CORE TEXT


The LCP is a multi-professional document that incorporates evidence-based practice and appropriate guidance and support related to Care of the Dying. It provides a template which describes the process of care which is generally delivered in a clinical situation and incorporates the expected outcome of care delivery. The LCP replaces all other documentation in this phase of care. Care pathways can provide a potentially powerful aide to professionals involved in palliative care. In this book, basic principles of treatment are translated into daily practice, including bedside documentation systems, policies and procedures, standards of practice, continuing education, and quality improvement programmes. It also includes chapters on symptom control, ethical issues, communication skills, and spiritual care, written by experts in the field which underpin the use of the LCP.

OTHER REFERENCES


A literature review was undertaken to determine whether there is sufficient evidence that the LCP represents best practice in end of life care and whether patients cared for using the LCP receive better end of life care. Eight research articles were selected for inclusion in the review. The key themes of symptom management, communication and documentation were identified, and the research surrounding these themes was analysed. The analysis showed that use of the LCP promotes better care for patients in the terminal stage of illness; however, some weaknesses in the research were identified and recommendations have been made for further research and future practice.


Integrated care pathways are structured multidisciplinary care plans which detail essential steps in the care of patients with a specific clinical problem. They have been proposed as a way of encouraging the translation of national guidelines into local protocols and their subsequent application to clinical practice. They are also a means of improving systematic collection and abstraction of clinical data for audit and of promoting change in practice. The degree to which they succeed in realising this potential for improving patient care is still uncertain, but enough evidence exists in their favour to justify more widespread evaluation of
their impact. This paper describes integrated care pathways, shows how to create and use them, and reviews the evidence of their effectiveness.


An updated guide designed to help providers of health and adult social care to comply with the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 and the Care Quality Commission (Registration) Regulations 2009. It has two main parts. Part 1: Preparing to use the guidance which explains why the guide was produced, who it is for and how the guidance in part 2 is structured, including service prompts and definitions of key terms. Part 2: Details 28 Guidance Outcomes covering: Involvement and information; Personalised care, treatment and support; Safeguarding and safety; Suitability of staffing; Quality and management; Suitability of management.


Care in the last hours and days of life is an important part of medical practice. Ensuring a dignified death for patients with appropriate support for carers is a core activity of all healthcare professionals. Once a patient has entered the dying phase it is important that pain and other symptoms are managed appropriately. All medication that needs to be continued should be converted to the subcutaneous route when administration via the oral route is no longer possible. As required medication should be prescribed for the key symptoms that occur in dying patients, such as pain, agitation, respiratory tract secretions, dyspnoea, and nausea and vomiting. Futile treatments should also be discontinued at this time and consideration should be given to the discontinuation of antibiotics and blood tests. Normally a decision for a ‘Do Not Attempt Cardiopulmonary Resuscitation’ order is made at this time. Appropriate communication both with the patient and their family is key, both to ensure that the psychological and spiritual needs of the patient are met and that the family is aware that the patient is dying. Decision making and practice for care of the dying can be supported by use of the Liverpool Care Pathway for the Dying Patient (LCP).


This is the authors’ response to a previous article in which key issues in providing symptom control for dying critical care patients were highlighted and a small number of patient cases were discussed. Said patients were given large doses of opioids and benzodiazepines with the express purpose of shortening the dying process. This correlated with a quicker death for these patients. The Authors suggest that these findings underline first the lack of confidence felt by some intensive care unit (ICU) clinicians in managing patients in the dying phase, leading to deliberate steps being taken to hasten death, and second, the mistaken belief held by some that the administration of appropriate doses of medications for symptom control will shorten the dying process. A third implication of this study is that a cohort of patients may be receiving inadequate symptom control so as not to risk hastening death. A need for clear guidelines and protocols to provide direction, and support for ICU clinicians in end-of-life care
was reiterated. Further, the Liverpool Care Pathway ICU Model Pathway was proposed to provide a template of care to aide clarity, increase clinicians’ confidence and facilitate patient care assurances.


This study aimed to determine staff perceptions of the impact of the Liverpool Care Pathway for the dying patient (LCP) in three aged residential care facilities in New Zealand. A mixed methodology approach was adopted, including the use of a survey, focus groups, and individual interviews. Fifteen of 194 staff participated in the focus groups (five nurses and nine health-care assistants). The interviewees included three GPs, one registered nurse, and one manager. The post-implementation survey response rate of 13% was poorer than the 32% response rate to a pre-implementation survey reported elsewhere. Nevertheless, there was congruence across the data sources. The participating staff perceived multiple benefits to residents, family, whānau, and staff following implementation of the LCP. As a tool the LCP was therefore considered effective in supporting, guiding, and prompting care delivery. However, challenges remained, particularly regarding environmental factors.


Ensuring appropriate palliative and end-of-life (EOL) care in the acute environment is complex and challenging. The Liverpool Care Pathway (LCP) aims to support staff to provide holistic EOL care utilizing a structured framework to prompt and guide care. We report on the post-implementation findings of a mixed methodology (survey and focus group [FG] forums) study into staff perceptions of EOL care following the pilot implementation of the LCP into two acute wards. Study results suggest that within acute settings staff perceive that the LCP improves EOL care overall, assists interdisciplinary communication around death and dying, and that is a useful tool to positively influence decision making and care delivery. Further research into aspects of staff communication, diagnosing dying, changing direction of care, and the physical environment is warranted.


Care in the terminal phase is an important part of medical practice. Ensuring a dignified death for patients with appropriate support for carers is a core activity of all healthcare professionals. Once a patient has entered the dying phase it is important that pain and symptom control is managed appropriately. All medication that needs to be continued should be converted to the subcutaneous route. As required medication should be prescribed for the key symptoms that occur in dying patients, i.e. pain, agitation, respiratory tract secretions, dyspnoea, and nausea and vomiting. Futile treatments should also be discontinued at this time and consideration should be given to the discontinuation of antibiotics and blood tests. Normally a decision for a ‘Do Not Resuscitate’ order is made at this time. Appropriate communication both with the patient and their family is key, both to ensure that the psychological and spiritual needs of the patient are met and that the family is aware that the patient is dying. Decision-making and practice for care of the dying can be supported by use of the Liverpool Care Pathway for the Dying Patient.
This book highlights the predicted changing global health profiles and a currently inadequate hospital-based palliative care service followed by a proposed improvement plan. Subsequent chapters incorporate discussion on: The Liverpool Care Pathway for the Dying Patient (LCP); Patients at the end of life; The reshaping of interventions and therapies; The reorganization of nursing interventions at the end of life; The subcutaneous therapy; The relationship and communication with the patient at the end of life; The relationship and communication with the family.


Most cancer patients still die in hospital, mainly in medical wards. Many studies in different countries have shown the poor quality of end-of-life care delivery in hospitals. The Program "Liverpool Care Pathway for the dying patient" (LCP), developed in the UK to transfer the hospice model of care into hospitals and other care settings, is a complex intervention to improve the quality of end-of-life care. The results from qualitative and quantitative studies suggest that the LCP Program can significantly improve the quality of end-of-life care delivery in hospitals, but no randomised trial has been conducted till now. This is a randomized cluster trial, stratified by regions and matched for assessment period. Pairs of eligible medical wards from different hospitals will be randomized to receive the LCP-I Program or no intervention until the end of the trial. The LCP-I Program will be implemented by a Palliative Care Unit. The assessment of the end-points will be performed for all cancer deaths occurred in the six months after the end of the LCP-I implementation in the experimental wards and, in the same period of time, in the matched control wards. The primary end-point is the overall quality of end-of-life care provided on the ward to dying cancer patients and their families, assessed using the Global Scale of the Italian version of the Toolkit "After-death Bereaved Family Member Interview". This study can be interpreted as a Phase III trial according to the Medical Research Council Framework. In this study, the effectiveness of a fully defined intervention is assessed by comparing the distribution of the endpoints in the experimental and in the control arm.

Cull A, Sprangers M, Bjordal K, Aaronson N, on behalf of the EORTC Quality of Life Study Group ‘EORTC Quality of Life Study Group Translation Procedure’ July 1998 EORTC, Brussels

The aim of the EORTC QL Group is to secure good quality translations of its instruments. The QLQ-C30 is now available in 43 languages and several disease-specific modules already exist in multiple translations. Where an approved translation already exists this should normally be adopted. However, existing translations may on occasion require revision or refinement for subsequent use e.g. to produce gender-specific translations. Translations may be needed for use in countries where a variant of the parent language is spoken e.g. Spanish as spoken in Argentina or Mexico Vs Castilian Spanish. The original translation guidelines (Cull et al, 1994) have therefore been updated in the light of experience to introduce greater flexibility for dealing with such varying requirements efficiently while maintaining the quality controls.
required for EORTC approved translations. The aim of this procedure is to produce translations of questionnaires which are: 1) Clear i.e. able to be read and understood; 2) Expressed in language in common use; 3) Conceptually equivalent to the original. It is not the purpose of the translation procedure to modify the original questionnaire.


