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This statement provides an evidence based assessment of good practice in care of the dying in a hospital setting. It includes

- Recognised good practice in the clinical, social, psychological and spiritual support of a dying patient.
- Well evidenced care pathway(s) in care of the dying
- The timing of the introduction of such care
- Discussion with engagement and involvement of the patient, relatives and the multidisciplinary team in the timing and objectives of this care
- Any circumstances in which it would be justifiable to use curative treatment, e.g. antibiotics, in a patient receiving palliative care
- Views and experience on how well end of life care and care pathways are used in the UK and elsewhere generally eg is end of life care initiated when it should be.
- Any other matters considered relevant.

Patients reaching the end of life have complex needs and should be treated with compassion, respect and dignity; their total needs assessed and met by an appropriately skilled workforce. The resource of a specialist palliative care team, should be available for advice and support. All clinicians should be suitably trained to assess when further advice is needed and a specialist referral is required¹. This is no different to requesting a referral for specialist advice in any other area of medicine..

Competent end of life care requires that every healthcare worker should have core skills and knowledge (in any healthcare setting and for any condition²). Provider organisations have a responsibility to ensure that their staff are adequately trained, have access to specialist advice and clinical governance processes are in place to govern the quality of end of life care³.

An expected death in an acute hospital⁴ requires a pathway that includes:

- Discussions as the end of life approaches
- Assessment, care planning and review
- Co-ordination of care
- Delivery of high quality care in an acute hospital
- Care in the last days of life
- Care after death.

A number of end of life tools and pathways have been developed and their implementation recommended by the National End of Life Care Programme. Probably the best known of these is the Liverpool Care Pathway (LCP), which provides clinicians with a documented and auditable record of care given in the final days of life⁵. The evidence base for the LCP is limited⁶, however it is nationally and internationally recognised as 'accepted best practice'. Also widely and

¹ National Institute for Clinical Evidence (2004)

² National End of Life Care Programme, Department of Health, Skills for Care and Skills for Health (2009) Common core competences and principles for health and social care workers working with adults at the end of life. <http://tinyurl.com/yc99rsa>

³ Department of Health (2008) National End of Life Strategy.

⁴ National End of Life Care Programme (2010) The route to success in end of life care- achieving quality in acute hospitals. NHS.

⁵ Ellershaw J and Wilkinson S (2006) Care of the dying: A pathway to excellence. Oxford University Press. Oxford

⁶ National Audit Office (2009) End of Life Care. NAO. London

increasingly used to aid patient choice in determining their preferences for future care is the Preferred Priorities of Care document⁷ which is one form of Advance Care Plan⁸

End of Life care should be underpinned by senior clinical decision making, close to the patient, delivered by appropriately trained staff⁹ Ensuring delivery of this care can be particularly challenging in the acutely ill adult where the outcome is uncertain but where death is a possibility¹⁰ Clinical attention is often centred on the potential for recovery which can distract clinicians from ensuring that the needs of the patient and their family are fully addressed in the face of the possibility of death. This complex pathway of care is beginning to be the focus of work in acute hospitals as we strive to improve outcomes at the end of life. In patients with acute medical problems, the focus of clinicians is to manage the acute event and, to some, implementing an end of life pathway can feel counter intuitive. The ambiguity in determining whether a patient is critically ill or is dying can cause confusion and conflict for professionals caring for the critically ill adult in hospital. Further evidence is required to understand how we can fully integrate end of life care into 'critical' clinical practice¹¹

Recognition that death may occur should not preclude continuation of acute management, for example continuation of intravenous fluids or antibiotics. This can become a potential area for conflict acting as a barrier to the delivery of high quality end of life care. It is acceptable to continue active treatment if this facilitates symptom control. Treatment directed at managing an acute event can be delivered in parallel with effective palliative care.

Managing an acute event in a patient who is imminently dying is a balance between the burden of the intervention and the expected benefits. A patient who may be able to speak to their family for a few more days is a laudable outcome. For example, in a patient who has symptoms secondary to infection i.e. diarrhoea/abdominal pain, antibiotics may be the best symptom control available. However these interventions must be balanced with prescribing interventions that may lead to a prolonged death with unnecessary suffering.

Switching gear from acute to palliative care is essential to deliver appropriate management. The actual moment to do this can be extremely difficult to assess, and in most cases the decisions underlying this take place over a period of time as the clinical picture emerges. Best practice would seem to include the recognition that a patient could die and to have clearly documented contingency plans. These should be discussed between the multi-professional team. Knowledge of a patient's preferences and wishes can be invaluable when planning future care, therefore the views of the patient and family should be sought wherever possible. All stakeholders in care may have valuable contributions to make to the overall care plan. Delivery of high quality palliative care in parallel with acute medical care is not a paradox; indeed it is best practice and particularly relevant when there is uncertainty about the precise course of the illness. Consistent, open communication with the patient and family requires a multi-professional approach with a well defined management plan which may include forms of Advance Care Planning.

