One chance to get it right
- how do we deliver it?

7th LCA Palliative Care Stakeholder Forum
Thursday 18th September 2014
One chance to get it right
Brief Overview

Maureen McGinn
LCA Project Manager
One chance to get it right – the publication

• Drafted by the LACDP, established following the independent review of the LCP (July 2013)
• Published June 2014 – 167 pages of guidance
• The approach should be applied irrespective of the place in which someone is dying and regardless of whether those providers concerned were previously using the LCP.
• Approach developed to ensure high quality, consistent care for people in the last few days and hours of life
• Centred around five priorities for care and how they should be applied by providers, commissioners of care and education / training commissioners, as well as necessary commitments from national bodies.
The Five Priorities for Care

1. The possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken *in accordance with the person’s needs and wishes*, and these are regularly reviewed and decisions revised accordingly.
   - Recognising ‘dying’
   - Communicating about dying

2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.

3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
   - Involvement of families in decision-making
   - Professional responsibility for decisions about care and treatment
   - Communicating professional responsibility for care and treatment
   - Capacity and advance decisions
The Five Priorities for Care

4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

- Planning care
- Food and drink
- Use of sedatives and pain relief
- Advice from specialist palliative care teams
- Documenting treatment and care
Key National Developments

- **NICE new clinical guideline** on the care of dying adults, which it expects to publish in 2015.

- Supporting **CQC’s new approach to hospital inspections**, under which end of life care will be one of eight core service areas to be inspected.

- Informing the **CQC inspection of end of life care in hospices**, adult social care, community health services and general practice. It will also be taken into account as CQC undertakes a themed inspection focusing on end of life care in 2014/15.

- Health Education England and others will initiate work to guide in the use of the e-learning programme **e-ELCA**, as a resource to support education and training.

- The National Institute for Health Research (NIHR) has commissioned updates of **Cochrane Reviews** of evidence on medically assisted nutrition and on medically assisted hydration for palliative care patients (published April 2014). NIHR has also commissioned a **mapping of evidence requirements from the Priorities for Care**.

- The results of the NIHR mapping and the recently established James Lind Alliance Priority Setting Partnership to inform the **programme of future research** around care for people in the last few days and hours of life.
What we can and should measure to assess quality of care for the dying and their families?

Dr Nigel Sykes
LCA Palliative Care Group Chair
Medical Director, St Christopher’s Hospice
Kingston Hospital’s Response: Care of actively dying patients

Dr Lulu Kreeger
Consultant

&

Thora Thorhallsdottir
Lead Nurse
Plan

• Our response to the More Care Less Pathway report

• Headlines from
  – Staff survey of support needs
  – Audit of nursing documentation pre and post introduction of a nursing care plan for dying patients
Response to “More Care Less Pathway:

• Coincided with our EoLC Strategy Group
• Consultation around the hospital

– Stopped the LCP with new intake of doctors
– Created Principles of Care for Dying Patients
– Created Intranet Department
– Increased input from HPCT
Staff Survey of Support Needs

• Has stopping the LCP impacted on the way you care for patients?
  – If yes, in what way?

• Can you make any suggestions as to what would support you better to care for dying patients?

• Are you aware of the Principles of care for dying patients:
  – If yes, do you find them helpful?
TOTAL: 47
47% (22) Nursing
53% (25) Medical
Has stopping the LCP impacted on the way you care for dying patients?

1a. Has this impacted on the way you care for dying patients?

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<thead>
<tr>
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<th>Percentage</th>
<th>Count</th>
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<tbody>
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<td>Yes</td>
<td>39%</td>
<td>18</td>
</tr>
<tr>
<td>No</td>
<td>61%</td>
<td>28</td>
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</tbody>
</table>

* 46 total responses, 96% of submissions
Key themes (24 comments):

• Loss of prompt/framework

• Lack of consistency in care
  – Aspects of care being missed (nursing)

• Decision making concerns
  – Fear/reluctance to stop treatment, delaying support and appropriate care
  – Less clarity on aims and goals of care

• Sense of uncertainty
Suggestions - supporting staff
(31 comments)

- Holistic care plan/framework
- Training
  - Openness and Communication
  - Prescribing
  - Concept of personalised care plan
- Improved workforce on the wards
- De-briefing/reflective practice
- Better MDT models of care
  - Nursing a stronger voice
- Access to SPC support
  - Awareness of OOH cover
Are you aware of the Principles of Care for dying patients?

3a. Are you aware of the Principles of Care for Dying Patients, which is the Kingston Hospital teaching model for caring for actively dying patients in Kingston Hospital?

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<th>Percentage</th>
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<td>Yes</td>
<td>79%</td>
<td>37</td>
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<tr>
<td>No</td>
<td>21%</td>
<td>10</td>
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</table>

* 47 total responses, 98% of submissions

3b. If Yes, do you find it helpful?

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<thead>
<tr>
<th>Answer</th>
<th>Percentage</th>
<th>Count</th>
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<tr>
<td>Yes</td>
<td>97%</td>
<td>35</td>
</tr>
<tr>
<td>No</td>
<td>3%</td>
<td>1</td>
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</tbody>
</table>

* 36 total responses, 75% of submissions
Nursing Documentation:

Audit and development of a nursing care plan for dying patients
Nursing care plan for dying patients

- Developed in response to nursing feedback post LCP
- Reflects the areas highlighted on the back sheet of the Principles
- Piloted on four medical wards
- Audit of nursing documentation pre and post pilot
- Survey of experience of using the care plan
Audit Standards

- Nursing care for dying patients should include at a minimum of four hourly assessments of symptoms (pain, nausea, agitation, respiratory secretions).
- Excellent basic care should be reviewed and given at a minimum of four hourly and include mouth care, checking of bladder and bowel function, supporting oral intake as appropriate and ensuring dignity.
- Needs of family should be identified and supported including making available facilities known and contact numbers documented.
- The family bereavement booklet should be given to family.
- Spiritual needs of patient and family should be identified and referral made to Chaplaincy as appropriate.
Assessment of symptoms documented 4 hourly