Six Thinking Hats® is a simple, effective parallel thinking process that helps people be more productive, focused, and mindfully involved. The object is to learn how to separate thinking into six clear functions and roles. Each thinking role is identified with a coloured symbolic “thinking hat.” By mentally wearing and switching “hats,” you can easily switch focus or redirect thoughts and or interactions. The White Hat calls for information known or needed. The Yellow Hat symbolizes brightness and optimism. Under this hat you explore the positives and probe for value and benefit. The Black Hat is judgment - the devil’s advocate or why something may not work. The Red Hat signifies feelings, hunches and intuition. When using this hat you can express emotions and feelings and share fears, likes, dislikes, loves, and hates. The Green Hat focuses on creativity, possibilities, alternatives, and new ideas. The Blue Hat is used to manage the thinking process. It’s the control mechanism that ensures the Six Thinking Hats® guidelines are observed.


This book presents the theory of management called the system of Profound Knowledge that consists of four parts: appreciation for a system, knowledge about variation, theory of knowledge, and psychology. Deming describes how a management style based on cooperation rather than competition can help people develop joy in work and learning while also achieving market growth. He explores reasons to get rid of job performance reviews and grades in school.

Department of Health Quality Accounts

In High Quality Care for All, published in June 2008, three domains of quality care were identified: safety, effectiveness of care and patient experience. High Quality Care for All committed the Department of Health and the NHS to developing a Quality Framework to support clinical teams to improve the quality of care locally, a key part of which was publishing quality information. Quality Accounts are therefore one key component of this framework. Quality Accounts are annual reports to the public from providers of NHS healthcare services regarding the quality of services they provide. The public, patients and others with an interest in healthcare, would look to a Quality Account to understand what an organisation is doing well; where improvements in service quality are required; what the priorities for improvement are for the coming year; and how involved users of services, staff, and others with an interest in the organisation, are in determining these priorities for
improvement. Quality Accounts aim to enhance public accountability and engage the leaders of an organisation in their quality improvement agenda.


This paper outlines the Department of Health’s proposed methodology for identifying potential outliers in the national Patient Reported Outcome Measures (PROMs) programme which are based upon guidance prepared by the National Clinical Audit Advisory Group (NCAAG). One of the stated aims of the PROMs programme is to support evaluations by clinicians, managers, regulators, commissioners and patients of the relative clinical quality and performance of providers of relevant elective procedures. To date, there has been no single agreed methodology for identifying organisations that are performing relatively better or worse than others using PROMs data. While the PROMs programme is not a formal clinical audit as envisaged in the guidance document – data are published continuously on a monthly basis for continuous monitoring – there are common features. Specifically, the intention to produce comparisons of providers using batches of data for defined periods remains the same in both cases. This paper sets out the main elements of our outlier policy for PROMs. A draft policy document and example report on potential outliers, based on the PROMs data series for April 2009 to December 2010 (published in May 2011), are included.


In 2005, more than 140,000 people shared their thoughts, ideas and concerns with the Department of Health, through questionnaires and surveys, interviews and listening events. This information helped to build up a picture of how people feel about health and social care services – good and bad. The newly published White Paper ‘Our health, our care, our say: a new direction for community services’ explains in detail the improvements the Government is going to make, why it feels these changes are necessary and the steps it’s taking to make sure they happen, backed up by research figures and statistics. The points that scored most highly in the listening included: helping people to take better care of their health and providing more support for carers.


The End of Life Care Strategy was developed over a period of a year by an advisory board and six working groups and over 300 stakeholders were consulted. From this process a consistent message has emerged that a whole systems approach is needed. Within this, a care pathway approach both for commissioning services and for delivery of integrated care for individuals has been strongly recommended. The strategy sets out key areas, with the related actions and recommendations, being: Raising the profile; Strategic commissioning; Identifying people approaching the end of life; Care planning; Coordination of care; Rapid access to care; Delivery of high quality services in all locations; Last days of life and care after death;
Involving and supporting carers; Education and training and continuing professional development; Measurement and research; Funding.


The Department of Health published its End of Life Care Strategy in July 2008. During its development, the SHA End of Life Care Pathway Chairs identified that commissioners and providers needed support in delivering improvements in care. The resultant Quality Markers are intended to meet this need. The End of Life Care Strategy and these Quality Markers operate within the usual devolved NHS system. This means that they are not mandatory. Individual organisations will need to decide which of the Quality Markers they wish to adopt, depending on their local needs and circumstances. Top ten Quality Markers for providers:

1. Have an action plan for the delivery of high quality end of life care, which encompasses patients with all diagnoses, and is reviewed for impact and progress.
2. Institute effective mechanisms to identify those who are approaching the end of life.
3. Ensure that people approaching the end of life are offered a care plan.
4. Ensure that individuals’ preferences and choices, when they wish to express them, are documented and communicated to appropriate professionals.
5. Ensure that the needs of carers are appropriately assessed and recorded through a carer’s assessment.
6. Have mechanisms in place to ensure that care for individuals is co-ordinated across organisational boundaries.
7. Have essential services available and accessible 24/7 to all those approaching the end of life that need them.
8. Be aware of end of life care training opportunities and enable relevant workers to access or attend appropriate programmes dependent on their needs.
9. Adopt a standardised approach (the Liverpool Care Pathway or equivalent) to care for people in the last days of life.
10. Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.


The original Essence of Care benchmarks were created 10 years ago, with the first launch in February 2001. They are a tool to help healthcare practitioners take a patient-focused and structured approach to sharing and comparing practice. The updated Essence of Care 2010 supports and reflects a number of the themes in Equality and Excellence: Liberating the NHS and provides a suite of benchmarks to drive forward best practice in delivering the fundamentals of care and improving the experiences of people who use services. Essence of Care 2010 was developed in partnership with people and carers and as such reflects the views of their health and social care needs and preferences. The 12 sets of benchmarks are: Bladder, Bowel and Continence Care; Care Environment; Communication; Food and Drink; Prevention and Management of Pain; Personal Hygiene; Prevention and Management of Pressure Ulcers; Promoting Health and Well-being; Record Keeping; Respect and Dignity; Safety; Self Care.

This study is aimed at exploring the expectations about and the impact on healthcare staff of the Liverpool Care Pathway for the dying patient (LCP) in an Italian hospital. Qualitative information was derived from four focus group (FG) meetings that were carried out separately by profession and scheduled before the beginning and after the end of the implementation process of the Italian version of LCP for hospitals (LCP-I). Interview topics concerned end-of-life care related problems and expectations about the impact of the LCP-I programme. Tape recordings of the FGs were transcribed verbatim, and transcripts analysed independently by two research psychologists using thematic analysis. Five major topics were identified: managing pain and discontinuing inappropriate treatments, communicating with patients, communicating with relatives, communicating between professionals and practical issues. As compared with those reported in the initial FGs, responses from the final FGs highlighted that physicians felt more confident with pain management and with discontinuing inappropriate treatment, and were more inclined to recognize the value of the nurses' work. Nurses underlined advantages in using pro re nata medication, but stressed lack of personnel and time as obstacles in consistent improvement of end-of-life care. All participants seemed to acquire greater awareness of their difficulties in communication and, paradoxically, became more uncertain of their ability to liaise with dying patients and their families. LCP-I implementation may improve both knowledge about physical symptom management and professional awareness of the problems related to emotional and informative support in end-of-life care.


The delivery of two, three, four, or even five drugs in the same syringe is now considered routine practice. A continuous subcutaneous infusion is an effective method of drug administration that is particularly suited to palliative care, where other routes are inappropriate. Palliative care patients frequently have multiple symptoms that require the use of numerous drugs; as the patient's condition deteriorates, the oral route is often no longer suitable and the syringe driver ensures continued symptom control. This route increases patient comfort as it avoids the need for repeated injections, plasma concentration levels of drugs remain constant, and it maintains the patient's sense of independence. There have been several developments in this field since the first edition of this book published, including new devices and drugs. There is also a wealth of stability date provided, covering an extensive list of drug combinations. The book consists of four sections. The first provides an overview of syringe drivers and continuous subcutaneous infusions, including detailed set up information. The second section provides referenced information about drugs that are likely to be encountered, including certain drugs that should only be used by, or on the recommendation of, palliative care specialists. Section three provides information about symptom control in the last few days of life, concentrating specifically on the use of the syringe driver. Finally, the compatibility tables can be found in Section Four. 'The syringe driver' has proved to be an essential source of information for doctors, nurses, and pharmacists who work in palliative medicine.

Improvement in end-of-life-care is required for patients dying with chronic kidney disease (CKD). The UK government now recommends that tools such as the Liverpool Care Pathway for the Dying Patient (LCP) be used to enhance the care of those patients dying with CKD. The LCP was originally developed for patients dying with terminal cancer, however has been shown to be transferable to patients dying with heart failure or stroke. On this background, in 2005 a UK National Renal LCP Steering Group was formed. The aim was to determine whether or not the generic LCP was transferable to patients dying with CKD. An Expert Consensus subgroup was established to produce evidence-based prescribing guidelines to allow safe and effective symptom control for patients dying with renal failure. These guidelines were finalised by the Expert Consensus group in August 2007 and endorsed by the Department of Health in March 2008. A literature search on symptom control and end-of-life care in renal failure was performed. A summary of the evidence was presented at a National Steering Group meeting. Opinions were given and provisional guidelines discussed. A first draft was produced and individually reviewed by all members of the Expert Group. Following review, amendments were made and a second draft written. This was presented to the entire National Steering Group and again individual comments were taken into consideration. A third and fourth draft were written and individually reviewed, before the guidelines were finalised by the Expert Consensus group. Patients dying with advanced CKD suffer symptoms similar to patients dying of cancer. The Renal LCP prescribing guidelines aim to control the same symptoms as the generic LCP: pain, dyspnoea, terminal restlessness and agitation, nausea and respiratory tract secretions. The evidence for the production of the guidelines is discussed and how a consensus was reached. A summary of the guidelines is given and the complete guidelines document is available via the Marie Curie Palliative Care Institute, Liverpool website.


