End of Life Care in Middlesbrough

The South Tees Hospitals NHS Foundation Trust (STHFT) Perspective: an overview for the Middlesbrough Council Health Scrutiny Panel

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Paper prepared by Dr Alex Nicholson, Consultant in Palliative Medicine

Introduction

This brief paper summarizes the context in which end of life care features in health provision, identifies the main themes being addressed at STHFT and answers the specific questions posed in advance by the health scrutiny panel.

Context

In the last six years, end of life care has achieved a higher profile than at any time previously in the 62 years history of the NHS.
The Improving Outcomes Guidance 'Supportive and Palliative Care for Adults with Cancer' (NICE 2004) was created following the NHS Cancer Plan (2000) and highlighted the importance of end of life care, albeit focused on one particular disease group. Since then many National Service Frameworks for specific conditions have included reference to the need for quality end of life care provision.

The National End of life care programme (2004-2007) focused on delivery of three key ambitions:

- More widespread use of a care pathway for the last days of life (the End of life care pathway or Liverpool Care Pathway)
- Consideration of 'Preferred Place of Care' to prompt clinical teams to consider where a patient might wish to be cared for at the end of life, (note that the acronym PPC now refers to Preferred Priorities of Care) and
- Adoption of the Gold Standards Framework, a process designed for Primary Care teams to deliver coordinated palliative and end of life care to their patient population.

The Department of Health's publication of the first End of Life Strategy for the NHS in 2008 was linked closely with Lord Darzi's NHS review (end of life care being one of the eight work streams in his programme) and set out an ambitious but practical challenge for whole service review of end of life care provision across all healthcare settings.

Overview of Trust activity

The current focus on End of Life Care in the acute trust can be considered in relation to five domains and the key points are listed under the following headings: Strategic Issues, Service Development, Education, Governance and Patient/Carer Involvement.

Strategy
STHFT has an End of life strategy written by the Matron for End of Life Care and Bereavement (Elizabeth Price) and the Consultant in Palliative Medicine (Alex Nicholson) and approved by Formal Management Group in November 2009. Objectives are defined in line with themes from the national strategy, responsible personnel are specified, there are specific descriptors of methods of measurement and evaluation, and each objective is linked to the relevant measure(s) in the DoH Quality Markers for end of life care document (2009).

The objectives are grouped into the following themes

- Identifying patients approaching end of life
- Care planning
- Delivery of high quality care in all locations
- Involvement of carers
- Care after death

The strategy has a three year time line (2009-2011) and will report its halfway achievements to the Trust Clinical Standards Sub-group in autumn 2010.

The Trust engages with the locality and the region by Dr Nicholson's membership of the Tees End of Life Strategic Delivery Group and the NHS North East End of life Clinical Innovation Team.

Service Development
The Trust has achieved the following developments:

- Appointment of a Matron for End of Life Care and Bereavement in April 2008 to support developments and provide clinical expertise, including training, for nursing and medical staff.
- Successful implementation of the end of life care pathway on every adult ward in the Trust; work is ongoing on a paediatric end of life care pathway in line with national developments.
- A rapid discharge of the dying patient process has been developed over the last three years and is now being formally implemented through a two year pilot project, supported by a grant of £120,000 secured by Dr Nicholson from Macmillan Cancer Relief. The process achieves rapid safe well coordinated discharge of the dying patient to their preferred place of care for the last days of life and is being formally evaluated from a professional and carer perspective by the Centre for Health and Social Evaluation at Teesside University. The discharge process has been used to support discharge from every department in the Trust including intensive care.
- Developed and implemented an end of life care pathway specifically for use on the Intensive Care Unit.
- Refurbishment of a ward with an architect designed quiet area specifically for the care of patients who are dying, work undertaken by the Trust in conjunction with the Kings Fund's 'Enhancing the Healing Environment' initiative.

Education
End of life care is included in all induction events for new medical staff and in all junior medical training programmes. The Preceptorship programme for new nursing staff also includes end of life care.

A module on end of life care has been specifically developed by Teesside University for ward nurses at STHFT and is being run for the first time in Autumn 2010. It will be possible to run this module three times per year if staff are enabled to attend.

Update sessions on end of life care are provided for the nursing staff on a monthly basis.