<table>
<thead>
<tr>
<th></th>
<th>Pre new care plan (n=20)</th>
<th>Post new care plan (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Nausea</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>Agitation</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Respiratory Secrets</td>
<td>0</td>
<td>8</td>
</tr>
</tbody>
</table>
Any documentation of symptoms in last 24 hours

<table>
<thead>
<tr>
<th></th>
<th>Pre new care plan (n=20)</th>
<th>Post new care plan (n=20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>13 (65%)</td>
<td>9 (45%)</td>
</tr>
<tr>
<td>Nausea</td>
<td>4 (20%)</td>
<td>7 (35%)</td>
</tr>
<tr>
<td>Agitation</td>
<td>6 (30%)</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>Respiratory secretions</td>
<td>4 (20%)</td>
<td>9 (45%)</td>
</tr>
</tbody>
</table>
Action taken if symptoms were identified

<table>
<thead>
<tr>
<th>Symptom</th>
<th>All</th>
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<tbody>
<tr>
<td></td>
<td>Pre care plan</td>
</tr>
<tr>
<td>Pain</td>
<td>50% (4)</td>
</tr>
<tr>
<td>Nausea</td>
<td>60% (3)</td>
</tr>
<tr>
<td>Agitation</td>
<td>43% (3)</td>
</tr>
<tr>
<td>Respiratory Secretions</td>
<td>50% (3)</td>
</tr>
</tbody>
</table>
Documentation of family support needs

**Support needs of family documented**

- **Family bereavement booklet given**
  - Pre new care plan: 15% (3)
  - Post new care plan: 37% (7)

- **Chaplaincy support offered**
  - Pre new care plan: 5% (1)
  - Post new care plan: 42% (8)

- **Documentation of family spiritual needs**
  - Pre new care plan: 5% (1)
  - Post new care plan: 42% (8)

- **Documentation of patients spiritual needs**
  - Pre new care plan: 5% (1)
  - Post new care plan: 60% (12)

- **Fold up bed offered**
  - Pre new care plan: 0%
  - Post new care plan: 16% (3)

- **Parking permit offered**
  - Pre new care plan: 0%
  - Post new care plan: 16% (3)

- **Willow room code given to family**
  - Pre new care plan: 0%
  - Post new care plan: 16% (3)

- **Coping with dying leaflet**
  - Pre new care plan: 0%
  - Post new care plan: 16% (3)

- **Information / support sheet given to family**
  - Pre new care plan: 0%
  - Post new care plan: 16% (3)

- **Single room offered if available**
  - Pre new care plan: 10% (2)
  - Post new care plan: 32% (6)

- **Contact numbers for family members**
  - Pre new care plan: 5% (1)
  - Post new care plan: 32% (6)

- **Assessment of family support need documented**
  - Pre new care plan: 5% (1)
  - Post new care plan: 47% (9)
Survey amongst users of nursing care plan (15)

15/15 liked using it

What did you like/find helpful?
- Provides prompts
- Identifies needs of dying patients
- Informs staff on what to focus on

Does it help you looking after dying patient?
15/15 YES

- Easy to follow
- Patient focused and not paper work focused
- Provides triggers to check
- Helps newer staff what care should be provided
Next steps.....
Acknowledgements: Sam Eaton and the Audit Team at Kingston Hospital
Individualised Care Agreement for the Last Days of Life

Dr Charlotte Clare
Consultant in palliative medicine
North West London Hospitals Trust
Planning

• End of Life Care Steering Committee
  • Lines of reporting
  • Composition multidisciplinary, incl. user rep
• Offered three examples of alternative ‘LCP’ to choose from as starting point
  • Jane Cowap vs Kingston vs Welsh document
• ‘Task and finish’ approach
  • Short time schedule
  • 4 meetings; launched two weeks ago
First section

• Checklist
• Senior nurse and senior doctor to sign that patient thought to be in last days of life.
• Explain why thought to be in last days of life
• Facilities available for visitors/leaflet updated with ward info and given to relative.
• Care *agreed* with relatives/patient
• ‘Ceiling of care’ info
8. **Nutrition at the end of life.** Continue to offer appropriate foods for as long as able to swallow safely. Consider the potential benefits and adverse effects of different routes, particularly if the patient is - or becomes - unable to swallow.

What is the agreed plan?

..........................................................................................................................

..........................................................................................................................

..........................................................................................................................

..........................................................................................................................

Date: ........................................... Initials:...............................
3. **Prescribe prn drugs for managing the common symptoms at the end of life** (eg for pain, dyspnoea, agitation, nausea and respiratory secretions). Provide an explanation of when, how and why these might be used, including the indication for syringe driver if needed:

What information has been shared, and what is the agreed plan?

**Injectable medicines will be prescribed to be given by**

nurses only if need arises. If several doses required these

can be given by infusion under the skin to spare repeated

**Injections.**

Date: ……12/9/2014………... Initials: ……CMC………………
Nursing Assessments

- Baseline physical needs
- 4-hourly vs 2-hourly assessments
  - ‘Comfort Rounds’
- Signatures at bottom of each assessment time
- Exception reporting sheet: C = confirmed or O = Other
- Care after death checklist – including bereavement office information for audit
Advantages

- Multi disciplinary input for document with top down approval within the Trust

- Aide memoire for aspects of care in last days of life that should be *agreed* with family and/or patient – emphasis on communication
Disadvantages

• Seems like a long document at first glance!
  • 15 points to be completed over 5 sides of A4 of initial care agreement
  • When printed out from intranet includes information leaflet (4 sides), 3 days of assessments (3 sides per day), fax to GP, symptom control algorithms (7 sides), care after death check list (2 sides)

• Requires (re-)training of doctors in discussions around last days of life

PLUS

• Rubbish acronym!
How can we get it right

Liz Bunker
Lead Nurse Palliative and End of Life Care

Dr Yolande Saunders
Consultant Palliative Medicine
Background

- Liverpool Care Pathway
- Independent review
- The Leadership Alliance for the Care of Dying People
What would we want if LCP hadn’t existed