The introduction of fentanyl transdermal patches has led to concern and confusion regarding the management of pain control in the dying phase. Data were collected retrospectively from 94 dying patients. Two groups were identified—patients treated with fentanyl transdermal patch who remained on the patch in the dying phase and patients on oral morphine who converted to a 24-hour subcutaneous infusion of diamorphine via a syringe driver in the dying phase. Both the fentanyl group and the diamorphine group had good pain control in the last 48 hours of life. During the last 48 hours of life, the proportion of patients with controlled pain was statistically significant in favour of the fentanyl group in 2 of the 12 observations undertaken, in particular whether the fentanyl transdermal patch should be continued or discontinued. Patients in the fentanyl group received fewer ‘as required’ opioid doses compared to patients in the diamorphine group, although the difference was statistically significant only for the last day of life. This study showed that pain control was not compromised in the dying phase with continued use of the fentanyl patch.

One of the greatest challenges facing the palliative care world, and the aim of the LCP, is to transfer the model that has been developed in the hospice sector into the mainstream NHS and throughout healthcare. The national health agenda has drawn attention to and highlighted the need for improvement in the care of the dying. The NHS End of Life Care Programme has been established to promote the spread of the three frameworks of LCP, Gold Standard Framework and Preferred Place of Care into the cancer and non-cancer populations (NHS Modernisation Agency, 2004). In January 2005, the National Council for Palliative Care launched its Palliative Care Manifesto (National Council for Palliative Care, 2005) with four key pledges. The third pledge is ‘to introduce monitoring of care of the dying as a key element of performance management for NHS organizations at board level’. This challenge to monitor care of the dying throughout NHS organizations is indeed an opportunity to promote palliative care. The LCP, with its recorded outcomes of care, is a potential way to achieve this. Although the LCP has come some way in meeting the demands to improve care of the dying, it also challenges us to continually develop our education and research programmes to further improve the care of dying within our society.


The hospice model of care of the dying patient is regarded as a model of excellence; however, outcomes of this care have been poorly demonstrated. Integrated Care Pathways (ICPs) provide a method of recording and measuring outcomes of care. The ICP document replaces all previous documentation and is a multi-professional record of patient care. The aim of this study was to implement an ICP in an inpatient hospice setting in order to set standards of care for symptom control in the dying phase of a patient’s life. ICPs were analyzed from 168 inpatients who died over a one-year period. Symptoms of pain, agitation, and respiratory tract secretions (RTS) were monitored every four hours by nursing staff as either present or absent. For each symptom, 80% of patients had one episode or complete control of the symptom, 10% had two episodes, and 10% had three episodes or more recorded. As death neared, there was a statistically significant increase in the number of patients whose pain was controlled. The ICP has provided a means to measure symptom control in the dying patient and set standards of care, which is integrated into clinical practice.


**PALLIATIVE CARE DEVELOPED** in response to increasing concern about the standard of care for dying patients and their families. There were several widely publicized cases where patients died without dignity and with poorly controlled symptoms. These cases also revealed inadequate support for families and a disregard for the spiritual element of care. Health care professionals trained in a culture of “cure,” seemed unable to respond to the needs of the dying patient and their families. Dissatisfaction with this situation provided the impetus for the pioneers in palliative care, to demand a fundamental change in attitude toward the care of dying patients and their family/careers. It is imperative that as a palliative care movement we capture this model of excellence in care of the dying and hold it as a beacon to be clearly seen and understood. It can then be translated to other care settings and delivered by other health care professionals. Palliative care services include inpatient and outpatient care, day
therapy, bereavement care, and a specialist advisory role in both community and hospital settings. This clinical activity is supported by education and research activity. Palliative care services may offer all of these elements, but more commonly focus on specific areas. There is an increasing emphasis on rehabilitation and a current trend toward including non-cancer patients. These new developments may give the appearance of a reduced emphasis on the care of the dying. Specialists in palliative care may assume that this aspect of care is well recognized and so are keen to emphasize other aspects of care. This attitude may be complacent. The model of excellence for care of the dying developed throughout the palliative care world has been under-researched and poorly disseminated outside the palliative care unit/hospice setting. Innovations features the development of two palliative care services, those offered by the Beth Israel Medical Center in New York City and the Trondheim University Hospital in Norway. Drs. Portenoy and Kaasa share their respective experiences, which include the challenges of evolving new services. The interview with Dr. Bookbinder on the Palliative Care for Advanced Disease (PCAD) pathway, provides an important example of how best practice for care of the dying can be delivered in all health care settings by empowering healthcare professionals to deliver high quality care to dying patients.

Ellershaw JE, Ward C (2003) Care of the dying patient: the last hours or days of life. BMJ, 326: 30-34

Too many patients die an undignified death with uncontrolled symptoms. Transfer of best practice from a hospice setting to other care settings, including for non-cancer patients, is a major challenge. Diagnosing dying is an important clinical skill. One of the key aims of specialist palliative care is to empower generic healthcare workers to care for dying patients. Core education objectives related to the care of dying patients should be incorporated into the training of all relevant healthcare professionals. Resources should be made available to enable patients to die with dignity in a setting of their choice. National indicators for care of the dying patient should be identified and monitored.


This book focuses on the frameworks for delivering palliative care, including the LCP, and the role and relationships within them. It also comprehensively covers stress, communication and ethical issues. This practical guide with numerous examples, illustrations and references, includes boxes, tables, figures, self-assessment questions, points for reflection and case studies to aid comprehension. The intended audience includes all those working in community care, including nurses, nursing students, doctors and social workers, and those already involved to some extent in palliative care.


The main aim of this editorial is to revisit the history of care of the dying to illustrate its fluctuating priority within health care systems and to discuss the ethical, moral and practical issues inherent both in the delivery and in the measurement of high-quality care. Above all it aims to reinforce the fundamental societal importance in ensuring optimum care for dying patients and their relatives and emphasises the notion that the delivery of such care is the responsibility of all health care professionals. Direct experience of poor care of the dying and its lack of importance within health care systems, was central to the creation and philosophy of the development of palliative care by the pioneers of the hospice movement. This early vision to create an environment of care where patients could die a dignified death with
support from their carers was one that embraced multi-professional working and recognition that ‘journeying with’ is sometimes as appropriate as ‘problem solving’.


Even for the most experienced healthcare professional, managing the last few days of life can be difficult. This book provides guidelines for the care of the dying based on the Liverpool Integrated Care Pathway for the Dying Patient (LCP). Developed at a hospice, the information can be disseminated and adapted to fit different settings such as hospitals and nursing homes. The LCP is a multi-professional document that incorporates evidence-based practice and appropriate guidelines related to care of the dying. It provides a template that describes the process of care, which is generally delivered in a clinical situation and incorporates the expected outcome of care delivery. The LCP replaces all other documentation in this phase of care. Care pathways can provide a potentially powerful aid to professionals involved in palliative care. Basic principles of treatment are translated into daily practice, including bedside documentation systems, policies and procedures, standards of practice, continuing education, and quality improvement programmes. The book also includes chapters on symptom control, ethical issues, communication skills, and spiritual care.


The objective of this study was to evaluate the utility of participating in two benchmarking exercises to assess the care delivered to patients in the dying phase using the Liverpool Care Pathway for the Dying Patient (LCP). The study uses questionnaire evaluation of the benchmarking process assessing the quality/usefulness of: sector feedback reports, individual feedback reports and the workshop element. Healthcare professionals represented hospital, hospice and community settings. Sixty-two out of 75 potential participants (83%) returned completed questionnaires. A study-specific questionnaire was administered as part of the final workshop element of the benchmarking exercise. The questionnaire contained a mixture of ‘Likert’-type responses and open-ended questions. Participants from all sectors reported that the feedback reports contained the right amount and level of data (82–100%), that they were easy to understand (77–92%) and that they were useful to the organisation (94–100%). Respondents particularly valued the opportunity to discuss more fully the results of the benchmark and to network and share elements of good practice with other attendees in the workshops. Participants from the hospital sector identified changes in practice that had occurred as a result of participation. Using comparative audit data that are readily available from the LCP and using workshops to discuss the findings and plan future care was perceived as a valuable way in which to explore the care delivered to dying patients in a variety of settings.


A good death for all is now recognised as a priority at societal and political levels. To achieve this goal we need a fundamental shift of emphasis: to train and educate healthcare professionals, to ensure rigorous assessment of new end of life care services that aim to improve quality and choice, and to explore best use of resources. In view of the changing demographics of death, the changing pattern of dying, and the policy and financial imperatives, many new service configurations are likely to be tried. To deepen our
understanding of what works and why, we will need to hone our measurements of effect and support further research and evaluation. However, an even more radical shift may be necessary. Given a future of fewer carers, fewer resources, and a dramatic increase in chronic disease and comorbidities, we may need to consider whether communities, rather than health services, need to take on more of the burden of care at the end of life. In the meantime, we must strive to ensure that a good death is the expectation rather than the exception in all settings. Mandatory training in care of the dying alongside the LCP programme potentially provides an effective mechanism for the delivery of high quality care to achieve a good death for all.


