneys may not be functioning well and a person may become overhydrated, the lungs filling up with fluid, causing breathing difficulties. A systematic review of all the literature and studies evaluating the benefits of clinically assisted hydration in palliative care patients shows no clear benefit to either length or quality of life.[43]

42 The Liverpool Care Pathway for the Dying Patient (LCP) Core Documentation. Version 11, Goal 3 (Discontinue inappropriate interventions) advised clinicians to discontinue IV fluids where there was no clear benefit.

43 Good P, Cavenagh J, Mather M, Ravenscroft P. Medically assisted hydration for adult palliative care patients. Cochrane Database of Systematic Reviews 2008 (Updated 2011), Issue 2. Art. No.: CD006273. DOI: 10.1002/14651858.CD006273.pub2.

Furthermore, there is no moral or legal obligation to continue to administer and clinically assisted hydration or nutrition if they are having no beneficial effect.

1.55 If it does seem likely that clinically assisted hydration will increase comfort to the dying patient, rather than an intravenous infusion of fluid, it may be more appropriate to use a subcutaneous one, which is straightforward to administer in any setting.

1.56 The GMC has provided good advice to doctors on clinically assisted nutrition and hydration,[44] essentially that it should be a clinical decision made with reference to specialist input, in the best interests of the patient after taking into account the views of those close to the patient.

'He sipped on a water bottle of warm tea as long as he could hold it and long after he had the inclination to drink it, because it was his favourite drink and brought him pleasure.'

1.57 From the evidence submitted to the Review panel, it appears that in hospices and in community settings the direction in the LCP document that 'The patient should be supported to take fluids by mouth for as long as tolerated"[45] is generally interpreted correctly and applied well. In hospitals, however, there appear to have been too many instances demonstrating an inadequate understanding of the LCP's direction on hydration, particularly oral hydration. Panel members, lay and clinical, felt that removal of hydration inappropriately was a terrifying prospect.

1.58 The Review panel heard of many instances when hospital staff told patient's relatives or carers that a decision had been made to put their relative on the LCP and therefore "food and fluid had been withdrawn". The Review panel has an issue with the concept of 'withdrawing' food and fluid: the desire for food and drink usually diminishes as a patient reaches the end of life, and they may decline what is offered. However, refusing food and drink is a decision for the patient to make, not clinical staff. There was suspicion among a few respondents that withholding fluids was sometimes done to hasten death.

1.59 According to one respondent, an elderly man in hospital was described as 'nil by mouth' after a speech and language therapist made the assessment 'unsafe swallow, feeding risk.' His wife fiercely objected to this, claiming he was being starved to death and it was only after her protests that the ward team administered subcutaneous fluids, with little explanation that he was likely to die soon. He died on the ward eight days later, still awaiting a care home placement. It is clear that members of staff are often risk-averse and may recommend "nil by mouth" even if somebody is near death. Inexperienced staff may not have the confidence to override this instruction.

1.60 Some people said that their relative had been given drugs by a syringe driver so quickly that the patient became rapidly drowsy, therefore unable to initiate drinking themselves, and the offer of a drink was not discussed. Others talked about 'disobeying' the instructions to withhold fluids and giving drinks when the nursing staff left the room. Some talked about their relative sucking on the sponges that they had been given to wet the patient's mouth in an attempt to get fluid, when fluids had been deliberately withheld.

44 Treatment and Care towards the end of life: good practice in decision making, General Medical Council, May 2010, pp.54-59 (http://www.gmc.uk.org/Treatment_and_care_towards_the_end_of_life___English_0513.pdf_48902105.pdf

45 The Liverpool Care Pathway for the Dying Patient (LCP) Core Documentation. Version 12. December 2009Section 1, Goal 6

1.61 The Review panel was left with the impression that the fear of the fluid 'going the wrong way' was sometimes being used as an excuse by staff to withhold oral fluids, rather than being a practical decision based on the evidence of choking symptoms in the patient. Although patients, their relatives and carers may fear the prospect of choking, it occurs very rarely and is easily managed. Such a risk seems minor in comparison with the far greater distress caused by the person's thirst.

1.62 Although there is a risk/benefit judgement to be made when deciding whether to offer oral hydration, the presumption[46] should be that the patient will be supported to receive it for as long as possible.

There can be no clinical justification for denying a drink to a dying patient who wants one, unless doing so would cause them distress. The urge to drink when thirsty is very powerful and basic. Good mouth care if the patient simply has a dry mouth may well be sufficient, but to deny a drink to a thirsty patient is distressing and inhumane.

1.63 The GMC has issued clear guidance on supporting artificial nutrition and hydration, and the Review panel acknowledges that its guidance on supporting oral nutrition and hydration is unambiguous. However, in the light of the findings of this review, it is not sufficiently specific. The Review panel therefore **recommends** that the GMC reviews its guidance on supporting oral nutrition and hydration to consider whether stronger emphasis could be given to this issue. It also **recommends** that the NMC, which currently issues no guidance on this issue, produce it for nurses urgently.

1.64 The Review panel also **recommends** that:

- All staff in contact with patients should be trained in the appropriate use of hydration and nutrition at the end of life and how to discuss this with patients, their relatives and carers.
- There should be a duty on all staff to ensure that patients who are able to eat and drink should be supported to do so, unless they choose not to.
- Failure to support oral hydration and nutrition when still possible and desired should be regarded as professional misconduct.
- Specialist services, professional associations and the Royal Colleges should run and evaluate programmes of education, training and audit about how to discuss and decide with patients and relatives or carers how to manage hydration at the end of life.

SEDATION AND PAIN RELIEF

1.65 The Review panel saw a very mixed picture in relation to sedation and pain relief in all settings. There were many examples of appropriate and exemplary management. Both through written submissions to the Review panel and the family and carer events, people told the Review panel of their gratitude to the staff that, if their loved one had become more agitated or in greater pain as they died, they were able to die peacefully due to the right drugs being given to them at the right time, and in the right dose.

46 The Liverpool Care Pathway for the Dying Patient (LCP) Core Documentation. Version 12. December 2009, section 1 goal 7.

1.66 Sadly, the Review panel was also told of many experiences where this was not the case. There were complaints that opiate pain killers and tranquillisers were being used inappropriately and in what appeared to be too strong a dose as soon as the LCP was initiated, and that this had the effect of making the patient too drowsy or confused to be able to communicate and to ask for water. Relatives and carers were unsure whether this had meant that the death had occurred naturally or whether it was directly attributable to the drugs administered.

1.67 It would appear from many accounts received by the Review that dying people were started on strong pain killers, such as morphine, and/or sedatives by a continuous subcutaneous infusion, as a matter of course, not because of a need for symptom control. If this is the case, then goals a and b of the LCP, that the patient should be neither in pain nor agitated, were clearly not being reached; the intention may have been subverted by the unnecessary use of inappropriate drugs. This evidence of poor communication about the dying process provides a clear example of the need for a focus in audit on prioritising patient, relative and carer reported outcome measures.

A repeated observation by families was that starting the LCP seemed to mean that proper clinical assessments of the need for medication ceased, instead of occurring every four hours as recommended in the LCP document; the LCP was then experienced as if it were a protocol, even a "tick-box" exercise, through which the next step was to stop food and fluids and give continuous infusions of strong opioids and sedatives without justification or explanation.

1.68 Some relatives and carers told the Review panel that they felt as though the administration of diamorphine had directly killed the patient. There is some controversy, but much misunderstanding about this. The Review panel is aware of clear evidence from a number of definitive studies that opiates and tranquillisers given in the appropriate doses to deal with the patient's symptoms do not hasten death[47] and in fact may prolong life.[48] As with all medications, use of drugs at the end of life requires considerable skill and is much more complicated than simply giving the patient a larger dose of diamorphine. For example, concurrent problems such as renal failure require specific regimes, and a blocked urinary catheter or a urinary tract infection, or dehydration alone can cause a patient to become confused.

1.69 There have been too many people coming forward to the Review panel to state that they left their loved one in a calm and peaceful state, able to communicate, for a short time, or with a doctor or nurse for a check-up, only to return to find a syringe driver had been put in place and their loved one was never able to communicate again. One family was left with the impression that their relative had been overmedicated in order to allow him to die from dehydration. Often relatives and carers spend the most time with the patient, and the Review panel felt that patients, their relatives and carers should be told the reasons for "step changes" in treatment, and be given the opportunity to contribute to a discussion about appropriate care.[49]

1.70 It seems that, aside from a reasonable expectation that doctors can assess for pain and agitation, and prescribe analgesics and sedatives safely, much of the distress would have been

47 George R and Regnard C. Lethal opioids or dangerous prescribers? Palliative Medicine 2007; 21: 7780

48 Edwards M. Opioids and benzodiazepines appear paradoxically to delay inevitable death after ventilator withdrawal. J Palliat Care, 2005; 21: 299302.

49 Unless the patient has expressly asked for their relatives or carers not to be involved.

mitigated by better communication. In addition many relatives were concerned that the patient's 'regular' medication, for example insulin, had been stopped and the reasons for this were not explained. Relatives and carers would have been be less likely to link medication changes or stopping unnecessary and burdensome treatments to the cause of death, if there had been a clear and open discussion about the natural process of dying and how drugs can help with alleviating symptoms and distress, should they arise.

