Quality of Life and Palliative Care

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Director, Marie Curie Palliative Care Institute Liverpool
Overview

• What is Palliative Care?

• End of Life Care Into the Future

• Care of the Dying – Making a Difference
What is Palliative Care?
Palliative care is an approach which improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
WHO Definition of Palliative Care

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
Palliative Care:

- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
‘You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but to live until you die.’

(Cicely Saunders)
Model for Palliative Care
Hospice and Palliative Care Services (UK) 2006

- 221 Inpatient units with 3180 Beds
- 356 Home Care Teams
- 305 Hospital Support Teams
- 257 Day Care Units
- Specialists in Palliative Medicine and recognised training
<table>
<thead>
<tr>
<th></th>
<th>Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Inpatient services</td>
</tr>
<tr>
<td>2</td>
<td>OPD</td>
</tr>
<tr>
<td>3</td>
<td>Day Care</td>
</tr>
<tr>
<td>4</td>
<td>Bereavement service</td>
</tr>
</tbody>
</table>
Marie Curie Hospice Liverpool

1. Inpatient services
   12 admissions a week
   50% die  50% discharged home
2. OPD
   3,200 episodes a year
3. Day Care
   10 places a day
4. Bereavement service
   30% uptake of follow up
There’s nothing more we can do!
Model for Palliative Care

- Research
- Hospital
- Community
- Audit
- Specialist Unit
- Education
- Patients and Carers
Palliative Care Team Core

- Medical - consultant registrar
- 4 Clinical nurse specialists
- Social worker
- Secretary
- Audit assistant
- Pain team
Demographics

- Total number of referrals 720
- Median age 70 years
- 54% male  46% Female
- Non-cancer referrals  18%
PROMOTING THE DEVELOPMENT AND INTEGRATION OF PALLIATIVE CARE MOBILE SUPPORT TEAMS IN THE HOSPITAL

The fifth framework programme 1998–2002
"Quality of life and management of living resources"
# Three Phases of Development of a HMPCT

**Developmental Integrative and Sustaining**

<table>
<thead>
<tr>
<th>Focus of development</th>
<th>Phase of Development</th>
<th>Core Education and Training Categories</th>
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</thead>
<tbody>
<tr>
<td>Evaluation and development of skills and attitude</td>
<td>3. Sustaining Phase</td>
<td>10. Research</td>
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<tr>
<td></td>
<td></td>
<td>9. Outcome measures</td>
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<tr>
<td></td>
<td></td>
<td>8. Leadership and team issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>7. Education</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6. Ethics</td>
</tr>
<tr>
<td>Values and relationship with Institute</td>
<td>2. Integrative Phase</td>
<td>5. Human resources</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Management skills</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. System/Patient Centred Care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Liaison and communication skills</td>
</tr>
<tr>
<td>(Future) team members</td>
<td>1. Developmental Phase</td>
<td>1. Clinical and specific MPCT competencies</td>
</tr>
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</tbody>
</table>
Overview

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- End of Life Care Into the Future
- Care of the Dying – Making a Difference
National Cancer Plan
2000
The NHS National Cancer Plan

‘Providing the best possible care for dying patients remains of paramount importance. Too many patients still experience distressing symptoms, poor nursing care, poor psychological and social support and inadequate communication from healthcare professionals during the final stages of an illness. The care of all dying patients must improve to the level of the best’
Key Recommendation 14

In all locations, the particular needs of patients who are dying of cancer should be identified and addressed.

The Liverpool Care Pathway for the Dying Patient provides one mechanism for achieving this.
National Cancer Plan 2000

NICE Guidance 2004

End Of Life (EOL) Initiative 2004 - 2007

The Marie Curie Palliative Care Institute LIVERPOOL
Dept of Health : End of Life Care Programme

Aims
1) To extend the boundaries of palliative care provision...for all patients regardless of diagnosis

2) By enabling more patients to live and die in the place of their choice

- £12 million 2004 –2007

- Led by Professors Mike Richards and Ian Philp
Our health, our care, our say:
a new direction for community services

Health and social care working together in partnership
Dept of Health : White Paper 2006

‘All staff who work with people who are dying are properly trained to look after dying patients and their carers’

‘This means extending the role out of tools such as the Gold Standards Framework and the Liverpool Care Pathway for the Dying to cover the whole country’
End of Life Strategy

• All patients < 1 year prognosis

• Strategy to be produced autumn 2006

• Stakeholder event 5\textsuperscript{th} October 2006
  – Key perspectives
  – 50 questions for discussion
Three Key Perspectives

- Patient
- Service
- Societal
Patients

- Preferences not discussed
- Patients not dying in their place of choice
- Symptom control poor
- Lack of dignity, humanity, respect
- Inadequate support during illness and bereavement
End of Life Care – What Matters to Patients

• Symptom control
• Choice and control
• Being treated as an individual – dignity
• Quality of life
• Preparation – practical & personal
• Carers – empathic, kind have time to listen
• Co-ordination and continuity

Aspinal et al 2006
Meaning - Suffering
### Service

- Low profile of end of life care
- Lack of service planning within organisations and across boundaries
- Lack of co-ordination of care for individual patients
- Many staff inadequately trained
- Inequity of service provision, cancer and non-cancer
End of Life – Societal Awareness

- General public 34% had discussed dying
- >65 years 51%

- Why not?
  - I don’t want to think or talk about death
  - Death feels a long way off
  - I’m too young to discuss death