The need to treat dehydration in terminally ill patients has become a very controversial topic. Numerous reports in the literature illustrate opposing viewpoints from both clinical and ethical perspectives. Arguments for the maintenance of hydration in terminally ill patients have tended to come from “the traditional medical model”. Many health care professionals looking after terminally ill patients have reacted to the generalized use of intravenous fluids in dying patients and the perceived negative effects of this management. Our palliative care group has argued that the viewpoint that dehydration in dying patients is not a cause of symptom distress overlooks commonly reported problems, such as agitated delirium, that can be prevented or reversed by the management of dehydration. This review presents a summary of the traditional arguments, a different perspective on the controversy, biochemical parameters reported in terminally ill cancer patients, recent dehydration research, and the use of hypodermoclysis and rectal hydration. We conclude that the data reported to date are insufficient to allow a final conclusion on the benefit or harm of dehydration in terminally ill patients. Nevertheless, it is worth considering that while some dying patients may not suffer any ill effects from dehydration, there may be others who do manifest symptoms, such as confusion or opioid toxicity, that might be alleviated or prevented by parenteral hydration.


Although guidelines for the care of the dying patient exist the evidence base to support the guidelines is poor. Some of the factors contributing to this include failure to recruit to trials, protective healthcare professionals and subsequent attrition from trials due to the death of the patients. Recent studies report favourably on the use of cluster randomisation as an appropriate methodology for use in this patient group. A feasibility study was sought, exploring two types of randomisation as appropriate methodology for trials involving dying patients. Cluster randomisation and randomised consent were utilised following a crossover design at two sites, one oncology ward and one Macmillan unit within the Northwest Wales NHS Trust. All patients commencing on the Integrated Care Pathway (ICP) for the Last Days of Life will be eligible for inclusion in the study. Using the hypothesis that: it is not necessary to prescribe an anti-emetic medication when setting up a syringe driver for the dying patient, the study will evaluate different models of research methodology. The identification of the most appropriate methodology for use in studies concerning this patient group will inform the development of future clinical studies. Furthermore, the outcomes of this feasibility study will inform the development of a proposal seeking funding for Wales-wide trials in palliative care.
The identification of an appropriate methodology will provide a starting point for the establishment of a robust evidence base for the care of the dying patient.


Guidance regarding the patient centered management of agitation and restlessness reinforces the importance of considering underlying causes, non-pharmacological approaches to treatment and judicious use of medications titrated to patient need. In contrast, recent reports in the literature suggest that the practice of continuous deep sedation until death is prevalent in the UK. The Study aim was to use data from the National Care of the Dying Audit - Hospitals (NCDAH) to explore the administration of medication for management of agitation and restlessness in the last 24 h of life. Hospitals submitted data from up to 30 consecutive adult patients whose care in the final hours/days of life was supported by the Liverpool Care Pathway for the Dying Patient (LCP). Data on the total dose received in the last 24 h of life PRN and the last dose prescribed for administration via continuous subcutaneous infusion (CSCI) for agitation and restlessness were submitted. 155 hospitals provided data from 3893 patients. Median total doses in the last 24 h for midazolam, haloperidol and levomepromazine, respectively, were: PRN only, 2.5, 1.5 and 6.25 mg; CSCI only, 10, 3 and 6.25 mg; PRN+CSCI, 15, 3 and 12.5 mg. Only 51% of patients received medication to alleviate agitation and restlessness in the last 24 h of life. Median doses were low in comparison to doses recommended for continuous deep sedation, suggesting that there is no ‘blanket’ policy for continuous deep sedation at the end of life for patients whose care is supported by the LCP.


This is a response to comments by Sanjay H. Shah in which the evidence for the LCP in supporting a “good death” was challenged. Whilst Gambles et al acknowledged that evidence based research in palliative and end of life care is an emergent field, they did point out the methodological quality of studies that Shah cited to support a small effect of the LCP upon patient care. The difficulties of undertaking randomized control trials within palliative care is acknowledged but the authors report on comparative and evaluative studies which provide evidence for the LCP in improving patient care. In highlighting more recent methodologically rigorous studies, they illustrate statistically significant impacts on patient care.


The Liverpool Care of the Dying Pathway (LCP) was developed to transfer the hospice model of care into other care settings. It is a multi-professional document providing an evidence-based framework for the dying phase. Widely used in hospitals it has now been adopted for use in hospices. A qualitative study exploring hospice doctors’ and nurses’ perceptions of the impact of the LCP using semi-structured interviews of a purposive sample were undertaken in a 30 bed hospice in the north-west of England. Data was thematically analysed for emerging themes. Eleven interviews were undertaken (eight nurses, three doctors). The results suggest that despite some initial scepticism the LCP has a valuable place in the hospice setting according to the doctors and nurses sampled. Alongside the potential for use in audit and research, perceived benefits include improving documentation, promoting continuity of care
and enhancing communication and the care of relatives. Maintaining ongoing education and feedback on the use of the document were highlighted as important mechanisms for ensuring that the delivery of care remained optimum.


In order to illustrate the usefulness of a continuous quality improvement approach in care of the dying, this paper focuses on the process and outcomes of the first National Care of the Dying Audit in Hospitals in England. One hundred and eighteen individual hospitals delivering care to patients in the last hours and days of their lives using the Liverpool Care Pathway for the Dying Patient participated in the audit and provided 2672 patient datasets. The results illustrate both that important information can be gained about care delivery using this method and that the opportunity to engage in formal and collaborative reflection, discussion and action planning is useful in promoting continuous quality improvement. This process is likely not only to be of interest to clinicians working in the field but also to managers and planners striving to ensure continuous quality improvement for patients and carers and to inform the process of benchmarking for the future.


The case of Terri Schiavo resulted in substantial media attention about the use of artificial nutrition and hydration (ANH) especially by percutaneous endoscopic gastrostomy (PEG). In this article, I review ethical and legal principles governing decisions to choose or forgo ANH at the end of life, including issues of autonomy and decision-making capacity, similarities and differences between ANH and other medical treatments, the role of proxies when patients lack decision-making capacity, and the equivalence of withholding and withdrawing treatment. Evidence for palliative or life-sustaining benefits for ANH are reviewed in three disease processes: amyotrophic lateral sclerosis (ALS), cancer, and dementias, including Alzheimer’s disease. Although more recent studies suggest a possible palliative role for ANH in ALS and terminal cancer, feeding tubes do not appear to prolong survival or increase comfort in advanced dementia of the Alzheimer’s type.


The General Medical Council (GMC) is the statutory regulator for the medical profession in the UK, and this guidance applies to doctors working in all four UK countries. This guidance is based on long-established ethical principles, which include doctors’ obligations to show respect for human life; to protect the health of patients; to treat patients with respect and dignity; and to make the care of their patients their first concern. It expands on the principles of good practice in the GMC’s Good Medical Practice (2006) and Consent: patients and doctors making decisions together (2008), and replaces the booklet Withholding and Withdrawing Life-Prolonging Treatments (2002). This guidance takes account of, and is consistent with, current law across the UK, including the laws on decision making for patients who lack capacity (the Adults with Incapacity (Scotland) Act 2000 and the Mental Capacity Act 2005); the law prohibiting killing (including euthanasia) and assisting suicide; and the requirements of the Human Rights Act 1998. However, it is not intended as a statement of the legal principles or a substitute for legal advice. Doctors must seek up-to-date advice when
there is uncertainty about how a particular decision might be viewed in law, in the jurisdiction in which they practise. This guidance is addressed to doctors. However, it may also help patients and the public to understand what to expect of their doctors, in circumstances in which patients and those close to them may be particularly vulnerable and in need of support. Other members of the healthcare team may also benefit from it, given their crucial role in delivering end of life care.


Health Informatics Unit, Clinical Standards Department, Royal College of Physicians (2008) A Clinician’s Guide to Record Standards – Part 1: Why standardise the structure and content of medical records?

This good practice guide has been produced to inform hospital doctors about current developments in medical record keeping standards for the Electronic Patient Record. It describes why standards are needed for the structure and content of medical records and how their introduction will affect our work. The record standards, approved for all specialties by the Academy of Medical Royal Colleges, are published in “A Clinicians Guide to Record Standards - Part 2: Standards for the structure and content of medical records and communications when patients are admitted to hospital.” The standards should be used for all hospital patient records.

http://www.rcplondon.ac.uk/sites/default/files/clinicians-guide-part-1.pdf


In July 2004, the Healthcare Commission became responsible for independently reviewing complaints about the NHS that have not been resolved locally. This report is the first report of our work in reviewing complaints made by patients or their representatives. It covers the first 16,000 requests for independent review we received between July 2004 and July 2006 and highlights recurring themes and lessons learnt. The concerns of many patients have focused on the basic elements of healthcare, including communication between clinical staff and patients and their families, standards of care and safety, inefficient or ineffective non-clinical practices, such as administration, booking of appointments and transport, and the attitudes of staff. Unfortunately, these themes have been a reason for complaint against the NHS for a number of years. We have therefore included recommended actions and guidance in this report to help trusts to achieve the improvements needed.