1.71 As the LCP document states, if opiates are started, the appropriate drug or drugs and their use should be regularly reviewed, with the possibility that they could be stopped. It would be inappropriate for the Review panel to make a judgement on the correct usage of morphine and other painkilling drugs. However, it is concerned at clear indications that some of those deciding on the drugs to be given have not received training in their use to an acceptable level of competence, or indeed no training at all.

1.72 Not all dying patients are in pain: there are also some, for whom remaining lucid is their overwhelming priority; this is a position adopted by some religious traditions and by some individuals, irrespective of any religious belief. Whilst the principle of using a syringe driver at the right time is right and proper, too often it appears that a syringe driver is put in place as the 'next step' on the LCP, overlooking the needs and wishes of the patient. Many patients in the hospital setting appear to be put on a syringe driver with morphine, even if morphine is not the right drug, or pain relief is not what is needed. This is clinically indefensible.

1.73 For these reasons, the Review panel **recommends** that, before a syringe driver is commenced, this must be discussed as far as possible with the patient, their relatives or carer, and the reasoning documented.

1.74 Dehydration can sometimes cause a patient to become agitated and confused. If this happens, this can usually be improved by giving the patient fluids. If this agitation from dehydration is not recognised for what it is, and is then treated with sedatives, it makes the confused and agitated person even less able to accept any fluids offered to them, starting a vicious cycle. This is yet another example of how complex palliative care can be, and the high level of training and skill needed to treat dying patients effectively.

1.75 Drowsiness, with or without confusion and agitation, may have several causes and it can be difficult to distinguish between what is reversible and what is part of dying. Assessment and clinical diagnosis again needs skilled and senior clinicians familiar with such circumstances. A specialist palliative care referral may be necessary to deal with it, but such referrals are clearly not being made as frequently as they should.

1.76 The Review panel understands that there is very little evidence on the use of drugs to manage symptoms and distress in the last days of life, and that concepts of symptom management at the end of life are based historically on patients with very advanced cancer in hospices who were inevitably going to die in days to weeks, with no chance of recovery. The Review panel therefore **recommends** new research on the use of drugs at end of life, and in particular to what extent sedative and analgesic drugs themselves contribute to reduced consciousness, and perceived reduction of appetite and thirst.

ATTEMPTS AT CARDIOPULMONARY RESUSCITATION

'His GP came to see him in his care home and she asked if I was happy that he shouldn't be resuscitated. She told me that she would get the appropriate documents put in place. Liverpool pathway was not mentioned.'

'As a family we were involved in the LCP and DNR discussions, we understood it and agreed with it.'

1.77 The professional guidance for clinicians on attempting cardiopulmonary resuscitation (CPR) is not clear. There is a variety of guidelines for the senior clinician (a consultant, GP or a suitable experienced nurse) when considering recommending against attempts at cardiopulmonary resuscitation – the "DNACPR order". This is because there are different obligations attached to plans to start treatment, which requires consent and decisions not to begin a treatment, perhaps because it is futile,[50] or too risky. That decision lies with the senior responsible clinician and the MDT, although it is best practice to involve the patient and/or their relative or carer in the reasoning behind the final decision – they are entitled to an explanation.

1.78 The LCP guidance states that:

> 'The decision about whether attempts at CPR will be successful is a clinical one and the finalresponsibility for this assessment lies with the doctor in charge of the patient's care.'

1.79 The GMC guidance[51] states that on occasions when CPR is not judged likely to be successful:

> ...you must carefully consider whether it is necessary or appropriate to tell the patient... You should not make assumptions about a patient's wishes, but... explore how willing they might be to know...

However, if it is believed that it may be successful:

> ...this is not solely a clinical decision... When the benefits, burdens and risks are finely balanced, the patient's request will usually be the deciding factor.

'The nurse asked us if we wanted him to be resuscitated or force-fed, to which we replied that we did not... Two days later we found him without IV fluids and almost unconscious.'

1.80 In order to make the right decision for the patient, the clinical team should first explain the reasons for a particular course of action, and allow time for the patient and their relative or carer to question, understand and assimilate. Given the low chance of a success, many patients with a terminal diagnosis decide that, should their heart stop, they would prefer not to undergo a resuscitation attempt.[52]

50 meaning that the treatment will not succeed

51 GMC Guidance for Doctors, Treatment and care towards the end of life: Good practice in decision making, General Medical Council, May 2010, p 60 (http://www.gmc.uk.org/Treatment_and_care_towards_the_end_of_life___English_0513.pdf_48902105.pdf)

52 See guidance at http://www.endoflifecare.nhs.uk/search-resources/dnacpr-web-resource.aspx

'My experience of the LCP whilst my father was dying was an extremely positive one.... My father was in a Nursing Home and the staff discussed what dad would want... He was checked on by staff every hour (even though we were there the whole time)... The staff also cared for us as his family... All in all, both my two brothers valued the Liverpool Care Pathway as I'm sure our dad would have done.'

1.81 The LCP document, the GMC guidance and the joint guidance issued by the BMA, Resuscitation Council (UK) and the RCN,[53] are all clear that a conversation about cardiopulmonary resuscitation relates to CPR alone, and that all other appropriate medical treatment, if required, should be continued. The Review panel considers it essential that the discussion of cardiopulmonary resuscitation should be individually documented, even though it is recognised that the subject may arise during other conversations. The discussion that must be had about palliative care or end of life care might well occur at the same time as the conversation about cardiopulmonary resuscitation, but it should be documented separately, and the patient, family and carers must be clear that the two are not synonymous.

During the relatives' and carers' sessions held by the Review, numerous people recounted that agreement not to attempt cardiopulmonary resuscitation had been taken by the clinical staff as a proxy for agreement to start the LCP. This is completely inappropriate.

'He should not have been on the Care Pathway in a residential home where there are no medically trained staff and only two carers at weekends to look after 15 elderly residents with 50% of them having some form of dementia. He was alone for a lot of the time in his room.'

1.82 The Review panel has received evidence of conversations about attempts at cardiopulmonary resuscitation having been held sensitively, patients and their families and carers having felt both consulted and involved in the decision making. However, it has also heard that this can be a very vague conversation, in which relatives and carers feel that they have been pressurised to give an opinion, the implications which were not made clear to them.

USE OF THE LCP OUTSIDE ACUTE HOSPITALS

'What came into being as a way of improving patient care at the end of their lives seems now to be being used as a way of withdrawing their right to life when the medical profession decides it is not worth continuing treatment.'

1.83 Most of the evidence submitted to the Review related to the use and experience of the LCP in hospitals; community settings such as care homes, nursing homes and the patient's own home did not feature significantly. Submissions from relatives and carers showed a mixed picture, though the Gold Standards Framework Centre's submission did provide the results of a small survey carried out among GSF-accredited care homes: of the 116 respondents, 79 used the LCP and 16 used a local

53 See http://www.rcn.org.uk/data/assets/pdf_file/0004/108337/003206.pdf

adaptation of it. Of these, most found the LCP beneficial, few had experienced problems with it, and relatives' feedback on the use of the LCP had been good.

1.84 The prison population is aging and the need for appropriate end of life care is being acknowledged both in individual prisons and nationally. Not only do facilities need improving – for example, many cells will not accommodate hospital beds, but staff also need training in palliative care. Examples of how good end of life care can be provided in prisons, often with the support of specialist palliative care services in local hospices, should be shared more widely within the prisons service.

1.85 The Review received no specific information about the care of the dying in mental health units, though many of the submissions received told of end of life care for people with dementia in 'hospitals'; this could encompass both general and mental health hospitals. Many mental health service users will die of other diseases such as cancer, and their end of life care plan will need to take into account all of their needs.

GOOD CARE OF THE DYING IS NOT ASSISTED DYING

1.86 Amongst the many concerns expressed about the LCP, the most damaging has been the belief that to put someone on it is a way of deliberately hastening their death. Based on the evidence provided to the Review, the panel understands only too well how this fear has arisen. However, all clinical and major religious bodies essentially agree on the ethical principles that should provide the basis of good quality care in the last days and hours of a person's life. The Review panel agrees that the LCP reflects these principles, even if they have not always been reflected in practice.

1.87 The present religious and secular consensus is that any attempt deliberately to shorten a person's life is morally wrong as well as illegal, but that there is no obligation, moral or legal, to preserve life at all costs. If a treatment is burdensome and futile, it is right to refuse or stop it. It should be noted, however, that some patients might prioritise consciousness over pain relief and sedation (see paragraph 1.72).

1.88 There is a strand in some religious traditions which might make a patient, their relatives or carer, press for even more to be done, even if it is considered futile by most clinicians. These situations are very difficult for clinicians, but the Review panel reverts to the essential ethical principle that the clinician must put the best interest of the patients first. When a person lacks capacity to make such a decision, this should be made by the doctor in consultation with the patient's family. The patient may have already have made their wishes known by a binding Advanced Decision to refuse treatment.

