End of Life Care – The Amber Care Bundle for patients whose recovery is uncertain

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With acknowledgments to:
Dr Adrian Hopper
Professor Tom Robinson
Anita Hayes
End of Life Care – Acute stroke

- Context and national strategy
- Why stroke
- What is the AMBER care bundle
- What have we achieved
- Implementation
• Most preferred place of death: All England 63% home
• 53% all deaths in hospital
• 62% of CVD deaths occur in hospital (41% cancer)
We know that:

• End of life care is approached variably in acute stroke units.
• Outcome is difficult to predict in many patients
• The Liverpool Care pathway (LCP) is often not used as this appears too limiting and final where there is ‘uncertain recovery’.
• National Stroke strategy QM 11
  – People who are not likely to recover from their stroke receive care at the end of their lives which takes account of their needs and choices, and is delivered by a workforce with appropriate skills and experience in all care settings.
• **End of Life Care Strategy** - promoting high quality care for all adults at the end of life

• **NHS Outcomes Framework**: Domain 4
  Ensuring people have a positive experience of care
  
  – Improving the experience of care for people at the end of their lives
• End of life care, sections 5.28 – 5.33

• Actions 8 & 9
“It is now time for acute hospitals to embrace a positive culture in end of life care and recognise it as a core responsibility of every hospital and health care professional to deliver excellence for people at the end of life and their families

Professor Sir Mike Richards
What does good look like?
Possible Stroke Outcomes

• Those patients for whom a degree of recovery is anticipated and who are very likely to gain benefit from full rehabilitative measures.

• Those patients where there appears to be an extensive stroke with profound irreversible damage (and/or co-morbidities) such that death in a matter of days is a probable outcome.

• Those where the extent of stroke and/or the irreversible damage is moderate or unclear. There is associated uncertainty as to the patient’s likely survival. It is possible or likely that the patient might not survive the next 30 days.
Route to success: end of life care in acute hospitals

Five enablers

• Advance care planning
• The AMBER care bundle
• Liverpool Care Pathway
• Rapid discharge pathway
• Population based end of life care registers

A collaboration of 26 hospitals

Through productive ward methodology
Key enablers along the end of life care pathway

Pre-pathway
Identification of people in the last year of life

Step 1
Discussions as the end of life approaches

Step 2
Assessment, care planning and review

Step 3
Co-ordination of care

Step 4
Delivery of high quality of services in different settings

Step 5
Care in the last days of life

Step 6
Care after death

Advance Care Planning, including Preferred Priorities for Care

Electronic Palliative Care Co-ordination Systems

AMBER Care Bundle

LCP
Rapid Discharge

NHS Improvement
Guy’s and St Thomas’ NHS Foundation Trust
NHS National End of Life Care Programme
1. Integration within an Electronic Palliative Care Co-ordination system
2. Advance Care Planning model
3. The AMBER care bundle
4. Rapid Discharge Home to Die Pathway (RDHP) i.e. anticipated prognosis hours/days
5. Liverpool Care Pathway for the Dying Patient (LCP)

Hospital implementation of the five enablers in November 2012
Fully implemented, in process of implementing or have defined plans to implement

Baseline 2011
Final Nov 2012
Possible Stroke Outcomes

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The AMBER care bundle®
AMBER = Action

A - Assessment
M - Management
B - Best practice
E - Engagement
R - Recovery uncertain
Patients whose recovery is uncertain

Well | Uncertain recovery | Last days

---|---|---
Early planning | AMBER Care Bundle | Liverpool Care Pathway

- Critical care, full medical intervention, responding to treatment expected recovery
- Recognition of uncertain recovery
- Full intervention with added symptom control
- Recognition of the dying phase

Instructions
If yes to both questions proceed to implementation of AMBER bundle.
Care bundle

Bundle has:

- Four to five components
- Can be rapidly answered yes/no
- Based on evidence based or self evident good practice

Can be locally implemented / quality controlled

Helps communication and team working

Easy to measure
The AMBER care bundle

• Stage 1: identification
  – Is the patient deteriorating, clinically unstable, and with limited reversibility
  – Is the patient at risk of dying within the next 1-2 months

• Stage 2: day 1 interventions

• Stage 3: daily ACT

• Stage 4: stopping
Stage 1: Identification

Is the patient suitable for the AMBER care bundle?
1. Is the patient deteriorating, clinically unstable, and with limited reversibility; and,
2. Is the patient at risk of dying within the next 1-2 months?