The purpose of this study was to promote quality end-of-life care in eight independent nursing homes using an ‘integrated care pathway (ICP) for the last days of life’ document. Action research methodology underpinned the design of this study in order to promote collaboration between staff in the nursing homes and the research team, empower staff in the practice of quality end-of-life care, and promote sustainable development of end-of-life care once the study finished. Considerable barriers within the nursing home context highlighted initial difficulties. This is reported elsewhere (Watson et al., in press) (Bridges Initiative, 2004). However, key champions appointed in each nursing home and their subsequent support was a major part of facilitating the ICP implementation. This paper reports the qualitative analysis from the summative evaluation of the study. One overarching pattern of ‘dying being more...
central to care in the nursing homes’ emerged as a result of the study; five themes that contributed to this shift were: greater ‘openness’ around death and dying; recognising dying and taking responsibility; better ‘teamwork’; critically using palliative care knowledge to influence practice; more meaningful communication.


The evidence for the management of respiratory tract secretions (RTS) in dying patients with antimuscarinic drugs remains inconclusive. This study investigated the effectiveness of glycopyrronium versus hyoscine hydrobromide in controlling RTS using the Liverpool Care of the Dying Pathway (LCP) in 72 patients matched for age, diagnosis, and gender who died on a 30-bed specialist palliative care unit. All patients in the glycopyrronium group had some response to glycopyrronium, whereas 22% of patients in the hyoscine group had no response to hyoscine hydrobromide. There was a significant difference in overall response between the two groups (p < 0.01). Twenty-eight percent of patients in the glycopyrronium and 42% of patients in the hyoscine group died with RTS present. There was no statistically significant difference in the levels of agitation following administration of either drug. This study provides further evidence that the LCP can be a useful tool in the evaluation of new drugs for symptom control in dying patients and suggests that glycopyrronium may be at least as effective in controlling RTS in dying patients as hyoscine hydrobromide.


The Liverpool Care Pathway for the dying patient (LCP) was developed to transfer the hospice model of care into other care settings. It is a multi-professional document that provides an evidence-based framework for the dying phase. It provides guidance on the different aspects of care required including comfort measures, anticipatory prescribing of medication, and discontinuation of inappropriate interventions. Additionally, psychological and spiritual care and family support is included. This article presents the findings of a study to explore hospital nurses’ perceptions of the impact of the LCP using focus group interviews. Data were analysed for emerging themes using thematic analysis. The results suggest that the nurses have generally found that the LCP had a positive impact on patients, their families and also on nurses and doctors. This article will explore these benefits, as well as potential barriers to its use.


The palliative care network nurse programme was developed to educate and skill generalist nurses in the care of the dying patient within the acute hospital setting. It developed at the request of nurses who had been involved in the piloting of the Liverpool Care of the Dying Pathway. The programme consists of a monthly meeting that encompasses an educative component and networking opportunities. In a preliminary evaluation of the programme, a questionnaire was sent to the network nurses (response rate 80%, n=33). The nurses reported the programme to be beneficial in providing them with increased palliative care knowledge. Support and networking opportunities were also identified. This article discusses the programme, the evaluation findings and makes suggestions for further research.

A Research Letter: SIR—The Liverpool Care Pathway (LCP) provides an evidence-based framework for dying patients, initially developed to transfer the hospice model of care for cancer patients into the acute hospital. To provide optimal care for patients dying from stroke the LCP was introduced into this setting. A retrospective case note audit carried out prior to the implementation of the LCP was compared with an audit post implementation, assessing levels of documentation of key areas of care. The results indicated a marked improvement in levels of documentation, including a change in the prescribing of medication. The LCP is transferable into stroke care and potentially enhances care for dying stroke patients.


In order to investigate symptom burden in the last week of life, we conducted after-death interviews with close relatives of deceased older persons from a population-based sample of older people in The Netherlands (n _ 270). Results show that fatigue, pain, and shortness of breath were common (83%, 48% and 50%, respectively). Other symptoms were confusion (36%), anxiety (31%), depression (28%), and nausea and/or vomiting (25%). Cancer patients and patients with chronic obstructive pulmonary disease were clearly at a disadvantage with respect to pain and shortness of breath, respectively. Furthermore, cognitive decline turned out to be predictive of specific symptom burden. Persons with cognitive decline in the last three months had a higher symptom burden and different symptoms compared to patients with no cognitive decline. It is suggested that older persons with cognitive decline require specific attention.


Though patients usually die peacefully, problems may arise in the last period of a terminal illness. In the final days new symptoms may arise or there may be exacerbation or recurrence of symptoms previously well controlled. Two hundred consecutive hospice patients were studied. The incidence was noted of pain, dyspnea, moist breathing, nausea and vomiting, confusion, restlessness, jerking and twitching, difficulty in swallowing, incontinence and retention of urine, sweating, moaning and groaning, and loss of consciousness. Each symptom is considered and the results of the management employed are noted. Many of the features appearing in the last days of a terminal illness, especially cancer, can be attributed to organic brain disease consequent to metabolic disorder associated with multi-organ failure. An awareness of the nature of the problems that may arise in the last 48 hours of life makes it possible to keep the patient comfortable to the end.


There's a wealth of sensible advice on how to make decisions about care, where to find support and treatment resources, how to communicate with physicians, how to get effective pain management, when to let go of medical treatment, issues in hastening death, and many other fundamental concerns. There's a discussion of the ethical issues of assisted suicide that balances arguments from several sides of the question. The book handles many specialized
situations, with details on several common disease processes and types of death. A solid resource guide points readers to major sources of information for further study and support.


In most western societies the death of a child is a rare occurrence. When it does occur, it typically takes place after a period of intensive and often prolonged treatment. In light of the relative infrequency of these events in clinical practice, ensuring that all dying children and their families receive consistent and appropriate care remains a challenge. A retrospective audit of documentation of care for dying children in two paediatric units in the north-west of England illustrated that the care provided was not always documented consistently. This paper highlights work currently underway to develop an integrated care pathway for the care of the dying child based on the Liverpool Care Pathway (LCP). The aim of this work is to facilitate the delivery and recording of optimum care for all dying children and their families.


Providing good quality of care for dying patients and their families has been highlighted as a national priority in the UK. Defining and measuring the quality of this care is therefore important. Using the views of patients has practical and ethical difficulties, so an alternative approach is to seek the views of bereaved relatives and close friends after the patients’ death. This study aimed to identify and critically appraise instruments previously used with bereaved relatives to measure the quality of care for dying patients and the level of support provided to the family. A literature review was undertaken using Medline, Cinal, Embase and AMED databases from 1985 to 2005. The search strategy was based on the following headings: quality of care, dying, assessment and relatives. Key criteria were set for the appraisal of each instrument. Analysis of the 229 articles identified from the searches, yielded seven instruments used with bereaved relatives to assess the quality of ‘care for the dying’.

Discussion: Each of these instruments was carefully constructed and all but one had clear documentation of validity and reliability measures. Two instruments used ‘satisfaction’ as an outcome measure, limiting their ability to discriminate between adequate and excellent care. Only one instrument was developed in the UK making it more ‘user-friendly’ for direct use in the UK. None of the instruments in their current format could comprehensively evaluate ‘care for the dying’ in the UK healthcare setting. We would propose to develop and validate a tool specifically assigned for this purpose.


*Building on the First Round, this Second Round of the Audit provide a National snapshot of performance against the goals on the LCP against which individual Hospital performance is benchmarked. It also focuses on the prescription and administration of medication for agitation and restlessness in the last 24 hours of life, as well as providing more information about variance recording for a proportion of goals. Data driven Key Performance Indicators (KPIs) for the delivery of care to dying patients during the last hours and days of their lives*
have also been developed to promote the appropriate prioritisation of this area of care within Acute Hospital Trusts. 


Integrated care pathways (ICPs) have been developed as a tool for improving end-of-life care. The Liverpool Care Pathway for the Dying (LCP) is a multidisciplinary and evidence-based approach to caring for the dying person. At Wythenshawe hospital a clinical facilitator was appointed to facilitate the introduction of the LCP. This full time post, which existed for 18 months, involved supporting and educating staff about the pathway. The LCP is now used throughout the general surgical and medical wards and acute and regional coronary care units. This article reflects on the different aspects of the role and the development of the project.


The Mental Capacity Act 2005, covering England and Wales, provides a statutory framework for people who lack capacity to make decisions for themselves, or who have capacity and want to make preparations for a time when they may lack capacity in the future. It sets out who can take decisions, in which situations, and how they should go about this. The Act received Royal Assent on 7 April 2005 and will come into force during 2007. The legal framework provided by the Mental Capacity Act 2005 is supported by this Code of Practice (the Code), which provides guidance and information about how the Act works in practice. The Code has statutory force, which means that certain categories of people have a legal duty to have regard to it when working with or caring for adults who may lack capacity to make decisions for themselves. The Code of Practice provides guidance to anyone who is working with and/or caring for adults who may lack capacity to make particular decisions. It describes their responsibilities when acting or making decisions on behalf of individuals who lack the capacity to act or make these decisions for themselves.