• Personalised/Individual
• Involved the whole team, patient and family
• Applicable across all care settings
• Auditable
• Underpinned by competent, confident staff who can demonstrate basic communication skills
Our thoughts at Hillingdon

• Keep it simple
• Create a seamless transition between active and palliative management
• Still able to audit
• Don’t introduce copious amounts of new paperwork
THH INDIVIDUAL CARE PLAN FOR PATIENTS IN LAST HOURS OF DAYS OF LIFE

Using the priorities of care for the dying person checklist¹:

- **Recognise** Patient likely to die in next hours or days and reasoning for this
- Consider any reversible causes for deterioration and treat where appropriate / possible
- **Communicate** Communication of this recognition to patient and family / carers
- **Involve** Involve patient and family / carers in decisions about treatment care and place of care. Document where decisions are made in best interests
- **Support** Support the needs of patient and family / carers as far as possible
- **Plan and do** Create and deliver individual care plan which includes plan regarding food and drink, symptom control and social, psychological, spiritual support, and parameters to assess patient’s comfort every 4hours
• **Individual Care Plan for:** (NAME and identifier: DOB or Hospital Number)
• **Agreed with:** (Patient, HCP, family / carers)
• **Date:**
  - Recognition likely to die in next hours or days
• **Ceilings of care:**
  - Discussion re food and fluids;
  - Rationalisation of medications:
  - Discussion re symptom control including anticipatory (PRN) medications:
• **Ongoing assessment using modified NEWS Pain Assessment and O2 Obs Chart:**
• **Regular symptom assessment and care**
• **Signed:**
• **Documentation of agreement with senior clinician involved:**
  - Write Individualised Care plan in the notes and on the NEWS chart

• **Suggested modification of NEWS Pain Assessment and O2 Obs Chart:**
  - Modify the document to facilitate the individual care plan
  - Record adjustments on chart under ‘news’, ‘additional parameters’ and ‘clinical response’
  - Assess symptoms regularly: pain, N&V, dyspnoea, secretions, agitation
  - Use RR, pain scale, agitation score and N&V score to direct symptom control: eg. use of anticipatory medications, commencement of syringe driver, further review

• **Suggested use of drug chart:**
  - Rationalise medications
  - Anticipatory PRN medication prescribed for: pain, nausea, secretions, agitation
  - 4 hourly food and fluid offered
  - 4 hourly mouth care

• **Priorities for Care of the Dying Person Leadership Alliance for the Care of Dying People June 2014**
End of Life Care at King’s

Jennifer Karno – Palliative Care Matron

jenniferkarno@nhs.net
Objectives

- Care of the dying person at Kings
- Changes to practice
- Recognising the dying patient
- Impact on palliative care team
- “Principles of care of the dying” guidelines
- Evaluation and learning to date
- Further analysis
- Challenges and opportunities – moving forward
Our response

- Drop in events - FAQ + guide to identification orders
- 13th Aug 13 - EoLC plan identification (notification) - (PDN and Matron)
- Emphasis on supporting clinical teams to develop individualised end of life care plan.
- "Principles of care of the dying"
- Spiritual and mouthcare guidelines
- Patients with complex needs are referred to palliative care as normal
- AMBER care bundle “for patients whose recovery is uncertain”- is not a replacement for the LCP
Step 1- EoL care plan notification
Step 2

Order: End of Life Care Plan Identification
Order ID: 002PWP117
Requested By: Shepherd, Kate
Messages: 

Ordering Information:
- Conditional Order
- Template Name:

End of Life Referral - Zzztest, Lcp-One

Please complete the EPR 'End of life care plan order' if a patient under your care has been identified as dying, but you are happy that all their care needs and the needs of the family are being met. Please see http://kweb/kwiki/End_of_Life_Care

If you are concerned about the care and think you need extra support then please also complete the EPR 'palliative care referral'

EoL care plan started __________
Plan discussed with patient?
Plan discussed with relatives?
Sleep Number: 

[OK]
Step 3

Warning!

Zzztest, Lcp-One
End of Life Care Plan Identification

Alert 1 of 1

Please note; this is not a palliative care referral

This order identifies that this patient has an individualised End of Life care plan in place.

The palliative care matron or PDN will review the care plan with the ward team on the next working day.

Acknowledged

Comments

OK Cancel Help
Assessment / Audit tool

EOLC MDT assessment for the dying patient

Name of patient:                
Hospital no.             Ward: ... see below 
Names Dr/Nurse/Relative/Friend 

4. Holistic care

a) Spiritual needs of patient addressed? YES NO 
b) Spiritual needs of family addressed? YES NO 
c) Any previous wishes identified regarding organ / tissue donation? YES NO

d) Full explanation and discussion regarding the patient is dying and plan? YES NO 
e) Full explanation and discussion regarding DNAR status? YES NO 
f) Full explanation and discussion regarding hydration? YES NO 
g) Full explanation and discussion regarding nutrition? YES NO 
h) Are next of kin details recorded in notes? YES NO 
i) Has the team explained the process of events to follow? YES NO

5. On-going care plan

a) Have the family been offered support? YES NO 
b) Have the family been given written information on Care of the Dying YES NO 
c) Has the patient a mouth care pack by the bedside? YES NO 
d) How often mouth care given (circle)? 1hly, 2hly, 4 hly YES NO 
e) Does the patient appear comfortable at assessment? YES NO 
f) Is hospital specialist palliative care team involved? YES NO

c) Comments: 

Name & Position of Person Completing Form 
Name Job Title

3. Communication

a) With patient? YES NO 
b) With family? YES NO 

Who was present? - see below 
Names Dr/Nurse/Relative/Friend

c) Does the ward have a family room for meeting to occur? YES NO

2. Review of clinical interventions:

a) Review of appropriateness of medication YES NO 
b) Review of nursing and medical interventions e.g. freq. of obs, blood tests, other investigations. YES NO 
c) DNAR status YES NO 
d) Documentation of DNAR status by senior doctor YES NO 
e) Review of patient’s nutritional needs YES NO 
f) Decision re artificial nutrition by senior doctor YES NO 
g) Review of patient hydration needs YES NO 
h) Decision re artificial hydration by senior doctor YES NO 
i) Anticipatory prescribing for symptoms of pain, respiratory tract secretions, agitation, nausea and vomiting, dyspnoea YES NO