ICM/Endemol/BBC poll 2006
Societal

- Death is unfamiliar
- Media is sensationalist
- Euthanasia and assisted dying debate
- Death not a ‘natural process’
- Preferences not openly discussed in society
- Demographics
Charter for the Normalisation of Dying, Death and Loss (2005)
Essential elements of a Public Health approach toward End-Of-Life Care

- Recognition of the inevitability of death and the universality of loss
- Cultural sensitivity and adaptability
- Culture/settings approach
- Social justice by promoting equal access for all
- Population health approach
- Sustainability
End of Life Care Services

Advocate

Enable

Mediate

Community Permeability Permeability Permeability
Action Areas

1. Build Policy
2. Create supportive environments
3. Facilitate community action
4. Develop personal skills
5. Re-orient health services
Patient Pathway

Advanced Care Planning (ACP)
Gold Standards Framework (GSF)
Liverpool Care Pathway (LCP)
Overview

• What is Palliative Care

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Liverpool Care of the Dying Pathway
Framework of LCP document

• **1 Aim**
  - to improve care of the dying in the last hours / days of life

• **2 Key Themes**
  – Knowledge & Process
  – Quality

• **3 Key Sections in LCP**
  – Initial Assessment
  – Ongoing Care
  – Care After Death

• **4 Key Domains in LCP**
  – Physical
  – Psychological
  – Social
  – Spiritual
What are the key goals for care of the dying?
<table>
<thead>
<tr>
<th>Goal</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal 1</td>
<td>Current medication assessed</td>
</tr>
<tr>
<td>Goal 2</td>
<td>PRN medication prescribed</td>
</tr>
<tr>
<td>Goal 3</td>
<td>Inappropriate interventions discontinued</td>
</tr>
<tr>
<td>Goal 4</td>
<td>Patient ability to communicate assessed</td>
</tr>
<tr>
<td>Goal 5</td>
<td>Psychological insight into condition assessed</td>
</tr>
<tr>
<td>Goal 6</td>
<td>Religious needs assessed and met</td>
</tr>
<tr>
<td>Goal 7</td>
<td>How family to be informed of death identified</td>
</tr>
<tr>
<td>Goal 8</td>
<td>Relatives’ facilities leaflet given</td>
</tr>
<tr>
<td>Goal 9</td>
<td>GP practice contacted re: patient condition</td>
</tr>
<tr>
<td>Goal 10</td>
<td>Relatives express understanding of care</td>
</tr>
</tbody>
</table>
Goal 1

Current medication assessed and non essentials discontinued Yes □ No □

Appropriate oral drugs converted to subcutaneous route and syringe driver commenced if appropriate
Inappropriate medication discontinued
Goal 2

PRN subcutaneous medication written up for list below as per protocol
(See sheets at back of LCP for guidance)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Medication</th>
<th>Yes □ No □</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Analgesic</td>
<td>Yes □ No □</td>
</tr>
<tr>
<td>Agitation</td>
<td>Sedative</td>
<td>Yes □ No □</td>
</tr>
<tr>
<td>Respiratory tract secretions</td>
<td>Anticholinergic</td>
<td>Yes □ No □</td>
</tr>
<tr>
<td>Nausea and vomiting</td>
<td>Anti-emetic</td>
<td>Yes □ No □</td>
</tr>
<tr>
<td>Dyspnoea</td>
<td>Anxiolytic</td>
<td>Yes □ No □</td>
</tr>
</tbody>
</table>
## Goal 3

**Discontinue inappropriate interventions**

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Yes □ No □ N/A □</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blood tests (including BM Monitoring)</td>
<td></td>
</tr>
<tr>
<td>Antibiotics</td>
<td></td>
</tr>
<tr>
<td>I.V.s (fluids/medications)</td>
<td></td>
</tr>
<tr>
<td>Not for cardiopulmonary resuscitation recorded</td>
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</tr>
</tbody>
</table>
Hospital - Achieved Initial Assessment Goals.

Achieved Initial Assessment Goals

valid percent

G1  G2  G3  G4  G5  G6  G7  G8  G9  G11

Achieved Initial Assessment Goals

The Marie Curie Palliative Care Institute
LIVERPOOL
LCP – Part of a Process of Change

Register with Liverpool Institute

Base Review

Supporting Documentation

Education Programme

LCP

Analysis 20 LCP

BENCHMARKING
**LCP - Activity**

- 600 Registered parties across 4 sectors - UK
- 3,200 health care professionals 05 / 06 – Educational Events
- Support to more than 350 LCP Facilitators across UK
- Resources
  - Health care professionals
  - Patients and carers
- Non cancer programme
National Care of the Dying Audit – Hospitals (NCDAH) Design

• MCPCIL with the Royal College of Physicians
• Retrospective Audit
• Patient Level Data Collection
  – Data from a sample of 30 patients who received care in the last days and hours of life via the LCP.
• Hospital Level Data Collection
  – Size, scope, number of deaths etc to contextualise the data from the LCP
Participants

- 96 (60%) Trusts - accepted into Audit (124 Hospitals)

- September – November (inclusive)
  - Data gathering period

- 2007 regional workshops – develop action plan for improving the care of the dying
LCP - UK - International

- Wales
- Scotland
- Northern Ireland
- Netherlands
- New Zealand
- Australia
- Republic of Ireland
- Sweden
- Switzerland
- Germany
- China
- India
- Italy
- Japan
- Slovenia
- Spain
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