Merseyside and Cheshire Palliative care Network Audit Group. Standards and guidelines. 4th edn. Liverpool: Marie Curie Palliative Care Institute; 2010;


Available evidence suggests that whist over 50% of all patients wish to spend their final days at home in practice fewer than 20% of patients actually do so. In 2004 NICE recommended that people with incurable illnesses should be able to make choices relating to end of life care including where to die. The rapid discharge pathway was formulated following critical analysis of an emergency call from the Intensive Therapy Unit (ITU). It was designed to support the transfer of a dying patient who was not expected to survive more than a few hours following extubation from ITU to home. There is a clear emphasis upon patient assessment including: comfort measures; psychological; spiritual/religious support; communication with family and the primary health care team. The Rapid Discharge Pathway has been subject to a pilot study and repeated cycles of change and evaluation. The Liverpool
Rapid Discharge Pathway provides a structured and coordinated process to enable a dying patient to go home to die.


Following the admission of patients in an emergency or urgent setting there is often no formal assessment of co-morbidities. Many, otherwise remediable, medical conditions go uncorrected, problems are overlooked, surgical complication rates are high and deaths occur despite the best anaesthetic, surgical and medical expertise available1. The study presented in this report revisits some of the themes highlighted in the 20021, 20032 and 20073 NCEPOD reports, to evaluate current practice and see what changes have been made. Key findings include: Delays in consultants initial reviews; Poor communication between and within clinical teams and other health care professionals; poor decision making and lack of senior input, particularly in the evenings and night time. Access to CT scanning, MRI scanning and on site angiography (non cardiac) is a substantial problem; District hospitals may have particular problems delivering high standard of care when dealing with very sick children and it is recognised that a well co-ordinated team approach is required. In 16.9% (219/1293) of patients who were not expected to survive on admission there was no evidence of any discussion between the health care team and either the patient or relatives on treatment limitation. In 21.8% of cases DNAR orders were signed by very junior trainee doctors. There were examples of where health care professionals were judged not to have the skills required to care for patients nearing the end of their lives. This was particularly so in relation to a lack of the abilities to identify patients approaching the end of life, inadequate implementation of end of life care and the poor communication with patients, relatives and other health care professions.


The 2008 end of life care (EoLC) strategy emphasised that improved EoLC provision in acute hospitals is crucial given that more than half of all deaths take place there. As well as ensuring that those who die in hospital have ‘a good death’, the strategy called for improved discharge arrangements and better co-ordination with a range of community services so that more people can die at home if this is their preferred choice. This guide aims to provide practical support for NHS managers and clinicians as they seek to deliver that agenda when pressure to make best use of resources is increasing. It can help trusts re-shape how their staff work with each other, their patients and community and social care partners to improve care quality and meet the agenda of Quality, Innovation, Productivity and Prevention (QIPP) by reacting to problems before they become a crisis perhaps requiring admission to hospital.

National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. London, NICE

Cancer service guidance supports the implementation of The NHS Cancer Plan for England, and the NHS Plan for Wales Improving Health in Wales.2 The service guidance programme was initiated in 1995 to follow on from the Calman-Hine Report, A Policy Framework for Commissioning Cancer Services. The focus of the cancer service guidance is to guide the
commissioning of services and is therefore different from clinical practice guidelines. Health services in England and Wales have organisational arrangements in place for securing improvements in cancer services and those responsible for their operation should take this guidance into account when planning, commissioning and organising services for cancer patients. The recommendations in the guidance concentrate on aspects of services that are likely to have significant impact on health outcomes. Both the objectives and resource implications of implementing the recommendations are considered. This guidance can be used to identify gaps in local provision and to check the appropriateness of existing services. 


This NICE quality standard defines clinical best practice within this topic area. It provides specific, concise quality statements, measures and audience descriptors to provide the public, health and social care professionals, commissioners and service providers with definitions of high-quality care. This quality standard covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. The quality standard does not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents. It sets out markers of high-quality care for adults aged 18 years and older with advanced, progressive, incurable conditions; adults who may die within 12 months; and those with life-threatening acute conditions. It also covers support for the families and carers of people in these groups. It is not expected that each quality statement will apply to all groups. Similarly, some quality statements may need special consideration when applied to certain groups. For example, people with dementia may need to participate in advance care planning significantly earlier in the pathway than people with cancer. 


Prescribing guidelines to ensure best practice in the care of kidney patients during the last weeks or days of their lives. This forms part of the LCP programme to extend LCP to kidney disease. The guidelines were developed by an expert project group, overseen by the LCP Renal Steering Group, and have been endorsed by the Department of Health, the Renal Association and the British Renal Society.

Nowarska A. (2011). To Feed or not to feed? Clinical aspects of withholding and withdrawing food and fluids at End of Life. Advances in Palliative Medicine, 10, 3–10

The issue of withholding and withdrawing clinically assisted nutrition and hydration (CANH) for imminently dying patients is very contentious. There is no agreement between medical professionals and problem of forgoing CANH is subject of a fierce and sometimes emotional debate. This paper makes an attempt to examine briefly current clinical evidence on withdrawing and withholding CANH at the end of life. It tries to assess whether it is always beneficial for a patient to provide CANH or whether providing CANH may sometimes cause
more harm than good. It also addresses a question whether forgoing CANH for some imminently dying patients is consistent with fundamentals of palliative care. For this reason withholding or withdrawing CANH will be analysed in a context of basic assumptions of palliative care which are presented in the World Health Organisation’s definition of this distinctive branch of medicine.


Nurses working in palliative and end-of-life care, as well as healthcare professionals based in the community and those working in hospices, hospitals or care homes will find the contributions to this book useful. The chapters are self-contained and cover many areas pertinent to palliative and end-of-life care. The subject areas include symptom management; grief and loss; the Liverpool Care Pathway; spiritual care and communication. Attention is also given to palliative care and sexuality. Each chapter is thoroughly and extensively referenced.

Royal College of Physicians http://www.rcplondon.ac.uk/resources/clinical/audits (last accessed 7th November 2011)

Continuous improvement in the quality of care is the responsibility of all physicians, with the provision of health services ideally driven by the best evidence for clinical practice – this has been the RCP role since its inception. With quality now looking certain to be the principal driver of service improvement over the next few years, the RCP is well placed to support this agenda with well established and extensive work programmes. In August 2011 the RCP released the document ‘A Strategy for Quality’ which further updates our approach to pursuing improvements in healthcare and the health of the population. Our clinical guidelines provide recommendations on the appropriate treatment and care of people with specific diseases/conditions and are based on the best available clinical and cost evidence. By design they support healthcare professionals in their work, and are useful for patients as they make decisions about their care. The national clinical audits that we coordinate use standards of care embedded in clinical guidelines to measure practice and subsequently drive improvements in healthcare services.


Spiritual needs change with time and circumstances. The National Institute for Clinical Excellence guidance acknowledges this and recommends that healthcare teams ensure accurate and timely evaluation of spiritual issues through regular assessment. This reflects the increasing emphasis on spirituality as a factor contributing to wellbeing and coping strategies. Some key words occur quite regularly in the various descriptions of spirituality in journals and textbooks (box). In health research we should differentiate between the terms spiritual and religious since, if they are used interchangeably, reports of spirituality may be describing religious practice and affiliation. These can be interrelated. Spiritual belief may or may not be religious, but most religious people will be spiritual. A need exists for user friendly and brief measures to assess spiritual need in the absence of religious faith, so that it may be addressed properly rather than as some general panacea which is assumed to be good but is not individually tailored. Only in this way may we “ensure that the spiritual elements of disease are taken into account,” as recommended in the guidance from NICE.
Opioids and sedative drugs are commonly used to control symptoms in patients with advanced cancer. However, it is often assumed that the use of these drugs inevitably results in shortening of life. Ethically, this outcome is excused by reference to the doctrine of double effect. In this review, we assess the evidence for patterns of use of opioids and sedatives in palliative care and examine whether the doctrine of double effect is needed to justify their use. We conclude that patients are more likely to receive higher doses of both opioids and sedatives as they get closer to death. However, there is no evidence that initiation of treatment, or increases in dose of opioids or sedatives, is associated with precipitation of death. Thus, we conclude that the doctrine of double effect is not essential for justification of the use of these drugs, and may act as a deterrent to the provision of good symptom control.


The LCP empowers nurses and doctors to deliver high-quality care to dying patients and their families. It facilitates and focuses multi-professional communication and documentation, integrating national guidelines into clinical practice. The project also provides a focus for education and demonstrable outcomes to support clinical governance. Caring for dying patients should be every health care professional’s business and a core competency. It is not just the job of hospices to care for patients that are dying - the reality is that the majority of deaths occur in the acute setting. It is imperative nurses are equipped with the skills and knowledge necessary to offer the basic human right of high-quality care at the end of life. The LCP offers opportunities to implement this irrespective of diagnosis or place of death.


Modern palliative care evolved from the practices of the hospice movement, which was pioneered in England by Dame Cicely Saunders. In 1974, the first palliative care mobile team in London, based in an acute care hospital, was set up. Following the establishment of this and other UK mobile teams, the mobile team concept spread to Europe. The European research project ‘Promoting the integration of continuous care in the hospital’ intends to identify the challenges in integrating continuous care through an inventory and analysis of the activity of palliative care mobile teams in several countries of Europe. Competencies for PCMTs have been derived, and based on these, a pilot educational programme with PCMTs undertaken and evaluated. After a brief review of the project’s methodology, the brochure
gives 25 recommendations on the integration, education and training of palliative care mobile teams in Europe.