FINANCIAL INCENTIVES

> ' I am deeply disturbed that financial incentives are linked with LCP, which must call into question at least some of the prognoses and decisions made.'

1.89 The NHS Service offers a range of financial incentives for the implementation of best practice. The Department of Health commissioned an evaluation of the Commissioning for Quality and Innovation Framework (CQUIN)[54] scheme, and the evaluation report[55] shows that the results of the scheme were disappointing, some aspects of implementation hindering improvements in the quality of care.

1.90 The culture of financial incentives for good practice lies outside the scope of this review. However, the fact that, in some local incentive schemes, money can be attached to the percentage of dying patients implemented on the LCP, gives rise to a suspicion among some that people are being hastened towards death to help the financial situation of the Trust in question. Whatever the arguments for and against the use of financial incentives in other parts of the NHS, the Review panel believed it to be detrimental in this context. Not only has it given rise to fears about hastening death, but it may well have encouraged a "box ticking" approach to what should always be a matter of sensitive and skilled clinical judgement.

Hospitals need the right resources to provide good end of life care. But there is a very real risk that providing a payment for each patient implemented on the LCP, or equivalent approach, looks like an incentive to do so, rather than a means of providing sufficient resources for good quality and compassionate care to be provided.

1.91 Any linking between financial incentives and the care of the dying is extremely problematic. There would have to be very substantial advantages in promoting good patient care to overcome the problem in perception caused by such incentives, but local CQUINs are inappropriate**,** and the Review panel **recommends** that payments 'per patient implemented on the LCP, or equivalent approach' should cease. Some better way of paying for good care for the dying must be found, and the Review panel is encouraged that, following the funding review of palliative care,[56] pilots are currently in the process of developing tariff structures for specialist palliative care services. This would mean that instead of palliative care being delivered as a cost pressure to the organisation, it would be a core and funded service.

54 The CQUIN payment framework enables commissioners to reward excellence, by linking a proportion of English healthcare providers' income to the achievement of local quality improvement goals.

55 Evaluation of the Commissioning for Quality and Innovation Framework Final Report, Universities of Nottingham and Manchester, February 2013

56 Palliative Care Funding Review , Thomas Hughes-Hallett and Professor Alan Craft 2011 – see the review's report at http://palliativecarefunding.org.uk/PCFRFinal%20Report.pdf

CHAPTER 2

WIDER ISSUES RAISED BY THIS REVIEW

2.1 In reviewing the use and experience of the LCP, wider issues, some very serious, came to the attention of the Review panel. The Review panel has also reached a view on good practice in some important areas of care for the dying that examination of the use of the LCP has highlighted. There also appear to be some large and deeply concerning systemic issues. These in part explain problems in the use of the LCP that were discussed in the previous chapter; but they also extend well beyond the confines of the LCP, and so merit discussion here.

ENVIRONMENT

'It's a frightening prospect facing someone's demise and it needs to be conducted in a suitable area. ITU is not the place for this.'

'Privacy screens were normally open so that all visitors, cleaning staff and the other patients could witness my uncle's distress and imminent demise.'

'I did at times feel families needed more privacy and wherever possible a side ward would be found but this wasn't always possible so curtains would be drawn but I didn't feel comfortable with this although it couldn't be helped. On the flip side we had relatives that wanted to stay on a main ward, they didn't want to feel like their relative was being shoved away on a side ward and forgotten about which is completely understandable too.' (Healthcare Assistant)

2.2 While the provision of a private room may not always be possible because of a sudden and unexpected decline in the patient's' condition, or through lack of availability, it should be given the highest priority for the sake of the patient, relatives and carers, and other patients on the ward. Where the wishes of the patient are known in respect of the environment in which they die, these should be respected. This may include the playing of music, provision of flowers, pictures, or anything else which can reasonably be accommodated for their comfort and emotional well-being.

2.3 The Department of Health's End of life care strategy[57] recommends that rooms are made available where patients and relatives or carers can talk privately or to meet and confer with staff. These facilities are not always available, with the result that we have been told that conversations about starting the LCP have been held 'over the patient' or in corridors.

2.4 Relatives and carers of loved ones who are deteriorating to the point that they might die soon should be able to access their loved one freely outside normal visiting times to enable them to be together at this important and difficult time. During this time the medical and nursing staff should be able to build a rapport to help and support the family members through a difficult

57 End of life care strategy, Fourth Annual Report, Department of Health, October 2012

time. Relatives and carers should be signposted to areas where they can sit privately away from the bedside or obtain refreshments, and extra chairs should be available for them to sit at the patient's bedside.

2.5 If applicable and requested, relatives or carers should be able to request single rooms if available so that they can assume some degree of normal life in privacy and, if available, a room with a view to enable their loved ones to see the world outside the hospital. A room with an opening window is often helpful, should there be inadequate air conditioning.

SUPPORTING RELATIVES AND CARERS AFTER THE DEATH

'Each setting is very different but the emphasis of care is the same ... To strive to enable individuals to have a peaceful, comfortable and pain free death in the place of their choice and to provide families with the much needed emotional support both pre and post bereavement.' (palliative care social worker)

2.6 Despite some excellent examples of the provision of bereavement suites for relatives, some hospitals are still requiring relatives to return to the ward where their relative has died to collect personal property and the death certificate. This can be particularly traumatic especially if another patient has now occupied the bed where their loved died. Consideration must be given to the relatives, through the provision of a quiet, peaceful environment immediately after the death and that provision should be made for property to be delivered to them without the necessity of re-visiting the ward where they have recently suffered loss, if that is their wish.

2.7 Bereavement support should be available at the point of need from suitably trained staff; this is another example where good practice in hospices could be shared with other institutions to great effect. The Review panel heard that some relatives or carers were told that they would be contacted by their local bereavement centre to see how they were coping, only for there to be no further follow up. 'Tell us once' services[58] did not always function well.

2.8 Where necessary, relatives and carers should be put in contact with suitable organisations who may be able to help them raise concerns about the care of loved ones and that the response times for dealing with these issues should be strictly adhered to in order to help with the process of moving forward rather than hindering the process and reliving the grief.

ACCOUNTABILITY

2.9 Sections 17–23 of the GMC's guidance, *Treatment and care towards the end of life, good practice in decision making*[59] deal with the relevant duties and responsibilities of medical professionals, patients, relatives and carers, and with the need for clarity in these areas. From experiences described to the Review panel, it is clear that patients, their relatives and carers need to know better who is the senior responsible doctor in their care and under what circumstances a further specialist, such as a palliative care consultant or member of the specialist palliative care team, would be called in.

58 'Tell Us Once is a service' offered by most local authorities on behalf of the Department for Work and Pensions (DWP). The service allows the bereaved person to inform central and local government services of the death at one time rather than having to write, telephone or even attend each service individually.

59 GMC Guide for doctors. Treatment and care towards the end of life: good practice in decision making, July 2010 http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

2.10 In primary care, a patient is now registered with the practice rather than an individual doctor. Some families spoke about the reassurance they had when a GP told them that they were taking clinical responsibility for the care of a dying patient. In some cases they told us that GPs had provided a telephone number so that they could be reached out of hours in the event of an emergency. The Review panel saw this as an example of particularly good practice, and **recommends** that a named consultant or GP should respectively take overall responsibility for the care of patients who are dying in hospital or the community.

'We believed that the consultant was in charge of her care but are now left wondering how it happened that someone else in the hospital could override his expertise...it should be clear who has medical authority to make a decision regarding implementation of the LCP and a decision should always be approved by a patients consultant'

2.11 In the community in particular, the district nurse is likely to have a key role in coordinating care, in consultation with the GP and the palliative care team. In line with the recommendations in this review in relation to improving competence, and as long as a medical practitioner is available, the Review panel considers that the responsible clinician role in the future could be held by nurse with the right experience and competencies.

2.12 The responsible clinician is not only responsible for the care of the patient – he or she also bears some responsibility for that of their relatives and carers. The Review panel **recommends** that the name of a registered nurse responsible for leading the nursing care of the dying patient should be allocated at the beginning of each shift. This nurse will be responsible also for communicating effectively with the family, checking their understanding, and ensuring that any emerging concerns are addressed.

2.13 Being accountable also means being liable: the registration bodies for doctors and nurses should make it clear to their members that, if there is finding of serious professional misconduct in the treatment of patients at the end of life, the normal sanctions for professional misconduct apply.

'The hospital management had withdrawn the use of the soft sponge lollipops because a patient had bitten the end off one of them and that as a result, they were deemed to be a health and safety hazard. We were told that if we wanted to give her anything to drink then the only way would be for the family to soak a paper towel from the dispenser in the toilet and let her suck it.'

2.14 It is not only clinicians that are accountable and liable: organisations providing care for the dying need to take particular care to ensure that the right systems are in place to ensure they deliver consistently good care. The Review panel **recommends** that the boards of healthcare providers providing care for the dying give responsibility for this to one of its members – preferably a lay member whose focus will be on the dying patient, their relatives and carers – as a matter of urgency. This is particularly important for acute hospitals, where the Review panel has found most cause for concern.