1. Identification of dying (prognosis days):

a) Date patient identified as dying YES NO 

Which members of the MDT are involved in the decision:

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<thead>
<tr>
<th>Names</th>
<th>Position</th>
<th>Date</th>
<th>Time</th>
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</table>

b) Discussion documented in notes YES NO 
c) Senior clinician documentation that patient is dying YES NO

Diagnosis: 

Name & Position of Person Completing Form 
Name Job Title

Name of patient:                
Hospital no.             Ward: ... see below 
Names Dr/Nurse/Relative/Friend 

b) Discussion documented in notes YES NO 
c) Senior clinician documentation that patient is dying YES NO

3. Communication

a) With patient? YES NO 
b) With family? YES NO 

Who was present? - see below 
Names Dr/Nurse/Relative/Friend

c) Does the ward have a family room for meeting to occur? YES NO

Name & Position of Person Completing Form 
Name Job Title

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### Which area of palliative care?

<table>
<thead>
<tr>
<th>Dying in hours or days</th>
<th>Complex pall care needs</th>
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<tr>
<td>1. inability to arouse patient at all</td>
<td>• Complex pain / symptom control</td>
</tr>
</tbody>
</table>
| 2. dramatic changes in the breathing pattern including apnoea, very rapid breathing  
3. inability to swallow any fluids  
4. marked decrease in urine output and urinary or bowel incontinence  
5. cyanosis, or a bluish or purple colouring to the patients arms and legs, especially the feet and hands                                                                 | • Complex social needs requiring referral to community palliative care services  
• Psychological distress  
• ‘Switch’ in the focus of care, consideration of advance care planning  
• Challenging ethical situations  
• Terminal care  
• Patient, team should be aware of reasons for referral  
• Also can refer family members for support                                                                                                           |

**End of life notification**  
**Palliative care referral**

**PDN+ MATRON**  
**MDT- palliative care**
The principles of care of the dying tool

Principles of Care for Dying Patients

- Identify
  - Deterioration in patient’s condition suggests the patient is actively dying i.e. has the potential to die in hours or short days.
  - Exclude reversible causes e.g. renal failure, infection, hypercalcemia, opioid toxicity, oversedation
  - Is specialist opinion needed from consultant with experience in patient’s condition?

- MDT Assessment
  - Wherever possible the decision to commence an end of life care plan should be made by the responsible Consultant following a face to face assessment of the patient and in consultation with a senior nurse who is familiar with the patient.
  - Where commencement of an end of life care plan appears to be urgent and the Consultant who knows the patient best is not available, the decision may be taken by an experienced Registrar in discussion with an available Consultant and a senior nurse.
  - This decision should be agreed with the relevant Consultant as soon as possible.

- Communicate
  - Explain the recognition of dying or the potential for dying and rationale for this to patient/family
  - Respond to patient/family questions/concerns
  - Inform the MDT

- Plan
  - Discuss and agree an individualised plan of care taking into account patient/family wishes (see overleaf for guidance)

- Document
  - Clearly document plan of care and all conversations in patient’s medical notes
  - Document reason if family contact genuinely impossible (e.g. no family)

- Reassessment
  - Minimum 4 hourly review and delivery of care by nursing staff
  - Minimum daily review by responsible medical team
  - MDT review (to include the responsible Consultant or Registrar and a senior ward nurse) minimum of every 3 days and/or the patient improves or the patient and/or family or healthcare professional express any concern over the plan of care.
  - Is plan of care still appropriate? E.g. has patient condition improved?
  - Refer to palliative care team if required – e.g. uncontrolled symptoms, support for patient, family and/or MDT

For further advice contact the Palliative Care Team: Denmark Hill site: Mon to Fri 9-5pm ext 4060. OOH advice: contact palliative care doctor on-call via switchboard
FRUH site: Mon to Fri 9–5pm ext 65667 or bleep 133/134/706/120/703. OOH advice: contact the St Christopher’s Palliative Care Consultant on-call: 020 8768 4500
### Daily Care Plan Review

**Daily Care Plan Review**

**Review**
- Review both medical & nursing care being given to the patient - ensure all comfort measures are in place
  - Stop any investigations, treatments or medications that are of no benefit to the patient
  - Review hydration and nutrition needs
  - Ensure a DNAR order is in place.

**Communicate and Document**
- Communicate with patient/family to update on a regular basis and following any change in management.
- Document significant conversations in the notes and record contact numbers for key family members
  - This may include preferences around place of care, support needs, and specific issues such as tissue donation.

**Care**
- Maintain excellent basic care - frequent assessment, action, and review
  - Regular mouth care and turning for comfort as appropriate
  - Encourage and support oral food/hydration as patient is able
  - Check bladder and bowel function
  - Ensure dignity and compassion in all care

**Symptoms**
- Assess symptoms regularly - frequent assessment, action, and review
  - Prescribe medications as required for anticipated symptoms e.g. pain, nausea, agitation, respiratory secretions
  - Medications may be required via subcutaneous syringe pump if symptomatic/no longer tolerating oral meds
  - Advice available from the Palliative Care Team, see also Kwiki Palliative Care

**Family**
- Identify support needs of family
  - Ensure contact numbers and contact preferences updated for key family members
  - Explain facilities available e.g. restaurant, parking permits, folding beds if available
  - Consider single room for patient if available

**Spirituality**
- Identify spiritual needs - for both patient and family
  - Document specific actions required
  - Refer to chaplaincy as appropriate

**Care After Death**
- Timely certification of death (often important for bereaved families)
- Family bereavement booklet
- Inform GP and other involved clinicians
Referring professional

FY1    SpR    SHO    Consultant    Sister    Junior Clinical...  ST4    CT2    FY2    House Officer    GP Trainee    Staff Nurse    STR    Specialist Nurse    Registrar    ST1    Clinical Fellow    CNS    Locum staff grade    Charge nurse    Social worker    ST5    Pharmacist
Further analysis