Controversies amongst specialist palliative care clinicians exist and as yet there is no clearly defined best practice regarding delivery of palliative care in the acutely ill patient. Not only do generalists find this area of care difficult but some specialist palliative care services choose to remain in the comfort zone of managing predictable deaths and demonstrating a reluctance to use their transferrable skills in the acute setting. More evidence is required in this area.

⁷ Preferred Priorities of Care. <http://www.endoflifecareforadults.nhs.uk/tools/core-tools/preferredprioritiesforcare>

⁸ Royal College of Physicians (2009) Advance Care Planning: National Guidelines

⁹ General Medical Council (2010) Treatment and Care towards the end of life: good practice in decision making

¹⁰ National Confidential Enquiry into Patient Outcome and Death (2009) Caring to the End? A review of the care of patients who died in hospital within four days of admission

¹¹ Morgan J (2008) End of Life Care in UK critical care units – a literature review. Nursing in Critical Care. Vol 13. No 3 pp152 - 161

Recent initiatives have been developed in response to difficulties experienced in the acute setting and recognition of the need to develop systems that will improve quality of care in this area. Different approaches to identify patients who should be considered to receive a palliative approach to management (which may be in parallel with acute medical management) are emerging. The Gold Standards Framework¹² (GSF) was initially designed to help general practitioners identify patients, within their practice populations, who are approaching end of life. This enabled the primary care team to pay focus on their needs. This is now being piloted in a number of acute hospitals to test its appropriateness in the acute setting. Another initiative in the early stages of development and testing is the AMBER (Assessment Management, Best practice, Engagement) Care Bundle for patients whose recovery is uncertain but for whom there is certainly a risk of death occurring within 1-2 months¹³.

The recent National Patient Confidential Enquiry into Patient Outcome and Death (2009) allows us to gain perspective about the complexities of managing patients in the acute setting. 3022 patient episodes were assessed who died within 4 days of acute admission. 30% of these patients did not have a Do Not Attempt Resuscitation Order (DNAR). Half of these patients were expected to die in acute phase of their illness. In general, these patients had non cancer and acute medical problems rather than being cancer patients, who were expected to die in a 'planned' way.

Key contemporary issues raised in this and many other reports are:

- Too many decisions are made by junior doctors (Early decision making by a senior clinician on the limitation of treatment was considered a key element of delivery of appropriate high quality care)
- Not enough advance care planning is taking place; which includes a DNAR that has been discussed with the family. This would enable 'partners in care' to be proactive and react to anticipated problems before they become a crises
- Insufficient discussion about treatment withdrawal
- Differences in approach when care is delivered to patients with cancer compared to patients with non cancer conditions. This reflects the traditional view that palliative care is predominately for patients with a predictable end of life issues.
- Lack of recognition that a patient may die can deny patients and families having their total needs met.
- Lack of availability of hospital palliative care teams 7 days a week as recommended by NICE (2004)
- An understanding that death, in itself, is not a failure; the failure is if a person's death is not as restful and dignified as possible¹⁴

¹² Gold Standards Framework : <http://www.goldstandardsframework.nhs.uk>

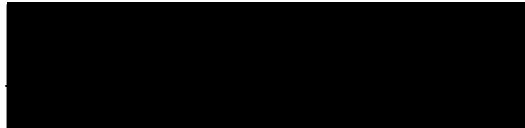
¹³ Southwark and Lambeth Modernisation Initiative End of Life Care Programme (2009) AMBER (Assessment, Management, Best Practice, Engagement for patients whose Recovery is uncertain). <http://tiny.cc/am3rs>

¹⁴ LCP Central Team UK: 10 Step Continuous Quality Improvement Programme (CQIP) for Care of the Dying using the LCP Framework Within a 4 Phased Improvement Model (Aug 2009)

ANNEX A (2)

**EXPERT WITNESS STATEMENT TO THE PUBLIC INQUIRY INTO THE
OUTBREAK OF CLOSTRIDIUM DIFFICILE IN THE NORTHERN TRUST
HOSPITALS**

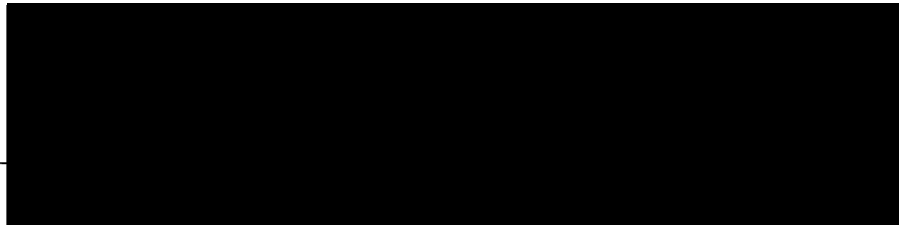
EXPERT WITNESS NAME:



I hereby attach a report dated 22 Aug 2010 which forms my written statement of evidence to this Inquiry.

I declare that this statement is true and accurate to the best of my knowledge and belief.

Signed: -



Date: -

23. Aug 2010.

Please return with your report.