'I cannot fail the compassion, caring, support and the general feeling that my mother's best interests were still at the heart of the staff despite what had happened to her and what was about to happen.'

'Catering staff asking quite loudly in the middle of the ward to other patients what food and drink they would like is completely inappropriate when my uncle was under the LCP.'

CARE WITH COMPASSION

2.15 Numerous relatives and carers told the Review panel that, once the decision was made to put the patient on the LCP, doctors and nurses stopped engaging with the dying person's clinical needs, almost as though these needs were no longer relevant. Some families were left to carry out as much as they could themselves, such as suction for secretions, washing and mouth care. Misguidedly, professionals may rationalise this as giving relatives or carers time to be with the patient, even if they feel reluctant to take on these aspects of nursing care. Giving the dying patient time with their relatives or carers is possible without ceasing clinical care of the dying patient.

2.16 Caring for the dying is an important part of any healthcare professional's role, and doing it well requires many skills as well as experience. High levels of technical competence, compassion and communication are required. Good care for the dying is as important as good care at any other time of life.

Caring with compassion for people at the end of their lives should be the aim of all doctors, nurses and healthcare staff. Exceptional standards of care are required to look after people who may have co-morbidities, be in pain and frightened, and their distressed and anxious families. Yet exceptional standards are all too often noticeable by their absence.

DOCUMENTING AN END OF LIFE CARE PLAN

2.17 Good documentation by clinicians is important, not only to ensure that those aspects of the end of life plan that do need consent or consultation under the MCA are properly authorised, but also because patients and their families are familiar with consent as a formal prerequisite of treatment, and where this does not happen, it may create the impression that the plan is something that is done to them, as opposed to being (as it sets out to be) something that happens in consultation with them. At the end of life, many patients and their families feel as though they have lost control over what is happening to them. Involving patients, their relatives or carers in discussions about the care plan is an important way of restoring a sense of control. Where a patient has no relatives or carers and so is unrepresented, the discussion about the care plan needs instead to involve a GP from their registered practice.

2.18 The Review panel **recommends** that guidance should specify that the senior clinician writes in the patient's notes a record of the face to face conversation in which the end of life care plan was first discussed with the patient's relatives or carers. The record of that conversation must include the following:

- That the clinician explained that the patient is now dying and when and how death might be expected to occur, using language which is clear, direct and unambiguous.
- If the family or carers do not accept that the patient is dying, the clinician has explained the basis for that judgement.
- That the relatives or carers had the opportunity to ask questions.

'Particular concerns have been raised regarding the use of the LCP in vulnerable groups such as those with dementia , the elderly and those with learning difficulties. In my opinion if they are dying then the LCP is absolutely the correct tool to use however it is in this group of patients I believe there may be a paternalistic failure to treat potentially reversible conditions, judgement nothing to do with LCP and indeed which breaches the criteria for its use.' (consultant)

2.19 During the course of the Review, relatives told the panel about difficulty in communicating with busy clinical staff in a hospital, saying that they would welcome a system that recorded their contribution, and in which they themselves could comment contemporaneously on the care received. The Review panel therefore **recommends** that a shared care folder, kept at the hospital bedside and designed for communication between patients, relatives and the staff, should be introduced, supported by training for staff on how to use it.

2.20 Although the Review received only a small proportion of evidence relating to community settings, it was nevertheless clear that a similar problem can prevail in the community. The Review panel therefore also **recommends** better integration in the community between LCP or other similar documentation and the existing system of shared care folders, so that the care provided by relatives and carers (professional or otherwise) is noted, and their contribution is incorporated into documentation.

CARE OF THE ELDERLY

2.21 During the course of this review, the Review panel was struck by the considerable body of evidence from relatives and carers which strongly suggests that care of dying older people is not always what it should be: the Review panel even suspects that age discrimination is occurring, though it is impossible to know for sure. This is unlawful: age is a 'protected characteristic' under the Equality Act 2010.

2.22 Old age should also not be taken as a proxy for lack of mental capacity. According to the Mental Capacity Act 2005 Code of Practice:[60]

- The starting assumption must always be that a person has the capacity to make a decision, unless it can be established that they lack capacity.
- A person's capacity must not be judged simply on the basis of their age, appearance, condition or an aspect of their behaviour.

2.23 While the Review did not receive a large body of evidence in relation to use of the LCP in care homes and nursing homes, clearly people living in nursing homes may be a vulnerable group.

60 http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/mca-code-practice-0509.pdf

However, GP cover for residents appears to be very variable, and this may be one of the reasons by residents all too often are admitted to hospital as an emergency, remaining there to die, when their wishes may well have been to remain in or return to their home to die.

'The staff are under enormous pressure, there just were not enough staff.'

'I spoke to the doctor on the ward on Monday morning as there were no consultants to speak to over the weekend and most of the doctors attending the elderly were FIs.'

'The weekend care at the hospital was appalling in comparison to the care provided during the week.'

2.24 Many of these elderly patients suffer from cognitive problems, including dementia, and are unable to express their wishes. Those who do not have close relatives and carers guarding their interests were by default unrepresented in the evidence submitted to the Review panel. The Review panel is very concerned about this, and **recommends** that each patient on an end of life care plan that has no means of expressing preferences and views on their care should be represented by an independent advocate, whether appointed under the Mental Capacity Act 2005, a chaplain, or an appropriate person provided through a voluntary organisation. This also applies to younger people who may lack capacity.

While some hospitals and areas are better than others, there is consistent evidence available that low levels of senior doctors continue to be linked to higher mortality rates at weekends. A lack of staff and services in hospital at weekends is bound to affect the quality of care available to patients, and this applies to care of the dying too.

AVAILABILITY OF STAFF AND EQUIPMENT

'It was left to us, as a family, to request the loan of a medical magnet from our local hospice. We had to make our own arrangements for collection of this device (by taxi – at our expense) and arrange for return of same after my husband's death'

2.25 The Review panel is not in a position to comment on individual examples of care and availability of staff. However, it is generally recognised that there are constant pressures on staff and that some find the workload unmanageable. This is unsurprising, given a recent study which shows that, while recommendations are that hospitals should run at 85% capacity, they are currently running at 90%.[61] This means that there are too many competing demands for staff attention and at times, when choices between care for someone with reversible clinical problems and care of the dying exist, care of the dying seems to take a lower priority.

61 http://download.drfosterintelligence.co.uk/Hospital_Guide_2012.pdf

'They advised that the doctor had been contacted earlier in the day but had not turned up... My father's own doctor turned up after 45 minutes... the district nurse visited approximate every THREE days.'

'The hospital's reason for delay was because it was a weekend they could not find a doctor to sign for a syringe driver.'

'However as it was by now the weekend we were informed that any equipment required at home could not be provided until the following Monday.'

'I felt so relieved when the palliative care nurse sat me down and explained what was really going on.'

2.26 Coupled with this is the rise in the number of people living longer. With comorbidities and their more intricate hospital needs, around a quarter of all hospital beds are used by those over the age of 85 who spend on average 11 days in hospital each time they are admitted.[62] Many of them will have cognitive problems. It appeared that the most of the respondents to the Review had relatives or friends dying from multiple conditions rather than cancer. The panel wondered whether this was because hospice care is easier to access for those suffering from cancer.

2.27 Patients and their relatives or carers complained that it was difficult to gain the attention of a nurse. At the drug rounds, they ask not to be disturbed and they are otherwise kept occupied at the nursing station – often completing documentation rather than delivering good nursing care to dying patients.

2.28 As the LCP document states,[63] it is crucial that the patient is seen by the 'right' staff with appropriate seniority, whether a GP or a specialist clinician. Palliative care is a speciality requiring considerable skill. That skill is apparent in hospice care, and the LCP, with the support of specific hospital-based specialists, was developed in order to transpose those skills and that care into the hospital setting.

2.29 Hospices and hospitals cannot be compared directly. In a hospice, there are invariably more doctors, nurses and volunteers available per patient. There is also a difference in philosophy and expectations. Communication is embedded and valued as the foundation of good care. Patients and families therefore have a greater understanding of what to expect from a hospice, because they have been spoken to explicitly as part of referral. The uncertainties of the dying process are generally clearly known, understood and communicated. Because specialist clinicians have this clear understanding, care is highly individualised, patients are closely monitored and the LCP is commonly used as it should be: as reminders and alerts with a single, common record. Removal from the 'pathway' is not a rarity. Around 10% of patients may appear briefly to be dying and then rally to have more time for a variety of reasons, most of which are social, emotional or spiritual.[64]

2.30 Most acute hospitals now have a palliative care team, whose role is usually only an advisory one; these arrangements have often been started with the help of a charitable organisation, such as Macmillan Cancer Support or Marie Curie Cancer Care. Typically, the team is small, as

62 The Kings Fund. Older people and Emergency Bed Use, August 2012 page 4

63 "...the Specialist Palliative Care Team are there for advice and support, especially if: Symptom control is difficult and/or there are difficult communication issues or you need advice or support regarding your care delivery supported by the LCP." "Patients on the LCP should be formally monitored at least daily"

64 Dein, S and George R, The time to die: Symbolic factors relating to the time of death, Mortality Vol6, No 2, 2001

they are usually funded by the hospital from existing budgets. There is currently no standardised tariff for palliative care, and it brings no specific income to an NHS Trust. Indeed, palliative care is seen as a cost pressure within the system, and so the Trust sees no obvious financial advantage in enlarging its palliative care team or investing in facilities to improve the care of the dying.