- Time from referral to death
- Consultant - leading on decision making
- Teaching
  - Generalists development of care plans
  - Roadshows
  - Mandatory E learning or face to face teaching
- Are the EoLC orders helping to improve practice?
  - Initial data collection on assessment of care plans indicate yes – mouth care available, spirituality assessments more frequently completed
  - Staff recognising the dying person and initiating care of the dying
  - Quality of EoLC plans documented and care provided
- Sustainability ????
Challenges and opportunities

Education and Training
- Palliative care tools-mouth care and spirituality guidelines
- Symptom control – administration of medications and PRN’s
- Care of the dying - teaching tool share knowledge
- Highlight wards areas that are not submitting notifications
- Champions – developing a education programme
- Documentation of the care plan provided in the dying phase
- Quality sampling 5 sets of notes each month

Carers needs and assessment
- Essential conversations (patient and carer) documentation
- Coping with dying leaflet and a facilities leaflet (in development)
- Provide comfort measures where possible, NoK details updated
- Anticipate discharge planning for this group of patients involving carers
- Bereavement support
- Famcare – family satisfaction (Guy’s and St Thomas Hospital)
Thank you

Acknowledgement in shared work:
Guy’s and St Thomas Hospital
Princess Royal University Hospital
One chance to get it right: our progress so far

Juliette Culora
Macmillan Palliative Care Matron
Key milestones

- **January 2014**
  - Launch ‘Principles of Care for the Dying’ (inpatients only)

- **September 2014**
  - Re-launch as ‘Priorities of Care for the Dying’
  - Launch of Priorities of Care for the Dying for community patients (Lambeth & Southwark)
New process

- Guy’s and St Thomas’ adapted their process of End of Life Care notification from King’s College Hospital, using the same Electronic (EPR) ordering process as shown in their presentation.

- When an order is placed the following two slides are printed off on the ward, along with printed information on End of Life Care for those important to the patient. The palliative care team and EoLC facilitator receive notification of the order so that care can be reviewed within one working day.

- As with King’s the EoLC notification is separate to making a palliative care referral.
Communicate

Multi professional team, with the person & those important to them, assess & agree individual care plan including review of interventions & medications. Document clearly.

The senior responsible clinician (consultant/competent delegate) should offer to discuss the agreed care plan with the person and those important to them, having explained:

- The person may be dying in hours or days with the reasons for this judgement and the uncertainties
- Respond to and document any questions or concerns
- Review resuscitation status
- If the person does not have capacity to make decisions regarding their clinical care, consult those important to the person and act in the person’s best interests. Record actions taken.
- Use clear language, listen, check understanding and document

Each person should have an individual care plan according to their assessed needs. This should include a daily medical review and re-evaluation. The plan should be discussed openly with the person and those identified as important to them.

Nursing care must be reviewed & documented
Seek advice from the specialist palliative care team if needed 24/7

The senior responsible clinician should ensure that the individual care plan and all conversations are documented clearly in the person’s medical records.

This should include: symptom control, including relief of pain & other discomforts.Prescribe according to end of life care symptom control guidance. Syringe pumps may be required and should be discussed with the person and those important to them before use. Encourage, support & review oral food and hydration if it won’t harm the person. Ensure regular review by the multi-professional team and senior responsible clinician

Actively seek to communicate, do not wait to be asked questions

Adapted from Kingston Hospital's version
Priorities for Care of the Dying Person – in hospital

Each dying person should have an individual care plan according to their needs which is discussed openly with the person (as they wish) and those important to them. It must be reviewed and documented at a minimum of every 4 hours

**Recognise**

- Recognise as a team the reasons why we think the person is dying & the uncertainties surrounding this

**Communicate**

- S sensitively check the understanding of the person and those important to them
- Listen to the wishes and views of the person and those important to them; this may include preferences around place of care
- If the person does not have capacity for a decision, consult with those important to the person and act in their best interests
- Be proactive with ongoing communication and document all significant conversations

**Involve**

- Ensure the person and those important to them know their named nurse and consultant; update white board during each shift
- Involve the person & those important to them to the extent they are able and wish to be involved
- Ensure contact details are documented - including overnight and weekends

**Support**

- Identify support and comfort needs of those people important to the person and review regularly
- Listen and acknowledge their needs and wishes, even when it is not possible to meet all of them
- Recognise that they may be physically and emotionally tired, anxious or fearful
- Ensure Family Care Packs are available for visitors staying overnight and also identify additional needs e.g. showering facilities, access to accommodation, quiet rooms and food and drink
- Identify spiritual, cultural and religious needs

**Plan & Do**

- Develop and document an individualised plan of care to meet the person’s assessed needs & wishes
- Ensure fundamentals of care needs are met and focus on comfort, dignity and compassion
- Pay attention to the person’s physical, psychological, social, spiritual and cultural needs
- Be proactive - consider how the person’s needs may change e.g. symptom control / nursing needs
- Medications may be required via a sub cutaneous syringe pump. It is best practice to discuss this with the person and those important to them prior to use
- Encourage and support oral food and hydration if it won’t harm the person
- Reassess regularly (at least 4 hourly) and update the plan of care as needed. Ensure any changes are discussed with the person and those important to them and clearly documented
- Remember that advice can be sought from the specialist palliative care team 24/7 if needed ( STH Bleep 1624, Guy’s Bleep 1625. Out of hours via switchboard)
- Care after death – refer to policy taking into account spiritual, cultural beliefs

Actively seek to communicate, do not wait to be asked questions
Engagement and uptake - inpatient

[Graph showing line charts with two lines representing 'Number of adult inpatient deaths' and 'Number of deaths supported by Priorities for Care']
Governance
Audit and evaluation

• **January 2014** Prospective audit within one working day of an EoLC notification being made (>20 measures ranging from consultant agreement that EoLC should be commenced to fundamental care needs of patient and family being met).