Stage 2: Day one interventions

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Action</th>
<th>Comments</th>
<th>Name Date &amp; Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical plan documented in patient record Including: current key issues, anticipated outcomes, resuscitation status</td>
<td>☐ Yes ☐ No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Escalation decision documented Including: □ Ward only □ HDU only □ ITU</td>
<td>☐ Yes ☐ No</td>
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<tr>
<td>Medical plan discussed and agreed with nursing staff</td>
<td>☐ Yes ☐ No</td>
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<td></td>
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<tr>
<td>Patient ± carer discussion or meeting held and clearly documented Which may include: uncertain recovery and treatment options, preferred place of care, any concerns or wishes, who was present</td>
<td>☐ Yes ☐ No</td>
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Record details in the patient’s record

Remember to apply the principles of the Mental Capacity Act 2005
Stage 3: Daily ACT – monitoring and review

• Day one: identification and initiation

• AMBER care bundle follow-up

  A “Is your patient still ‘AMBER’?”

  C “Has medical plan Changed?”

  T Have you Touched base with patient/carers - Is everything OK?”

Review patient’s preferred place of care. Has it changed?
Stage 4: The AMBER care bundle stops if

- Patient recovers
- LCP is commenced
- Patient dies
- Patient is discharged or transferred to a clinical area not familiar with its use (may be discharged on Gold Standards Framework)
Patients suitable for the AMBER care bundle in GSTFT

- Patients whose potential recovery was recognised as uncertain
- 638 patients (01/08/11-31/07/12)

<table>
<thead>
<tr>
<th></th>
<th>Number of patients</th>
<th>%</th>
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<tbody>
<tr>
<td>Died (care supported by AMBER care bundle)</td>
<td>81</td>
<td>13%</td>
</tr>
<tr>
<td>Died (care supported by LCP )</td>
<td>190</td>
<td>30%</td>
</tr>
<tr>
<td>Discharged from hospital</td>
<td>365</td>
<td>57%</td>
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<tr>
<td>Other (died ICU)</td>
<td>2</td>
<td>0.3%</td>
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<tr>
<td>Total</td>
<td>638</td>
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GSTFT learning

What we found out:

• Medical decision making inconsistent

• Ineffective communication within team

• Patient/carer discussions did not include:
  – Preferences
  – Uncertainty

What we’re doing differently:

• Generating multidisciplinary team discussion and understanding

• Consultant support for escalation framework where uncertainty exists

• Early pro-active patient/ carer discussions about uncertain recovery and preferences

• Systematic follow-up

• Reliability
AMBER care bundle supports QIPP:

Ensures best possible death and bereavement for hospital patients and their carers

- **Quality**: enhanced patient and carer experience and satisfaction through early and consistent conversations about care and treatment choices;

- **Productivity**: helping to avoid hospital readmissions through early recognition of end of life care needs, efficient team working and fewer unwanted tests and treatments;

- **Prevention**: by cutting out the delay in recognising and responding to end of life care needs.
Stroke Improvement programme -
Our aims:

• To establish the suitability of the Amber care bundle for use on the acute stroke unit

• Can the Amber care bundle be used without adaption?

• Does the Amber Care bundle support the delivery of appropriate end of life care if required?
What have we achieved:

• 2 pilot sites
  – Bournemouth, Wolverhampton
• Workshop 21 February 2013
• Referenced in the Cardiovascular Outcomes Strategy 2013
• End of Life Care parallel session at UKSF 2013
• Raised the profile on EoLC in stroke
Implementation

• Stroke initiated
  – New Cross, Wolverhampton
  – Bournemouth

• Palliative care/EoLC initiated through Transform programme
  – Worcester
  – Kings College London
Transform Programme Phase 1 and cascade sites
• Pleased to be involved in rolling out the AMBER care bundle on the ASU where a considerable cohort of patients potentially fit this profile. The AMBER Care Bundle gives a good framework to introduce the concept of not making a significant recovery after what are often devastating strokes. ‘I find family members often have unrealistic expectations of what recovery is possible or likely’.

• Inpatients supported by the AMBER Care Bundle can progress to LCP seamlessly if this becomes the most obviously beneficial route. The close family members and patient are ‘gentled’ into what hopefully will be a peaceful and dignified death.

• ‘I can think of several cases where the AMBER care bundle has been very helpful in guiding discussion and management.’
Amber network - expectations

• Agreements and licence – no fee
• Copyright and responsibility for implementation
• Terminology “the AMBER care bundle”
• Central point of knowledge in information: share your learning with AMBER care bundle design team
• Minimum dataset: heatmap and baseline & follow-up data 1 year after implementation
• Not for profit, sustainable central team to support learning
The AMBER care bundle Network

- Monthly telephone meetings
- AMBER care bundle heatmap analyses
- AMBER care bundle email / ad hoc support
- Resources
- Ideas, innovation, expertise
2013 developmental plans

- Transform End of Life in Acute Hospital cascade
- **Stroke** – gather data & spread??
- Community AMBER care bundle
- AMBER care bundle: Scotland
- Resources: web-based, materials
- Evaluation
What does good look like?