2.31 Many specialist clinicians say that palliative care services are seen and treated as an add-on luxury rather than integral to a comprehensive and necessary core of care provision. Hence, services overwhelmingly
are only advisory, supportive and not hands-on, only available during normal working hours Monday to Friday and at best supported by a palliative care specialist on call. Very few services are 24-hour, and a mere handful have any designated bed access. New referrals or face to face assessments may be difficult or impossible to get at weekends and at night in particular. Where there are specialist services, the bulk of the work and major decision-making must take place during the week and so cannot respond to sudden changes or altered needs. From the examples of good care the Review panel were given, it was clear that good communication and the effective management of symptoms was critical to clinicians' experience and needed substantial skills. These cannot be learned in lecture theatres or as e-learning modules – they are acquired working alongside competent practitioners.

2.32 The Review received numerous accounts about there being no access to the palliative care team outside office hours and at weekends. Relatives caring for patients at home have also reported being unable to contact palliative care advice out of hours and sometimes for days over holiday periods. They were therefore left caring for their relative with no advice for several days. As a result, appropriate care or changes in patient management that should have been instigated earlier had to wait until staff returned on duty.

2.33 As discussed in the previous chapter, there were also reports of junior doctors being asked to set up the LCP without reference to a palliative care team (or perhaps not realising that they could telephone a palliative care team member to discuss a difficult issue). In consequence, inexperienced doctors were often making difficult decisions about titrating opiate pain killers, anxiolytic sedatives or anti-secretory drugs, in isolation and without specific training, apparently sometimes getting it wrong. The Review panel regards this as very worrying.

2.34 The Review panel strongly endorses *Delivering Dignity*'s[65] recommendation that 'Hospitals, community care services and care homes should provide a seamless end-of-life care service to enable individuals and their families to exercise choices in their end-of-life care, including dying at home or in their care home. Hospital admissions should be avoided where possible, if that is not the wish of the individual.' A palliative care team which can act as a resource and a model of good practice within each hospital could do much to raise standards. But from some of the submissions, the Review panel heard that there was fragmentation in the different palliative care teams. In some places there are separate teams for the community, the hospital and in hospices. It is the Review panel's opinion that, with an aging population and a greater emphasis on caring for people in their own home, such fragmentation must not continue and that, wherever possible, palliative care teams should combine to form integrated palliative care services.

65 Delivering Dignity: Securing dignity in care for older people in hospitals and care homes, Commission on Dignity in Care, June 2012

2.35 There may be considerable advantages in hospitals designating particular wards or areas for palliative and end of life care, even if this entails devising new financial models to enable it. The Review panel welcomes such approaches for careful consideration by commissioners. Examples have been cited where this is working well, particularly when a strong partnership exists with the local hospice, providing a 'hospice within the hospital.' Different models are emerging with a range of staff from both hospices and hospitals being employed. These areas could have twofold benefit in not only improving end of life care but also in enabling hospital staff to gain additional expertise and experience in caring for the dying, having difficult conversations, and working with bereaved relatives. An adequately resourced specialist palliative care service, which can act as a model of good practice and hub for maintaining competencies within each hospital would do much to raise standards.

For most people, hospital is viewed as a place where you go to get better and the way that hospitals are funded seems to reflect this – with payment following the patient for each admission, operation, outpatient appointment or service delivered. Despite this focus on curing patients, about half of all deaths currently take place in hospital. This makes the dying a core duty of hospital trusts, irrespective of what might be aspirations or incentives to limit their work to other 'core business.'

2.36 Lack of funding may be the reason that patients report a lack of access to the hospital palliative care team in the weekends and evenings. Many patients told us that the service provided by the palliative care team was valued when they received it but that they would like more. Junior doctors told us that they would value more training and support from the palliative care team, together with assistance with dealing with complex issues such as initiating a syringe driver and titrating the doses of medication to achieve the correct therapeutic response.

'During one of my visits, my wife asked me to take her home. Whilst in the hospice she had been asked "if it came to it, where would you want to die?" She had replied...either in the hospice or at home and was asked to sign the relevant form... I promised her that the next day I would borrow a wheelchair to take her to the car and then home. However the following day when I asked for a wheelchair... I was told "you can't take her home. She is too ill."'

2.37 The Review panel strongly **recommends** that funding be made available to enable palliative care teams to be accessible at any time of the day or night, both in hospitals and in community settings, seven days a week.

2.38 The Review panel is concerned that, from some of the evidence received by the Review, little consideration appears to have been given to where the person might choose to die; this may account, at least in part, for the large number of hospital deaths despite evidence that most people would prefer to die at home.

2.39 Several submissions to the Review related how, though it was the patient's choice to die at home, once admitted they were prevented from being discharged home to die, particularly at weekends, because the system was unresponsive at night or any time other than from 9 to 5, Monday to Friday: the right staff were unavailable to effect

the discharge or to receive the patient back into the community. The right equipment was not available quickly enough in the community. Such instances suggest that rapid discharge 'pathways' for dying patients were not in place: rapid discharge arrangements must be put into place in all areas, not only some.

COMMUNICATIONS

Respectful treatment of the dying patient and her carers requires time to be taken over the difficult tasks of providing information, including the difficult task of delivering the news that the person is dying, understanding the person's needs and capacity to assimilate bad news and providing the opportunity to reflect on that information and to ask questions. This should be a non-negotiable aspect of best practice in end of life care.

'There was no prior consultation or discussion with the family about the seriousness of my uncle's condition and lack of further improvement before the meeting at which the consultant announced that there was no alternative but to place my uncle on the LCP.'

2.40 Giving patients, their relatives or carers information about what is going to happen to them is an aspect of treating them with respect and dignity. Effective communication with patients and families helps to inspire confidence and trust. Conversely, poor communication can lead to a loss of confidence and trust. Throughout the Review, the Review panel were made very aware of the depth of pain, anger, guilt and resentment felt by many respondents. While some of this is an inevitable part of bereavement, much can be attributed to lack of communication and consideration for the patient and carers during the final stages of life, and immediately afterwards.

2.41 Good communication is about the depth, and not the length, of an encounter. Time invested in an open, candid and comprehensive discussion with all concerned as soon as possible improves the whole tenor of care and is known to be critical in patients' sense of dignity.[66] With training and example, these skills can be learned and sensitive and important conversations can be concluded in minutes, rather than the hours that some clinicians suppose. Yet to see such time as wasteful is wrong – for the dying, this is as much a part of treatment as sophisticated procedures at other times in a person's life, and should be recognised and prioritised as such.

TRAINING

'I would welcome the availability of more training in terminal care for myself and my colleagues as well as a much more open public discussion.' (medical trainee)

2.42 Care of the dying requires not only substantial technical knowledge and clinical skill in assessing and adapting care to an individual's rapidly changing needs, but above all it needs excellent communication skills. These are an essential competence for doctors and nurses, and yet clinicians are sometimes particularly poor at dealing with discussions about a person's

66 Harvey Max Chochinov Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care BMJ 2007;335;184-187

impending death. Unless there has been good communication between staff and relatives or carers, unnecessary misunderstandings can arise. For example, cessation of routine observations; temperature, blood pressure and pulse may appear as though routine nursing care has stopped. To many relatives, an unexplained cessation of observations means there is a lack of care. From our evidence, it appears that some hospital doctors, no matter how senior, sometimes see communication as time-consuming and an optional extra, rather than at the heart of effective care. This is very disturbing. The Review panel felt that adequate training and continued support was the key to getting this aspect of care right.

'I don't remember the LCP being mentioned in any induction training, if it had it hadn't been enough to stay with me so firstly I'd like to say that more training should be offered to frontline staff so we know exactly was is required of us to follow the LCP and how it should be followed. LCP training, not mixed in with other basic induction but training in its own right because it's such an important issue.' (healthcare assistant)

2.43 Organisations such as acute hospitals that care for dying patients should be obliged to ensure that their new doctors and nurses are competent in caring for dying patients and in the care of the bereaved.[67] This should not only be part of their compulsory induction, but continue during their employment. Competence is established and maintained not just through training, but also through sustained modelling of good practice with local colleagues at the bedside. Commissioners of training, as well as services, should see the integrated role of providing a clinical service as inseparable from training and support. A hospital's specialist palliative care service should be commissioned with that in mind as a basic requirement. Other approaches for certain staff to establish skills may include placements in hospices, many of which run clinical attachments as part of their professional training programmes and are good examples of how to transfer palliative care skills to generalist clinicians caring for the dying.[68]

2.44 Medical training in palliative care is neither consistent nor adequate across the board. We heard from junior doctors that, whilst they may have had some training or exposure to palliative care at medical school, once qualified, they felt their training had not fully prepared them for the task of looking after dying patients. For example, we heard that, in one acute Trust, new doctors had an induction into the LCP that lasted only an hour. This involved no practical training and it was easy to miss. Nor was it compulsory.