• We identified key ‘red flags’ where immediate action would need to take to take place to ensure patient safety and minimum standards of communication with patient (if appropriate) and those important to them (see next slide). A clear escalation policy agreed throughout the Trust.

• CNS or facilitator provide information and support in the ward setting within one working day, logging feedback from staff and updating issue log

• Weekly review by senior palliative care staff to review audit data.

• Issue log maintained delay and reviewed weekly

• Monitoring and oversight by Trust Governance committee and Trust End of Life Care Committee

• **July/August 2014** staff focus groups on new process

• **August 2014** onwards, testing of FAMCARE for relatives/carers of those in days and hours of life
<table>
<thead>
<tr>
<th>Lack of documentation - Where feedback required</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
<th>Apr</th>
<th>May</th>
<th>Jun</th>
<th>Jul</th>
<th>Aug</th>
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<tr>
<td>Reversible causes considered</td>
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<tr>
<td>Consultant/designated senior doctor agreement</td>
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<td>Data from presentation available on request. Shows a marked improvement in all measure since new process introduced</td>
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<td>Communication with patient</td>
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<td>24 hour medical review</td>
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**NHS Foundation Trust**
Key challenges and improvements to care

- **Engagement:** new process, new terminology
- **Audit & Documentation:** ‘if it’s not written down it didn’t happen
- **Individualised plan of care:** practical implementation
- **Education, training and facilitation:** resource intensive, sustainability
- **Integration with critical care:** step down and withdrawal of care
- **Amber care bundle vs PoC:** appropriate use of each and transitions
- **Culture shift:** ownership, increasing confidence amongst MDTs
- **Evaluation:** of patient/carer experience of care
Evaluation: PDSA Testing FAMCARE2

- Prospective

- Inclusion: Relatives, carers, important others of patients who have received an EoLC notification

- Exclusion: English not first language, lack of mental capacity, patient deceased

- Administered by a senior palliative care nurse (Matron)

- 6 FamCare2 completed so far
FAMCARE2 – findings from testing so far

• All those surveyed wished the questions to be read to them and their answered scribed on their behalf, did not wish to be left with a questionnaire

• Half found questions repetitive

• A third found there to be too many answer options (Likert scale)

• All felt it was acceptable to undertake survey at the time of administration

• The survey process as an intervention in itself

• Questionnaire can lead to relatives/carers questioning what they have been asking of clinical teams

• The need for senior nurse

• Validated tool, however, selection bias and lack of anonymity in current testing
Priorities of Care for the Dying - Out of hospital
Launched 1\textsuperscript{st} September 2014

- Patients receiving community nursing care in Lambeth and Southwark

- Shared working (G.P’s, District Nursing, End of Life Care coordinators, Care homes, Guy’s and St Thomas’ community palliative care team and St Christopher’s community palliative care team)

- 9 referrals received:
  - 5 under the care of St Christopher’s Hospice and
  - 4 under the care of Guy’s and St Thomas’

- Still in developmental phase with key stakeholders
Priorities for Care of the Dying Person – out of hospital

1. Consider reversible causes eg, infection, opioid toxicity, oversedation, renal failure and hypercalcaemia
2. Is an additional specialist opinion needed?

- Multi professional team, with the person & those important to them, assess & agree individual care plan including review of interventions & medications. Document clearly.

The senior responsible clinician (GP/competent delegate) should offer to discuss the agreed care plan with the person and those important to them, having explained:

- The person may be dying in hours or days with the reasons for this judgement and the uncertainties
- Respond to and document any questions or concerns
- Review resuscitation status
- If the person does not have capacity to make decisions regarding their clinical care, consult those important to the person and act in the person’s best interest. Record actions taken.
- Use clear language, listen, check understanding and document

Each person should have an individual care plan according to their assessed needs. This should include a regular medical review and re-evaluation. The plan should be discussed openly with the person and those identified as important to them.

- Nursing care must be reviewed & documented
- Seek advice from the specialist palliative care team if needed 24/7

The senior responsible clinician should ensure that the individual care plan and all conversations are documented clearly in the person’s medical records.

This should include: symptom control, including relief of pain & other discomforts. Prescribe according to end of life care symptom control guidance. Syringe pumps may be required and should be discussed with the person and those important to them before use. Encourage, support & review oral food and hydration if it won’t harm the person. Ensure regular review by the multi-professional team and senior responsible clinician

Adapted from Kingston Hospital’s version
Priorities for Care of the Dying Person – out of hospital

Each dying person should have an individual care plan according to their needs which is discussed openly with the person (as they wish) and those important to them. It must be reviewed and documented at least daily.

Recognise
- Recognise as a team the reasons why we think the person is dying & the uncertainties surrounding this

Communicate
- Sensitively check the understanding of the person and those important to them
- Listen to the wishes and views of the person and those important to them; this may include preferences around place of care
- If the person does not have capacity for a decision, consult with those important to the person and act in their best interests
- Be proactive with ongoing communication and document all significant conversations

Involve
- Ensure the person and those important to them know the names of the key nurse, GP, other professionals and teams who are providing their care
- Contact the End of Life Care team to arrange joint review
- Involve the person & those important to them to the extent they are able and wish to be involved
- Ensure contact details are documented - including overnight and weekends

Support
- Identify support and comfort needs of those people important to the person and review regularly
- Listen and acknowledge their needs and wishes, even when it is not possible to meet all of them
- Recognise that they may be physically and emotionally tired, anxious or fearful

Plan & Do
- Develop and document an individualised plan of care to meet the person’s assessed needs & wishes
- Ensure fundamentals of care needs are met and focus on comfort, dignity and compassion
- Pay attention to the person’s physical, psychological, social, spiritual and cultural needs
- Be proactive - consider how the person’s needs may change e.g. symptom control / nursing needs
- Medications may be required via a sub cutaneous syringe pump. It is best practice to discuss this with the person and those important to them prior to use
- Encourage and support oral food and hydration if it won’t harm the person
- Reassess daily and update the plan of care as needed, ensuring any changes are discussed with the person and those important to them
- Seek advice from the specialist palliative care team 24/7 if advice is needed or you, the person or those important to them raise concerns
- If the patient dies, follow the care after death policy, ensure equipment is picked up quickly and information is given regarding next steps and bereavement support

Actively seek to communicate, do not wait to be asked questions
Implementation of new individualised end of life care plan

Dr Laura Cottingham
Community Consultant in Palliative Medicine
St Raphael’s Hospice, Cheam
Our aim

- To develop interim paperwork which could capture essential aspects of end of life care
- Ensure correct documentation of conversations and actions
- Avoid a “tick box” document
- Allow easy audit of patient notes
COMFORT & DIGNITY IN THE ‘DYING STAGE’

Having identified the patient as being in the “dying stage” it is important that emphasis is given to the following areas; COMMUNICATION, COMFORT AND CARE.

