The Last Days of Life Care Pathway
Southend Hospital NHS Foundation Trust 2013

Background
There has been recent media focus on the use of the Liverpool Care Pathway in caring for patients who are dying. The following information will explain the how Southend Hospital NHS Trust manages care in the last days of life.

Firstly, it is important to provide a brief background.

In 2008 The Department of Health published and detailed the first ever End of life care Strategy. This promoted high quality care in all settings for all adults who were approaching the end of their life recommending key elements of an end of life care pathway (see table). It was acknowledged that time frames differ depending on the patients illness – in South East Essex the End of life pathway is considered when the patient is in their last year of life.

Following earlier guidance from NICE 2004, (and successive national policy frameworks), the End of life Strategy highlighted and recommended the use of End of life tools. This included the 'Liverpool care pathway for the dying' seen widely as to enable a high standard of care in the last hours and days of a patient's life. It is important to recognise that the Liverpool care pathway is not the same as the End of life care Pathway.

The Liverpool Integrated care pathway
The Liverpool care pathway was pioneered by the Marie Curie Palliative Care Institute Liverpool at the end of the 1990's to provide a model of best practice based on care of the dying provided by hospices. In 2001 it was recognised as a model of best practice in the NHS Beacon Programme and subsequently incorporated into National care and End of life care programmes. During this time it has been reviewed and updated.

Essentially it is a model of care /care plan that enables the healthcare team to focus on care in the last days and hours of life when death is expected. The Care pathway should be tailored to the patient's needs taking consideration of their physical, social, spiritual and psychological needs.

Locally in South Essex
In South Essex the pathway is known as the 'Last days of life care pathway'. It was first piloted in both hospitals 2003-4. Following the pilot, Southend Hospital secured funding for a 2 year training and education programme to support implementation.

Alongside the acute Trust implementation programme, South West primary care and both Hospices implemented the pathway. More recently, South East Essex Primary care has begun implementation and is in very early stages of this.

Process of using the Last Days of Life Care Pathway

Decision making

The Pathway is considered when it is recognised that the patient is dying and only when there is no reversible treatment available, this is in the last days and hours of the patient's life. The decision making is by the multi- disciplinary team – led by the doctor. When is recognised that the patient is dying and care should focus on looking after the patient in their last days of life all care needs to be reviewed in order to ensure it is appropriate and provides the best comfort and support as is possible.

This may mean that some interventions are discontinued (such as taking blood samples) and some are started (such as mouthcare) – but all care decisions are based on the individual patients need.

Communication

Good, comprehensive clear communication is pivotal.
Our intention is that communication must be of the highest standard between the patient, family and healthcare team. Where the patient has had a progressive illness, open discussion regarding end of life care may have already been started earlier in their illness. However, the Team aim not to assume this. When the patient enters the last days of life the healthcare team need to discuss about the last days of life and impending expected death, including care to support the patient as they die. This includes discussing the use of the Last days of life care pathway as a guide to care. However, the pathway is not a treatment, but a framework for good practice, therefore written consent is not required.

The Team always aim to check the patients understanding and insight into their condition, including how much they would like to know and whether family members should be present. As much as the patient wishes, the discussion should be open and honest, allowing room for questions and thoughts. Where the patient lacks capacity, then decisions are made in their best interests and staff aim where possible to consulted family as part of the process. The Team try to ensure families and next of kin are informed that the patient is dying, in particular where change of focus in care is planned.

Medication

Medication should be reviewed; this is to ensure that the most common symptoms (including pain and restlessness) and ongoing symptoms the patient may be experiencing are well managed. It may be necessary to stop some medicines that are no longer required (such as blood pressure medicine) as they may make the patient feel worse. It may be that some medication that although will not reverse the process could be used for symptom measure – such as antibiotics.