2.45 If care of the dying forms part of a doctor's working practice, they should demonstrate proficiency in caring for the dying as part of each five-year cycle of revalidation. This should not simply be some token online training, but should form part of a CME-recognised course where, as well as a technical update, there should be a particular focus on developing and improving communication skills.

2.46 The Review panel believes that the principle of setting requirements to demonstrate proficiency in caring for the dying should also apply to nurses. It would support the release of nurses for training placements in the local or with specialist palliative care service, NHS or

67 'Competence' also includes being able to recognise their limitations
68 http://www.stchristophers.org.uk/tags/qelca

voluntary sectors, together with reciprocal arrangements where hospice or community palliative care nurses are seconded to hospital wards where they will be able to disseminate and demonstrate good practice around care of the dying, as well as updating their own skills.

2.47 The Review panel notes that in 2010 the NMC issued revised standards for pre-registration training for nurses,[69] and that these make specific reference to the care of people requiring end of life care. It is understood that the NMC will be keeping these standards under review. However, the Review panel has noted the absence of specific NMC guidance for nurses caring for patients at end of life or who are dying, although such guidance from the GMC exists for doctors. The RCN does provide some condition-specific guidance for nurses caring for patients with, for example dementia, at the ends of their lives, and it is understood that more generic guidance for end of life care is currently being developed.

2.48 The Review panel has also noted that the NMC Code[70] clearly states that nurses should 'make the care of people their first concern, treating them as individuals and respecting their dignity.' Furthermore, 'nurses must provide a high standard of practice and care at all times.' The Review panel is concerned at this lack of guidance for nurses caring for people at end of life, because this is an essential and integral part of nursing practice; it may explain, at least in part, why the Review panel has heard in this review so many examples of poor quality nursing of the dying. It therefore **recommends** that, as part of its work to review the Code in preparation for revalidation, the NMC provides such guidance as a matter of priority. This should encompass the good-practice guidance on decision-making recommended in paragraph 1.42.

2.49 To establish and maintain the necessary clinical competence will depend on the exposure that the practitioner will have to the dying. Relevant training should therefore continue throughout a clinician's career, and in particular areas of practice, to demonstrate continued competence it might be appropriate for it to form part of their continuing professional development and appraisal. This will need guidance in appropriate specialities from the NMC, GMC and the Medical Royal Colleges.

2.50 The Review panel was disappointed that the recently published Secretary of State for Health's mandate to Health Education England (HEE)[71] makes no mention of end of life care. One of HEE's objectives, however, is "to work through the LETBs[72] to lead a process of improved workforce planning to ensure sufficient staff are trained with the right skills in the right locations to enable healthcare providers to deliver their commissioning plans." The panel therefore **recommends** that HEE pay particular attention in this regard to the pressing need for more evidence based education and care in all settings that care for the dying.

69 http://standards.nmc-uk.org/Pages/Welcome.aspx
70 http://www.nmc-uk.org/Nurses-and-midwives/Standards-and-guidance1/The-code/The-code-in-full/
71 Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values, A mandate from the Government to Health Education England: April 2013 to March 2015, Department of Health, May 2013
72 Local Education and Training Board

CHAPTER 3

CONCLUSION

GUIDANCE FOR CARE FOR THE DYING

3.1 The Review panel recognises that, in the right hands, the Liverpool Care Pathway can provide a model of good practice for the last days or hours of life for many patients. The ambition to transpose hospice-like standards of care into the hospital setting is admirable: before the widespread introduction of the LCP into hospitals, the care that patients received was variable and there were many examples of poor care. But it is clear that, in the wrong hands, the LCP has been used as an excuse for poor quality care. The LCP's position is a fragile one while poor practice continues and considerable deficiencies in its use are not addressed.

3.2 Based on the evidence examined by the Review, much of which came from clinicians, the Review panel has concluded that the LCP is not being applied properly in all cases. Generic protocols, as the LCP has come to be seen, intended to be applicable for all patients in the last hours or days of their lives, in any setting, are the wrong approach. The Review panel strongly **recommends** the development of a series of guides and alerts that reflect the common principles of good palliative care, linking directly to the GMC's Guidance, and that of the NMC when it is developed. Implementation of this should be the personal responsibility of clinicians. The Review panel envisages that, in addition to the core driving palliative care philosophy that will be common to all guidance, there would be elements of technical guidance specific to certain disease groups, such as solid cancers, haematological cancers and other blood diseases, organ failure and cardio-respiratory diseases, neurological conditions, respiratory conditions, and for patients with dementia. An important requirement for these guidelines is that they be designed to be readily adapted for local use to meet the needs of individuals.

3.3 The Review panel strongly **recommends** that use of the Liverpool Care Pathway be replaced within the next six to 12 months by an end of life care plan for each patient, backed up by condition-specific good practice guidance.

A SYSTEM-WIDE APPROACH TO IMPROVING END OF LIFE CARE

'I find it incredible that, in my experience and in the 21st century, end of life isn't dealt with well in hospitals.'

3.4 But new guidelines cannot of themselves make the sea change that is urgently needed to raise the quality of care for the dying. A system-wide approach to professional practice and institution provision, measurable and monitored, is required to bring it about.

3.5 The Review panel strongly **recommends** a strategic approach to the problem. We need a coalition of regulatory and professional bodies, NHS England and patient groups, setting clear expectations for a high standard of care for dying patients – care that will also meet the important and sometimes neglected needs of their relatives and carers. Working together strategically, such a coalition could lead the way in creating and delivering the knowledge base, the education training and skills and the long term commitment needed to make high quality

care for dying patients a reality, not just an ambition. As a minimum, this would entail close co-operation between the GMC, NMC, the Royal Colleges, the CQC, NHS England and NICE.

3.6 Under this approach, the GMC and NMC would take the lead with the Royal Colleges, HEE and NHS England in:

- Providing any additional good practice guidance, building on the standards set out in the GMC guidance on treatment and care towards the end of life.[73]
- Reviewing whether current education and training standards adequately address care of the dying; setting requirements based on agreed levels of competence in the care of dying patients; and quality assuring the outcomes and effectiveness of teaching and learning.
- Setting relevant standards for continuing professional development, for all clinicians (generalist and specialists) who have a role in caring for dying patients and their families. And, where appropriate, encouraging or facilitating the development of relevant resources or programmes for continuing professional development.

3.7 Speaking as one voice, each organisation in such a coalition could use the platforms available to it to raise the profile of the issues identified in this report, and to advocate for the improvements in practice that can best be achieved through a unified effort of this kind.

3.8 As part of this coalition, the CQC would collaborate with patient groups in defining what good quality end of life care services should look like and then inspect against those standards. The Review panel welcomes the newly announced role of CQC Chief Inspector of Hospitals. and **recommends** that end of life care should be incorporated urgently into the new hospital inspection programme It also strongly **recommends** that the CQC should carry out a thematic review within the next 12 months of how dying patients are treated across the various settings, from acute hospitals to nursing and care homes, as well as hospice and the community.

3.9 The report has notably not focused on the commissioning of care for the dying. However, the Review panel now **recommends** that NHS England, using its full powers and mindful of its general duties, should work with clinical commissioning groups to address what are clearly considerable inconsistencies in the quality of care for the dying, to drive up quality by means of considerably better commissioning practices. Hospital provision in particular must from now on be commissioned and prioritised according to local need, to ensure that properly constituted multidisciplinary specialist services available for support around the clock as a hub of expertise, support and training.

3.10 Not surprisingly, this Review has uncovered issues strongly echoing those raised in the Mid Staffordshire Public Inquiry: notable among the many similar themes arising were a lack of openness and candour among clinical staff; a lack of compassion; a need for improved skills and competencies in caring for the dying; and a need to put the patient, their relatives and carers first, treating them with dignity and respect. The Review panel notes that, in responding to the Francis report on events at Mid-Staffordshire Hospital, the Government has set out a collective commitment and plan of action for the whole health and care system to put greater emphasis on caring and compassion and better training and support for staff to deliver this. Caring for the dying is an area where the values of caring and compassion are needed more than ever, as the evidence received by this Review showed.

73 GMC Guide for doctors. Treatment and care towards the end of life: good practice in decision making, July 2010 http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

3.11 The Review panel has noted that the current NHS Mandate makes end of life care one of a large number of priorities for NHS England. In view of the panel's serious concerns about the current state of care for the dying, it strongly **recommends** that the Government set improved quality of care for the dying as a priority for NHS England in the next Mandate. The panel welcomed the Secretary of State's announcement on 13 May 2013 that he will launch a plan for vulnerable older people in the autumn. Given the very strong links between the vulnerability of older people and the quality of care for the dying, the Review panel further **recommends** that the Vulnerable Older People's Plan announced by the Government should include a strand on care for the dying, and that NHS England's contribution to it be specified also as a priority in the NHS Mandate.