The patient will require all nursing care, with special consideration given to Comfort and Dignity. Symptom assessment and management will be required each shift and appropriate spiritual support given.

Explanation and ongoing updates should be given to relatives/carers with regard to hydration, symptom management and the patient’s general condition.

This sheet should be placed in section 8 of the notes at the time of identifying the patient as being in the “dying stage” and documentation continued after, with specific emphasis on documenting ongoing Communication, Comfort and Care for both the patient and relatives.
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<thead>
<tr>
<th>Date &amp; Time</th>
<th>Topic</th>
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<tbody>
<tr>
<td></td>
<td>....... has now entered the “Dying Stage” of his/her illness</td>
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<td></td>
<td>Dr. Signature........................................</td>
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<tr>
<td></td>
<td>Nurse Signature.........................................</td>
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<td></td>
<td>This has been communicated to the relatives or carer by</td>
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<tr>
<td></td>
<td>Name..................................................................</td>
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<td></td>
<td>Signature.............................................</td>
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<td>How have the relatives/carers psychosocial needs been addressed?</td>
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<td>Signature.............................................</td>
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<td></td>
<td>The patient’s religious and any spiritual needs/wishes identified</td>
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<td>Yes              No                              Signature........................................</td>
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<tr>
<td></td>
<td>Any comments</td>
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<td></td>
<td>Hospice facilities explained and contact telephone numbers checked</td>
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<td></td>
<td>Yes              No                              Signature........................................</td>
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<td></td>
<td>Any comments</td>
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<td>Topic</td>
<td>Oral medications rationalised by</td>
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<td>Signature..........................</td>
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<td>Comments...............................</td>
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</table>

Based on the patient’s individual needs, how have all relevant symptoms been assessed and managed:

**PAIN:**

**AGITATION:**

**NAUSEA / VOMITING:**

**RESPIRATORY TRACT SECRETIONS / DYSPNOEA**

**BLADDER DISTENSION:**

**THIRST:**

**OTHER:**

*Assess symptoms and document clearly each shift using the coding guidelines below.*
## 8 CARE AFTER DEATH

<table>
<thead>
<tr>
<th>Date &amp; Time</th>
<th>Topic</th>
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<tbody>
<tr>
<td></td>
<td>Date, time and verification of death</td>
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<td></td>
<td>Date                             Time                             Signature</td>
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<td></td>
<td>Comments</td>
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<tr>
<td></td>
<td>Have any spiritual or cultural rituals been identified and met?</td>
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<td>Signature</td>
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<td></td>
<td>Next of kin/relative/carer notified by</td>
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<td></td>
<td>Signature</td>
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<tr>
<td></td>
<td>Information or documentation given to relative/carer regarding medical certificate and registrar by</td>
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<tr>
<td></td>
<td>Signature</td>
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<tr>
<td></td>
<td>Comments</td>
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</tbody>
</table>

**CVS** = cardiovascular system  
**MS** = musculoskeletal  
**MH** = mental health  
**GI** = gastrointestinal  
**NS** = nervous system  
**PS** = psychosocial/spiritual  
**GU** = genitourinary  
**RS** = respiratory system  
**SOC** = social care  
**LS** = lymphatic system  
**O** = Other
<table>
<thead>
<tr>
<th>Date &amp; Time</th>
<th>Topic</th>
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<tbody>
<tr>
<td></td>
<td>Follow up meeting /conversation with relative /carer post death</td>
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<tr>
<th>Date</th>
<th>Time</th>
<th>Signature</th>
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<th>Names of those present:</th>
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<tr>
<th>Comment on any bereavement concerns</th>
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<th>If there are bereavement concerns please notify the bereavement team</th>
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<th>Referral made by:</th>
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**TOPIC KEY**

<table>
<thead>
<tr>
<th>CVS = cardiovascular system</th>
<th>MS = musculoskeletal</th>
<th>MH = mental health</th>
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</thead>
<tbody>
<tr>
<td>GI = gastrointestinal</td>
<td>NS = nervous system</td>
<td>PS = psychosocial/spiritual</td>
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<tr>
<td>GU = genitourinary</td>
<td>RS = respiratory system</td>
<td>SOC = social care</td>
</tr>
<tr>
<td>LS = lymphatic system</td>
<td>pain</td>
<td>O = Other</td>
</tr>
</tbody>
</table>
Going forward

- Currently undertaking audit reviewing quality of notes and mapping against the 5 priorities of care

- Adapt paperwork in light of the audit and feedback from staff/LCA
Introducing the IPP

An Integrated Personalised Plan for residents dying in nursing homes

Julie Kinley
Nurse Consultant for Care Homes
Care Home Project Team
St Christopher’s Hospice
j.kinley@stchristophers.org.uk
Nursing home residents
Demographic details – from 2,444 residents

◆ The mean length of stay: 20 months with a median of 8 months
◆ Length of stay:
  ❖ Nineteen per-cent of residents died within their first month of admission
  ❖ Thirty-four per-cent of residents within the first three months of admission
  ❖ Fifty six per-cent died within a year
‘The way in which the Priorities for care are achieved will vary, to reflect the needs and preferences of the dying person and the setting in which they are being cared for.’
Implementing change into practice