Furthermore, medication needs should be anticipated and prescribed if required ('just in case'), allowing injectable medicines for where patient cannot swallow if necessary. However, medication for symptoms will only be given when needed and in a response to symptoms at the right dose and time. This is individually assessed and only what is required is given.

Care planning
The care pathway aims to support care but does not ever replace clinical judgement. Care planning covers all care needs from the patients personal care and hygiene needs to support for family as possible. The pathway guides care as the patient dies, into caring for the deceased patient and further for the family into after death care.

The team review the patient regularly and reassess the patient's needs and plan of care. The patient should be reviewed as needed; however in hospital the patient should be reviewed every 4 hrs, in particular to assess comfort, pain and other needs, providing care where needed.

Artificial (clinically assisted) nutrition or hydration
The care pathway does not preclude a patient having artificial hydration or nutrition. All clinical decisions are individually based and should be made in the patient's best interest. This means that some patients may need to start, continue or stop intravenous fluids - depending on their individual need. Indeed this will is monitored and reviewed regularly.

Sedation
Continuous sedation is not recommended by the pathway. Sedation medicine is prescribed for patients who are agitated and restless. However, this is in line with the overall medication review and again is individually assessed and managed for only those who require these symptoms to be managed.

Questions and Answers

1. **Will food and water be withheld at Southend Hospital NHS Trust?**
   No. the patient will be individually assessed and for as long as they are able to safely manage eating and drinking will be supported to do so. It is recognised however, that loss of appetite and interest in food and drinks is a normal feature as someone dies.

2. **Does the pathway hasten death?**
   As previously outlined the pathway is a care framework and not a treatment and will not hasten, nor will it delay death.

3. **Why do some people come off the pathway? Does this happen at Southend Hospital NHS Trust?**
   The diagnosing or recognition that a patient is dying is very difficult irrespective of diagnosis or history. There are therefore occasions where patients who were thought to be dying live longer than expected, Indeed, as part of the ongoing review it is vital to reassess the continued use of the pathway on an individual basis where there are any changes or improvements in the patients condition .

   Yes, this does happen at Southend Hospital NHS Trust, not commonly but can happen occasionally as above.

4. **What training do staff have at Southend Hospital NHS Trust?**
   a) All newly qualified nurses receive Advanced care planning (ACP) training (2012)
   b) All newly qualified nurses receive communication training (ongoing)
   c) Junior medical staff on induction, on last days of life / care pathway management
   d) South Essex Cancer and Palliative care course since (2006)
   e) Last Days of life training day (from 2011 - for all levels of nursing staff and MDT- prior to this was taught on newly qualified nurses programme)
   f) Senior medical staff receives training through education fora – Grand Round. Lead consultants access Advanced Communication skills training.

5. **Does Southend Hospital NHS Trust receive funding for the use of the Pathway?**
   No. Southend Hospital NHS Trust did not apply for CQUINS for end of life care

6. **Is there any written support for patients and family?**
   Yes, there is a short information leaflet 'Last Days of life' for past few years – this is currently undergoing planned update, revised version will be available February -March 2012

7. **What framework is in place to support staff?**
   'Guidelines for the care of the dying adult and their family' (multi-disciplinary) are in place.
   'Southend Hospital NHS Trust End of life Strategy' (under development)
   End of life Working Party (Trustwide and multi-disciplinary)
   Multi-disciplinary Team working
   Specialist Palliative Care Team
   Education and training – Trustwide
   National End of life care programme – DH website

8. **How can ward staff get help?**
   As above.
   Specifically from Specialist Palliative Care Team mon -fri 9-5 (potentially 7 day service by 2014)
   Out of Hours Specialist Palliative care advice – for all healthcare staff consultant led.

Next steps

Southend Hospital will await the Department of Health independent review led by Baroness Neuberger into the use and experience of the Liverpool care pathway, due to report to the Department of health ministers and the NHS commissioning Board by summer 2013.

We anticipate auditing current practice between now and the review outcomes, which will provide baseline for possible DH recommendations later 2013.