3.12 The Review panel has made the recommendations in this report in the context of considerable concern that many of the problems in the care of the dying highlighted are due to poor understanding among clinicians of existing guidance in care for the dying, and a shocking unwillingness to discuss with patients, their relatives and carers the prospect of death. No matter how much effort is put into training clinicians in good communication skills, unless everyone in society – members of the public, the press, clinicians, public figures – is prepared to talk openly and honestly about dying, death and bereavement, accepting these as a normal part of life, the quality of care and the range of services for the dying, their relatives and carers will remain inconsistent. The Review panel strongly supports the work of organisations that promote public awareness of dying, death and bereavement.

3.13 While the Government cannot itself change the way the nation thinks about death and dying, the professional bodies can play their part by taking a lead among their members. What the Government can do, however, is ensure its arm's length bodies collaborate with the clinical professional bodies and other key players in the system, and it can inject considerable funding into the system, to ensure that guidance on care for the dying is properly understood and acted upon, and tick-box exercises are confined to the waste paper basket for ever.

3.14 The Review panel feels so strongly about this that it is going to continue to meet at its own expense and volition, to monitor closely what happens next in response to its recommendations.

FURTHER INFORMATION ON THE REVIEW

The Review's terms of reference were as follows:

'The review will:

- examine systematically the experience of patients and families of the use of the Liverpool Care Pathway
- examine the experience and opinions of health professionals about the use of the Liverpool Care Pathway
- examine hospital complaints about end of life care and in particular those about the Liverpool Care Pathway
- review the literature about the Liverpool Care Pathway in practice;
- consider the role of financial incentives in this area
- make recommendations about what steps can be taken to:
- improve care
- ensure that patients are always treated with dignity and are involved in decisions about their care wherever possible
- ensure that carers and families are always properly involved in the decision-making process
- restore public confidence.

The review will report to Department of Health Ministers and the NHS Commissioning Board with its conclusions and recommendations by summer of 2013.'

PANEL MEMBERS

In addition to Baroness Julia Neuberger, Senior Rabbi at the West London Synagogue and former Chief Executive of the King's Fund (chair), panel members were:

- David Aaronovitch – columnist for The Times
- Tony Bonser – fund-raiser for Macmillan Cancer Support; North Western Champion for the Dying Matters Coalition
- Denise Charlesworth-Smith – national campaigner on the use of the LCP after her father's death in January 2012
- Dr Dennis Cox – Royal College of General Practitioners
- Lord Charles Guthrie – Chancellor of Liverpool Hope University; Chairman of both the Hospital of St John and St Elizabeth and St John's Hospice

- Lord Khalid Hameed – Chairman of the Alpha Hospital Group; Chairman & CEO of the London International Hospital
- Professor Lord Harries of Pentregarth – Former Bishop of Oxford
- Professor Emily Jackson – Professor of Law at the London School of Economics
- Sarah Waller CBE – Former trust chief nurse and director of human resources: currently lead for The King's Fund's Enhancing the Healing Environment Programme

EXPERT ADVISOR TO THE PANEL

The Review panel was extremely grateful for invaluable support and expert advice from Professor Rob George MA MD FRCP, Professor Palliative Care, Cicely Saunders Institute, Kings College London; Consultant in Palliative Care, Guy's & St Thomas' Hospitals NHS Foundation Trust

FURTHER CLINICAL ADVICE

The Review panel considered all of the many very informative submissions received from clinicians working in a wide range of settings. Members of the panel also consulted clinicians, to whom the Review is very grateful. Among these were:

- Professor John Ellershaw, Director, Marie Curie Palliative Care Institute Liverpool, University of Liverpool
- Deborah Murphy, Associate Director, Marie Curie Palliative Care Institute Liverpool, University of Liverpool
- Liverpool, University of Liverpool, UKProfessor Sam H Ahmedzai BSc MBChB FRCP(Lond) FRCPS(Glas) FRCP(Edin), Professor of Palliative Medicine, Head of Academic Unit of Supportive Care, Department of Oncology, School of Medicine and Biomedical Science, University of Sheffield
- Professor Irene J Higginson, BMBS BMedSci PhD FFPHM FRCP OBE, Professor of Palliative Care, Policy and Rehabilitation, King's College London and Scientific Director, Cicely Saunders International
- Professor Paddy Stone MA MD FRCP, Professor of palliative medicine, St George's University of London and honorary consultant, St George's Healthcare NHS Trust
- Dr Nigel Sykes MA FRCP FRCGP, Consultant in Palliative Medicine and Medical Director, St Christopher's Hospice

TABLE OF RECOMMENDATIONS

REC. NO.	THEME		PARAGRAPH
1	Terminology	NHS England should work speedily to issue clear definitions of time frames relating to end of life decision-making, and these definitions should be embedded firmly into the context of existing policies and programmes so that there is no room for doubt.	1.11
2		NHS England and the National Institute for Health and Care Excellence should review urgently the terms they are using to define clinical 'pathways', as opposed to protocols, standard operating procedures, guidelines, guidance, and best practice models.	1.19
3		The name 'Liverpool Care Pathway' should be abandoned, and within the area of end of life care, the term 'pathway' should be avoided. An 'end of life care plan' should be sufficient for both professionals and lay people.	1.21
4	Evidence base	The CQC and the Health Quality Improvement Partnership, should conduct fully independent assessments of the role of healthcare professionals in end of life care in England, focusing on the outcomes and experience of care, as reported by patients, their relatives and carers, as well as the quality of dying.	1.24
5		The National Institute for Health Research fund should fund research into the biology of dying.	1.25
6		The National Institute for Health Research fund should fund research into the experience of dying. Research priorities must extend also to systematic, qualitative and mixed methods research into communication in the patient and relative or carer experience.	1.26
7	Falsification of documentation	Clinicians should be reminded by their registration bodies that the deliberate falsification of any document or clinical record, in order to deflect future criticism of a failure of care, is contrary to GMC and NMC guidelines, and therefore a disciplinary matter.	1.30
8	Diagnosis of dying – prognostic tools	NHS England and Health Education England should collaborate to promote: the use of evidence-based prognostic tools, including awareness of their limitations; and Evidence-based education and competency based training, with regular refresher modules, for all professionals working with people approaching the end of their lives, both in the use of prognostic tools and in explanation to patients and relatives or carers of how they are used and the unavoidable uncertainties that accompany an individual's dying.	1.35

REC. NO.	THEME		PARAGRAPH
9		The National Institute for Health Research should fund research on improving, where possible, the accuracy of prognostic tools for the last weeks to days of life. This would cover, for example, the accuracy of prognostication where that is possible, suitably configured, mixed method trials of different forms of care during dying, specific interventions, such as hydration and nutrition, and symptom control measures.	1.36
11	Diagnosis of dying – communicating uncertainty	The National Institute for Health Research should as a matter of priority fund research into the development and evaluation of education and training methods and programmes addressing uncertainty and communication when caring for the dying.	1.36
10		The General Medical Council should review whether adequate education and training is currently provided at undergraduate and postgraduate levels to ensure competence. It should also consider how, given its recently increased responsibilities for specialist training and enhanced role in continuing professional development, it can ensure that practising doctors maintain and improve their knowledge and skills in these areas.	1.37
12	Guidance on diagnosis of dying	Clear guidance should be issued by the National Institute of Health and Care Excellence on: diagnosis and who should ultimately be responsible for diagnosing that someone is beginning to die the necessity for multidisciplinary decision-making the usefulness or otherwise of laboratory and other biological evidence the importance of case notes review for diagnosis how any uncertainty about whether a patient is in the active process of dying should be taken into account in the clinical management of the patient, in different healthcare settings.	1.38
13	Good practice guidance for nurses on decision-making	As a matter of urgency the Nursing and Midwifery Council should issue for nurses guidance on good practice in decision-making in end of life care, equivalent to that issued by the General Medical Council for doctors.	1.42

REC. NO.	THEME		PARAGRAPH
14	Decisions to initiate an end of life care plan out of hours	Every patient diagnosed as dying should have a clearly identified senior responsible clinician accountable for their care during any 'out of hours' period. Unless it is unavoidable, urgent, and is clearly in the patient's best interests, the decision to withdraw or not to start a life-prolonging treatment should be taken in the cool light of day by the senior responsible clinician in consultation with the healthcare team. The practice of making such decisions in the middle of the night, at weekends or on Bank Holidays, by staff that do not have the requisite training and competence, should cease forthwith.	1.43
15		The General Medical Council, the Health and Care Professions Council and the Nursing and Midwifery Council should ensure their professional standards clearly place the responsibility for such decisions on the senior responsible clinician, and they should take steps to emphasise how clinicians will be held to account against these standards. Furthermore, NHS England must ensure that appropriate systems are in place, with adequate levels of staffing to deliver these arrangements in practice. And CQC and Monitor should ensure their inspection regimes focus on this important aspect of the patient experience.	1.43
16	Training in shared decision-making	The Review panel is deeply concerned that the GMC guidance is clearly not always being followed in the care of the dying, and recommends that the Royal Colleges review the effectiveness of any training in shared decision-making that they provide, examining the extent to which it closely reflects the professional standards in GMC and NMC guidance and required competencies in this area, with a view to ensuring continued competence is maintained across the education and training spectrum from undergraduate teaching and learning through to continued professional development.	1.50
17	Nutrition and hydration	The General Medical Council should review its guidance on supporting oral nutrition and hydration to consider whether stronger emphasis could be given to this issue.	1.63
18		The Nursing and Midwifery Council should urgently produce guidance for nurses on supporting oral nutrition and hydration.	1.63
19		All staff in contact with patients should be trained in the appropriate use of hydration and nutrition at the end of life and how to discuss this with patients, their relatives and carers.	1.64
20		There should be duty on all staff to ensure that patients who are able to eat and drink should be supported to do so.	1.64
21		Failure to support oral hydration and nutrition when still possible and desired should be regarded as professional misconduct.	1.64