The provision of end of life care services has become increasingly complex: people are living longer and the incidence of frailty and multiple conditions in older people is increasing. As a result, people approaching the end of their life require a combination of health and social care services provided in the community, hospitals, care homes, or hospices. Care is also provided by informal carers such as family members, close friends or volunteers. Primary care trusts (PCTs) spent an estimated £245 million on specialist palliative care services in 2006-07. The Department of Health (the Department) estimates that the overall annual cost of end of life care to NHS and social care services is measured in billions of pounds. The Department considers that the implementation of its End of Life Strategy should reduce inappropriate admissions to hospital and enable more people approaching the end of their life to live and die in the place of their choice. To this end the Department has committed additional funding of £286 million over 2009-10 and 2010-11. Against this background, this report considers the scope for improving the pattern of care in light of the available evidence on the impact and appropriateness of existing provision. In preparing this report, we drew on the knowledge and experiences of a wide range of health and social care staff involved in the delivery of end of life care and, most importantly, people approaching the end of their life and those caring for them. In addition to our censuses of PCTs and independent and NHS hospices and our survey of care homes, three unique features of our methodology include a detailed examination of the patient records of 348 people who died in Sheffield in October 2007 to identify the potential for people to die in their preferred place of care; modelling of the provision of end of life care services to identify whether the quality of such services can be improved within existing resources; and detailed reviews of end of life care services provided by three PCTs.


Changing Gear is a practical manual of guidelines designed for health and social care professionals of all levels. The guidelines have been designed for the use of health care professionals who are caring for dying patients in all settings including primary care, care homes as well as in hospices. Changing Gear includes a section on the use of drugs in the last days of life.


The Liverpool Care Pathway makes it possible to incorporate available evidence and national or regional policies into decision making at the end of life and thereby promote good practice. When difficult decisions are required Health Professionals can then feel reassured both in moral as well as in legal terms. Advice contained in the LCP can only be presented in general terms. Central to care of the dying is the recognition that the decision making process has to
be tailored to the individual. The information contained in this chapter when used alongside the LCP can facilitate this process but must be supplemented by effective multidisciplinary team working and sensitive communication. This chapter therefore discusses ethical considerations including: withholding and withdrawing interventions; decisions between life sustaining and comfort treatments; Cardiopulmonary resuscitation; hydration and nutrition; Ventilation; double effect and assisted dying; mental capacity and decision making.


This book is about multi-disciplinary pathways of care. Its many chapters range from descriptions of implementing pathways of care in a variety of clinical settings through to the application and relationship of pathways in areas such as purchasing, quality, risk management, legal issues, clinical audit and clinical effectiveness. Each chapter reinforced the benefits of using pathways, but left no doubt about the considerable investment in time and energy required.


Clinical pathways are used all over the world to make care processes transparent and to improve the efficiency and quality of care. They represent one way to describe the structure of a care process. Differences in definitions, as well as the actual use of pathways and the methods to develop pathways, lead to confusion about which care processes are supported by clinical pathways and which are not. This dissertation seeks to investigate and answer four research questions, being; 1) Which instruments known as clinical pathway audit tools) are available to measure the clinical pathway level of a care process? 2) What are the characteristics of a well-organised care process? 3) Do pathways improve the organisation of care processes? 4) What is the relationship between clinical pathways, the organisation of care processes, and patient outcomes—the three cornerstones of the care process organisation triangle?


This thesis seeks to investigate and answer the following research questions: What is the effect of LCP use on: 1. the quality of life of patients in the last three days of life? 2. the content of care for patients in the last three days of life? 3. the communication in the last three days of life and the level of bereavement of relatives?

The main conclusion of the study is that the use of the LCP can be recommended for the care for dying patients. It is a noteworthy result that, according to the nurses and the relatives, LCP use contributes to better symptom control in dying patients. Further, LCP use facilitates and improves the documentation of care. It is suggested that the routine assessment of symptoms, the prescription of medication as required, and the explicit attention to informing the relatives about what to expect from symptoms during the dying phase contributed to this effect.
During the dying phase, patients often receive interventions that are not aimed at promoting their comfort. We investigated how recognition of the dying phase affects the use of interventions by comparing patients for whom the dying phase had been recognized with patients for whom it had not been recognized. We included 489 of 613 patients (80%) who died either in a hospital, nursing home, or primary care setting between November 2003 and February 2006. After the death of patients, nurses filled in questionnaires, and patient records were searched for information about therapeutic and diagnostic interventions applied during the dying phase. Caregivers had recognized the dying phase of 380 patients (78%). The number of patients who had received diagnostic interventions during the last three days of life was significantly lower when the dying phase had been recognized (39% vs. 57%) (p = 0.00). Therapeutic interventions were used in similar frequencies in both groups. We conclude that recognition of the dying phase reduces the number of undesirable diagnostic interventions.

The Liverpool Care Pathway (LCP) is aimed at improving care and communication in the dying phase. The authors studied whether use of the LCP affects relatives’ retrospective evaluation of communication and their level of bereavement. An intervention study was conducted. During the baseline period, usual care was provided to dying patients. During the intervention period, the LCP was used for 79% of the patients. In total, bereaved relatives filled in a questionnaire for 57% of the patients, on average 4 months after death. In the intervention period, relatives had lower bereavement levels when compared with relatives in the baseline period (P = .01). Communication was evaluated similarly for both periods. We conclude that LCP use during the dying phase seems to moderately contribute to lower levels of bereavement in relatives.

We studied the effect of the Liverpool Care Pathway (LCP) on the documentation of care, symptom burden and communication in three health care settings. Between November 2003 and February 2005 (baseline period), the care was provided as usual. Between February 2005 and February 2006 (intervention period), the LCP was used for all patients for whom the dying phase had started. After death of the patient, a nurse and a relative filled in a questionnaire. In the baseline period, 219 nurses and 130 relatives filled in a questionnaire for 220 deceased patients. In the intervention period, 253 nurses and 139 relatives filled in a questionnaire for 255 deceased patients. The LCP was used for 197 of them. In the intervention period, the documentation of care was significantly more comprehensive compared with the baseline period, whereas the average total symptom burden was significantly lower in the intervention period. LCP use contributes to the quality of documentation and symptom control.

Little is known about the characteristics of dying in different care settings, such as the hospital, the nursing home, or the home-care setting. We measured the burden of symptoms, medical and nursing interventions, and aspects of communication during the last 3 days of life within each of these settings. We included 239 of 321 patients (74%) who died in one of these settings in the southwest of The Netherlands, between November 2003 and February 2005. After the patient’s death, a nurse filled in a questionnaire. Pain and shortness of breath were more severe in hospital patients as compared to nursing home and homecare patients, whereas incontinence was less severe in hospital patients. Several medical interventions, such as a syringe driver, vena punctures or lab tests, radiology or ECG, antibiotics, and drainage of body fluids were more often applied during the last 3 days of life to hospital patients than to nursing home and home-care patients. This also holds for the measurement of body temperature and blood pressure. In the hospital setting, the patient and the family were more often informed about the imminence of death of the patient than elsewhere. The general practitioner and other professional caregivers were less often informed about the imminence of death of hospital patients than of other patients. We conclude that pain and shortness of breath were more severe among hospital patients, whereas incontinence was more severe among nursing home and home-care patients. Hospital patients relatively often receive medical interventions and standard controls during the last 3 days of life. In hospital, communication about impending death seems to take place more often shortly before death.


The Liverpool Care Pathway (LCP) provides an evidence-based framework of care for the dying patient and provides guidance on comfort measures, discontinuation of inappropriate interventions, anticipatory prescribing, holistic care and care of the family after death. End-of-life care is becoming an important issue in critical care, and the LCP has been adapted for use in intensive care units in the United Kingdom. A qualitative study using descriptive phenomenology was used to explore doctor and nurse experiences of the impact of the LCP in two intensive care units in a 1000-bed teaching hospital in the north-west Midlands. The staff experience of the LCP was dependent on their role, with mixed reports about frequency of use and level of education received on the LCP. Education and adequate support was identified as being pivotal to the successful implementation of any type of LCP.


This paper explores the barriers that needed to be overcome during the process of implementing an integrated care pathway for the last days of life as a way of developing quality end-of-life care in nursing homes. An action research methodology underpinned the study. Qualitative and quantitative data were collected in eight nursing homes before, during and after the implementation of the care pathway. Six main barriers were identified: a lack of knowledge of palliative care drugs and control of symptoms at the end of life; lack of preparation for approaching death; not knowing when someone is dying or understanding the
dying process; lack of multidisciplinary team working in nursing homes; lack of confidence in communicating about dying; some nursing homes are not ready or able to change. These findings highlight a functional 'rehabilitative' culture that may not be so appropriate in the current context of nursing home care, and one that makes implementing an integrated care pathway for the last days of life less straightforward than in other settings. It cannot be presumed that the implementation of a care pathway for the last days of life in nursing homes is straightforward. This study suggests that an action research framework was extremely useful in highlighting and overcoming some obstacles when developing evidence-based practice. Action at both local and public policy level is required to fully address barriers that prevent quality end-of-life care in nursing homes.