**Three** elements are crucial:

- Context
- Evidence
- Facilitation

(Kitson et al 1998)
Context

The care home context is reported as having a lack of end of life/palliative care knowledge and skills:

‘I think there’s no, none of the staff, qualified or not, had any particular palliative care experience.’ [F9]

‘Difficult at times when Registered General Nurses have no experience with palliative care. I was a little shocked at the first meeting when we had to raise hands to let you know how many nurses had seen a dead patient. ¾ did not put their hand up.’ [C.HF7. 028]

‘Some staff themselves is very fearful and lack confidence to deal with death as a whole.’ [C.HF+AL3.001]
Context

- Mostly Health Care Assistants
- Work is task driven (Sedan 2003)
- Poor retention of staff (Redfern et al 2002) which is worsening. In 2004 only 4% of respondents had worked in their current workplace for less than one year this had risen to 26% in 2011 (RCN 2011)
Context

- Mostly Health Care Assistants
- Work is task driven (Sedan 2003)
- Poor retention of staff (Redfern et al 2002) which is worsening. In 2004 only 4% of respondents had worked in their current workplace for less than one year this had risen to 26% in 2011 (RCN 2011)
Evidence

◆ Action Research Study - Care home staff adjusted the LCP to fit their context (Hockley et al 2005)

◆ This became the Integrated Care Pathway (ICP) for the last days of life

◆ Nursing home managers requested it was altered to the Integrated care plan (ICP) for the last days of life

◆ ICP becomes IPP
## Use of the ICP from deaths occurring in nursing homes

<table>
<thead>
<tr>
<th>CCG</th>
<th>2009/10</th>
<th>2010/11</th>
<th>2011/12</th>
<th>2012/13</th>
<th>2013/14</th>
</tr>
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<tbody>
<tr>
<td>CCG 1</td>
<td>33%</td>
<td>59%</td>
<td>70%</td>
<td>74%</td>
<td>50%</td>
</tr>
<tr>
<td>CCG 2</td>
<td></td>
<td>32%</td>
<td>51%</td>
<td>51%</td>
<td></td>
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<tr>
<td>CCG 3</td>
<td></td>
<td>42%</td>
<td>70%</td>
<td>61%</td>
<td>59%</td>
</tr>
<tr>
<td>CCG 4</td>
<td>17%</td>
<td>37%</td>
<td>59%</td>
<td>58%</td>
<td>58%</td>
</tr>
<tr>
<td>CCG 5</td>
<td>44%</td>
<td>60%</td>
<td>72%</td>
<td>68%</td>
<td>49%</td>
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</tbody>
</table>
Communication sheet for family/friends

<table>
<thead>
<tr>
<th>Name of resident</th>
</tr>
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<tbody>
<tr>
<td>Date of birth</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>NHS No.</td>
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</tbody>
</table>

Use this sheet to record any thoughts (good or bad) you have about the care of your relative/friend

<table>
<thead>
<tr>
<th>DATE</th>
<th>TIME</th>
<th>COMMUNICATION</th>
<th>SIGNATURE</th>
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<tr>
<td>ACTION 4</td>
<td>Ability to communicate in English assessed as adequate</td>
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<td>-----------</td>
<td>------------------------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resident</td>
<td>Too ill [ ] Yes [ ] No [ ]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family/other</td>
<td>Yes [ ] No [ ]</td>
<td></td>
<td></td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>ACTION 5A</th>
<th>Encouraging ‘open’ communication about dying</th>
</tr>
</thead>
<tbody>
<tr>
<td>Encouraging ‘open’ communication about dying is important – even with cognitive impairment, many residents are aware they are dying but may use symbolic language to suggest so. Remember to ask: ‘Is there anything worrying or frightening you?’ Detail any conversations with the resident (if appropriate) and family/friends, and relevant information from ACP discussions concerning last days of life and any other current needs.</td>
<td></td>
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<table>
<thead>
<tr>
<th>ACTION 5B</th>
<th>An electronic palliative care co-ordination system (Coordinate My Care)</th>
</tr>
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| to inform out of hour services has been updated | Yes [ ] No [ ]
<table>
<thead>
<tr>
<th><strong>ASSESSMENT OF COMMON SYMPTOMS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Ensure resident is pain free</strong></td>
</tr>
<tr>
<td>If awake, ask them if they are in pain. However, if they are not able to respond/unconscious then assess for pain when moving them.</td>
</tr>
<tr>
<td><strong>Ensure resident is peaceful ie. not agitated, restless, nor fearful</strong></td>
</tr>
<tr>
<td>Agitation can be due to a number of reasons which need to be understood. Delirium is one cause (ie. plucking at bedclothes). Sometimes the resident's body 'jerks' – this can be caused by too much morphine. If the bladder/bowels are full this can make a dying person restless. Finally, agitation can be due to fearfulness.</td>
</tr>
<tr>
<td><strong>Ensure resident's breathing is calm, regular and not noisy</strong></td>
</tr>
<tr>
<td>Towards the last stage in dying, the breathing can become 'rattly' because of secretions in the chest. This can be helped by changing position and/or medication.</td>
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</tbody>
</table>
‘To achieve this nursing home staff need more than documentation’
Facilitation / Implementation

TRAINING:
1. PRE-IMPLEMENTATION
2. IMPLEMENTATION
3. POST-IMPLEMENTATION

Guidance for the education, training and practice development for care home staff implementing and using the INTEGRATED PERSONALISED PLAN (IPP) for care in the last days of life
Audit

- We are currently undertaking an audit – looking at bereaved relatives' perception of the quality of end-of-life care using the Family Perception of Care Scale questionnaire.
- Audit the implementation of the IPP.
- Audit the usefulness of the document to guide the delivery of quality end-of-life care in nursing homes.
- Leading onto a research study.
Questions for debate:

1. How do we take this forward, making sure that the five priorities are adopted everywhere?
2. How do we avoid making this look like the LCP all over again?
3. How do we evaluate the impact of the various approaches?
4. How do we encourage those who have not yet engaged in any of this, either because of capacity or awareness?
5. What do SPC clinicians expect from the LCA Palliative Care Group? How can we best support you?