REC. NO.	THEME		PARAGRAPH
22		Specialist services, professional associations and the Royal Colleges should run and evaluate programmes of education, training and audit about how to discuss and decide with patients and relatives or carers how to manage hydration at the end of life.	1.64
23	Sedation and pain relief	Before a syringe driver is commenced, this must be discussed as far as possible with the patient, their relatives or carers, and the reasoning documented.	1.73
24		New research is needed on the use of drugs at end of life, and in particular on the extent to which sedative and analgesic drugs themselves contribute to reduced consciousness, and perceived reduction of appetite and thirst.	1.76
25	Financial incentives	Payments 'per patient implemented on the LCP, or equivalent approach' should cease.	1.91
26	Accountability	A named consultant or GP, respectively, should take overall responsibility for the care of patients who are dying in hospital or the community.	2.9
27		The name of a registered nurse responsible for leading the nursing care of the dying patient should be allocated at the beginning of each shift. This nurse will be responsible also for communicating effectively with the family, checking their understanding, and ensuring that any emerging concerns are addressed.	2.11
28		The boards of healthcare providers providing care for the dying should give responsibility for this to one of its members – preferably a lay member whose focus will be on the dying patient, their relatives and carers – as a matter of urgency. This is particularly important for acute hospitals.	2.13
29	Documenting an end of life care plan	Guidance should specify that the senior clinician writes in the patient's notes a record of the face to face conversation in which the end of life care plan was first discussed with the patient's relatives or carers. The record of that conversation must include the following: That the clinician explained that the patient is now dying and when and how death might be expected to occur. If the family or carers do not accept that the patient is dying, the clinician has explained the basis for that judgement. That the relatives or carers had the opportunity to ask questions.	2.17

REC. NO.	THEME		PARAGRAPH
30		A shared care folder, kept at the hospital bedside and designed for communication between patients, relatives and the staff, should be introduced, supported by training for staff on how to use it.	2.18
31		There should be better integration in the community between LCP or other similar documentation and the existing system of shared care folders, so that the care provided by relatives and carers (professional or otherwise) is noted, and their contribution is incorporated into documentation.	2.19
32	Independent advocacy	For each patient on an end of life care plan that has no means of expressing preferences and no representation by a relative or carer, views on their care should be represented by an independent advocate, whether appointed under the Mental Capacity Act 2005, a chaplain, or an appropriate person provided through a voluntary organisation. This applies to people of whatever age who lack capacity.	2.23
33	Availability of palliative care support	Funding should be made available to enable palliative care teams to be accessible at any time of the day or night, both in hospitals and in community settings, seven days a week.	2.36
34	Guidance for nurses in end of life care	As part of its work to review the Nursing and Midwifery Code in preparation for revalidation, and as a matter of priority the Nursing and Midwifery Council should provide guidance for nurses caring for people at end of life. This should encompass the good practice guidance on decision-making recommended in paragraph 1.42 (see recommendation 13).	2.47
35	Education in care for the dying	Health Education England should pay particular attention to the pressing need for more evidence based education in all settings that care for the dying in its work to improve workforce planning to ensure sufficient staff are trained with the right skills in the right locations to enable healthcare providers to deliver their commissioning plans.	2.49
36	Guidance	A series of guides and alerts should be developed that reflect the common principles of good palliative care and link directly to the General Medical Council's and Nursing and Midwifery Council's guidance (when the latter is developed). Implementation of this guidance should be the personal responsibility of clinicians.	3.2
37		In addition to the core driving palliative care philosophy common to all the guidance, there would be elements of technical guidance specific to certain disease groups. They should be designed to be readily adapted for local use to meet the needs of individuals.	3.2
38	End of life care plan	Use of the Liverpool Care Pathway should be replaced within the next six to 12 months by an end of life care plan for each patient, backed up by condition-specific good practice guidance.	3.3

REC. NO.	THEME		PARAGRAPH
39	A system-wide, strategic approach to improving care for the dying	The system needs a coalition of regulatory and professional bodies with NHS England, along with patient groups, setting clear expectations for a high standard of care for dying patients – care that will also meet the important and sometimes neglected needs of their relatives and carers. Working together strategically, such a coalition should lead the way in creating and delivering the knowledge base, the education training and skills and the long term commitment needed to make high quality care for dying patients a reality, not just an ambition. As a minimum, this would entail close co-operation between the GMC, NMC, the Royal Colleges, the CQC, NHS England and NICE. Under this approach, the GMC and NMC would take the lead with the Royal Colleges, Health Education England and NHS England in: Providing any additional good practice guidance, building on the standards set out in the GMC guidance on treatment and care towards the end of life Reviewing whether current education and training standards adequately address care of the dying; setting requirements based on agreed levels of competence in the care of dying patients; and quality assuring the outcomes and effectiveness of teaching and learning. Setting relevant standards for continuing professional development, for all clinicians (generalist and specialists) who have a role in caring for dying patients and their relatives or carers. And, where appropriate, encouraging or facilitating the development of relevant resources or programmes for continuing professional development. As part of this coalition, the CQC would collaborate with patient groups in defining what good quality end of life care services should look like and then inspect against those standards.	3.6
40	Hospital inspections	End of life care should be incorporated urgently into the hospital inspection programme of the newly announced Chief Inspector of Hospitals.	3.8
41	Thematic review of end of life care	The Care Quality Commission should carry out a thematic review within the next 12 months, of how dying patients are treated across the various settings, from acute hospitals to nursing and care homes, as well as hospice and the community.	3.8
42	Commissioning	Using its full powers and mindful of its general duties, NHS England should work with clinical commissioning groups to address what are clearly considerable inconsistencies in the quality of care for the dying, to drive up quality by means of considerably better commissioning practices than persist at present.	3.9

REC. NO.	THEME		PARAGRAPH
43	Mandate to NHS England	The Government should set improved quality of care for the dying as a priority for NHS England in the next Mandate.	3.11
44		Given the very strong links between the vulnerability of older people and the quality of care for the dying, the Vulnerable Older People's Plan should include a strand on care for the dying, and that NHS England's contribution to it should be specified also as a priority in the NHS Mandate.	3.11

GLOSSARY

Amber care bundle: an approach developed at Guys and St Thomas to improve the quality of care of patients who at risk of dying in the next one or two months but who may still be receiving active treatment.

Care Plan: for people with long-term conditions. It is an agreement between the patient and health professionals to help manage the patients' health day to day.

Clinician: a health professional, such as a doctor or a nurse who is involved in clinical practice.

CQC: Care Quality Commission

CQUIN: Commissioning for Quality and Innovation

DNACPR: Do Not Attempt Cardiopulmonary Resuscitation

End of life: patients are classed as reaching the end of life when they are likely to die within the next 12 months

GMC: General Medical Council

Gold standards Framework: a systematic, evidence based approach to optimising care for all patients approaching the end of life, delivered by frontline care providers.

HCPC: Health and Care Professions Council

HEE: Health Education England

HQIP: Health Quality Improvement Partnership

Integrated care plan: similar to a care plan but detail the clinical steps in the care of patients with a clinical condition

Intravenous infusion: fluids are given to the patient directly into a vein

LCP: Liverpool Care Pathway for the Dying Patient

LETB: Local Education and Training Board

MCPCIL: Marie Curie Palliative Care Institute Liverpool

MDT: Multidisciplinary Team. The MDT can be made up of a wide range of health professionals depending on the illness such as surgeons, radiologists, palliative care clinicians, clinical nurse specialists, language and speech therapists, or your GP.

Mental Capacity: the ability to make personal decisions. The Mental Capacity Act 2005 provides for people whose brain, for whatever reason (such as an illness or an accident) cannot make decisions for themselves.

NHS IQ: National Health Service Improving Quality

NIHR: National Institute for Health Research

NMC: Nursing and Midwifery Council

Palliative Care: focuses on the relief of pain and other symptoms and problems experienced in serious illness. The goal of palliative care is to improve quality of life, by increasing comfort, promoting dignity and providing a support system to the person who is ill and those close to them.

Pathway: a management tool for health professionals for specific patients with a predictable clinical course where the different interventions are defined, optimised and sequenced.

Protocol: a document to guide decisions and criteria regarding diagnosis, management and treatment of a condition.

Royal Colleges: institutions, such as the Royal College of Nursing and the Royal College of Physicians.

Subcutaneous infusion: fluids are given to the patient under the skin.

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