An e-learning package for all staff is in the final stages of development and addresses end of life care in general, advance care planning, the care pathway foe the last days of life and awareness of the discharge of a dying patient process.
The consultant in palliative medicine conducts joint ward rounds with consultants in the departments of oncology and respiratory medicine, and is a frequent visitor to departmental meetings across the whole organization.

Governance
The Trust has participated in both cycles of the National Care of the Dying Audit with results reported back to the Nursing and Midwifery Professional Practice Group and the Clinical Standards Group.

The implications of the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report for the Trust have been summarized and presented to the Clinical Standards Group.

The End of Life Care Pathway for the last days of life is currently being revised in line with the latest national recommendations, and the current revision has been a collaboration between the community palliative care team, community hospitals, hospice and acute hospital so that the same care pathway documentation is used in all care settings for consistency and the ability to transfer patient care directly can take place without replication of paperwork.

A quarterly audit on end of life care has been established which examines particularly the use of the end of life care pathway in expected deaths (part of the Commissioning for Quality and Innovation (CQUIN scheme) and the quality of the records kept. The audit samples case notes from all departments and results are shared across the Trust.

All complaints about end of life care are reviewed by the consultant in palliative medicine to identify 'lessons learned' and themes which may guide service and educational developments.

Patient/Carer Involvement
Information leaflets have been produced ('Advance Decisions' and 'When someone is Dying') which all wards can provide to support patients/carers with information.

Examples of best practice have been shared around the Trust via the End of Life Strategy, for example two departments offer bereavement support consultations following a death, another sends a card of condolence and offers an appointment with the duty consultant at the time of the relative's death and another encouraged a feedback comments process following a bereavement.

The Tees End of Life Carers Group has been consulted or attended by the End of Life Matron to gather views on developments; the patient/carer representative on the Tees Supportive and Palliative Group is also consulted.

Response to specific questions submitted in advance

- ***Does the South Tees Trust have a policy or strategy as to how EOLC is delivered at JCUH?***

The STHFT strategy is outlined above.

- ***The Panel has heard elsewhere that a significant number of people die in an acute hospital unnecessarily. Is this a view that the Trust shares and if so, what should the local health & social care economy, including the Trust, do about it?***

There are several dimensions to this problem. The simple answer is 'yes' but the reasons are highly complex and often multiple. An 'unnecessary' inpatient death may arise because of one or more of the following:

- Lack of clarity about patient choice
- Failure to recognize patient's approaching end of life
- Failure to engage in future care planning, possibly due to perception of inadequate skills or experience, fear of upsetting the patient/family/carers by exploring sensitive issues
- Carer fear or fatigue after supporting a patient at home with increasing health and social care needs – frequently compounded by lack of extended family support available
- Lack of appropriate advice to manage symptoms that change at home or provide reassurance about a given change or development in the patient's condition
- Inappropriate admission to hospital of a patient who could have been cared for where they were, perhaps due to being visited by an unfamiliar doctor or one who fears litigation from appearing neglectful by not admitting the patient
- Inadequate provision of alternatives to admission to acute hospital

What to do about it?

- Support clinicians to consider the 'surprise question' ('Would I be surprised if this patient died in the next 6-12 months?') as advocated by the NHS North East End of life group and endorsed in the STHFT end of life strategy and thereby give an indication to primary care clinicians that future care planning needs to begin. The problem with this is that it is not easy to be sure of the answer, provokes distress if discussed, may appear to the patient (in some cases but not all) to indicate a negative attitude and prospect rather than being seen as an opportunity for empowerment to allow discussion of personal preferences in advance of these being difficult to determine. For this to become 'commonplace' it needs not only action by clinicians (and training for them to communicate the issues well and empathetically and to be able to negotiate future care plan discussions) but also a societal change to consider that this sort of forward thinking is not meant to be morbid, but helpful. This is work for all of us and in part is underway.
- Develop more community care both professional and lay – possibly even volunteers
- Certainly protect, and probably increase, community hospital bed provision as an alternative to acute hospital when 24hr care is unavoidable
- Develop 'super' care homes with high calibre staff, rewarded with a higher tariff, to provide an option for admission from home in a crisis rather than acute hospital.
- Support the Gold Standards Framework for care homes programme and other educational developments for care home staff so they are empowered to keep residents in the care homes and not admit them when they deteriorate but stand to gain nothing from acute admission
- Support out of hours doctors by greater use of care plans and clear information about escalation of care decisions for frail and 'nearing end of life' patients so they have the confidence to arrange symptom relief but not admission when this is the right thing to do
- Provide resources for access to 'out of hours' palliative care professionals at the very least with properly funded advice lines and probably with the potential for a visit to advise on care at weekends/bank holidays. The advice support should be robustly configured '24/7'; the visiting service could be day-time hours, seven days per week.