The importance of effective communication between health professionals and patients with cancer is widely recognized. Training programmes aimed at improving key communication skills are becoming increasingly available. The aim of this study was to evaluate a communication skills programme delivered to 308 cancer nurses as part of degree/diploma courses. Based on previous work, it was hypothesized that a statistically significant improvement between pre- and post intervention scores would be observed. Audio-taped nursing assessments with patients were undertaken before and after the course. These were evaluated according to coverage of nine previously identified key areas of communication.

Results. Mean post course scores rose by 5Æ9 points (P < 0Æ001) to 16Æ3 (out of a possible 27). All nine individual areas of the assessment showed statistically significant improvements post intervention (P < 0Æ001). The areas showing most improvement were those with a high emotional content. This study has demonstrated that an integrated approach to communication skills training has the potential to improve nurses’ skills, particularly in emotionally laden areas across the spectrum of roles in cancer care.

Willner (2003) Keeping Pace with Technology: Implantable Cardiac Devices in Palliative Care

There are provocative ethical and legal issues surrounding the removal or deactivation of implanted cardiac devices. Some object to the practice on the grounds that it represents “mercy killing”; however, others argue that it is akin to withdrawing other specific therapies, such as dialysis, and therefore protected by the firmly established right of informed patients to be free of unwanted medical intervention. Even though justifiable on moral and legal grounds, whether, or when, it is the right thing to recommend can be difficult – if not impossible – to know. For the unique identity of each patient, as both a clinical being and a sovereign person, makes sudden death “the ultimate paradox” - mercifully sought by some, but actively feared by others. Ultimately, then, a decision such as this, like so many others in the practice of medicine and the lives of patients, must be highly individualized.


This guide focuses primarily on the care of patients who are expected to die in the near future, however much of the content is relevant to other situations such as sudden death. The first
section of the Guide offers practical advice on how to provide good spiritual care, making no assumptions about whether or not the dying person or the healthcare professional has a particular religious faith. The second section looks at some of the common ethical questions that might arise at this time, for example, withdrawing or withholding medical treatment. And the third offers a reflection on the experience of dying, its personal and mysterious dimension and offers with a view to stimulating a more sensitive and attentive approach to the subject. The Guide originates within a Catholic Christian perspective, but it is not addressed exclusively to Catholics either as patients or healthcare providers. Its aim is simply to bring the resources of this perspective – experience, practice, ethical and theological reflection - to end of life care. It tries to keep the whole person in view, in their spiritual, physical and psychological reality and it respects that there are many different ways and traditions, religious and non-religious, in which these aspects find expression in a person’s life and care.
FURTHER READING


Little is known about the effects of spiritual care training for professionals in palliative medicine. We therefore investigated prospectively the effects of such training over a six month period. All 63 participants of the three and a half-day training were asked to fill out three questionnaires: before and after the training, as well as six months later. The questionnaires included demographic data, numeric rating scales about general attitudes towards the work in palliative care, the Self-Transcendence Scale (STS), the spiritual subscale of the Functional Assessment of Chronic Illness Therapy (FACIT-Sp) and the Idler Index of Religiosity (IIR). Forty-eight participants (76%) completed all three questionnaires (91% women, median age 49 years; 51% nurses, 16% hospice volunteers, 14% physicians). Significant and sustained improvements were found in self-perceived compassion for the dying (after the training: P_ 0.002; 6 months later: P_ 0.025), compassion for oneself (PB 0.001; P_ 0.013), attitude towards one’s family (P_ 0.001; P_ 0.031), satisfaction with work (PB 0.001; P_ 0.039), reduction in work-related stress (PB 0.001; P_ 0.033), and attitude towards colleagues (P_ 0.039; P_ 0.040), as well as in the FACIT-Sp (PB 0.001; P_ 0.040). Our results suggest that the spiritual care training had a positive influence on the spiritual well-being and the attitudes of the participating palliative care professionals which was preserved over a six-month period.


The delivery of spiritual and religious care has received a high profile in national reports, guidelines and standards since the start of the millennium, yet there is, to date, no recognized definition of spirituality or spiritual care nor a validated assessment tool. This article suggests an alternative to the search for a definition and assessment tool, and seeks to set spiritual care in a practical context by offering a model for spiritual assessment and care based on the individual competence of all healthcare professionals to deliver spiritual and religious care. Through the evaluation of a pilot study to familiarize staff with the Spiritual and Religious Care Competencies for Specialist Palliative Care developed by Marie Curie Cancer Care, the authors conclude that competencies are a viable and crucial first step in ‘earthing’ spiritual care in practice, and evidencing this illusive area of care.


Spiritual needs change with time and circumstances. The National Institute for Clinical Excellence guidance, Supportive and Palliative Care for Adults with Cancer, published in March 2004, acknowledges this and recommends that healthcare teams ensure accurate and timely evaluation of spiritual issues through regular assessment. This reflects the increasing emphasis on spirituality as a factor contributing to wellbeing.
and coping strategies. A proliferation of textbooks and book chapters with titles containing the word “spirituality” seek to elucidate what spiritual care is, how it might be assessed, and how needs might be met. However, a lack of consensus remains as to what spirituality actually is.

4. Spiritual and Religious Care Competencies for Specialist Palliative Care:
   Assessment Tools level 1&2
   Self-assessment tools levels 3&4
   David Mitchell & Tom Gordon. Marie Curie Cancer Care -

   These competencies have been developed with an understanding of spiritual care in its broadest sense. It is acknowledged that Spirituality includes whatever gives a person meaning, value and worth in their life. Spirituality and Religion are clearly distinguished: religion can be an important part in a person’s spirituality but how important, if at all, will depend on the individual. Although spiritual care is traditionally seen as the chaplain’s area of expertise these competencies assume that all staff and volunteers can and do provide spiritual care. The competencies are set out in four levels. They specify levels of competency that should be achieved by staff and volunteers working in all areas of care, through those with increasing depth of contact with patients and their families/carers, to those whose primary responsibility is for spiritual care, normally chaplains. Each level is prefaced by a statement giving guidance on which groups of staff and volunteers would normally be expected to achieve or be working towards achieving this level.


   The review by Berger highlights the complex end-of-life issues posed by the presence of ICDs. We agree with Berger that formal guidelines do not exist to address these issues and to date, most discussion has centered on illustrative cases. Improvement of the dying process for patients with ICDs demands open and objective discussion with patients and their families (or surrogates) regarding the usefulness of these technologies as the underlying disease progresses. Uncertainties specific to prognostication in heart failure should be acknowledged. Opportunities for such interaction may occur at the time of ICD implantation, when preferences for resuscitation are explored in the setting of advanced disease or impending death, after withdrawal of antiarrhythmic therapy, or on recovery from a crisis typical of the heart failure disease trajectory. We have recently incorporated ICD deactivation as a formal element of the Liverpool Care Pathway for the care of those dying of heart failure in the hospital (5), and we will soon pilot this protocol in a multicenter study in England.

The purpose of this guide is to assist front-line staff in identifying spiritual need in their patients and to feel confident in their ability to provide it. Whether we have a religious belief or not, we can recognise that the human person is more than the sum of their physical parts. Indeed, if we only focus on the illness, consciously or unconsciously, then we distort, instrumentalise and thereby devalue a life. This guide focuses primarily on the care of patients who are expected to die in the near future, however much of the content is relevant to other situations such as sudden death. The first section of the Guide offers practical advice on how to provide good spiritual care, making no assumptions about whether or not the dying person or the healthcare professional has a particular religious faith. The second section looks at some of the common ethical questions that might arise at this time, for example, withdrawing or withholding medical treatment. And the third offers a reflection on the experience of dying, its personal and mysterious dimension and offers with a view to stimulating a more sensitive and attentive approach to the subject. The Guide originates within a Catholic Christian perspective, but it is not addressed exclusively to Catholics either as patients or healthcare providers. Its aim is simply to bring the resources of this perspective – experience, practice, ethical and theological reflection - to end of life care. It tries to keep the whole person in view, in their spiritual, physical and psychological reality and it respects that there are many different ways and traditions, religious and non-religious, in which these aspects find expression in a person’s life and care.

OTHER USEFUL WEBSITES

1. Marie Curie Palliative Care Institute Liverpool  
   www.mcpcil.org.uk

2. Marie Curie Cancer Care  
   www.mariecure.org.uk

3. End of Life Care Programme  
   www.endoflifecareforadults.nhs.uk

4. National End of Life Care Intelligence Network  
   www.endoflifecare-intelligence.org.uk

5. National Council for Palliative Care  
   www.ncpc.org.uk

6. Dying Matters - Raising awareness of dying, death and bereavement  
   www.dyingmatters.org

7. Palliative Care for People with Learning Disabilities  
   www.pcpld.org

8. Care Quality Commission  
   www.cqc.org.uk

   www.lcpnz.org.nz

10. Mental Capacity Act Code of practice:  

10. Decision relating to Cardiopulmonary Resuscitation:  
    http://www.bma.org.uk/ap.nsf/Content/CPRDecisions07

11. The Decision to withdraw Implantable Cardioverter Defibrillator (ICD) Therapy in an Adult Patient:  
    http://www.cmcn.nhs.uk/guidelines/icds.html