- ***What role should an Acute Trust, and particularly a busy Acute Hospital, play in the provision of EOLC?***
  - High quality care for those patients who are not expected to die but who do so nevertheless
  - Rapid assessment and symptom review of patients admitted who might have been kept at 'home', with speedy review of social and health care packages (integrating with community health and social care professionals) and repatriation to 'home'. Developments including the Acute Oncology Service and a swifter access to specialist support in Accident & Emergency would be expected to support this process.
  - Expert advice from secondary clinicians to primary clinicians on those

patients who may be approaching end of life (i.e. last 6-12 months of life) as far as it is possible to determine in order to facilitate commencement of future care planning.

- ***How does the Trust feel that Middlesbrough, as a health and social care system, deals with those at the end of their life and their care?***

There is a lot of good and excellent care about and excellent developments and initiatives for the future. However, provision is patchy and we need further work to increase the skills of all to the skills of the best. We need to improve the support services in community to prevent unnecessary admissions as discussed above.

- ***Is the Trust confident that frontline staff have sufficient training to deal with people at the end of their life?***

There is plenty of training available although, due to multiple competing demands it can be difficult for managers of clinical teams to release staff for training whilst prioritizing clinical service provision in the face of real financial constraints. The Clinical Matron and Consultant for Palliative Medicine provide both formal and opportunistic training for staff at all levels.

- ***Does the Trust feel that EOLC in Middlesbrough is sufficiently '24 hour'?***

The crucial word is 'sufficiently'. There are good services available, including 24hr district nursing and the palliative care out of hours nursing service. However the specialist palliative care team provision in the acute (and community) settings is still 'office hours' orientated and this needs to change, with attendant resource implications.

There is an informal arrangement for Teesside Hospice to provide an out of hours advice service but this distracts clinical staff, especially at nights and weekends, from hands-on clinical care. (A commissioning proposal to secure a more robust service submitted last autumn through the cancer commissioning round was unsuccessful).

The consultant out of hours rota (Tees-wide) provides only for telephone advice and is not resourced to support a visiting or face to face consultation service. No palliative care specialist nurses currently work at weekends. The question is whether specialist staff are needed out of hours or whether further investment and support to district nursing teams would be a more appropriate. This is unclear and it would be helpful to scope some work to determine whether having a specialist nurse or doctor on duty would actually prevent the unnecessary transfer of a patient into acute setting, or whether more 'hours' support from health care assistants and district nurses would actually be more productive.

- ***Is the Trust confident that its patients who are approaching the end of life, and their carers, are engaged early enough, where clinically possible,***

to allow people to exercise choice over their end of life care?

There is still more to be done here and it links to the points made earlier about recognizing the approach of end of life, and having skills, time and opportunity to discuss future care plans with a population receptive to the idea of talking about them at all. Not all of these crucial elements are currently in place.

- ***Is the Trust satisfied with the role it plays relating to EOLC in Middlesbrough?***

To be satisfied would suggest complacency. There is always more to be done. Providing the core elements consistently well with a fully engaged work force who recognize the importance of this care is the objective of the Trust's End of Life Strategy. This has not yet been achieved and a formal mid-point review will be an objective of the end of life Matron when she returns from maternity leave in early autumn. Future developments are suggested below.

- ***Where next for EOLC in Middlesbrough? Where does it need to develop?***

From a Trust perspective the main issues are to implement the strategy fully and to be highly collaborative in the provision of end of life care to ensure that patients' priorities are realized with the support of a skilled and attentive workforce. Across the health and social economy the greatest opportunity for the future lies in an even greater education and research agenda building on the existing excellent School of Health and Social Care at Teesside University.